

**ARCH**

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## National Resource Center for Respite and Crisis Care Services

A Division of the National Respite Network

### Chapel Hill Training-Outreach Project

800 Eastowne Drive, Suite 105, Chapel Hill, NC 27514

Phone: (800) 473-1727 or (919) 490-5577; Fax: (919) 490-4905

E-mail: [ylayden@intrex.net](mailto:ylayden@intrex.net) — Web: <http://chtop.com/archbroc.htm>

## Siblings of Children with Special Health and Developmental Needs Programs, Services and Considerations

### Background

Since 1986, when Congress passed the *Temporary Child Care for Children with Disabilities and Crisis Nurseries Act* (as amended), respite care programs for children with special health and developmental needs have expanded to almost every state. Increasingly, agencies that administer these programs are broadening their attention to include all family members, and to offer many family support services in addition to respite care.

While the parents of the child with special health and developmental needs have been the first to benefit from this heightened awareness, agencies are now beginning to understand that brothers and sisters of children with special needs have concerns that in many ways parallel their parents' experience. But compared with their parents, these brothers and sisters enjoy far fewer programs, services and considerations—even though the sibling relationship is frequently the longest lasting relationship in the family.

In the last several years, however, this has been changing. Research has documented the concerns of siblings of children with special health and developmental needs as programs designed specifically for these siblings have been developed. The following information provides an overview of some of the special concerns of brothers and sisters, one model approach to address these concerns, and a number of considerations for respite care agencies.

### Understanding the Concerns of Siblings

Through research and clinical literature, the concerns of brothers and sisters have been well-documented. The concerns include feelings of *loss and isolation* when a parent's time and attention is consumed by a sibling's disability or illness. Siblings may feel "left out of the loop" when parents and service providers, wanting to protect them from possible stress, do not share information about a sibling's condition. They may feel isolated with their concerns if they do not have opportunities to talk with peers who are experiencing similar concerns.

Although they frequently have a life-long *need for information* about the disability or illness and its implications, siblings have far fewer opportunities for obtaining information than their parents do. Written information about disabilities or chronic illnesses is not often developed for young readers. Should brothers or sisters accompany their parents to a clinic visit or an IEP (Individualized Education Program) or an IFSP (Individualized Family Services Plan) meeting, their questions, thoughts or opinions are rarely solicited.

Although both brothers and sisters help care for children with developmental disabilities, studies show that older sisters especially have *increased caregiving demands*. Research suggests that these sisters participate less in their own activities outside the home and have more conflict with the child who has the disability.

Other concerns siblings may have include *over identification* (fearing that they also have the siblings' condition); a perceived *pressure to achieve* in academics, or sports; feelings of *guilt* about having caused the illness or disability or of being spared the condition; feelings of *resentment* when the child with special needs becomes the focus of the family's attention or is permitted to engage in behavior unacceptable for other family members; and *concerns about their and their sibling's future*.

Increasingly, the opportunities many siblings experience by growing up with a brother or sister with special needs are also being acknowledged. These include *insight* on the human condition; *maturity* from successfully coping with a siblings' special needs; *pride* in their siblings' abilities; *loyalty* toward their siblings and families; and *appreciation* for their own good health and families.

### **Creating Programs Specifically for Brothers and Sisters**

Like their parents, brothers and sisters appreciate opportunities to meet others who have had similar experiences, discussing their common joys and concerns and learning more about issues and services that affect their families. Understanding this, agencies are more frequently creating programs designed specifically for siblings by providing some of the following opportunities:

***To meet other siblings in a relaxed, recreational setting.*** The chance to meet peers in a casual atmosphere has several benefits. First, it can help reduce a sibling's sense of isolation. Participants quickly learn that there are others who share the special joys and challenges that they experience. Second, the casual atmosphere and recreational activities promote informal sharing and friendships among participants. Third, the recreational setting helps make the experience rewarding to attend. If a brother or sister regards any service aimed at siblings as yet another time demand associated with the child with special needs, he or she may find it hard to be receptive to the information presented. Sibling events should offer activities that are personally satisfying for the participant, so that he or she is likely to attend in the future.

***To discuss the joys and concerns common to brothers and sisters of children with special needs.***

Siblings need opportunities, such as sibling support groups, to network. Through these discussions, siblings may realize they have many common concerns and experiences. These support systems can help decrease feelings of isolation and provide an opportunity for ongoing support. Serve refreshments and incorporate fun activities along with more serious discussions.

***To learn how others handle situations commonly experienced by siblings of children with special needs.*** Brothers and sisters of children with special health and developmental needs routinely face problems that are not experienced by other children. Defending a brother or sister from name-calling, responding to questions from friends and strangers, and coping with a lack of attention or exceedingly high expectations from parents are only a few of the problems siblings may experience. Special events for siblings can offer a sibling a broad array of solutions from which to choose.

***To learn more about the implications of their brothers' and sisters' special needs.*** Brothers and sisters need information to answer their own questions as well as the questions of friends, classmates and strangers. Siblings want to know how the disability or illness may affect their brother or sister's life, schooling and future.

***To give parents and service providers opportunities to learn more about the common concerns of the siblings.*** Because parents and service providers often are unaware of the range of sibling issues, activities can be conducted to try to help them better understand "life as a sib." For example, a panel of young adult and adult siblings might relate what they appreciated in their parents' treatment of the children in their families and also what they wish their parents had done differently.

#### ***A National Model Format***

One model that has been used successfully throughout the U.S. offers brothers and sisters of children with special health and developmental needs peer support and education through workshops as brief as two hours and as long as a weekend. Typical workshops in this model are approximately four hours long, usually from 10 A.M. until 2 P.M. on Saturdays. Generally they are held monthly or bimonthly. During these workshops, information

and discussion activities are mixed with lively recreational activities. These might include “New Games” designed to be unique, slightly off-beat, and appealing to a wide range of abilities; cooking; and special guests, who may teach participants mime or juggling. A workshop schedule might look something like this:

**Trickle-in activity:** Group Juggling

**Warm up activity:** Human Bingo

**Discussion #1:** Strengths and Weaknesses

**Game:** Stand Up!

**Game:** Sightless Sculpture

**Lunch:** Supernachos

**Game:** Push-pin Soccer

**Discussion #2:** Dear Aunt Blabby

**Game:** Triangle Tag

**Guest:** Physical Therapist

**Closing activity:** Sound Off

Sibling support programs in this model were designed originally for children eight to thirteen years old, but they can be adapted easily for younger or older children. Originally begun for siblings of children with developmental disabilities, these workshops have expanded to include brothers and sisters of children with other special needs, such as cancer, hearing impairments, epilepsy, emotional disturbances and HIV+ status, and for children who have lost a family member.

### **Including Brothers and Sisters: a Checklist for Agencies**

Here are a few considerations to facilitate the inclusion of siblings in planning and implementing family support services.

#### ***Are siblings included in the definition of “family?”***

Many educational and health care agencies have begun to embrace an expansive definition of families (e.g., IFSPs, family-centered care). However, providers may still need to be reminded that there is more to a family than the child with special needs and his or her parents. Organizations that use the word “parent” when “family” or “family member” is more appropriate send a message to brothers and sisters, grandparents and other family members that the organization is not for them.

With siblings and primary-caregiver grandparents assuming increasingly active roles in the lives of people with disabilities and health impairments, we cannot afford to exclude anyone.

***Does the agency reach out to brothers and sisters?*** Parents and agency personnel should consider inviting (but not requiring) brothers and sisters to attend informational, IEP, IFSP, and transition planning meetings and clinic visits. Siblings frequently have legitimate questions that can be answered by service providers. Brothers and sister also have informed opinions and perspectives and can make significant contributions to the child’s team.

***Does the agency educate staff about issues facing young and adult brothers and sisters?*** A sibling panel is a valuable way for staff members to learn more about life as a brother or sister of a person with a disability or chronic illness. Guidelines for panel discussions can be prepared in advance to help facilitate a meaningful discussion. Other methods to help educate agency staff include videotapes, books, and newsletters.

#### ***Does the agency have a program specifically for brothers and sisters?***

Programs for siblings—preschoolers, school-age children, teens, and adults—are growing in number across the United States. Determine the needs of families served in your local community and develop sibling support programs to meet identified needs.

***Does the agency have brothers and sisters on the advisory board and policies reflecting the importance of including siblings?*** Reserving board seats for siblings will give the board a unique and important perspective and indicate the agency’s concern for siblings. Developing policy based on the important roles played by brothers and sisters will help assure that their concerns and contributions are a part of the agency’s commitment to families.

### **Summary**

Acknowledging the contributions of the siblings of children with disabilities or chronic illnesses is an important step toward recognizing the valuable role they play in families. In addition to recogni-

tion, siblings need information, support, and the opportunity to *be children* and to form relationships with other children who have similar experiences. Many crisis nurseries and respite care programs serve all family members and may benefit from understanding sibling issues.

## Resources

### ***Curricula for starting sibling programs:***

Meyer, D. J., Vadasy, P. F., and Fewell, R. R. (1986). *Sibshops: A Handbook for Implementing Workshops for Brothers and Sisters of Children with Special Needs*. Seattle: University of Washington Press.

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.

Fish, T. *The Next Step* (videotape on sibling issues). Publications Office, Nissonger Center UAP, 434 McCampbell Hall, Ohio State University, 1581 Dodd Drive, Columbus, OH 43210.

### ***Books on sibling issues:***

For parents and service providers: Powell, T.H., and Gallagher, P.A. (1993). *Brothers & Sisters: A Special Part of Exceptional Families*. Baltimore: Paul H. Brookes Publishing Co.

For school age brothers and sisters: Meyer, D.J., Vadasy, P.F., and Fewell, R.R. (1985). *Living with a Brother or Sister with Special Needs: A Book for Sibs*. Seattle: University of Washington Press.

### ***Newsletters:***

*NASP* (National Association of Sibling Programs) *Newsletter*. Published by the Sibling Support Project, Children's Hospital and Medical Center, P.O. Box 5371, CL-09, Seattle, WA 98105-0371.

*The Sibling Information Network Newsletter*. Published by the A.J. Pappanikou Center, University of Connecticut, 1776 Ellington Road, South Windsor, CT 06074.

### ***Organizations:***

*The Sibling Support Project*. The goal of the Sibling Support Project is to increase peer support and education programs for brothers and sisters of children with special health and developmental

needs, providing training, demonstration Sibshops and technical assistance to agencies and organizations wishing to add a program for siblings to their existing services. For more information, contact: The Sibling Support Project, Children's Hospital and Medical Center, P.O. Box 5371, CL-09, Seattle, WA 98105-0371. (206) 368-4911.

***About the Author:*** Donald Meyer is the Director of the Sibling Support Project, and, for the past fifteen years, has been involved with programs for traditionally underserved family members of children with special needs.

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