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## **Being the “Other Child” Part 1**

### **Social, Emotional, and Practical Issues Faced by Siblings**

*By Amy S. Tully*

When I look at my 15-year-old sister Kathleen, I see a beautiful girl with bouncy blonde hair, a smile that lights up her face, a great sense of humor, and multiple disabilities. It has not always been easy to see her this way. Like many other siblings of people with disabilities, I faced many issues while growing up. Fifteen years ago, Kathleen’s medical problems frightened me. Ten years ago, her odd behavior embarrassed me. Only recently, with the help of my parents, have I been able to accept and love her exactly as she is, disabilities and all. Although I worry about the future and still feel those old emotions from time to time, I now realize how lucky I am to have such a loving, amazing person as Kathleen as my sister.

Many child and young adult siblings of people with disabilities face issues that can affect their personalities, social experiences, and family relationships. According to the National Information Center for Children and Youth with Disabilities (NICHCY), these issues often follow a progression that corresponds with the sibling’s developmental growth. Very young siblings most frequently face emotional issues, school-aged siblings commonly face social issues, and young adult siblings often face practical issues. By identifying these issues, their causes, and their effects, one can seek to address them effectively so that having a sibling with a disability can be a positive experience.

Young children often face emotional issues because their intellectual and emotional immaturity makes it difficult for them to comprehend their sibling’s disability and interpret it accurately. These emotional issues include anxiety, fear, resentment, rejection, and envy. Derenda Timmons Schubert, Ph.D., from Pacific Northwest Children’s Services, proposes that these issues can cause problems such as depression, perfectionism, low self-esteem, and somatic symptoms (like stomachaches and headaches) if left untreated. Unresolved issues may also have adverse effects on family relationships. Thus, it is important to examine these issues and ways to address them to ensure siblings without disabilities experience emotional well-being and strong family relationships.

It is easy to imagine how frightening a sibling’s disability could be for a young child. A sibling’s abnormal behavior, medical problems, or special equipment could cause anxiety and fear in a 3- or 4-year-old, especially when coupled with a child’s perceptions of his parents’ related anxiety. Young siblings may worry intensely about what is “wrong” with their sibling. According to Lawrence Kutner, Ph.D., a child developmentalist, young children often fear “catching” their sibling’s disability. Dr. Kutner also states that children may worry they did something to cause their sibling’s disability.

I experienced this fear and anxiety during the first few years of Kathleen’s life, when she had several life-threatening grand

mal seizures. I witnessed a few of them firsthand; the times I saw Kathleen's eyes roll back in their sockets and her body shake violently were some of the most frightening experiences of my life. I have distinct memories of hiding under couch cushions while paramedics whisked her away, of having horrible anxiety-induced stomachaches in elementary school, and of leaving my third-grade classroom in tears one day because Kathleen had a seizure earlier that morning. The fear of these episodes became so strong that I did not like playing with or holding Kathleen because I was afraid she would start convulsing in my arms. I also had panicked feelings every time I saw or heard an ambulance because I feared that it would be going to my house.

My parents helped me deal with these feelings by explaining Kathleen's seizures in simple, age-appropriate terms. They listened to my concerns and explained the causes and triggers of Kathleen's seizures. This information helped me deal with my anxiety and fear. After learning that fevers triggered Kathleen's seizures, I stopped being afraid to hold her because I knew that she would not have a spontaneous seizure. My stomachaches became less frequent, and I experienced less fear when Kathleen actually did have a seizure. Although the anxiety and fear caused by these seizures will never completely subside, my parents' actions helped ease them greatly.

Disability resources stress the importance of giving children age-appropriate information about their sibling's disability or medical problems. A fact sheet about siblings from the ARC, an organization for people with developmental disabilities and their families, suggests speaking openly about concerns with children and answering their questions

simply and precisely. Dr. Kutner stresses the importance of reassuring children that they did not cause, nor can they catch, their sibling's disability. Information is helpful because it eliminates uncertainties that can cause a lot of siblings' anxiety and fears.

Feelings of resentment, rejection, and envy are also common in young children. Children with disabilities often require more of their parents' time and attention than their siblings do, and young children may resent or envy the extra attention paid to their brother or sister with a disability. Young children may not understand that their sibling's needs make this extra attention necessary; they may feel that their parents are rejecting them because they did something wrong or because their parents love their sibling more. Young children may feel resentful if they have to perform chores from which their sibling with a disability is exempt or if their sibling "gets away" with behavior for which they would be punished. Young children may not understand how their sibling's disability affects her behavior and thus may not understand why she is exempt from certain tasks or punishments.

A young sibling participating in a panel discussion at an ACC conference described a situation from her early childhood that illuminates a possible source of feelings of resentment and rejection. Her parents had explained to her that her brother was "special" and that his "special needs" meant that they had to give him more attention than they gave her. While they thought this was a satisfactory explanation, the girl felt that it meant she was not special.

This example illustrates the importance of giving children precise, age-appropriate information. Dr. Schubert advises parents to explain a child with a disability's strengths and weaknesses to their other children. It

would be appropriate to explain in simple terms why the sibling needs extra attention or cannot be punished for a certain behavior. Dr. Schubert also suggests that parents explain ways for siblings to interact and help with their sibling who has a disability. This hands-on experience can help displace feelings of envy and resentment because it helps children learn about their sibling's limitations and needs firsthand. I found it a lot easier to understand that Kathleen needed more attention once I was old enough to help my mom take care of her. Once I had actually helped give her a bath, get her dressed, and feed her, I realized exactly why she needed much more time and attention than I did.

When children enter school, their exposure to other children increases, and they begin to notice the differences between their sibling and children who are not disabled. Social problems with peers and with strangers may arise as children become more aware of their sibling's challenges. If left unrecognized, these social issues can cause school phobia, social withdrawal, depression, and many other problems. They may also strain family relationships. It is essential to address these issues as they arise so that siblings may have normal, healthy social experiences.

School-aged siblings may have problems with peers because they feel embarrassed about their sibling's disability. They may react by either avoiding contact with their sibling with a disability or by avoiding exposing their peers to their sibling. It is not hard to understand the root of this behavior; one can imagine what it must be like for a child to overhear their peers making fun of a "retarded" kid and to speculate how those peers would react to their sibling. On the other hand, siblings

may also feel the need to protect and support their siblings in social situations, which may cause alienation from their peers. Anyone who has experienced the social pressures of being a school-aged child can imagine what standing up for a brother or sister with a disability might do to your social reputation.

This issue was the root of my younger brother Kevin's first and only fistfight, which occurred in his bedroom when he was about seven. Kevin's best friend, who was visiting, called Kathleen a "retard." Kevin's reaction was one of defense and protection; he punched his friend in the face. This action could have caused Kevin many problems, but fortunately Kevin and his friend were able to talk the situation over once they both stopped crying. Five years later, that friend is quite accepting of Kathleen.

Dr. Kutner advises parents to teach their children how to explain their sibling's disability to their peers in an effective and nonviolent way. Often, peers fear people with disabilities because they do not understand them, so explanations may decrease negative social situations. NICHCY suggests that educators teach children about accepting and respecting people with disabilities and that parents consider presenting information about their child with disabilities to their other children's classmates. Several participants in the ACC Network Sibling Panel corroborated this suggestion and described how their peers' negative attitudes changed to curious ones after their parents did presentations in their classrooms.

School-aged children also begin to notice the way that strangers in public places regard their siblings. They may feel embarrassed if their sibling's behavior or appearance attracts negative attention from

strangers. They may also feel angry or resentful toward those strangers for their lack of respect for people with disabilities.

I remember the first time I noticed people's reactions to Kathleen in public. My mom, Kathleen, my older sister Molly, and I were standing in a checkout line at a mall when I overheard some girls behind us calling Kathleen "spastic" and a "stupid retard." I was angry and hurt, but later that day, when Kathleen started screaming in the middle of a store and people stared at us, I started feeling embarrassed because of her.

This issue proves hard for parents to address. Indeed, none of my sources included any practical suggestions for dealing with such problems. I can only offer my own advice as someone who continues to deal with these problems. One important thing my parents taught me was that people who reacted negatively to Kathleen were acting inappropriately and that the proper reaction to people with disabilities was one of respect and acceptance. Just understanding that the problem lay in others' reactions, not in Kathleen's disabilities, helped ease my embarrassment. Anger is a more difficult response to overcome; I still have problems with it. I have learned to deal

with it by talking to close friends about it or writing about it in a journal, rather than confronting the source of my anger. In my experiences, I have found confronting the source only leads to more anger.

Young siblings of people with disabilities face unique emotional, social, and practical issues that can adversely affect their emotional well-being, social experiences, and family relationships if not dealt with effectively. If parents and siblings address these concerns, however, the experience of having a sibling with a disability can be a positive one. My experiences with Kathleen illustrate the ways in which addressing my own personal issues have helped me to accept Kathleen and experience the immense love and joy she offers me. In the next issue of *The Callosal Connection*, I will write about sibling issues that confront adolescents and young adults.

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# Will My Child Talk?

## Activities for the Wait-and-See Period

*By JoAnne Tully, M.S., SLP*

One of the most frustrating times for parents of young children with ACC is the period when you are advised that you can only “wait and see” whether your child will talk. In reality, this is a time when parents can be active in laying the groundwork for communication. Encouraging your child’s speech awareness occurs at several different levels.

### **Turning sounds *on* and *off***

Babies are born with several skills for communication, the most obvious of which is crying. Your child may cry to indicate hunger, discomfort, and sometimes a desire for attention. Another powerful communication tool that infants have is vocalization. Babies begin vocalizing early in their lives, usually by making soft vowel sounds. You can help make your baby aware that he controls the “start” and “stop” of these sounds by responding to his sounds in a positive, pleasing way. Carrying on a “conversation” with your baby helps him discover the turn-taking aspect of communication. Sometimes a child will vocalize with his mother while nursing, as is illustrated in this child psychologist’s description of an exchange between a baby and his mother:

I watched a mother nursing her baby boy of several months old exchange sounds with him. The baby stopped sucking and vocalized. The mother said something like, “Oh, are you finished?” and then paused. The baby vocalized again. The mother said another sentence to the baby and paused. This exchange went on for a full 20 minutes.

As your child gets a little older, he may begin to make vocalizations such as “ma,” “nng,” and “ga” that include consonants as well as vowel sounds. You should respond to these sounds in some way, yet your response will depend a great deal on the age of your child. With an infant, you might simply smile and talk back to your child in a soft voice. However, some children with ACC remain at this stage of vocalization for several years. An older child might be quite advanced in other skills such as walking, pointing, and eating. In such a case, you can still make him aware that he controls the “start” and “stop” of his sounds by causing something to happen as a result of their sound (e.g., dropping a ball, turning on a light, knocking over an action figure).

### **Repeating sounds**

It may take some time before your child is ready to repeat her own sounds, but you can begin quite early to familiarize her with the concept of repeating a behavior. For instance, you can help your child clap her hands or play “so big” with her arms. Then ask her to “do it again,” helping her to repeat that behavior. “Do it again” should become a habit in all the games you play with your child.

Watch for times when your child purposely seems to be making or playing with verbal sounds. When she makes a sound, repeat it yourself and say, “Do that again!” She might repeat the sound, and if she does, turn it into a back and forth game until she gets tired of it. Some children are so excited about this game that they will continue for several turns. If she doesn’t repeat the sound, just repeat it yourself so she sees that “do it again” is associated with repetition; you can try it again later. In all of these activities, be sure to allow enough time

for your child to respond, but not so much time that she loses track of what you are doing.

### **Learning that sounds have meaning**

After your child seems aware that he can make and repeat sounds, you can begin to assign meaning to some of his sounds. Listen to a specific sound he is making, and think of a word that it might represent. For example, “bah” could sound like “ball.” When he makes the sound, repeat it yourself, and show him an object or motion that demonstrates the word. You can turn this into a back-and-forth game, as in the following scenario:

Child: Uh.

Dad: Uh – that sounded like up!

(Dad puts his arms up in the air.)

Dad: You said, “Up!” Say it again!

Child: Uh.

Dad: Yes, up!

(Puts arms into air again.)

Child: Uh.

Dad: Up! (Puts arms into air again.)

Child giggles, and the game continues, with Dad exaggeratedly putting arms up each time child says the word.

This type of game can go on with many different sounds. It doesn’t matter if the same sound is used for several different meanings; the object is to teach your child that a sound can mean something and that he can say it on purpose. Thus, “buh” could mean “ball,” “book,” or “bug” on different occasions. Your child can perfect the more subtle differences between sounds later.

### **Imitating sounds made by others**

After your child is repeating her own sounds successfully, you can encourage her to imitate new sounds that you make. This is a difficult step, and it may take a long time

before your child succeeds. Imitating a new sound requires the use of a completely new set of motor plans. It will take a lot of concentration and can be frustrating for her to attempt.

When you are ready to begin this step, be sure to start with single sounds that are easy for her to “see” when you make them. Sounds such as “f” and “p” are quite visible to your child, especially if you make exaggerated mouth movements when producing them. If you aren’t sure about a sound, look in a mirror to determine whether it is easy to see.

### **Communicating with meaningful sounds**

At this stage, you can use several techniques to encourage your child’s use of speech to communicate. Read familiar books and sing songs that use “words” your child can say, leaving a blank in the story or song for him to fill in. This gives him practice at coming up with familiar words. Don’t worry if the word is only an approximation; the objective is to get him to come up with sounds and use them for a purpose.

Set up speech temptations for your child, such as placing a desired object that he can name slightly out of reach. If he has learned to say “cup,” for example, place a cup just out of reach, and wait for him to ask for it. Be sure to reinforce this behavior immediately if he says the word; give him the cup, repeat “cup,” and cheer his success! If your child seems easily frustrated by this type of activity, demonstrate it at first, asking your child to give an out-of-reach cup to you. Later you can take turns asking each other for the cup.

Other activities include playing grocery store or hide-the-toy games that require him to ask for desired objects. You also can play guessing games with illustrated flash cards or collections of objects.

As you can see, you have many opportunities to lay the foundation for speech long before the words begin to emerge. Creating opportunities for your young child with ACC to use sounds in a playful, interactive way can turn waiting to see into a dynamic and rewarding time. ☺

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## Resources for Sibling Issues

### Books

**A Difference in the Family: Life with a Disabled Child**, by H. Featherstone (1980). New York: Basic Books.

*An exploration of the impact of a child with a disability on the family, including parents, siblings, and grandparents. Written for families and professionals by an educator who is also the mother of a child with a disability. Although published in the 1980s, the overview of family issues remains relevant and insightful.*

**Brothers, Sisters, and Special Needs: Information and Activities for Helping Young Siblings of Children with Chronic Illnesses and Developmental Disabilities**, by D. J. Lobato (1990). Baltimore: Paul H. Brookes Publishing.

*Written for parents and professionals to facilitate understanding of the unique issues affecting young siblings of children with disabilities. Offers practical strategies for identifying and addressing those needs and guidelines for developing and administering sibling support services.*

**Special Siblings: Growing Up with Someone with a Disability**, by M. McHugh (2003). Baltimore: Paul H. Brookes Publishing.

*An adult sibling looks back on her own experiences growing up with a brother with developmental disabilities. Weaves current research and personal experiences to encompass issues spanning the life cycle of sibling relationships.*

**Views from Our Shoes: Growing Up with a Brother or Sister with Special Needs**, by D. Meyer (Ed.) (1997). Bethesda, MD: Woodbine House.

*Children aged 4-18 share their thoughts and feelings about being a sibling of someone with a disability in a collection of poignant essays. Includes listings of additional resources and a glossary of the more common conditions.*

**Living with Brother or Sister with Special Needs: A Book for Sibs**, (2<sup>nd</sup> ed.) by D. Meyer & P. Vadasy (1996). Seattle, WA: University of Washington Press.

*Although written for siblings, this book offers insights important for families and professionals as well. Family stories illustrate common concerns, emotions, and needs of siblings. This book includes suggestions for dealing with sibling issues, easy-to-read information about specific disabilities and disability services, and extensive resource lists for further reading.*

## Electronic resources

“Insights of Parents: When a Sibling is Disabled,” by L. Kutner. Retrieved November 17, 2003, from [http://www.drkutner.com/articles/disabled\\_sib.html](http://www.drkutner.com/articles/disabled_sib.html)

“Children with Disabilities: Understanding Sibling Issues,” by the National Information Center for Children and Youth with Disabilities. Retrieved November 17, 2003, from <http://www.nichcy.org/pubs/outprint/nd11.txt.htm>

“Siblings: Brothers and Sisters of People Who Have Mental Retardation,” by The ARC. Retrieved November 17, 2003, from <http://www.thearc.org/faqs/qa-siblings.htm>

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