
The Kinship of My Kids: A Mom's Perspective

by Melinda Shipman
CDBS Family Specialist

Mom, she's looking at me." "Mom, tell him to stay out of my room." As a parent of five children, I have many of the same experiences that other parents have. I have spent many sleepless nights with a sick child. I have waited up for teenagers to come home from dates. I have heard the complaints about the unfairness of sharing a room, the last piece of cake, my time. I have had to figure out how to provide school clothes for five kids when I don't even have enough money for one. I have also enjoyed the pleasure of pictures and "A" spelling tests on my refrigerator, choir performances, homemade valentines and hugs and kisses. Families with "typical" children who have a sibling who is deaf-blind also experience blessings and challenges that are unique.

The experience of having a brother like Adam, who is deaf-blind, has enriched the lives of my other children. All of them seem to have a spirit of tenderness and compassion that stands as an example to their friends, their teachers, the world around them—and to me. My two oldest, especially, have a wisdom and maturity I wish I'd had at their age (17 & 19). They are not only protective of their brother, but also of each other and anyone the world seems to pick on or attempts to cast out. The friends they bring home seem to be carefully chosen. In our home you are going to hear strange noises and see strange behaviors. Adam may climb in your lap and begin grinding his teeth, flapping his hands or engage in other types of self-stimulation. He may grab you by the hand and drag you somewhere and try to make you do something, and you have to figure out what that something is. You might have to go to the

mall or out to eat and have people stare at you or ask you questions. You might have to play Nintendo or watch a video with Adam standing right in front of your view. You'll have to learn a little sign language and patience and have a good sense of humor. Everyone that comes home with my kids accepts and is involved with the everyday uniqueness of Adam or we don't see them much. This isn't something I taught them; it is a benefit of knowing Adam.

My youngest daughter, Alex, has chosen a dual role with her older brother. She's both playmate and teacher. She and her older sister, Karianne, play school with Adam and use him as the baby when they play house. He never seems to get to be the dad or the teacher. However, like their older siblings, they are very demanding for time with me on their own and for time alone.

Because of Adam's special needs, ours is a very busy household. There always seems to be someone coming over or someone needing to go somewhere because of Adam. The lives of his siblings are frequently being interrupted by the tyranny of the urgent. Adam's brother and sisters often become overwhelmed and crave normalcy. They cry out, "Why does everything have to be about Adam?!" They need to go somewhere or be with someone that is totally disconnected from Adam and his issues. This doesn't always happen as it should and resentment builds and a sadness envelopes the household. We have to find ways to direct our time and energy into the non-Adam person so that Adam's brother and sisters can hang on to the spirit of tenderness and the wisdom that is theirs because of Adam.

Sibling Issues (continued from page 1)

It's not always easy and it's not always fun. Sometimes it's ugly and seemingly hopeless to think that you can have a dream of your own when your brother is deaf-blind. My kids want to know who is going to be responsible to care for Adam in the future. They want to know if they can dream a dream that doesn't include Adam. They want to know it's okay to not want to be connected to him in every aspect of their lives. They need a safe place to say it's not fun and to not have someone think they're less accepting and compassionate than they should be. I want to be able to do that too, so why shouldn't they? I think being Adam's brother or sister—when they like it and when they don't—makes them wonderful human beings.

Strategies for Enhancing Relationships Among Siblings

1. Listen to your children.
2. Encourage open and honest communication among all family members.
3. Provide children with accurate information at a level comparable to their understanding about the disability and other issues that you want to talk with them about.
4. Your children are children first. Allow them to enjoy their childhood. Give them permission to be children.
5. Remember that each sibling is an individual first with unique needs, experiences, and contributions to make. Each young person brings a unique gift to your family, something that enriches and brings joy to the lives of the individual family members of your family and the family as a whole.
6. Acknowledge all family members for their accomplishments, whatever they may be, and you will probably see more of them. Express your appreciation at the successes of each individual as well as your entire family.
7. Provide each child with the opportunity to see his/her strengths and gifts — their contribution to your family.
8. The quality of time you spend with each child is essential. You might consider arranging a special time and special activities to do with each of your children.
9. Give yourself and your children permission to dream about the future. If you are not used to dreaming about the future, it may be scary at first. Allow yourself to create a vision of the future, a positive future, for each individual member of your family and your entire family. Consider the elements that create quality of life—close relationships, good health, financial security, a home, a career, making a difference... Take action so that you and your children get closer to making these dreams real.
10. Encourage children to be as independent and competent as possible.
11. Encourage your children to make choices in life, in particular about the nature of their relationship within the family and with their sibling.
12. Explore community activities that your children might enjoy. Perhaps they could include recreation, music, a support group for siblings, etc.
13. When appropriate, request the support of other family members, parents, and professionals. It's okay to ask for what you want.
14. Remember that each individual within your family is changing as well as the family as a whole. Across the family life cycle, different issues may arise. Based on individual needs, explore a variety of resources.
15. Look to create situations where everyone can win.
16. Remember that your children look to you. You are a model for them.
17. Laughter—it's a wonderful way to live life.
18. Use everything that happens as a vehicle to learn, to your advancement.
19. Make sure that you take good care of yourself; that way, you can take good care of others.

From: "What is it Really Like to be a Sibling?" by Judy S. Itzkowitz, Ph.D. Sibling Information Network Newsletter, Vol. 9, No. 2, 1994.

Sibling Resources: By phone, fax, mail, and the Internet

The Sibling Support Project

Children's Hospital and Medical Center

P.O. Box 5371, CL-09

Seattle, WA 98105-0371

Voice: (206) 368-4911

Fax: (206) 368-4816

Email: dmeyer@chmc.org

Web: <http://www.chmc.org/departmt/sibsupp/default.htm>

Comprehensive information on sibling issues including SibShops and chatrooms.

Project LISN (Low Incidence Support Network)

The Exceptional Family Resource Center

9245 Sky Park Court, Suite 130

San Diego, CA 92123

Toll-free within California: (877) 268-8252

Fax: (619) 268-4275

[Website under construction]

Provides person-to-person support, central access to information and resources for families, care providers and professionals statewide who serve children with low incidence disabilities.

Family Village

Web: <http://www.familyvillage.wisc.edu/index.html>

A global community that integrates information, resources, and communication opportunities on the Internet for persons with disabilities, for their families, and for those that provide them services and support.

Sibling Information Network

249 Glenbrook Road

P.O. Box U64

Storrs, CT 06260-2064

Voice: (860) 486-4985

Fax: (860) 486-5037

Information, referrals, and resources for siblings of individuals with disabilities.

Looking for Good Times? Come to the CDBS 1999 Summer Family Camp!

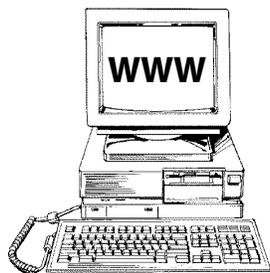
California Deaf-Blind Services is planning a family camp for the summer of 1999. The date and location will be announced soon. The camp will feature activities such as an astro-jump, campfires, arts and crafts, hiking, massage for families, parent information and discussion sessions, special groups for siblings, evening entertainment, and much more!

CDBS welcomes camp applications and queries from the following individuals:

- School-age individuals who are deaf-blind and their families
- Counselors/Support Service Providers (with or without previous experience)
- Nurses
- Lifeguards
- Individuals with experience in recreation leadership or art therapy
- Individuals who have expertise in deaf-blindness and who are interested in leading a workshop for parents

Family space is limited to those individuals who reside in California. CDBS welcomes counselors and other staff from out-of-state but they are responsible for their own transportation.

Applications, as well as a confirmed date and site for the camp, should be available by late March. For more information or an application, please contact Jackie Kenley at CDBS: 604 Font Blvd, San Francisco, CA 94132. Tel. within California 1-800-822-7884, ext. 21 V/TTY or outside California 415-239-8089, ext. 21, V/TTY, or via email: cdbsjk@sfsu.edu. Watch the CDBS website for more information: <http://www.sfsu.edu/~cadbs>



**Don't forget to check the CDBS website regularly
to keep informed of upcoming events!**

<http://www.sfsu.edu/~cadbs>

Sisters and Brothers Speak Out

Ben and Me

by Michelle Boisot

age 12

My brother, Ben, was born on September 20, 1989, when I was only three years old. I remember visiting mom and seeing Ben at the hospital on the day he was born. I wanted to take him from his hospital crib, hold and feed him and bring him home so we could play.

It wasn't at home that I spent my time playing with him or holding, it was in doctors' offices and their waiting rooms until he was three years old. Ben was born deaf, blind, and with physical and developmental disabilities.

My mom and I spent a lot of time talking during those first years. We still do, just not in doctors' offices so much anymore. During those conversations, we talked about the attention Ben received from the doctors, therapists, and my parents. From those conversations I came to understand that Ben was part of our family, and that was just the way it was. My parents make sure my brother gets the help, love, and care that he needs to survive, the same way I do. He just needs more. I discovered this is no reflection as to the amount of love my parents have for us. The fact is I loved him from the day my mom told me we were going to have a baby, and his disabilities didn't change that. Our life was just different than I had planned or thought it would be.

When I was in the first grade and Ben was three, mom asked me how I would feel if Ben went to the same school as me when he was old enough. I remember thinking, "What a funny question?" I told mom that I thought it

was only fair since my friends' brothers and sisters went to school with them.

I also remember mom telling me that Ben going to my school would be difficult because the school wasn't very excited about him coming yet. We would have to help them understand Ben was a kid too.

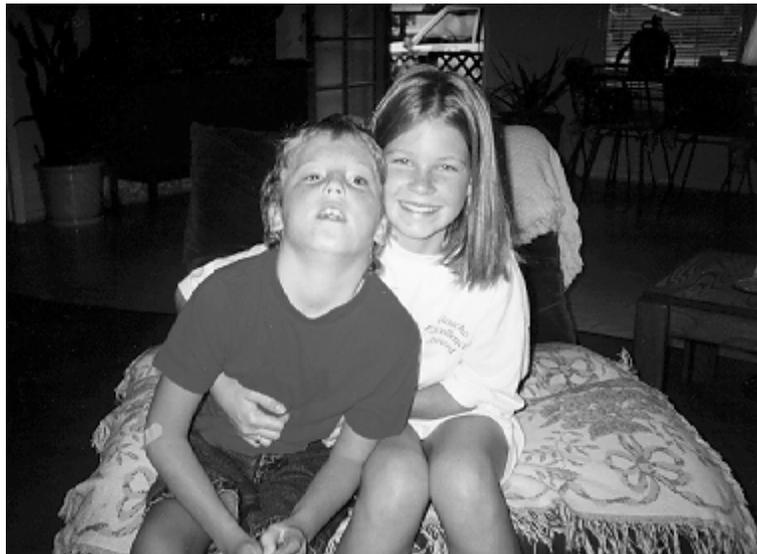
From then on I helped promote Ben's acceptance throughout the school until he became old enough for kindergarten. In first grade I started sharing my sign language skills with my friends, classmates and teacher. I brought in Ben's braces, glasses, contact lenses and

even Ben in on sharing day. I talked to my friends about the sibling support group I attended that went on fun excursions, and they saw me on the Easter Seal Telethon on TV. Whenever my parents brought Ben to a school event, I would hold his hand and give him hugs so people could see how important he was to our family. I became a celebrity and other kids

started telling me they wanted a brother like Ben, too.

By the time he started kindergarten, his teacher had fallen in love with him and I felt like I helped that happen. He made friends of the entire class because everyone thought he was "cool". Ben was included in everything the class did, even if it had to be adapted.

I remained a big part of Ben's inclusion throughout my elementary school years. This has definitely helped me to feel good about myself because I have been a part of his success too. Until I graduated last year, I taught sign language to the kids in Ben's class twice a week. The kids really enjoyed it and it helped me establish a good relationship with his peers.



Sisters and Brothers Speak Out (continued from page 4)

When I taught sign language to Ben's class, I remember feeling like a big kid because I was the oldest kid in the class at that time. All of his friends were so excited when I came, because they really wanted to know how to communicate with him, and they looked up to me. Ben's teachers like me too, so that made it a comfortable and enjoyable experience.

My friends have been accepting of Ben because he was around at school and they grew to understand and like him. If he had not attended the same school as me, my friends might ignore him because they might not understand him and feel comfortable. That would hurt a lot.

One summer, my friends, Ben, and I were in the pool and my mom wanted to take a picture. As we were getting ready for the shot, one of my friends pulled Ben into the picture so he would not be left out. My friends love Ben and accept him, in any way, shape, or form.

Ben's disabilities don't prevent our family from doing anything together. Ben loves the waterslide at Lake Lopez. Even though it is not easy getting him up and down the slide, he has a great time. We go to the beach, swim in the pool, we lose him at the grocery store sometimes, and we visit family out of town. His favorite rides at Disneyland are Splash Mountain and Space Mountain (not mine, they're too scary) and he loves to ride on airplanes. One day, in his wheelchair, he went through the doors to the warehouse at K-Mart and we lost him for a while. Whoops!

Today we have a great relationship and are good friends. We hang out and watch TV, and go on excursions. On Saturday morning, I like to watch TV in Ben's bed with him and, even though he can't see the TV, we like to hang out together anyway.

I feel important to Ben, although he can be a pain sometimes and I can get really mad at him. He is my family and I love him a lot, and I know he loves me a lot, too.



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- Add me to your mailing list.
- Note change of address.
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From Michael's Brothers

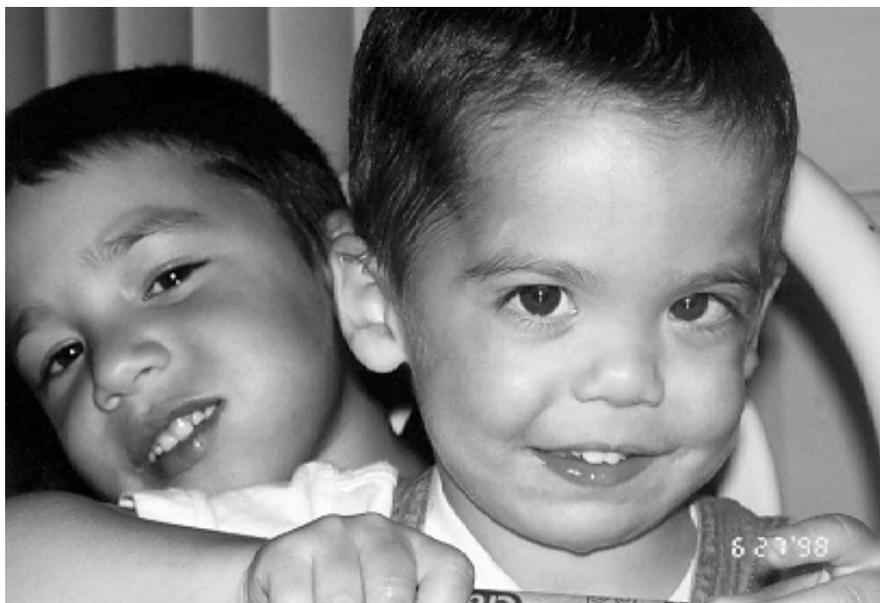
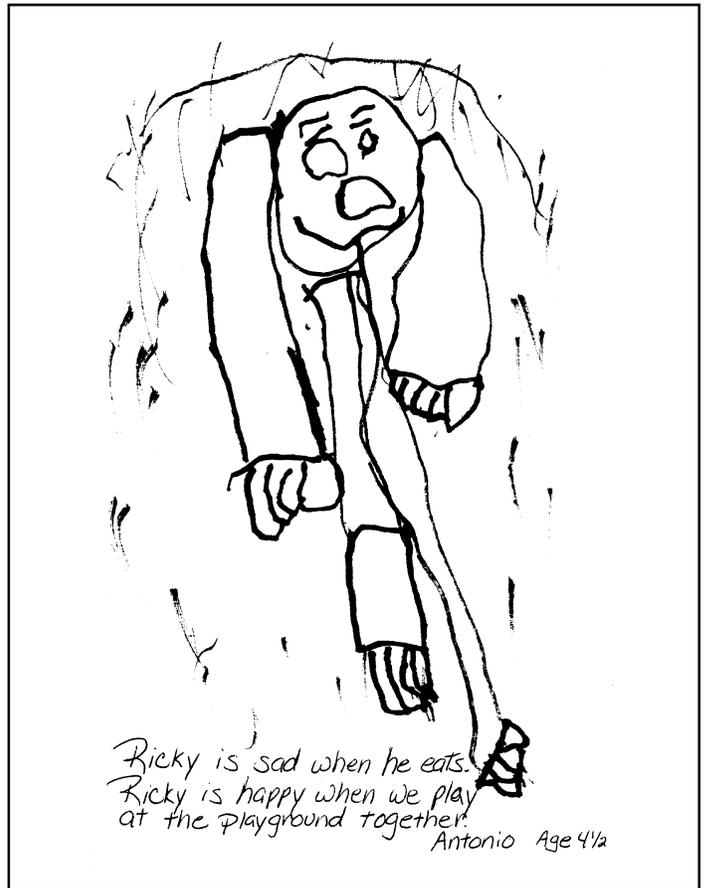
by David Beatty
age 10

It is hard to live with Michael. There are times when I get very mad at him, like when he kicks me. But sometimes it is fun to play with him. When he looks at you it is worth it. I sometimes read him books. It has made our life harder. But also we get handicapped spaces. I love him. He has this look that you can tell he loves you, too. His hair is funny. It almost always sticks up. Sometimes I have to stop him from rocking. Then he starts crying and I make him stop. I am glad he is my brother.

by Scott Beatty
age 9

It is hard to take care of a handicapped brother. I get very mad when he kicks me. Sometimes I read him a book.

Ricky's Brother Likes to Draw



Antonio Luiz Torres, Jr., age 4-1/2 with brother Enrique "Ricky" Christopher Torres, age 3.

Summer Opportunities for Individuals who are Deaf-Blind

BREAK THE BARRIERS. Sport and Art Day Camp, ages 6 and older. Counselor/camper ratio 1:6, campers with behavioral issues are invited to attend but need to bring their own support. 181 E. Sierra, Fresno. Call for dates: (559) 432-6292.

DISABLED SPORTS USA. Summer Program, day and overnight trips. White water rafting trips, water skiing, overnight camping trips in Donner State Park. Reservations required. Ability to meet the needs of people with behavioral challenges decided on an individual basis. For camper ratio and price call (530) 581-4161. (Ask about their winter ski program at Tahoe Adaptive Ski School.)

ENCHANTED HILLS/LIGHTHOUSE FOR THE BLIND. Campers who are deaf-blind welcome. Contact Megan Jones 415-431-1481 ext.238. Camp sessions July 13–August 20 for campers 5–18. Camp session for campers who are vision impaired multi-handicapped August 16–20. Free for campers under 18. Contact Tony Fletcher (415) 431-1481.

CAMP RUBBERSOLE. Mendocino County on the coast between Albion and Mendocino. Fully certified respite care recreation camp. Open to persons with any disability. Four sessions that are one week each. Camper/counselor ratio 1:1 or 2:1. Call Rachael Miller at (707) 937-0722.

CAMP BLOOMFIELD. Operated by the Foundation for the Junior Blind. The camp is in Malibu. Eight sessions, one to two weeks in length. June 21–August 27. Cost \$25 per person. Counselors may not be proficient in signed communication. Call for information: Bob Cabeza (323) 295-4555 or (310) 457-5330.

GIRL SCOUT CAMPING. Providing opportunities to include all female campers. No. California, Camp Botcin, Marin County. Call SF Bay Area Girl Scout Council: (510) 562-8470, Kohlim Jaeger, ext. 138. So. California, Camp Sherman, Riverside County, fully equipped for persons with special needs. Call Girl Scout Council of Orange County: (619) 298-8391.

AMERICAN CAMPING ASSOCIATION. Has available a national guide for camps for children of all abilities for \$19.95. (800) 428-2267; Fax (765) 342-2065.

EASTER SEAL NATIONAL HEADQUARTERS. Provides a list of camps for children with disabilities free of charge. Voice (800) 221-6827; TTY (312-726-4258).

GOLDEN ACCESS PASSPORT. Passport holders receive free lifetime entrance to most federal parks, historic sites, recreation areas that charge an entrance fee and gives free admittance to accompanying passengers in a vehicle. It can be obtained from a visitor center or entrance station that charges an entrance fee. Requires note from physician stating disability. Call National Park Service information in Washington, D.C., (202) 208-4747; Accessibility Office (202) 565-1255; <http://www.nps.gov>

WILDERNESS INQUIRY. The company combines people of all ability levels and ages in its trips and will conquer almost any natural barrier for travelers: white-water rafting, sea kayaking, and dog sledding are just a few of the outdoor adventures. (800) 728-0719.

ACCESS-ABLE. Providing access info to disabled travelers. <http://www.access-able.com>



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