



## Sibling/Extended Family Support

September, 2001

### The Role of Brothers and Sisters

Relationships between brothers and sisters are among the most rich and enduring bonds that children and adults experience. Brothers and sisters generally spend more time with one another than they do with their parents, not only during childhood, but throughout the course of their lives. The parent's role will fade, but the brothers and sisters will carry that relationship for a lifetime.

One of the most critical factors in siblings' functioning is the way they interpret their parents' attitude toward the child with special needs. The parents' emotional health and availability are a powerful influence in the siblings' ability to cope and find their own identity. If they are unable to claim an important place in the family based on their own individuality, siblings often try, usually unconsciously, to develop an identity or role related to the special needs; becoming over-protective and over-responsible caretakers, developing special needs of their own, striving to be perfect, or acting out in negative ways. Only recently has there been a general awareness that siblings have the same need for information and support as do parents when a child in the family has a disability.

Given that understanding, sibling support should include targeted appropriate material. Although it is a frequently used approach, sibling support does not only mean Sibshops, or other formal purchased materials or curriculums. Local family support teams who choose to acknowledge and support the fact that siblings are caught between two worlds, can utilize some excellent resources available. Just as for parents, often the first step in sibling support is an informal event for networking and connecting. Other useful components of sibling support training include: information, effective communication techniques and the use of "I" messages, and problem solving skills. Sibling groups provide a forum where siblings can discuss their experiences, share ideas and give each other support. Involving the siblings in planning training or events to reach a point of ownership and buy in is an important step.

### Suggestions for parents from a panel of siblings:

- Accept their child's disability or chronic illness in order to help others do the same.
- Express their own thoughts and feelings to the whole family.
- Regularly spend time alone with each child.
- Listen to siblings and allow them to express negative feelings.
- Tell each child what they admire about him and acknowledge his contribution to the family.
- Obtain children's books or other resources about special needs.
- Involve siblings in decision making and care of the child with special needs

*(continued)*





## Sibling/Extended Family Support

*(continued)*

while maintaining appropriate limits on how much they are expected to do.

- Allow the child with special needs to do as much as she can for herself.
- Use respite care and other support services.
- Be fair.
- Teach siblings positive ways to interact.
- Let siblings settle their own differences.
- Welcome other children and friends into the home.
- Recognize situations that are stressful for siblings and plan ahead to minimize negative effects.
- Encourage “normal” family life and activities.
- Join or promote the development of sibling programs and support groups.
- When appropriate, consult professionals to help siblings cope with stress.
- Don’t expect siblings to be saints.

### Grandparents and Extended Family

A grandparent’s life is impacted by the birth of a child with a disability. Many resources refer to the double grief that grandparents experience, for both their grandchild and their child. But grandparents can influence a family’s adjustment. They have the ability and are often called upon to provide support to the entire family. They can lend to both generations the strength and love of the extended family.

The diagnosis of a child’s disability can dramatically alter parents’ relationships with grandparents, relatives, and friends. Grandparents, relatives, and friends experience many of the same reactions that parents do: shock, denial, anger, sadness and depression. Yet each person grieves in a different way, at a different pace. The different attitudes and coping styles may be compatible, or they may create misunderstanding and hard feelings between parents and others. Grandparents, relatives, and friends can serve as a tremendous source of support, but this may not always happen.

Parents of children with special needs report that these responses from family and close friends can be especially challenging:

- needing long or repeated explanations in order to understand the disability
- requiring tremendous support from the child’s parents in order to overcome their own fear and grief
- appearing uncomfortable talking or hearing about the child’s condition
- denying a problem even exists
- embracing the child with special needs as a favorite
- not talking to or about the child with disabilities
- conveying their concern through incessant advice giving

*(continued)*





## Sibling/Extended Family

(continued)

- feeling anxious or embarrassed about telling others that someone in their family has a disability

Grandparents ability or failure to be supportive and accepting of a child's special needs can have a significant effect on how other relatives, and even the child's parents, handle the situation. When they are unable to move beyond shock or denial and fail to accept the diagnosis, grandparents' feelings can be transferred to others and influence their behavior toward the child. On the other hand, when they are involved with the child and family in positive, supportive ways, it may encourage others to do the same.

Consider these tips on how grandparents, close friends, and family can best help their children and grandchildren:

- offer support but don't hover
- ask how you can help in practical matters
- learn as much about the disability or diagnosis as possible
- offer opinions only if asked
- accept your grandchild as he or she is
- take responsibility for your own grieving

To be an effective supporter, grandparents and others must first address their own needs and concerns. A grandparent-to-grandparent program can serve as a useful tool to meet and share with others, gain information, and to learn helpful support strategies to enrich and empower the entire family network.

### References:

Lobato, D.J. (1990). *Brothers, Sisters, and Special Needs: Information and Activities for Helping Young Siblings of Children with Chronic Illness and Developmental Disabilities.* Baltimore: Paul H. Brookes Publishing Co., Inc.

MELD Special, (1993). MELD, 219 North 2nd St., Suite 200, Minneapolis, MN 55401. (612) 332-7563. Email address: info@meld.org

Meyer, D.J. & Vadasy, P.F. (1994). *Sibshops: Workshops for Brothers and Sisters of Children with Special Needs.* Baltimore: Paul H. Brookes Publishing Co., Inc.

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

The Sibling Support Project, Children's Hospital and Medical Center, 4800 Sand Point Way NE, Seattle, WA, 98105. (206) 527-5712. email: dmeyer@chmc.org. <http://www.chmc.org/departmt/sibsupp>

LD Online: Tips for Grandparents, [www.olonline.org/ld\\_indepth/family/grandparents.html](http://www.olonline.org/ld_indepth/family/grandparents.html)

PACER'S Grandparent to Grandparent Program, PACER, 8161 Normandale Blvd., Minneapolis, MN 55437. (952)838-9000. Fax: (952)838-0199., email: [pacer@pacer.org](mailto:pacer@pacer.org), [www.pacer.org/parent/grand.htm](http://www.pacer.org/parent/grand.htm)

