

# Meeting the Unique Concerns of Brothers and Sisters of People with Special Needs

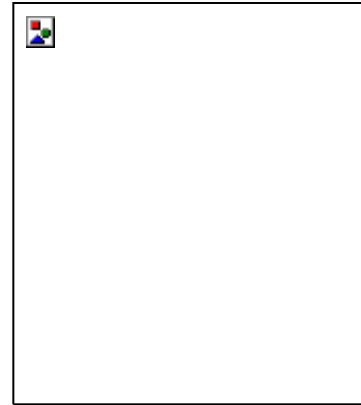
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In the United States, over 6.5 million children have disabilities. Most have brothers and sisters. With the exception of the child's mother, no one in the family spends more time with children who have special needs than do brothers and sisters. Throughout their lives, these brothers and sisters will share many--if not most--of the same concerns that parents of children with special needs experience, as well as issues that are uniquely theirs. And, because the sibling relationship is usually the longest-lasting relationship in a family, brothers and sisters will likely be involved in the life of the child who has special needs longer than *anyone*—including the child's parents.

Siblings' concerns are well known to their parents and have been documented in the research and clinical literature. Among the concerns mentioned by authors, parents, and siblings themselves include:

- a life-long and ever-changing need for information about the disability or illness (Lobato, 1990; Schorr-Ribera, 1992; Powell & Gallagher, 1993).
- feelings of isolation when siblings are excluded from information available to other family members (Bendor, 1990), ignored by service providers (Doherty 1992), or denied access to peers who share their often ambivalent feelings about their siblings (Meyer & Vadasy, 1994);
- feelings of guilt about having caused the illness or disability, or being spared having the condition (Koch-Hattem, 1986),
- feelings of resentment when the child with special needs becomes the focus of the family's attention or when the child with special needs is indulged, overprotected, or permitted to engage in

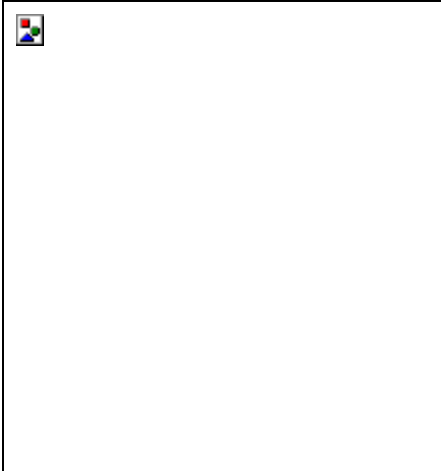
behaviors unacceptable by other family members (Podeanu-Czehotsky, 1975; Bendor, 1990);



- a perceived pressure to achieve in academics, sports, or behavior (Coleman, 1990);
- increased caregiving demands, especially for older sisters (Seligman, 1979); and
- concerns about their role in their sibling's future (Fish & Fitzgerald, 1980; Powell & Gallagher, 1993).

Increasingly, opportunities experienced by these brothers and sisters are also being acknowledged (Meyer & Vadasy, 1994; Powell & Gallagher, 1993; Turnbull & Turnbull, 1993). A short list of opportunities observed by parents and brothers and sisters could include:

- the insights a sibling will have on the human condition as a result of growing up with a brother or sister with special needs:  
"She taught me how to love without reservation; without expectation of returned love. She taught me that everyone has strengths and weaknesses. Martha is no exception. She taught me that human value is not measured with IQ tests." (Westra, 1992, p.4)



- the maturity many brothers or sisters develop as a result of successfully coping with a sibling's special needs:  
"I have a different outlook on life than many other people my age. I understand that you can't take anything for granted. And you have to be able to look at the positives...With Jennifer, there are negatives, but there's so much more that is good." (Andrea, age 19, in Binkard et al., 1987, p. 19);
- the pride brothers and sisters report in their sibling's abilities:  
"Jennifer has probably achieved more than I have. She's been through so much. She couldn't even talk when she started school; now she can, and she can understand others. She's really fulfilling her potential. I'm not sure the rest of us are." (Cassie, age 18, in Binkard et al., 1987, p. 17)
- the loyalty brothers and sisters display toward their siblings and families:  
"I'm used to being kind to my brother and sister, so I'm kind to everybody else. But, if someone starts a fight, I will fight. I won't put up with anyone teasing Wade or Jolene." (Morrow, 1992, p.4)
- and the appreciation many brothers and sisters have for their good health and own families.  
"People tend to think in simplistic terms, not in reality. My mother, for example, is not a saint. In some ways she has still not come to terms with my sister's disability.

Yet I see her as a tower of strength. I don't know if I would have that much strength." (Julie, in Remsburg, 1989, p. 3)

"Living with Melissa's handicaps makes me so much more cognizant of my own blessings. She provides a constant reminder of what life could have been like for me if I had been my parents' oldest daughter. This encourages me to take advantage of my mental capacities and to take care of my healthy body." (Watson, 1991 p. 108)

Acknowledging siblings' many unique opportunities is not to view their experience from Pollyanna's perspective--many of these benefits are hard-earned. In short, siblings' experiences closely parallel their parents' experiences.

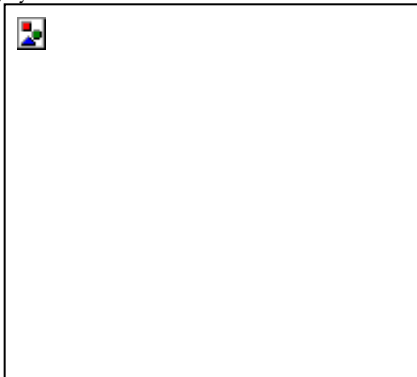
Brothers' and sisters' unique joys, concerns, and contributions make them too important to ignore. Still, siblings remain overlooked—even by agencies that value family-centered practices. Most brothers and sisters grow up without resources--such as access to support programs and sources of information--that would help them in their roles, and that many parents may take for granted. The Sibling Support Project encourages development of services, considerations, and policies that acknowledge the concerns of siblings as well as their expertise and insight. We support systemic change that recognizes brothers' and sisters' legitimate concerns and supports them in the life-long, critical roles they will play in the lives of their siblings with special needs. We feel that when siblings' concerns are addressed everyone benefits: brothers, sisters, parents, providers, agencies, and *especially* the family member who has a disability.

**B**elow are suggestions for parents and service providers to minimize siblings' concerns and maximize their opportunities:

- *Provide brothers and sisters with age-appropriate information.* Most brothers and sisters have a life-long, and ever-changing need for information. Parents and service

providers have an obligation to proactively provide siblings with helpful information. Agencies representing specific disabilities and illnesses should be challenged to prepare materials specifically for young readers.

- *Provide siblings with opportunities to meet other siblings of children with special needs.* For most parents, the thought of "going it alone," without the benefit of knowing another parent in a similar situation is unthinkable. Yet, this happens routinely to brothers and sisters. Sibshops and similar efforts offer siblings the same common-sense support that parents value. They let brothers and sisters know that they are not alone with their unique joys and concerns.



- *Encourage good communication with typically developing children.* While good communication between parent and child is important, it is especially important in families where there is child with special needs. An evening course in active listening can help improve communication among all family members. Also, books, such as *How to Talk So Kids Will Listen and Listen So Kids Will Talk* and *Siblings Without Rivalry* (both by Adele Faber and Elaine Mazlich) provide helpful tips on communicating with children.
- *Encourage parents to set aside special time to spend with the typically developing children.* Children need to know from their parents' deeds and words that their parents care about them as individuals. When parents carve time out of a busy

schedule to grab a bite at a local burger joint or window shop at the mall with the typically developing child, it conveys a message that parents "are there" for them as well.

- *Parents and service providers need to learn more about siblings' experiences.* Sibling panels, books, newsletters and videos are all excellent means of learning more about sibling issues. A bibliography is available from the Sibling Support Project.
- *Encourage parents to reassure their typically developing children by planning for the future of the child with special needs..* Early in life, brothers and sisters worry about what obligations they will have toward their sibling in the days to come. Parents should be encouraged to plan for the future and share these plans with their children. When brothers and sisters are "brought into the loop" and given the message that they have their parents' blessing to pursue their dreams, their future involvement with their sibling will be a choice instead of an obligation.

Many agencies are beginning to realize that siblings are too valuable to ignore, and have begun changing policies and procedures to acknowledge the important roles brothers and sisters play. Here are a few considerations for agencies:

*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 program is not for them. With siblings and grandparents assuming increasingly active roles in the lives of people with disabilities, 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, transition planning meetings, and clinic visits. Siblings frequently have legitimate questions that can be answered by service providers. Brothers and sisters also have informed opinions and perspectives and can make positive contributions to the child's team.

*Does the agency educate staff about issues facing brothers and sisters?*

A sibling panel is a valuable way for staff to learn more about life as a brother or sister of a person with a disability or chronic illness. Guidelines for conducting a sibling panel are available from the Sibling Support Project. Other methods to help educate agency staff include videotapes, books, and newsletters. A bibliography is available from the Sibling Support Project.

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

Like their parents, brothers and sisters benefit from talking with others who "get it." Sibshops and other programs for preschool, school-age, teen, and adult siblings are growing in number. The Sibling Support Project, which maintains a database of over 200 Sibshops and other sibling programs, provides technical assistance on creating local programs for siblings.

*Does the agency have brothers and sisters on an advisory board and policies reflecting the importance of including siblings?*

Reserving board seats for siblings will give the board a unique, important perspective and reflect the agency's concern for the well-being of brothers and sisters. 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.

*(This article was adapted from SIBSHOPS: WORKSHOPS FOR SIBLINGS OF CHILDREN WITH SPECIAL NEEDS by Donald Meyer and Patricia Vadasy, 1994, Paul H. Brookes Publishing Company. All rights reserved.)*



***About the Sibling Support Project.***

The Sibling Support Project is a national program dedicated to the interests of brothers and sisters of people with special health and developmental needs. The Project's primary goal is to increase the availability of peer support and education programs for brothers and sisters of people with special health and developmental needs.

To accomplish this goal, project staff:

- create awareness materials (e.g., curricula, children's books, websites, newsletters) for parents, service providers, and brothers and sisters;
- conduct workshops in each of the 50 states for parents and providers on the life-long issues facing brothers and sisters and how to start a Sibshop;
- provide technical assistance to those starting a local Sibshop;
- maintain a database of over 200 Sibshops and other sibling programs across the United States;
- conduct Sibshops for Seattle-area brothers and sisters of children with special health and developmental needs and
- evaluate the effects of programs for siblings.

Materials created by Sibling Support Project staff include:

- *Sibshops: Workshops for brothers and sisters of children with special needs*, 1994, by Donald J. Meyer and Patricia F. Vadasy (Baltimore: Paul H. Brookes). To order call 1-800-638-3775. Also available at Barnes and Noble Bookstores
- *Living with a brother or sister with special needs: A book for sibs*, 1996, (2nd edition, revised and expanded) by Donald Meyer and Patricia Vadasy (Seattle: University of Washington Press). To order call 1-800-441-4115. Also available at Barnes and Noble Bookstores.
- *Uncommon Fathers: Reflections on raising a child with a disability*, 1995, Donald Meyer (ed.). (Bethesda, Maryland: Woodbine House). To order, call 1-800-843-7323. Also available from Barnes and Noble bookstores.
- *Views from our Shoes: Growing up with a brother or sister with special needs*, 1997, by Donald Meyer (ed.) (Bethesda, Maryland: Woodbine House). To order, call 1-800-843-7323. Also available from Barnes and Noble bookstores.
- *Sibling Support Project Web Page*: [www.seattlechildrens.org/sibsupp](http://www.seattlechildrens.org/sibsupp)
- *The SibNet and SibKids Listservs*, email-type bulletin boards for brothers and sisters of all ages and others interested in the well-being of siblings. For a *free* subscription, visit the Sibling Support Project Web Page or contact the Sibling Support Project.

For more information about Sibshops and the Sibling Support Project, contact:

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