Sibling of your Special Needs Child...

Dilemmas and Advantages of Siblings of Special Needs Children

Some of common concerns expressed by siblings of disabled children are:
- Feeling guilty about being “spared” a disability
- Embarrassment of siblings’ behavior or appearance in front of friends
- Anger or jealousy over the amount of attention the disabled child is receiving
- Pressure to “make up” for a sibling’s disability by excelling in school or sports
- Care giving, especially if it conflicts with social plans

Benefits of being the sibling of a special needs child include:
- Developing a level of maturity that is greater than their same age peers
- Increased frequency of pro-social behaviors (helping others, empathy, etc.)
- Deep understanding of challenges of others and the advantages most people take for granted
- Increased tolerance for diversity
- Feeling of pride about accomplishments of disabled sibling
- A deep sense of loyalty and caring towards sibling (defending siblings)

Parental Considerations regarding Sibling of Special Needs Child*

Preschoolers (before age 5)...
- Can’t understand the exact nature of their sibling’s disability
- Will notice some differences and will try to teach their sibling how to do things

Elementary School (6-12)...
- Can understand definition and explanation of sibling’s special needs
- May worry that the disability is contagious
- May feel guilty about having negative thoughts and feelings about their sibling
- Can become either over-helpful and well-behaved or noncompliant to get attention
- May have conflicting feelings about their sibling (love, resentment, anger, loyalty)

Adolescents (13-17)
- Can understand complex explanation of the disability
- May ask detailed and provocative questions of parents
- May be embarrassed in front of friends and dates
- May be torn between their need for independence and their desire for a unique relationship with their sibling
- May resent the amount of responsibility they have for the care of their sibling

*Sources: The Siblings Support Project of the Arc of the United States; ARCH (National Resource Center for Respite and Crisis Care Services; Derenda Timmons Schubert, Ph.D. (2004); Meyer and Vadasy (1994); Steinberg (2004)
Addressing Common Challenges of Siblings of Special Needs Children

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| Limited parental time and attention           | o Protect certain times to spend with your unaffected child *(movies, bedtime)*  
|                                               | o Organize short-term care for your disabled child in order to be able to participate in special events for the sibling *(sports)*  
|                                               | o From time to time, put the needs of your unaffected child first |
| Worry about bringing friends home             | o Talk with your child about their feelings                             
|                                               | o Invite friends over when your disabled child is away                  
|                                               | o Don’t expect the sibling to always include the disabled child in their activities |
| Stressful life at home                        | o Encourage your child to develop their own social life                 
|                                               | o Ensure privacy of your unaffected child and protect their possessions from being damaged *(lock on bedroom door)* |
|                                               | o Get help for handling caring responsibilities and difficult behaviors of your disabled child |
| Limits on family activities and outings       | o Find family activities that everyone can enjoy *(swimming, picnic)*   
|                                               | o Ask for help from family or friends for care of your disabled child during activities she/he is unable to participate in  |
| Guilt about feeling angry with a disabled sibling | o Make it clear that its o.k. to feel anger                                 
|                                               | o Share some of your own mixed feelings                                 |
| Embarrassment about a sibling in public       | o Find social situations where your disabled child is accepted               
|                                               | o With older children, split them up on outings for a while               |
| Being teased or bullied about their sibling   | o Ask your child’s teachers to encourage positive attitudes towards disability  
|                                               | o Rehearse with your child how to handle unpleasant remarks               |

More considerations

o Maintain an honest dialogue with your unaffected child about their sibling’s disability. Use age-appropriate language with younger children, but be as honest as possible.

o Arrange for your unaffected child to meet other siblings of special needs children to begin to appreciate that they are not alone with their feelings and experiences.

*Sources: The Siblings Support Project of the Arc of the United States; ARCH (National Resource Center for Respite and Crisis Care Services; Derenda Timmons Schubert, Ph.D. (2004); Meyer and Vadasy (1994); Steinberg (2004)*
Plan for the future of your special needs child, and share this with your unaffected child. Express to your child your “permission” and “blessing” for him/her to pursue his/her dreams. This way any future involvement with siblings is a choice and not an obligation.

Avoid using siblings as caregivers. Treat your unaffected child as a child, not another adult caretaker. Don’t expect her to take on responsibilities for which she is unprepared.

Give siblings choices and involve them in decision making. Discuss family matters with your children, especially if it affects them personally. Ask and value their opinion.

**Sibling Rivalry**

Certain amount of conflict (teasing, name-calling, arguing) between siblings can be a beneficial part of normal social development. For example, a child with Down syndrome who grows up sometimes fighting with her siblings may be better prepared to face life than a child with Down syndrome who grows up being sheltered. However, siblings may feel jealous about the extra attention their disabled sibling receives, and may misbehave to get the parent’s attention.

**Tactics for Reducing Sibling Rivalry***

- Treat all your children equally. Be as fair as possible.
- Assign your disabled child chores so everyone in the family has a responsibility.
- Set up siblings to cooperate rather than compete (*have them work on a chore as a team rather than individually*).
- Devote time to family activities that everyone enjoys.

**Red Flags about Sibling Rivalry**

If rivalry gets out of hand (*physical violence*) or you detect depression or anxiety, seek professional help immediately. Look out for problems with appetite or sleep, hopelessness, poor concentration, talk of hurting self, loss of interest in activities, frequent crying or worrying, difficulty separating from parents, or physical symptoms such as headaches or stomach aches. If these behaviors continue for more than two weeks, seek professional assistance.

*Sources: The Siblings Support Project of the Arc of the United States; ARCH (National Resource Center for Respite and Crisis Care Services); Derenda Timmons Schubert, Ph.D. (2004); Meyer and Vadasy (1994); Steinberg (2004)
Resources

Books for parents on sibling issues
- Brothers, Sisters, and Special Needs: Information and Activities for Helping Young Siblings of Children with Chronic Illnesses and Developmental Disabilities by Debra Lobato (1990)
- Brothers & Sisters-A Special Part of Exceptional Families by Thomas Powell & Peggy Gallagher (1993)
- Listening to Siblings – The Experiences of Children and Young People who have a Brother or Sister with a Severe Disability by Janet Ratcliff (2003)

Fiction for young siblings
- We’ll Paint the Octopus Red by Stephanie Stuve-Bodeen & Pam Devito (1998)
- Are You Alone on Purpose? By Nancy Werlin (1994)
- Tru Confessions by Janet Tashjian (1997)
- Way to Go, Alex! By Robin Pulver & Elizabeth Wolf (1999)
- My Brother, Matthew by Mary Thompson (1992)
- Our Brother has Down syndrome by Shelley Cairo (1988)
- The Summer of the Swans by Betsy Byars (1996)
- Princess Pooh by Kathleen Muldoon (1989)
- Welcome Home, Jellybean by Marlene Fanta Shyer (1988)

Non-Fiction for young siblings:
- Views from Our Shoes: Growing Up With a Brother or Sister with Special Needs by Donald Meyer & Cary Pillo (1997)
- Living with a Brother or Sister with Special Needs: A Book for Sibs by Donald Meyer & Patricia Vadasay (1996)

Non-Fiction and memoirs by adult siblings:
- Siblings: Brothers and Sisters of Children with Special Needs by Kate Strohm (2002)
- Special Siblings: Growing Up with Someone with a Disability by Mary McHugh (1999)
- My Sister’s Keeper by Margaret Moorman
- Without apology, a documentary film by Susan Hamovitch

Fiction about adult sibling issues
- I Know This Much is True by Wally Lamb (1990)

*Sources: The Siblings Support Project of the Arc of the United States; ARCH (National Resource Center for Respite and Crisis Care Services; Derenda Timmons Schubert, Ph.D. (2004); Meyer and Vadasy (1994); Steinberg (2004)
Films featuring sibling issues
- *Tru Confessions* (Disney Channel Movie)
- *What’s Eating Gilbert Grape* (PG-13)
- *Benny and Joon* (PG)
- *Dominick and Eugene* (PG-13)

Websites
- [http://www.sibs.org.uk](http://www.sibs.org.uk)
- [http://www.sibspace.org](http://www.sibspace.org)
- [http://www.thearc.org/siblingsupport](http://www.thearc.org/siblingsupport)
- [http://www.siblink.org](http://www.siblink.org)

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 this project is to increase peer support and education programs for brothers and sisters of children with special health and developmental needs. Contact The Sibling Support Project, Children’s Hospital and Medical Center, P.O. Box 5371, CL-09, Seattle, WA 98105-0371

*Sources: The Siblings Support Project of the Arc of the United States; ARCH (National Resource Center for Respite and Crisis Care Services); Derenda Timmons Schubert, Ph.D. (2004); Meyer and Vadasy (1994); Steinberg (2004)*