

Let's Talk About Siblings

DDI VANTAGE, Learning Links

Considerations

- Children with disabilities require a large portion of family time, attention, money, and psychological support
- The non-disabled child's reaction to a sibling with disabilities can affect the overall adjustment and development of self esteem in BOTH CHILDREN
- Each sibling and each relationship between siblings is unique, important, and special
- Sibling relationships typically comprise a child's first social network and are a basis for all future interactions with people outside the family
- Each child's temperament plays a role in their response to a sibling. Both positive and negative feelings exist in all relationships. For most children relationships with a sibling who has disabilities tends to be more positive than negative.
- Children who have a sibling with disabilities, overall, have more positive and fewer negative interactions with other children than do those with only non-disabled siblings. These things include more empathy and altruism, increased tolerance for differences, increased sense of maturity and responsibility, and more pride in their sibling's accomplishments

Emotional Phases of Sibling

- Siblings are playmates first. Their relationship may expand over the years to include a number of different roles: teacher, friend, companion, follower, protector, enemy, competitor, confidant, role model, etc.
- Siblings of a child with a disability experience a similar range of emotions to a child of a sibling without disabilities. These feelings may include: love, empathy, pride, guilt, anger, support, etc. Of importance is that these feelings have a great impact on the levels of stress and coping ability of the sibling with a disability.
- Each child's reaction varies depending on his/her age and developmental level. These responses tend to change over time as the siblings adapt. For example:
 - o Preschool age children- may mimic the physical or behavioral actions of the child with disabilities. May regress in behavioral development as an attention seeking method. Commons emotions include feelings of confusion, fear, anxiety, and anger. Resentment of parent time spent with child who has disabilities and perceive it as rejection. Perception that parents love child with a disability more,

wonder what is wrong with them. Extremes such as acting out to get attention or become the “perfect child”

- o Elementary school aged children – Embarrassment or ashamed as they recognize differences between their sibling and other children’s siblings. May worry about “catching” or developing a problem themselves. Guilt because they don’t have a disability and are beginning to fully realize the things their sibling can’t do. May feel protective and supportive of sibling to the point of triggering conflicts with peers.
- o Young adults – Future oriented concerns. Concern about how peers (people they date, socialize with, and potentially marry) will accept their sibling with disabilities. Could even extend to concerns about genetic counseling when planning own family and coping with anxiety about future responsibilities for sibling with a disability.
- Feelings of obligation to compensate or “make up for” the limitations of the child with disabilities
- May act as a surrogate parent
- The younger the child, the more difficult it may be for her to realistically understand the situation and interpret events accurately

How to Help the Siblings with their Emotional Coping and Growth

- ⊙ Honesty and information! Remember that your children have limited life experience to help them put such things in perspective.
- Explanation for the tensions within the family and the cause of such tension
- Provide avenues to safely discuss feelings and emotions. Remember, siblings may have no knowledge of what life was like without a brother or sister with a disability
- Give them an explanation for their sibling’s difficulties so they will not make incorrect assumptions
- Understand that there will be a gap between the nondisabled sibling’s knowledge and actions. The sibling may be able to rationally explain a brother or sister’s disability to friends and neighbors, but may still exhibit signs of emotional difficulty at home
- Remember that knowledge is empowering and puts fear into perspective. Just knowing the facts about a disease or disability may remove the sting of embarrassment, uncertainty, and fear.

Future Planning

While it is true you don't yet know what your child with disabilities will be able to do or what the future will hold, it is still important to plan for the future to decrease stress on yourself and your other children. When developing this plan be sure to consider all necessary things such as mobility, social and communication skills, education, and the individual's own ideas about where they want to live and work.

A file regarding future planning should be kept in a safe place that is known to all family members. Consider the following ideas when developing this plan:

1. Develop financial plans for the future care including the possibility of setting up a trust for the child with disabilities. Make sure your attorney is experienced in writing a will for those who have an heir with a disability.
2. Know your state's laws regarding guardianship and independence. Establish whether the sibling with a disability requires no, partial, or full guardianship. Be sure your guardianship plans are recorded in writing.
3. Siblings without disabilities should know where to access needed educational, vocational, and medical records
4. Consider the future health of the sibling with a disability in regard to needed services and care.
5. Understand legal and eligibility requirements of programs such as Supplemental Security Income (SSI), independent living centers, and so forth
6. Remember that as the family grows and changes the members within it change as do their needs. Set a future date to re-evaluate your family's plan.
7. Encourage your child with disabilities to be as independent as possible.
8. Take every opportunity to integrate your child into the "non-disabled" world
9. Make sure your child gets as much "real world" training as possible in school
10. Talk to an attorney about estate planning and set up an executorship
11. Have a plan for your children with specific caregivers outlined who can care for your children should death occur unexpectedly

Notes from the book *Siblings Without Rivalry*

by Derenda Timmons Schubert, Ph.D.
Pacific Northwest Children's Services
Waverly Children's Home
3550 SE Woodward Avenue
Portland, OR 97202

I would like to introduce families to a book that might help address issues related to sibling rivalry. All sibling relationships can have their good times and their rocky times. In the book, *Siblings Without Rivalry*, by Adele Faber and Elaine Mazlish, parents are provided with an easy to read, down-to-earth approach to managing sibling conflict. Plus, there are many entertaining cartoons illustrating every day parent/sibling experiences. One particular aspect of the book is "What do you do with sibling rivalry when one of the siblings has a disability." The following are suggestions provided by the authors:

- Focus on children's ABILITIES rather than DISABILITIES; Encourage ABILITIES.
- ACKNOWLEDGE ALL of children's FEELINGS about their siblings with special needs. Sometimes it can be difficult to respond empathetically when one sibling is making negative remarks about the child with a special need. However, when children know that they can express the full range of their emotional experience, the emotion is less likely to transform into behavior (i.e. ignoring a sibling, hitting a sibling) or physical complaints (i.e. stomachaches, headaches).
- Resist the urge to compare children even when those COMPARISONS involve positive comments. Such comparisons can make a child feel less than unique.
- Resist the tendency to place children in ROLES. It is likely that one child in the family will possess special talent in an area. It is important to encourage, support, and celebrate this child's accomplishment; while at the same time, sending the message to other children in the family that such experiences are for everyone not just those who excel in the area. For example, phrases such as the following need to be kept in check: "He's our athlete," "She never gives us any problem," "He's the smart one."
- Instead of worrying about spending EQUAL time with children, focus on individual needs and showing children that they are loved UNIQUELY. For instance, tell a child why you think he is a terrific person.
- Sibling Support Project – www.siblingsupport.org. Classes and workshops, books, and other resources, for siblings and parents of a child with disabilities.
- Google “siblings of children with disabilities” TONS of resources online

What are some other sources of information and support?

- The National Information Center for Children and Youth with Disabilities (NICHCY) News Digest #11 Children with Disabilities: Understanding Sibling Issues delves into issues of siblings of children with special needs. This lengthy digest features several interesting articles, different points of view, suggestions for parents, and reviews research findings. It's available in text-only (17 pages) and PDF (12 pages) versions.
- The Sibling Support Project is a national program for brothers and sisters of people with special health and developmental needs. The Project's main goal is to promote peer support and education programs for brothers and sisters of people with special needs. They create books and newsletters to raise awareness, conduct workshops, and sponsor listservs. The website has a great list of books and other resources for children and adults. You can also find local events for siblings of special-needs kids. They also run a listserv just for kids, called SibKids.
- Q&A about siblings of people with mental retardation from the ARC. Also available in Spanish.
- Siblings of Children with Special Health and Developmental Needs: Programs, Services and Considerations
- Siblings for Significant Change is a national network that works to build mutual support for siblings of handicapped persons. They train siblings to be advocates for themselves and their families, and provide networking for support and socializing, quarterly meetings, newsletter, on-line network, speakers bureau, audio-visual material, and local chapters. Write: Siblings for Significant Change, 250 Fifth Ave., Room 627, New York, NY 10118. Call 1-212-645-2600 or 1-800-641-8251.
- "SNIP, the Sibling Need and Involvement Profile" is a tool you can use with your child to provide you with feedback and start needed discussion. You can order a copy of SNIP for \$2.00, which includes postage and handling, from the Nisonger Center Publications Office, The Ohio State University, 357E McCampbell Hall, 1581 Dodd Drive, Columbus, OH 43210-1257, USA. Call 614-247-7900 for information.

What are some recommended books on parenting siblings of kids with special needs?

- It Isn't Fair! Edited by Stanley D. Klein and Maxwell J. Schleifer. *Presents a wide range of perspectives on the relationship of siblings to children with disabilities, written by parents, young adult siblings, younger siblings, and professionals. The issues of fairness, expectations, rewards, punishments, caretaking responsibilities, and negative feelings are all thoroughly discussed.*
- Living with a Brother or Sister with Special Needs: A Book for Siblings, by Donald Meyer and Patricia Vadasy. *May be useful for both parents and children to read.*
- Brothers and Sisters: A Special Part of Exceptional Families, by Thomas Power and Peggy Gallagher.
- Profile of the Other Child: A Sibling Guide for Parents, by Frances McCaffrey and Thomas Fish. *This pamphlet may be available for \$2.00 from the Nisonger Center at Ohio State University.*
- Siblings Without Rivalry, by Adele Faber and Elaine Mazlish. *A real classic—a quick and easy read with powerful techniques you can start using right away.*
- How to Cope with Mental Illness in Your Family: A Self Care Guide for Siblings, Offspring and Parents, by Diane Marsh, Rex Dickens and E. Fuller Torrey.
- When Madness Comes Home: Help and Hope for the Children, Siblings and Partners of the Mentally Ill, by Victoria Secunda.

What are some titles of books for kids about special siblings?

Sometimes reading book with your child can open up a dialog about:

issues they are facing. Check out some of these books and see if they help get your kids talking about their feelings and experiences. Here are a few titles. Many more are listed on the [Sibling Support Project](#) resources page.

- **Well Paint the Octopus Red**, by Stephanie Stuve-Bodeen
Ages 3-7. Emma's baby brother Isaac is born with Down syndrome.
Ben, King of the River, by David Gitaldi.
- Ages 5-8. Chad, the older brother of a developmentally disabled boy, narrates this story about the family's first camping trip. Chad's frank story-telling gets across the highs and lows of the trip and of life with Ben, and his mixed emotions. Includes a page of tips for siblings of kids with special needs.
- **My Brother, Mätthew**, by Mary Thompson
Ages 4-11. Offers a sibling's point-of-view of the ups and downs of life when your brother is born with a disability. David, the older brother, wryly shares the worry, impatience, feeling left out, being talked down to by grown-ups—and the positive ways in which he has built a unique relationship with his brother.
- **Way to Go, Alex!**, by Robin Pulver.
Ages 4-8. Carly feels the dual emotions that many siblings of special-needs children may feel. Her older brother Alex participates in the Special Olympics.
- **Sara's Secret**, by Suzanne Wainos.
Ages 7-9. Sara's secret is her little brother Justin, who has cerebral palsy and mental retardation. Her love for him and the discomfort he causes her at school are realistically portrayed.
- **My Sister, Annie**, by Bill Dodds.
Ages 8-15. Twelve-year-old Charlie's sister Annie has Down syndrome. This is a thoughtful novel about his growing pains and struggle to accept a sister who is "different".
- **Views from Our Shoes: Growing Up With a Brother or Sister With Special Needs**, edited by Donald J. Meyer
For ages 7 and up. 45 children aged 4-18 contributed to this book. They share their experiences as the brother or sister of someone with a disability—the good and the bad, as well as many thoughtful observations.
- **The Summer of the Swans**, by Betsy Byars
Ages 9-15. A 14-year-old girl's mentally retarded little brother gets lost, and the family realizes how much they really appreciate him.
- **A Real Christmas This Year**, by Karen Williams.
Ages 9-15. Megan's special-needs little brother makes life harder on her family, just when she already has lots of things going on in her own life. Realistically portrays the life of the family in caring for a disabled child.
- **Welcome Home, Jellybean**, by Marlene Shyer.
Ages 9-15. Neil's sister, Gert, comes home from an institution to live with their family.
- Lots more kids' books and a list of publishers in this [bibliography](#) from NICHCY

How to Help Children Cope

1. Talking to them when they act out can help them deal with their feelings. Listen to them.
2. Talking about your own feelings helps, too. By modeling good communication skills, you can teach your children to recognize and express their own feelings.
3. Remember that all siblings "hate" each other sometimes. Must give kids room to be normal kids.
4. Look at the situation from their point of view. (Remember how normal you wanted to be at that age.)
5. Balance the special things the child with the disability gets with special things for the siblings.
6. Giving each of the children special time alone with mom and dad helps defuse the jealousy.
7. Giving the other children specific tasks to do to help their sibling can also defuse resentment over his extra attention. (But not too many tasks.)
8. Parents should not have a double standard for the children in the family. (Egs. All should be disciplined the same.)
9. Be open and honest. Help the children understand the disability. Share information.
10. Welcome other children and friends into the home.
11. Require the child with the disability to do as much for himself as possible.

12. Recognize each child's unique qualities and family contribution.
13. Recognize special stress times for siblings and plan to minimize negative effects.
14. Provide opportunities for a normal family life and normal family activities.
15. Join sibling-related organizations.