

# Deafblind Focus

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## A Sibling Speaks Out

### Gifts from my Sister

By Susannah Kenley, San Francisco

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Growing up as Laura's older sister hasn't always been easy, and without laughter I hardly think I could make it through. Tears and laughter, pain and

happiness, embarrassment and pride, and thousands of other emotions have all been a part of the adventure of being an older sister to a sibling born with CHARGE Syndrome. Being born with CHARGE, Laura does not hear, is extremely vision impaired, and has heart defects. But besides all of that, Laura is a goofy teenager with lots of personality, strong likes and dislikes, a very smart and pranky sense of humor, and a little attitude to go along with her age of seventeen. Laura is an extremely complex girl. And living with her has been no less if not more complex than Laura herself. Laura has made me feel thousands of different ways. She has made me want to crawl under the table at a restaurant and hide from people staring, scream out in frustration, punch a wall,

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## Under the Magnifying Glass: Sibling Support

### Support for Siblings

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Many factors, such as a sibling's age and the family atmosphere and attitude, impact the issues that siblings deal with in relation to their brother or sister who has a disability. Although there will be issues and concerns to address, siblings often turn out to be some of the most caring and compassionate people with an increased tolerance for negative people and situations because of the insight they have into the value of life. Siblings tend to show a greater sense of maturity and often demonstrate a great sense of loyalty and appreciation for their family as a whole. Parents need to be in tune to the needs of their children without a disability by providing information, support, and opportunities to be their own person. The following are some tips for how to accomplish this.

- **Provide information:** All siblings need some level of information about their brother or sister's disability. How detailed the explanation is depends on the age and level of understanding of the sibling. Knowledge helps siblings cope more effectively with their brother or sister's disability.
- **Alleviate fears:** Siblings sometimes fear that the disability that their brother or sister has might happen to them, too. Help them to understand that they won't "catch" their sibling's disability.

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# Under the Magnifying Glass: Sibling Support

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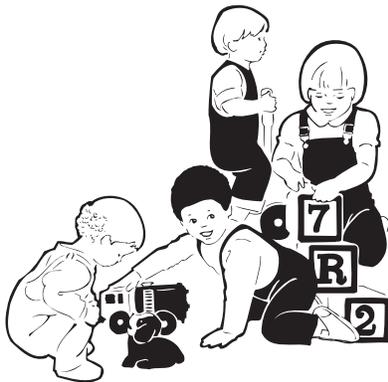
- **Treat all children fairly:** Parents should treat all of their children fairly, but must recognize that it may not be possible to treat each child equally. This can be difficult, but try to treat each child with the same standards for their behavior, even though those standards may not be exactly the same. Explain to the sibling about these differences in expectations to help them to try to understand. Remember that, in cases where the child's disability is severe, it appears to the sibling that their brother or sister is not able to do anything wrong.
- **Be aware of their drive to succeed:** Many siblings, once they have grown into adults, express that they felt pressure to achieve and had higher expectations than their friends who did not have a brother or sister with a disability. The expectations, though, were not set by the parents, but by their own self in an effort to help compensate for the loss that they think their parents feel for the child with a disability. Parents should be aware of this and help their child balance the priorities in their lives.
- **Monitor their independence:** Because of the demands of a child with special needs, siblings often think that they need to take care of their own needs, such as making lunch or entertaining themselves, in order to help out the rest of the family. Although this lends to the development of mature and responsible behavior, siblings need to know that they are not expected to be independent. Using respite care and help from extended family members can help.
- **Openly communicate:** Siblings need to feel free to express their feelings without guilt. Emotions they feel can include sad, mad, loss, isolation, resentment, guilt, and confusion. Parents can help by openly displaying their own emotions in an appropriate manner and explaining to their children that it is all right to show emotions.
- **Watch for warning signs:** Be aware of emotional and physical signs that the sibling is not doing well. Some warning signs are a decline in academic performance, sleep disorder, appetite problems, headaches, stomach aches, and preoccupation with their own health. If communication with your child does not seem to help, seek help from a physician, counselor, or other professional.
- **Create special times:** Siblings often feel that their parents do not spend as much time with them as their brother or sister who has a disability. They often recognize their parents preoccupation with their brother or sister and the absence of their parents during hospital stays and numerous appointments. Try to create special times to be with the sibling and to create regular rituals, such as reading every night together, to create a personal bond.
- **Teach social coping skills:** Some siblings have problems with the reactions of people to their brother or sister when they are out in public. Explain to the sibling why people react the way they do and appropriate ways to respond to them. Rehearse how to answer questions that friends or strangers might ask.
- **Involve siblings when making decisions:** As siblings get older, they should be encouraged, but not forced, to be involved with the medical, financial, educational, and daily living decisions in regard to their brother or sister's care.
- **Understand sibling rivalry:** Parents should recognize that sibling rivalry exists, even when one of the siblings is disabled. If issues seem to be developing beyond the parents control, though, professional help should be sought.
- **Plan for the future:** As siblings gets older, they may begin to realize that they might be their brother or sister's caregiver one day. As mentioned earlier, involve the sibling in the decision making process and help them to learn more about their brother or sister's options for the future.

# A Sibling Speaks Out "Gifts from My Sister"

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slam doors and cry. But Laura can also make me laugh like no one else can.

Just like any other relationship between family members, Laura and my relationship has gone through many phases, both good and bad. The one thing I can say for sure is that over the years, being Laura's sister has become a lot easier. I can't ever remember a time in my life when Laura was not my little sister; she was born when I was only two years old so she is a part of nearly all my childhood memories. I even went to preschool with Laura at the San Francisco Hearing and Speech center for a few years. I loved going to school there because I could not only hang out with my baby sister, but I learned how to sing kids' songs using sign language and hang out with kids like myself and like my sister. Although I was not aware of it then, being in an environment like that let me know that I was not alone and that there were other kids like me who were siblings of deaf children. Trips to PAAVI - an early intervention family training project - and Easter Seals to play were also wonderful experiences for the same reasons. Going to summer camps that focused on families of children with disabilities were always exciting places to play, relax, and also to spend time with people who were dealing with the same life experiences that I was. I will always be thankful for the opportunities my parents gave me to get involved in the deaf-blind community at such an early age.



Spending lots of time with Laura when I was very young is probably the reason why the two of us have stayed so close over the years. Having fun with Laura when I was young set the tone for the type of relationship I have with her now. Laura's life is full of doctors, teachers, therapists and caretakers. Being involved in Laura's social life from the start has let me know that I do not have

to be another doctor or teacher of Laura's, and it is okay for me to just be her sister and friend.

It is easy to feel responsible for a sibling with disabilities, especially if you are older than they are. My parents have helped me work through that by explaining that I am not now and never will be the only one responsible for Laura. Although I know I do need to help out with her, I also know that my parents are doing the best that they can to support Laura, even in case something should happen to either of them. Wills and future living situations and dreams for Laura have all been explained to me, so I have never been left worrying whether or not I will be spending my time as an adult caring for Laura. Communication about these real-life, real-world issues has made me feel comfortable about being Laura's sister in the future.

Having Laura as my little sister has undoubtedly changed the way I look at myself and at the rest of the world. It has taught me how not to get embarrassed so easily, how to deal with the unexpected, and how to appreciate the little things in life (like the fact that dinner has not been thrown all over the kitchen for once, or that no one threw a fit in the middle of the shopping mall). But more than that, Laura has taught me that lots of people out there need help (myself often included). Because of Laura I have chosen Sociology as my area of study in college, and have spent spare time volunteering in California and Louisiana. But most importantly, because of Laura I am able to look at life in an extremely positive way and with a sense of humor, and although that may sound cliché, it is the truth. Not many people can or ever will be able to appreciate life and its blessings the way that I can and my sister Laura is the person I have to thank for those gifts.



The following list contains just a few of the sibling resources available for loan through our Resource Materials Center. To borrow these items or ask about other holdings contact us at 1-800-622-3035.

*Brothers & Sisters - A Special Part of Exceptional Families*, by Thomas H. Powell and Petty Ahrenhold Ogle, Paul H. Brookes, 1985. An older resource but



# Resources



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still an excellent guide that includes strategies for supporting siblings, including keys to effective communication, counseling issues, and considerations for encouraging sibling interaction (B-FAM.S30).

*Differences in common: Straight talk on mental retardation, down syndrome, and life*, by M. Trainer, Woodbine House, 1991. This book is a collection of essays targeted towards parents, but also those who do not know about mental retardation. Its aim is to touch us all in a common way (B-FAM.S33).

*Other Resources not in the Materials Resource Library:*

*Sibshops: Workshops for Siblings of Children with Special Needs*, by Donald J. Meyer and Patricia F. Vadasy, Paul H. Brookes Publishing Co., 1994. This book serves as a guide to everything you need to know to plan and conduct a Sibshop. Sibshops are events held for brothers and sisters of children with disabilities to give siblings the chance to meet other siblings and share common feelings - all in a relaxed, recreational atmosphere.

*Views From Our Shoes: Growing up with a brother or sister with special needs*, edited by Donald Meyer, Woodbine House, Inc., 1997. This book contains short essays written by 45 siblings who have brothers or sisters with disabilities. The writers range in age from four to eighteen years old, and each writes with sensitivity and heartfelt honesty about their experiences. The essays are in order of the age of the writer, from youngest to oldest.

# Upcoming Events

## March 20-22, 2003

*Indiana Early Childhood Conference 2003, children's opportunities - our responsibilities*, Indianapolis Convention Center, Indianapolis, IN. For more information visit: [www.iaeyc.org](http://www.iaeyc.org)

## August 7-9, 2003

*Today's Student . . . Tomorrow's Adult: Building Successful Transitions*, Sheraton Indianapolis Hotel and Suites, Keystone at the Crossing, Indianapolis, IN  
Speakers include: Ako Kambon, Visionary Leadership Institute in Columbus, OH; Kathie Snow, Woodland Park, CO; Michael Wehmeyer, Ph.D., Univ. of Kansas, Lawrence, KS. For more information visit [www.iidc.indiana.edu/cclc/events.htm](http://www.iidc.indiana.edu/cclc/events.htm)

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