

**I Have a Sister.
My Sister is Different: So What!**
Becky Cornelius, Age 15

Parents and siblings...I mean moms, dads, sisters, and brothers; how's it goin'? My name is Rebecca and I'm 15 years old and I have a sister who is nine years old and really annoying. Her name is Amy and she was born with C.H.A.R.G.E. association. That's an acronym for colobomas, heart problems, atrecia, retarded growth and development, (underdeveloped genitalia in males) and finally ear deformity and/or deafness. My sister has the "C" the "H" the "R" and the "E" which means she is deaf-blind along with some other stuff. But before all the long words and the medical junk, she is my sister and I love her. To me she is just the little blonde haired rug rat who gets into all of my stuff. But other people don't see her that way. The doctors see her as a "case". The teachers and specialists see her as a little girl with problems. To people on the streets, she is "that little girl with glasses". It gets really tiring when, day after day for ten years, you have to explain to someone (or a group of someones) what is wrong with your sister? It is especially hard for me because to me there is nothing wrong with my sister. She is just not like the other kids. In some way, it is better this way because-for instance-she doesn't talk back when I tell her to do something, she just doesn't do it and when I say something, she doesn't argue or tell me I'm wrong. Most of the time she doesn't respond at all! Pretty cool, huh?

I felt this article would not be complete if I didn't attack the issue of communication. Here goes. My sister communicates through sign, verbal and object communication. Because she is so creative, (she got it from me) she makes up her own signs, which takes my mom awhile to figure out. My mom's kind of slow.

One last thing. To all brothers and sisters out there: the world might think your siblings are "strange," "weird" or "different." But as long as you think they are perfect just the way they are...they are!!!

Adam's Our Little Brother
Riccille Shipman, Age 16

I was really excited when I found out we were adopting a baby. My parents said that he was going to be a "special" baby, trying to explain it in words that I could understand. When I met Adam he seemed normal to me, except for the feeding tube which came out of his stomach. As time went on, I realized that he was different from the other babies I had seen. His eyes looked different and he was much smaller compared to other children. I finally began to realize that Adam was "special" just as my parents had told me. I learned that he had CHARGE syndrome,

and in simple words he is deaf, almost completely blind and has several other things that would keep him from being called normal.

Adam is nine years old now, he's still in diapers and he still eats baby food. Changing his diapers is one of the hardest things to deal with about Adam because he's so tall and big which makes things much more difficult. Feeding him is a task in itself. All he eats is baby food and he only drinks Ensure, but he is very messy. Adam was never supposed to crawl or even sit up, but he started walking a few years ago. He can walk up and down steps if he has something to hold on to. We gave his wheelchair to his school since he didn't need it anymore. Adam has been labeled "Houdini" because he can get out of situations that I never thought would be possible. He's so smart but we could communicate better with him. I think that is the thing that I regret the most is not learning more sign language. He can usually tell us what he wants such as food or when he wants his diaper changed or something like that, but sometimes he starts crying for no reason at all and we can't understand what he wants us to do. That's always very frustrating not knowing what he wants and how we could help.

Adam does something called stimming. He flaps his arms and kicks his feet, not because he's throwing a fit, but that's just how he keeps from getting bored. Sometimes I'm holding him and he pulls on my earrings and my hair. One day I took him off the bus and he was stimming because he was so happy. He started pulling my hair and so I put him down but he held on tight to it. Adam was literally hanging on to me by my hair. Adam kept laughing and stimming, thinking this was very funny while I was in pain. I began to panic and started hitting him in any place that I could. He finally let go, taking a handful of hair with him. He was still laughing and giggling, not knowing what he had done.

Adam is a very loving child and sometimes he will climb up in your lap and cuddle with you for no reason at all. It's really fun to tickle him. He has the cutest laugh you'll ever hear. He loves lights, especially flashing or colored ones. I think his favorite holiday is the fourth of July because of the fireworks. He just giggles and giggles until he is blue in the face when he sees them. I love watching him at Christmas. He could care less about the presents but he could just sit by the tree and look at the lights for hours if we would let him.

I love Adam with all my heart and wouldn't trade him for the world. He has changed my life in so many ways and I wouldn't change the past at all. Even though he can't tell me with his words, I know Adam loves me too in his own special way.

Charles Shipman, Age 14

My parents have always been caring and enthusiastic about helping other people. When they told me that they were considering adopting a child I thought of a normal little baby. Adam was definitely a little baby, but he was far from normal. He was born three months premature and given a G (gastrostomy) tube soon after birth. When his birth parents found out that Adam had CHARGE syndrome, was mentally retarded and deaf-blind, they made a very difficult decision to place him up for adoption. From the time we heard about Adam, our lives began to change. We had to move to a new home because our small two bedroom apartment could not support a

family of five. We moved to a big house in Vacaville where my mom quit her teaching job to care for Adam. My mom did day care in our home to help with the many bills. We lived there until I was seven. From that time on we have lived in Woodland. The nine years I have lived with Adam have been very exciting. Watching him progress and grow has been fun for me. In his own little way, Adam is one of the most interesting people I know. The way his mind works, how he looks at things and the things he does to show his emotions are different from anything I have ever seen. Living with a young person like Adam is not always easy or fun. The cleaning, feeding and changing of a nine year old baby boy are the everyday tasks that need to be done to care for him. I have never seen Adam do anything with bad intention, even though he often tears school reports, books and magazines. It is just him being curious. These nine years living with Adam have been educational, interesting and hard. But overall having Adam in my life has been one of the best things that has happened to me. I love my brother and his own way that he tells me he loves me too.

My Sister, My Friend

Alison Aulenbach, Age 28

Well, my sister wasn't always my friend. Actually when I was young, I had a lot of mixed feelings about my deaf and legally blind older sister. I loved my sister very much, however there were many times when I can honestly say we didn't like each other much. We used to love to tell each other how much we were annoyed by one another. She was annoyed that I got to be in charge, although she is two years older than me, and I was annoyed that I had to stay home to be in charge because Mom and Dad wanted to go out. I would play tricks on her, she would tell Mom and Dad to get me in trouble. I was embarrassed to sign to her in public because everyone would watch and I'm sure she wasn't too thrilled to have to be with me, period. We got in amazing fights that usually ended in tears with both banished to our rooms and missing a handful or two of hair.

In spite of all the fighting and arguing, I would not stand for anyone else making comments about my sister or her handicaps. I was very protective. When people asked me "What's wrong with her?" I would say "nothing is wrong, she just can't hear as well as we do". Or, when she had very short hair and a cashier at a store called her a "he", I as a nine year old, firmly told him that "he" was a she, and mumbled under my breath that my sister wasn't as blind as he was. If I ever overheard anyone call her "death" instead of deaf, I would quickly correct them and would be totally annoyed that they could make the mistake. I felt no one really knew the very, very talented and gifted person that she was and could be as they only saw a girl with multiple handicaps. One of my favorite times I have spent with my older sister, Heidi, was on her wedding day. Family and friends flew out of state to where Heidi lives for the big event. Heidi, the maid of honor and I stayed the night at her apartment the night before the wedding. It was a girls night! Heidi and I both woke up earlier than her maid of honor and so she put on a pot of coffee/tea for two the of us and we climbed into her bed and had a nice long sister-to-sister talk about life, love, dreams and goals. She listened to me and gave me input and I listened to her and gave her input. It was a wonderful two hours just being sisters. She and I have come a long way and I know that I have one of the best sisters in the world. The other best sister is four years older and lives 15 miles from me.

I am lucky to have two wonderful friends who happen to be my sisters. They are always there for me and I try to be there for them. We are different in many ways, but we all have a respect for who we are as individuals.

He's Not Heavy, He's My Brother

Maretha Tyce, Age 18

As the silence of darkness surrounds me, I lie motionless upon my bed. Once again a long day in my busy life has come and gone. On this particular night, amongst many others, I find myself wondering what life would be like if I were the one who was deaf-blind and not my brother. Although I have managed to lead a normal life there has always been a difference between myself and other teenagers. The difference being that I am the sibling of a brother who is deaf-blind.

Altogether our family consists of seven members which include: our mother, father, two sisters ages 14 and ten and my eight month old son. My brother Danny is 22 years old and I, Maretha am 18 years old which makes Danny my big brother. Having my brother in the family was always a exciting experience. There was always some new skill or task that my brother could show me up in. When it came to athletics my brother was the athlete of our entire family. The only difference between my brother and I is our sight and hearing. D J, which is what I call my brother, enjoys most of the same things that I do. He loves swimming, amusement parks and of course, driving. When we were little I can still remember going to the amusement parks and riding all the big rides with my brother. He enjoyed parades with all the marching bands just as much as I did. He even loved running through the sprinklers in the middle of the yard on a hot summer day. We were the typical brother and sister pair without the fights.

Even though we lived a good life, I always felt different. I always had to choose friends who I knew would accept my brother for who he was. I knew that if my friends couldn't accept my brother then they wouldn't accept me either. It was the same way when it came to boyfriends as they too had to accept my brother and his differences. Amazingly enough everyone came to love my brother. Though they were sort of scared at first, after a few visits with him, they came to understand and accept that he was just as good as anyone else. He, too was human.

I must admit that I was even jealous of my brother at times. When we were growing up it seemed that D J got all the best toys at Christmas. When my brother was hungry he got to eat out. We however had to eat whatever was in the kitchen. It just seemed so unfair. In the end my mother always explained that he would never be able to do all the things we would get to do later in life such as get married and have children, drive a car, or move out on his own. By hearing this it was easier to accept his special treatment.

Living with a sibling who is deaf-blind has made me a more understanding person. Although my brother is very capable, people in society fear him because of his disabilities. They do not understand that he is human just as they are. People fear what they do not understand. As I grow older, I see the struggle that it has become just to find someone willing to allow my brother to

show his skills in their workplace. It is frustrating because they do not see my brother as I do.

Living with Danny has also given me a more positive outlook on life. My brother has been a teacher as well as an inspiration to me. Just when I think I can not continue struggling with everyday life, I look at D J. When I look I see someone who has overcome so many obstacles and prejudices. I figure if he can do it then so can I. By living his life to the fullest even with his disabilities, I have learned that anything is possible. I can now look at others with disabilities and see them for who they really are. They are people, and should be treated as such.

How My Deaf-Blind Sister Influenced My Life

Gretchen Cawley, Age 33

It is remarkable how much my childhood experiences have influenced the behaviors and attitudes I possess as an adult. For years I only told those closest to me that I had a sister with special needs. It was something that I held very personal. Looking back maybe I was a little embarrassed because I thought that made me different. This difference also gave me the opportunity to have experiences many children and adults are never afforded, experiences that break down stereotypes and allow me to look at the possibilities of achievement for all individuals no matter what their limitations may be.

My sister is deaf and legally blind. In her teen years, we also discovered she has epilepsy. My first recollection of the difference between Heidi, myself and my other sister was a visit we took to an assessment center where Heidi stayed for six weeks as a 15 month old. There I was with children living in cribs, their bodies twisted, with strange guttural sounds coming from them. My sister was not in this environment for long. But the memory of it remains with me still (I often wonder if she has any memory of it). Then I remember the friends she had at the Hawaii School for the Deaf and Blind. They were all so different from my friends. Each of Heidi's friends had different special needs. They also had very definite personalities that were not defined by their handicaps. When we moved to California, I remember a sense of relief that my sisters would be going to the same school. Heidi would be mainstreamed. I need not consider her different any longer. Well, this was unrealistic and I believe it was at this point that I began to accept that Heidi would always be "different". From this revelation I learned to appreciate her talents. She is extremely creative; her artistic abilities are phenomenal. She has a great sense of humor and is excellent with children.

Appreciating these talents in my sister was not always easy, but as an adult I know they have helped to shape my abilities to look for potential in all individuals. For the last ten years I have been the Director of child development programs. I have been responsible for the care and learning experiences of hundreds of children. Every day I am reminded of each child's individual personality and how their environment affects their behaviors. I will always have a soft place in my heart for the children who are not developing in a typical pattern; those whose language does not develop as quickly or who have a more difficult time with socialization or infants who cry more often. For the most part, these children remain within the typical scale of development. Just a little different. There have been a few though who have captured my heart because their development was not typical. They would have challenges all their lives.

One child who made a profound impact on my life was Joe (name changed). Joe entered our program at 16 months and from the first day there was something different. Joe only made guttural sounds, wandered around the room patting the wall and did not welcome the teacher's touch. I read the information from the parents. They noted he had been seen by a neurologist for an eye problem, but did not mention any other concerns. I contacted Joe's mother. She said she was concerned over the lack of language Joe was exhibiting but had been told not to worry about it. It would be checked again at his next appointment. I grabbed hold of this concern and offered to have a pediatrician that I knew call her to discuss her concerns more specifically. This was the beginning of a very difficult journey for Joe's parents; the realization that their child would never follow a typical path of development. With the assistance of medical specialists from the school district, a course of treatment was designed for Joe that would help him develop to his fullest potential. His diagnosis sounded so bleak. He was pervasively delayed and exhibited many characteristics of autism. Many times my staff at the child development center challenged me saying this was not the right program for him, he needed specialized care. I fought back with training, having special education teachers come in and talk to them, sending them to the local special education program to learn techniques to use in working with Joe. The road was difficult at times. Joe required more care than the other children but he was not aggressive. Therefore I made the decision that as long as the professionals agreed our program could meet his needs, Joe would stay. Joe transitioned into a two-year old room. Though his social skills were limited and his language unintelligible. We kept seeing progress. The special education coordinator who worked with us was continually amazed at his growth and success. I left the program before Joe. When I left they were considering how much longer our program would be able to meet his needs and when it would be appropriate to put him in the special education preschool program. Many times I think how much easier it would have been if I had suggested to the parents that they find another program but then I remember Joe's smile and the look in his face when he recognized someone.

I know my experience growing up with special needs children gave me the compassion to understand the potential of children who are handicapped and to work with their parents and other professionals to provide care and learning experiences at whatever level is achievable. I continue to sense the attitude in teachers I work with and their hesitancy in seeing beyond these children's limitations, to concentrate on their potential. I continue to offer them training and hope that I have made an impact on extending their comfort zone in dealing with children with special needs. I know that my experiences of having a sister with special needs has expanded my comfort zone and allowed me to look beyond limitations and concentrate on possibilities.

My Helper

Adrienne D'luna, Age 10

She can be my eyes and my ears,
Even though she's said to be hard of hearing,
and legally blind.
She has made me open to new ideas,
And given me hope that will last

my whole life through!
She can comfort me,
Yet it hurts when she doesn't understand
She can be strong, even though she is weak.
She gives me more than she receives from me
in the long term
Her spirit is free, even though
her body has difficulty.
I really love Alexis, my sister.

The Sibling Support Group
by Lizz Domash, Marin County
Registered Music Therapist (RMT)
Master in Creative Arts Therapist (MCAT)

Brothers and sisters of children with special needs routinely face problems that are not experienced by other children. These children have far fewer opportunities for peer support and education, compared to their parents.

Common themes that these children may experience are: feeling isolated, pressure to achieve, concerns about their sibling's future, conflicting feelings of guilt, fear, anger, resentment, envy, embarrassment, confusion, etc., etc.

Brothers and sisters of children with special needs have a lot to teach one another, if they are given the chance. It is healing to be involved with others who are "in the same boat", and who understands better than anyone what it is like to be the sibling of a brother or sister with special needs.

Purpose and Goals:

The Sibling Support Group seeks to provide brothers and sisters of children with special needs opportunities for peer support and education, through activities designed to accomplish the following

Goals:

- To meet other siblings in a relaxed and supportive setting.
- To provide siblings with opportunities to discuss common joys and concerns with other siblings.
- To provide siblings with opportunities to learn how others handle situations commonly experienced by siblings of children with special needs.
- To provide siblings with opportunities to learn more about the implications of their brothers and sisters special needs.

Value and Benefits of this Group:

- Provides a safe and supportive environment for children to share their feelings, concerns, questions, problems, etc.
- This Group creates an atmosphere for positive change and adaptation.
- Reduces a sibling's sense of isolation; Siblings find out that they are not the only ones.
- New friendships develop.
- Growth of more positive attitudes toward the sibling with special needs. Increases sensitivity to their sister or brother's uniqueness.
- Children gain a better understanding of disabilities, specific to their siblings and in general.
- Siblings develop greater appreciation for the child with special needs.
- Offers siblings a broad array of solutions from which they may choose.
- Can prevent psychological trauma/difficulties in later years.
- Siblings gain a sense of their own specialness, knowing that the Sibling Group was developed just for them!

What Do Group Members Think of the Sibling Support Group in San Francisco?

“A lot of feelings come out here at the Sibling Group. Sometimes it's lonely, and I feel trapped. The Sibling Group lets me let it out. We can talk about anything here! Even stuff that I don't tell my Parents....I would be mad if I couldn't be part of this Group.”

-Raya

“I enjoy coming to this Group because I get to express my feelings with people I like to spend time with. Joining the Sibling Group is one of the best things that's happened to me!”

-Allison

“This Group is very fun, and it's great! It's my favorite day of the week.”

-Sara

“This is where I can tell other kids how I feel, and they listen to me. It's not like that at School. I get teased at school.”

-Matt

“I want the Sibling Group to meet two times a week, not just one time. We need more time together. Everyone has stories to tell...”

-Jason

“It is very fun to be here”

-Evan

(This article consists of excerpts from a grant proposal written to support a new Sibling Support Group.)

Featured Resources

The following resources are available for short-term loan from the CDBS libraries. To borrow these materials or to request information on other available resources, contact CDBS: (800) 822-7884 voice/tty

Finding a Way: Living with Exceptional Brothers and Sisters

by Maxine B. Rosenberg. New York: Lothrop, Lee & Shepard Books, 1988. 48 pages.
This book tells the story of Danielle, Danny, and Rachel, each of whom has a sister or brother with a disability. The three children share their thoughts and experiences in an honest and easy-to-read way. The book includes many photographs of the all brothers and sisters and their families playing, going to school, and living together at home.

Families, Disability, and Empowerment: Active Coping Skills and Strategies for Family Interventions

edited by George H. S. Singer and Laurie E. Powers. Baltimore: Paul H. Brookes Co., 1993. 423 pages.

This is a book for both families and professionals, and presents strategies for building strong partnerships between these two groups. The book includes a chapter by Betsy Gibbs titled *Providing Support to Sisters and Brothers of Children with Disabilities*. This chapter provides information on common issues shared by siblings of children with disabilities, and methods and resources for supporting siblings.

Siblings of children who use signed communication may enjoy the following three video tapes. The tapes provide sign language instruction or review in an entertaining way:

David Parker: The Sign for Friends

Pittsburgh, Pennsylvania: Yellin Tabor Visual Production. VHS color, 30 minutes.
This video tape is a live performance by David Parker, a talented singer and mime. He leads a small group of children in songs and stories while naturally incorporating into his performance instruction in signed communication. This tape can be enjoyed by children and adults.

Jingle Bell Foolin' and Little Red Riding Hood (2 videos)

Charlotte, North Carolina: United American Video. VHS color 30 minutes.
These two tapes include stories and public domain cartoons that are interspersed with open captioned narration using Signing Exact English.