Spring **The Reference Shelf** 2003

The Strength of Siblings

By Julie Smith, program coordinator, SESA

Many of our earliest — and most memorable — lessons in sharing, trust, respect, patience, tolerance, jealousy, and frustration have been learned through everyday experiences with brothers and sisters. We should expect no less from siblings that have a brother or sister who experiences special needs. In fact, we as parents and service providers need to heighten our sensitivity to the sometimes subtle and well-hidden complexities a child with special needs brings to the sibling relationship.

For over 10 years, I have been privileged to be invited into the homes and lives of many Alaskan families. During this time, I have had the opportunity to know the siblings of the children I've worked with and have observed the spectrum of feelings and behaviors that siblings can experience. As with typical sibling relationships, brothers and sisters of children with special needs can motivate their siblings and facilitate on-going growth and development. Siblings can be considered socializing agents, providing the first and possibly most intense peer relationships children experience (Powell & Gallagher, 1993; Zukow, 1999). We cannot afford to disregard the incredible resource siblings of special needs children represent.

However, the art is in the balance — we also cannot afford to place undue stress on these sibling resources. Research shows that brothers and sisters of children with special needs experience guilt, embarrassment, resentment, and pressure to succeed (Meyer & Vadasy, 1994). All of these feelings are typical, and it is important to let siblings know that it is okay to feel these emotions regarding their brothers and sisters — and that those feelings might change many times in the course of a single day.

Since attending a Pathways Conference session focusing on brothers and sisters of children with special needs, I have made a conscious effort to include siblings in my home visit plans. I often find that if I bring a book, puzzle or special toy just for the sibling, they are very excited that they have been remembered and this reduces the need to vie with their sibling for attention. It makes a difference to parents, too — they appreciate the fact that their other children are acknowledged and accepted as an intrinsic part of the family. Knowledge of the unique concerns and opportunities siblings of children with special needs experience has changed my perspective and enhanced my relationship with siblings I meet in the course of my work.

Research has also found that siblings of children with special needs have unusual opportunities throughout their lifetime. These include maturity, social competence, insight, appreciation for their sibling's abilities, tolerance, and pride (Meyer & Vadasy, 1994). As parents, educators, therapists and medical providers we, too, have the unique opportunity of reaching out to the siblings of those in our care. It doesn't take much effort to ask a sibling how they're doing, or thank them for all the things they do for their brother or sister; the acknowledgment of their contributions, concerns and needs will enrich their self-concept and well-being. It is my hope that the information in this insert will help us reflect on the expectations held for siblings and create strategies to provide them with encouragement and support.

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Meeting the Unique Concerns of Brothers and Sisters of Children with Special Needs

By Donald Meyer, director, The Sibling Support Project, The Arc of the United States

In the United States, over 5.8 million children have disabilities. Most have 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. These 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 Remsberg, 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.

Within the family, siblings will likely spend more time with the child with special needs than any other person, with the exception of the child's mother. And, because the sibling relationship is generally the longest-lasting relationship in the family, brothers and sisters are likely to experience these concerns for a long period of time. Sibling issues are lifespan issues: preschool age siblings will grapple with issues not faced by their peers in the community; so will siblings who are senior citizens. Yet, many 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.

Below 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

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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 a 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.

> *Recognition has been slow in coming that the sisters and brothers of children with mental retardation and/or other handicaps are important people in the total picture of human exceptionality. They have their own special needs, which must be recognized and met. Their ability to contribute to the growth and happiness of their handicapped sibling is substantial. Their investment is large, and they have the right to assistance and support.*
>
> *Allen C. Crocker, 1983*

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. Children's 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.

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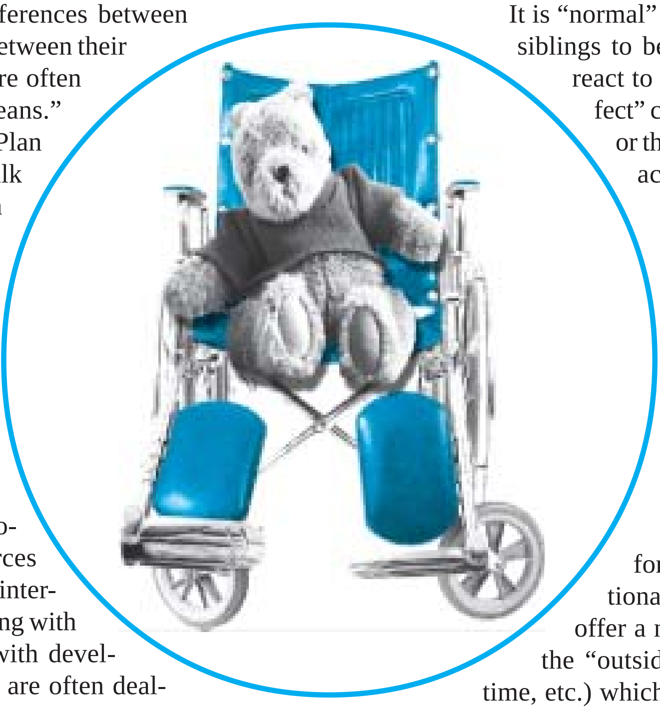
THE UPLIFT EDUCATIONAL SERIES:

Siblings

Parents of siblings of children with emotional and behavioral issues are often concerned about the effect of being raised in a home that is often chaotic and stressful. Siblings feel many of the same things that parents feel, with less understanding of how to deal with those feelings. The following ideas on siblings may help with some of those concerns.

Awareness:

Siblings are aware of the differences between themselves and their siblings and between their family dynamics and others, but are often unsure of what the disability "means." Explain the disability to siblings. Plan one-on-one time with siblings to talk about their concerns. They often feel left "out of the loop." BUT also give them time where the child with emotional/behavior issues is NOT the main issue. As parents, it is easy for us to become overfocused on the child with the most obvious needs, but siblings need time to relax and feel they are important in our lives as well. Get books and videotapes about the emotional/behavior issues (see resources list). Arrange time for siblings to interact with other siblings that are dealing with disabilities. Siblings of children with developmental and physical disabilities are often dealing with many of the same issues.



Feelings:

Encourage siblings to talk about and understand their feelings— both positive and negative. Children with behavior/emotional issues are often frustrating and embarrassing for their siblings, just as they are for parents. Siblings often feel as though they are the only one dealing with the highly charged emotions that seem to follow the child with emotional or behavior issues. Siblings may feel anger and jealousy because their parents are distracted. Disciplines may not be consistent with all children in the family. There may be an imbalance in the praise parents give the siblings. It is natural to "expect" the sibling to behave. They may feel grief over the loss of a "normal" family. They may feel guilty about their feelings toward the child with emotional or behavior issues. Allow and encourage siblings to share their feelings without judging them. Realize that the feelings a sibling may express today, may not be the same feelings they express later. Allow the siblings and peers to tell their siblings how they feel. Encourage positive comments and gestures. This is an effective way of shaping behaviors of the child with emotional or behavior issues that may not be socially expectable. Listen carefully and if necessary explain that parents don't always have all the answers. Parents may not be able to "fix" the sibling's feelings. Don't assume that siblings are upset because of the child with emotional or behavior issues. Siblings have lives that are beyond their sibling with emotional or behavior issues. Some children are more comfortable than others in expressing their thoughts and feelings.

Expectations:

It is "normal" (and easier) for parents to expect siblings to be "little adults." Siblings tend to react to this by either becoming the "perfect" child (top grades, peacemaker, etc.) or the "problem" child (argumentative, acting out behaviors, etc.). Allow siblings to be themselves without the adult expectations. They may be confused about their place in the family. Arrange for the sibling to have "alone" time with their friends without the child with behavior or emotional issues.

Helping:

Include siblings in strategies for dealing with the child with emotional and behavioral issues. They can offer a new perspective and are aware of the "outside" environments (school, social time, etc.) which needs to be taken into consideration. This allows siblings to feel as though they are "a part of," rather than "a part from." Explain that "raising" the child with emotional or behavior issues is the parents' job and that responsibility is not for the sibling. Pay close attention to how often you ask siblings to help, as well as what you ask them to help with. Use babysitters, rather than always depending on the sibling.

Advocacy:

Siblings can offer a new perspective and should be allowed to share their opinions when they are ready (family plans, Individual Education Plan meetings, social interactions, etc.). As parents, it may not always be what we want to hear, but it should be valued. DO NOT put the sibling in the position of informer or expect them to always want to talk about their sibling. They need their time apart from the issues, as do parents.

Forgive yourself:

As parents, we often realize that we have made mistakes when raising all of our children. That is part of the process. Make an effort to change or correct your mistakes and realize that you

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will probably fall back into "old" patterns. People under stress say and do amazingly stupid things. Dwelling on those mistakes only creates more stress. Train yourself to value each child's individualism. Realize that parents go through a grief process and that is normal.

Take care of yourself:

Children learn how to take care of themselves by watching their parents. Re-evaluate "family" outings. What works for family members? There is nothing wrong with admitting that some time alone or with your spouse is needed. When with your spouse, take time to keep in touch with each other, without always dwelling on your children and their problems. Take time to understand your partner's feelings. Fathers deal with issues in completely different ways than mothers and often feel left out and unnoticed. Family counseling may be needed for family members to understand and learn coping skills.

Maintain your sense of humor:

Having a child with emotional or behavior issues is like looking at your hand one inch from your face—that's all you can see. Consciously, move your hand as far as you can reach and you'll realize that there is a whole world out there. Your child with emotional/behavior issues is a small part of the world, community and family. Realize that the stress and problems are natural under the circumstances, but that there is more "out there." Laugh often—it's therapeutic. Find joy in life and hang on to that joy. Value each family member for their individualism.

Learn all you can learn:

Take advantage of conferences and workshops available on disabilities to learn new strategies. There are many overlapping issues between the disabilities. Read books and magazine articles to gain a new perspective. Pick up related brochures in doctor offices. Talk with other parents dealing with similar issues. Join a support group. Research the Internet, but realize that not all information is accurate—check it out!

Re-evaluate often:

Are your expectations realistic? Do you assign roles to the sibling that aren't consistent with their personalities? Do you demand your children always like each other and not share their feelings? Do family members respect each other? Do your children realize that "fair" is a different concept from "equal?" Do you expect the sibling to give in to make life easier? Are "family" times fun or stressful? How could they be altered? Is a family dinner or vacations necessary for your family? Are your expectations for your family based on unrealistic concepts? Are you valuing all members of the family, including yourself? Keep a journal to see progress in behaviors.

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When is it My Turn? Sibshops: A Special Time for Siblings

By Julie Smith, program coordinator, SESA

Sibshops are opportunities for brothers and sisters of children with special health and developmental needs to obtain peer support and education within a recreational context. The Sibshop model was developed by Don Meyer of the Sibling Support Project, and has been implemented worldwide. Mr. Meyer offers this description of Sibshops:

> *Sibshops are lively, pedal-to-the-metal celebrations of the many contributions made by brothers and sisters of kids with special needs. Sibshops acknowledge that being the brother or sister of a person with special needs is for some a good thing, others a not-so-good thing, and for many, somewhere in between. They reflect a belief that brothers and sisters have much to offer one another—if they are given a chance. The Sibshop model mixes information and discussion activities with new games (designed to be unique, offbeat, and appealing to a wide ability range), and special guests.*

The goals of the Sibshop model include:

- √ providing brothers and sisters of children with special needs the opportunity to discuss common joys and concerns with other siblings,
- √ providing siblings an opportunity to learn how others handle situations commonly experienced by siblings of children with special needs,
- √ providing siblings with an opportunity to learn more about the implications of their sibling's special needs,
- √ providing parents and other professionals with opportunities to learn more about the unique concerns and opportunities frequently experienced by siblings of people with special needs.

There is currently one Sibshop offered in Alaska, and it is through HOPE Community Resource's Family Support Project in Anchorage. A group is offered once a month for 6 to 9 year-olds, with plans to add another group for 10 to 13 year-olds in September, 2003. The Sibshops are facilitated by Julie Smith, who has received training from Don Meyer about the Sibshop model. For more information, contact Yvette Wilson, HOPE Community Resources, at (907) 272-5912 or ywilson @hopealaska.org.

Don Meyer's book **Sibshops: Workshops for Siblings of Children with Special Needs** provides comprehensive information on how to organize and run Sibshops. This book, along with the Sibling Support Project website (www.thearc.org/siblingsupport), are the best resources if you are interested in beginning Sibshops in your area.

Sibling Needs

Helpful Information for Parents

The Importance of Information

Unlike their parents, siblings may have no knowledge of life without a brother or sister with a disability (Featherstone, 1980). McKeever (1983) tells us that siblings generally are poorly informed about disabilities. Yet siblings' needs for information may be as great, or greater than those of parents, because of their identification with their brother or sister with a disability. It is important to bear in mind that they have limited life experiences to assist them in putting a disability into perspective (Featherstone, 1980). Parents should respect the nondisabled sibling's need to be recognized as an individual who has concerns and questions as well as his or her right to know about the disability. Nondisabled siblings may require information throughout their lives in a manner and form appropriate to their maturity.

Information puts fears into perspective. In most instances, simply knowing the facts about disability or chronic illness takes away the sting of embarrassment, as well as uncertainty and fear. While embarrassment can and does occur in many situations over the years, knowledge can help one cope.

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What do you tell...

By Derenda Timmons Schubert, Ph.D.

Preschoolers (before age 5)

Children in this age group are unable to articulate their feelings about things, so they will likely show their feelings through behaviors. They will be unable to understand the special needs of their sibling, but they will notice differences and try to teach their brother or sister. Children of this age are likely to enjoy their sibling because they have not learned to be judgmental, and their feelings toward their siblings will likely be linked to "normal" sibling interactions.

Elementary School Age (6-12)

These children start venturing out into the world and become acutely aware of the differences between people. They have the ability to understand a definition and explanation of their sibling's special need as long as it is explained to them in terms they can understand. They may worry that the disability is contagious or wonder if something is wrong with them, too. They may also experience guilt for having negative thoughts or feelings about their sibling as well as, guilt for being the child who is not disabled.

Some typical responses of children this age are to become OVER helpful and well-behaved or to become non-compliant in order to obtain a parent's attention. Throughout this age span, the children will have conflicting feelings about their sibling. This happens in sibling relationships that do not include a disability, too.

Adolescents (13-17)

Adolescents have the capability of understanding more elaborate explanations of the particular disability. They may ask detailed and provocative questions. The developmental task of adolescence is to begin discovering oneself outside of the family. At the same time, conformity with a peer group is important. Therefore for children this age, having a sibling who is different MAY be embarrassing in front of friends and dates. They may feel torn between their desire for independence from the family and maintaining a special relationship with their sibling. They may resent the amount of responsibility, and they may begin worrying about their sibling's future.

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Life With Tanner

Tanner is the 10-year-old middle sibling of three boys. He had a premature birth, resulting in multiple disabilities which include cerebral palsy, seizure disorder and vision impairment. His younger brother Tommy and older brother T.J. share some thoughts on their lives with Tanner.

By Tommy as told to Julie Smith

My name is Tommy and I'm six years old. I like to go swimming and to Chuck E. Cheese.

Tanner can't talk or walk. He was born like that. My mom explained it to me. He gets to lay down in the chair all the time and I have to go to school. I have to do math at school and Tanner doesn't have to do math.

I tell mom what he's saying — when he's hungry and all that. I can understand him. I like to play with him. I like to help him push around on his little rolly-thingy [therapeutic crawler].

T.J. watches Tanner and I want to stay home but my mom or dad says I have to go with them. I like going with Tanner to the doctor or therapy.

I like to play with him. I like to take care of Tanner.

Sometimes I don't like it when he bites his fingers and it gets all yucky.

My friends don't make fun of Tanner. They don't talk to him.

I think my mom and dad should spend more time with Tanner teaching him how to kind of walk.

It's fun to go to Sibshop. I like to make stuff. I like to go there and all that. I like to play with things and make things. We all have brothers or sisters like Tanner.

I would wish for Tanner to play with us and walk and talk.

Siblings of Children with Disabilities

"Yes, I have other children but Susie needs so much care: doctor's appointments, therapy, nursing, special meals, clothes and lots more. I am exhausted."

And the other children are:

- exhausted,
- isolated,
- afraid they might develop the disability,
- jealous over the attention the disability generates,
- embarrassed,
- angry, and pressured.

They need support and understanding but most of all they need awareness that they also have needs. Sometimes the simple acknowledgment of that can ease a great deal of frustration.

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By T.J.

Hi - my name is T.J. and I am 14 years old. I like to play hockey, I've been playing since I was two. I've been asked to talk about my brother Tanner who has cerebral palsy.

Tanner was born when I was about four years old, so I don't really remember what my mom told me about him. I just knew he was a little different. My life hasn't really changed with him having this disability. Kids in my neighborhood treat him as any other person they know. Sometimes it kind of stinks that I can't play basketball and hockey with my brother, and my friends can with theirs.

The good things about having a brother like Tanner is you take care of him. You can talk to him and tell him anything that you want. The not so good parts about having a brother with special needs is he can't talk back to you. Another thing is he can't walk around and play outside with you. Parents with kids that have special needs should just take care of them as best as they can. Teachers, doctors, and professionals should also do what they can to make them as happy as possible.

If I had a wish for Tanner I would wish for him to be able to talk and be pain free.

That's all I have to say so I thank you for your time.

Looking Ahead

One of the unique concerns of brothers and sisters of people who experience disabilities is considering what will happen in the future. They wonder what their responsibilities will be when their parents can no longer care for the special needs sibling, and how those responsibilities will impact their opportunity to attend college or begin their own families. An adult sibling offers her experiences and ideas for how families and providers can help prepare for the adult lives of all the siblings...

Planning for the Future: An Adult Siblings' Suggestions

When I was about eleven, my older brother and I developed a scheme to dupe my mom. One of us would find an excuse to keep her out of the house as long as possible while the other would "teach" our little sister how to climb the stairs. Karen has severe disabilities and Mom was afraid she would really hurt herself falling down the stairs. My brother and I were typical kids, we didn't think about the risks, just that all kids need to get around by themselves and Karen should learn to climb stairs. I can't recall how many times Karen tried and tried (and fortunately I've just about forgotten how many times she bounced off the bottom step), but I remember vividly the day my brother brought Mom to the stairs and said, "Look what Karen can do!" That was a red letter day for all members of our family.

It is essential to avoid seeing the person with a disability as "the dependent." The sibling with a disability should be empowered through early training and attitudes to act as independently as possible, and to make his or her own choices; as with all of us, some choices will be mistakes. It is equally important to avoid making the sibling without disabilities adopt a parental attitude of responsibility toward the sibling with disabilities.

> "**P**arents have to sit down and talk to the brothers and sisters who are nonhandicapped about what the handicap really means. **K**ids don't automatically understand it by themselves."

I want to be involved in making crucial family decisions. If a family member has a disability, it is important to involve that person, as all others, in any decision making.

When I was young I used to get pretty good grades, but I went through a very painful period wondering when my grades would change and I would "grow retarded" like my sister. I never talked with anyone about those fears. Initially, I was afraid to talk about this because I dreaded the answer. Later, when I understood what retardation was, I felt guilty that I had such thoughts. As I grew older, one of my most pressing concerns was what would happen to Karen as she became an adult. I was concerned about my family's ability to provide adequate care for her and where she would live and work as an adult.

I strongly recommend that siblings without disabilities, as well as persons with disabilities, be involved in planning for the future as soon as they are old enough to understand the issues. Thus these financial and future planning discussions will most likely begin during early adolescence. The teenage years are a terrible time to have to cope with mortality. However, I can promise you that sitting down and getting these issues out into the open will be much easier in the long run for everyone.

I've had many sleepless nights, starting when I was a teenager, working through these problems by myself, afraid and overwhelmed, before my family started discussing the issues more openly with me.

Introduction written by Julie Smith, program coordinator, SESA

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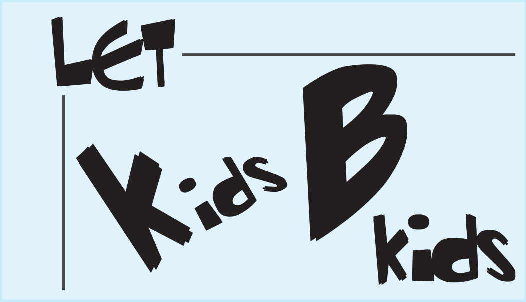
Consider This

From Sibs to Parents

- Give children equal responsibilities based on abilities.—Cassie and Mikelle Russell
- Remember that being a sibling to a brother or sister with special needs is an ever changing process.—Kitty Porterfield.
- Let kids be kids. Some teasing and fighting is part of a healthy family. — Vida Arnparo Ferlow
- Don't put your head in the sand. You will not live forever. Things will not magically fall into place for your child after you are gone when no planning has taken place. Plans must be made. The sooner you start, the better.—Susan Duvall
- Treat each child as a special child whether or not they have a disability. All children need to be recognized as a special person.—Linda Haley
- Update your plans for the future as your children grow or as circumstances change. — Susan Duvall.
- Treat each child as a special person. Regardless of their abilities, each child needs to be recognized. — Linda Haley
- Just keep trying. Your children will feel your efforts and find them very comforting.—Kitty Porterfield.
- Take care of yourself. Sometimes this is hard, but it is very important.—Susan Duvall
- Talk about how you're feeling. Find an adult or another sibling to talk to, write to, or send e-mail to. You are not alone!—Cassie and Mikelle Russell
- Let your parents know when you need extra attention.—Cassie and Mikelle Russell
- Remember, you have a right to your own friends, interests, and to pursue your own goals just like any other brother or sister would.—Jim Botta
- If you are feeling neglected because your parents are spending a lot of time with your brother or sister with a disability, make a list. First, list the things you get to do that he or she can not. Second, list the special things your parents do with or for you. Then ask yourself: do you really want to be treated exactly the same as your sibling or the way they already treat you?—Lisa Donohue (age 11)
- Encourage your parents to make plans for your sibling and to include you in the process.—Susan Duvall

Tips for Parents

- Do not force siblings to help with your child with special needs. It needs to be a choice.
- Talk with your children about what is happening with their sibling in a way they can understand. Be open and honest.
- Allow and encourage siblings to express their feelings. Feelings of hate, jealousy, resentment and even depression are not uncommon for siblings.
- Help each child, with or without a disability, explore and cultivate their own interests, outlets, and hobbies.
- Invite siblings to be involved in the decision-making process, including family decisions, IEP/IFSP meetings, medical concerns, and so on.
- Reinforce positive behavior, advocacy, and compassion. Surround yourself with people who are positive. Encourage your children to do that too. Attitudes make a difference.
- Celebrate each child's accomplishments.
- Keep the challenges of parenting in perspective and try not to let them "swallow up" you or the siblings too.
- When you talk about plans, procedures or a new diagnosis, have children repeat what they are hearing to you. Reflective listening and repeating what is understood is a helpful tool.
- Try to read your children's cues when they need extra attention. This may happen during stressful times when you, yourself need extra attention. Tell your children without special needs to let you know in a positive way, when they are feeling that they are not getting enough attention. When we were involved in a due process hearing, I told my children, "We are going to be very busy. I really need you to let me know when you're feeling you're not getting the attention that you need. Look me in the eyes and tell me!" It worked. Or perhaps you could develop a cue to indicate this.



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SCHOOL-BASED STRATEGIES

By Dr. Thomas H. Powell, director, The Sibling Support Project, The Arc of the United States

> The key is an understanding teacher who is willing to listen.

To address the special problems siblings may experience in the school situation, intervention strategies have been developed that focus on the role of teachers, the parental role, sibling involvement in the IEP process, and the school structure.

Teachers

Both regular and special education teachers play a vital role in helping siblings deal with special problems. The teacher's assistance is enhanced by attention to a number of strategies.

Recognizing the Sibling as an Individual Teachers should respect the individuality of each family member, recognizing individual contributions and strengths. Because some siblings may be preoccupied with the notion that they, too, are considered handicapped by others, the teacher must be particularly sensitive to the sibling's need to have his or her own achievements and individual differences recognized. This recognition can be conveyed through conversations with the sibling that revolve around the sibling's activities, not the activities of the handicapped child. Calling attention to accomplishments, asking questions, and providing words of encouragement and praise communicate a respect for the sibling as an individual.

Demystifying Special Education Special education teachers are in the best position to help siblings understand what the handicapped child will experience at school. Michaelis (1980) has suggested two strategies to help demystify special education. The first strategy is informal in nature and readily implemented; in fact, it calls for the special education teacher to simply be available for the sibling. A brief, guided walk through the classroom and straightforward explanations of materials and content can be very helpful to siblings. Friends of the sibling should be welcome to come on informal tours. Michaelis's second strategy involves the establishment of a "sibling school." A sibling school is a more structured gathering where siblings have an opportunity to meet one another and learn about the special education program and the staff who work with their brothers and sisters.

Being Available to Talk Sometimes siblings need someone with whom to talk who will understand their special needs and react in a nonjudgmental manner. As Michaelis (1980) has noted, a sibling may have difficulty talking about feelings and problems with parents, and the teacher is a likely and available adult alternative. Having someone who will truly listen to problems and concerns and offer practical advice may help make the difference between a smooth and an uneven adjustment for a sibling with a handicapped brother or sister. This informal counseling can help a sibling deal more effectively with problems. The key is an understanding teacher who is willing to listen.

Providing "Space" Closely related to "being available" is sensing when the sibling would rather not be involved with teachers, especially special education teachers. Some siblings prefer not to be reminded of their handicapped sister or brother and actively avoid any association with the special teacher. Sensitive teachers will recognize this and not presume that all siblings need or want to be involved with the special classroom.

Talking with Parents When arranging meetings with parents, teachers should remember to schedule separate conferences for each child, or to at least discuss each sibling separately within the same meeting. Conferring about one child at a time helps to reinforce the idea that children, even brothers and sisters, are unique individuals. Parents need to hear about the accomplishments of each child. By noting, for instance, the accomplishments of a nonhandicapped sibling in an informal meeting with parents, special education teachers can help parents feel recognized for some of their successful parenting skills that might otherwise have been overlooked in the midst of concentrated efforts to help the child with a handicap.

Providing Educational Experiences Jones (1983) has described an experience in which one of her children, Aaron, was actively encouraged to discuss his brother's handicapping condition, Down syndrome, as part of a science lesson on genes and chromosomes. This project grew into a formal report and the sharing of a photo album that depicted Aaron's brother, Jay, at several stages of development, as well as interacting with others in a natural way. According to Jones, "the children at school not only enjoyed the album but learned by looking at the pictures that Jay was pretty much a regular little guy." Similar experiences could be developed by regular classroom teachers, provided the sibling is willing to share such experiences and knowledge. To ensure a successful experience, the sibling's teacher may wish to consult with the special education teacher when planning the project.

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RESOURCES

Internet Sites

The Sibling Support Project: The definitive source for all things sibling! This site was created by Don Meyer, the creator of Sibshops and author of many books and articles addressing the unique needs of brothers and sisters of siblings with special needs. www.thearc.org/siblingsupport

The Sibling Project: This Australian project has a website that contains information for siblings, parents and providers about meeting the needs of special needs siblings. www.wch.sa.gov.au/sibling/

Band-Aides and Blackboards: When Chronic Illness - Or Some Other Medical Problem - Goes To School: This is a wonderfully comprehensive site that provides kid-friendly information on a variety of disabilities and medical concerns. It also has a section specific to siblings. It was created by Joan Fleitas, who is a nurse that teaches at Fairfield University in Connecticut. www.faculty.fairfield. edu/fleitas/contents.html

A Sibling's Site: This site was created by a 16-year-old young woman who has a brother with a form of arthritis. She created this site as a place for support for siblings of children with special needs or chronic illnesses. She has information about special education, and there is also a message board community of siblings posting questions, answers, and support. www.asiblingssite.com

Johns Hopkins Children's Center: Child Life – Sibling's Guide: This page has hints on how to prepare a child when his/her sibling will be entering the hospital. www.hopkinschildrens.org/pages/clinical/childlife_ sibling.cfm

"Sibling Center" on The Center for the Study of Autism website: This site focuses specifically on autism issues, and has a "Sibling Center" with a number of informational sections and links. www.autism.org/contents.html

Ohio SIBS — Special Initiatives by Brothers and Sisters: This organization is at Ohio State University and focuses specifically on the issues and needs of adult siblings. As parents grow older and people who have special needs become adults, the concerns of their siblings turn to housing, vocational, and long-term care needs. This site provides information and resources to help address these concerns. They also have a conference for adult siblings. www.ohiosibs.org

Living with Disabilities: Your Family's Web Guide for Living and Learning Together: This site has an extensive list of books and publications that are appropriate for siblings at many ages and developmental levels, as well as resources for parents and professionals. www.pediatricpt.com/articles/siblings.htm

Siblings: Brothers and Sisters of People Who Have Mental Retardation: This web page has frequently asked questions on the impact of having a sibling who experiences mental retardation. www.thearc.org/faqs/sibling.html

IRSC: Internet Resources for Special Children: Along with sibling information, this is another site that has extensive information on disabilities, chronic illness, and special education. www.irsc.org:8080/irsc/irscmain.nsf

Family Village: This well-known site encompasses many aspects of the special needs community. They have a sibling section with links and recommended readings. www.familyvillage.wisc.edu/general/frc_sibl.htm

Siblings R Special 2: This site was created by a parent with the hope of having a warm and friendly place parents and caregivers can find support and share information with others in similar situations. www.geocities.com/Heartland/Bluffs/6928/index4.html

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Books/Publications for Siblings

Views from Our Shoes: Growing Up with a Brother or Sister with Special Needs. Edited by Donald J. Meyer. Published by Woodbine House, 1997.

Living with a Brother or Sister with Special Needs: A Book for Sibs. Donald Meyer and Patricia Vadasy. Published by University of Washington Press, 1996. [This book is out-of-print, but may be available through sources that sell previously owned books.]

What About Me? Growing up with a Developmentally Disabled Sibling. B. Seigel and S. Silverstein. Plenum Press, 1994.

Don't Forget Me, Mommy! K. Anderson. Marin Publishing Co., 1982.

I Know I Made It Happen: A Gentle Book About Feeling Guilty. L.B. Blackburn. Centering Corp., 1991.

I'm the Big Sister Now. M. Emmett. Albert Whitman, 1989.

Finding a Way: Living with Exceptional Brothers and Sisters. M.B. Rosenberg. Lothrop, Lee and Shepherd Books, 1998.

Books/Publications for Parents & Professionals

Sibshops: Workshops for Siblings with Special Needs. Donald J. Meyer and Patricia F. Vadasy. Published by Paul H. Brooks, 1994.

Brothers, Sisters, and Special Needs: Information and Activities for Helping Young Siblings of Children with Chronic Illnesses and Developmental Disabilities. Paul H. Brooks, 1990.

Brothers and Sisters: A Special Part of Exceptional Families. T.H. Powell and P.A. Gallagher. Published by Paul H. Brooks, 1993.

It Isn't Fair! Siblings of Children with Disabilites. S.D. Klein and M.J. Schleifer. Published by Bergin & Garvey, 1993.

Profiles of the Other Child: A Sibling Guide for Parents. F.D. McCaffrey and T. Fish. Ohio Sate University Nisonger Center, 1989.

Siblings of Children with Autism: A Guide for Families. S.L. Harris. Woodbine House, (1994).

Facing the Crowd: Managing Other People's Insensitivities to Your Child. Shannon Books, 1997.

My Sister's Keeper: Learning to Cope with a Sibling's Mental Illness. M. Moorman. W.W. Norton and Company, Inc., 1992.

The Effects of Mental Retardation Disability, and Illness on Sibling Relationships: Research Issues and Practices. Edited by Z. Stoneman and P. Berman. Paul H. Brooks, 1993.

Special Siblings: Growing Up With Someone With a Disability. Mary McHugh. Hyperion, 1999.

Mail Just for Sibs

(e-mail, that is)!!

The Sibling Support Project through the ARC has the only Internet ListServ for brothers and sisters of people with special needs.

By Julie Smith, program coordinator, SESA

A ListServ is a "mailing list" done through the Internet. If you subscribe to a ListServ, you can receive and send email to others and it will go to every person on the mailing list. SibKids and SibNet are designed specifically for siblings and it is your opportunity to "talk" with other siblings nation-wide. There are even siblings from Canada, Australia, and England! All you need to join is Internet access and an email address. If you don't have a computer at home, ask a teacher at your school or go to your local library and they should be able to help you.

You can talk about anything that interests you — music, your friends, school, your siblings with special needs. The great thing about this list is that everyone has a sibling with special needs — you get to talk to others who "get it." And, if you want, you can just "listen" — you can read the emails from other siblings and decide when you're comfortable and ready to join in.

The ListServ is a good place to go to learn lots of new things: you can ask questions about disabilities, how to talk to your parents about your needs, and how to handle situations when people stare at your sibling or ask you lots of questions about your sibling's disability.

SibKids is for younger siblings of kids with special needs, and you can find more information about SibKids at www.thearc.org/siblingsupport/sibkids.htm.

SibNet is for young adult and adult siblings and you can find more information about SibNet at www.thearc.org/siblingsupport/sibnet.htm.