

*Children with
Disabilities:
Understanding Sibling
Issues*

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For many families, raising a child with a disability or chronic illness poses many challenges. Some of these challenges focus on the relationship between the siblings in the family which influences the social, psychological, and emotional development of each child. The relationship between brothers and sisters in families that have a child with a disability or chronic illness is examined in this issue of NEWS DIGEST.

Many factors which affect sibling relationships are described, and research findings concerning siblings, one of whom has a disability or chronic illness, are reviewed. Guidelines and suggestions for parents and siblings, and siblings' suggestions for parents are discussed. Additionally, several different viewpoints about sibling relationships are presented from a sibling with a disability; two nondisabled, adult siblings who have a sister with a disability; and a parent of several children, the youngest with a disability. A support section concludes this issue, listing suggested readings and sibling support resources.

The birth of a child with a disability or chronic illness, or the discovery that a child has a disability, has a profound effect on a family. Children suddenly must adjust to a brother or sister who, because of their condition, may require a large portion of family time, attention, money, and psychological support. Yet it is an important concern to any family that the nondisabled sibling adjust to the sibling with a disability. It is important because the nondisabled child's reactions to a sibling with a disability can affect the overall adjustment and development of self-esteem in both children.

In any family, each sibling, and each relationship that siblings have, is unique,

important, and special. Brothers and sisters influence each other and play important roles in each other's lives. Indeed, sibling relationships make up a child's first social network and are the basis for his or her interactions with people outside the family (Powell & Ogle, 1985). Brothers and sisters are playmates first; as they mature, they take on new roles with each other. They may, over the years, be many things to each other—teacher, friend, companion, follower, protector, enemy, competitor, confidant, role model. When this relationship is affected by a sibling's disability or chronic illness, the long-term benefits of the relationship may be altered (Crnic & Leconte, 1986). For example, the child with a disability may have limited opportunities to interact with other children outside the family; thus, social interaction between siblings often takes on increasing importance.

Each child's personality and temperament play an important role in their response toward a sibling, including one with a disability. Although both positive and negative feelings exist in all sibling relationships, McHale and Gamble (1987) conclude, "...for school-age children and young adolescents, these relationships tend to be more positive than negative in their feeling tone. Furthermore, children with disabled siblings appear to have more positive and fewer negative behavioral interactions than do those with nondisabled siblings..." (p. 141). These positive aspects include higher levels of empathy and altruism, increased tolerance for differences, increased sense of maturity and responsibility, and pride in the sibling's accomplishments (Powell & Ogle, 1985).

Today, many areas have yet to be explored concerning siblings. Parents and professionals, for instance, need more information about sibling adjustment from the perspective of different family systems (Skrtec, Summers, Brotherson, & Turn-

bull, 1984). For example, how do different family compositions—the single parent, adopted children, foster children, and families of different cultures—affect sibling relationships? Powell and Ogle (1985) summarize the importance of studying siblings when they state: "Siblings have much to share; they have much to teach those who wish to help them. They can guide the actions of parents and professionals so that their needs can best be met." (p. 5).

Nondisabled Sibling Reactions and the Family Environment

Living with a brother or sister, including one with a disability, can be rewarding, confusing, instructive, and stressful. Siblings of a child with a disabling condition express a range of emotions and responses to that sibling, similar in most ways to the range of emotions experienced toward siblings who have no disability (Powell & Ogle, 1985). Children react toward a sibling with a disability with feelings of love, empathy, pride, guilt, anger, and support; the predominance and prevalence of these reactions have great impact on the levels of stress and coping ability of the sibling with a disability. The positive or negative nature of the relationships between siblings and among family members may be influenced by factors such as these:

- the family's resources;
- the family's lifestyle;
- the family's child-rearing practices;
- the kind and severity of the disability;
- the number of children in the family;
- the age differences between children in the family;
- the other stress-producing conditions that exist in the family;

“...responses and feelings of the nondisabled sibling toward the sibling with a disability are not likely to be static, but rather tend to change over time...”

- the kinds of coping mechanisms and interaction patterns that exist within the family; and
- the kind and quality of the support services available in the community.

Each child's reaction to having a sibling with a disability will vary depending on his or her age and developmental level. The responses and feelings of the nondisabled sibling toward the sibling with a disability are not likely to be static, but rather tend to change over time as the sibling adapts to having a brother or sister with a disability and copes with day-to-day realities. Pre-school-aged siblings, for example, may feel confused, afraid, anxious, and angry about a brother or sister's disability or illness. All children are different; the intensity of a child's concerns, needs, and experiences will vary from sibling to sibling, as will a child's reaction to and interpretation of events. The younger the child the more difficult it may be for him or her to understand the situation and to interpret events realistically. Nondisabled siblings may resent the time their parents give to the sibling with a handicap and perceive it as rejection. They may wonder what is wrong with them that their parents love their sister or brother with a disability more. During the early years the nondisabled sibling may mimic the physical or behavioral actions of the child with a disability, or the nondisabled sibling may regress in behavioral development. Later on, he or she may be prone to extremes of behavior such as "acting out" or becoming the "perfect" child.

Elementary school-aged children may feel embarrassed or ashamed as they recognize differences between their sibling and someone else's brother or sister. They may worry about "catching" or developing the problem, and they may feel guilt because they themselves do not have a disability. They may also feel protective and supportive of their sibling, and this

may trigger conflicts with peers.

Young adults may have future-oriented

Let the Good Times Roll

The article which follows provides the reflections of an older sibling growing up with a sister with mental retardation. They are now both adults, whose pre-Public Law 94-142 experiences reflect both the joys and frustrations of the sibling relationship.

"Let the Good Times Roll," by Terrell Dougan, from We Have Been There, com-

concerns. They may wonder what will become of their brother or sister with a disability. They may also be concerned about how the people they socialize with, date, and later marry will accept the brother or sister with a disability. Additional issues faced by young adults may include genetic counseling when planning their own families, and coping with anxiety about future responsibilities for the brother or sister with a disability or illness.

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If you're sitting there wondering how much damage it's going to do your other children to (a) keep your handicapped child at home or (b) send him to another home, I can clear that right up for you.

See, they did a study several years ago. In *Psychology Today*, they published the results: "How Siblings of the Mentally Retarded Are Affected."

Naturally, I ran to get my copy to see how I'd been affected, growing up with a sister with mental retardation. Was I damaged, having her like that? Was I enriched? I frantically thumbed through the article.

Are you ready?

Half and half. Half the siblings were somewhat the less for having been around mental retardation. The other half were somewhat more.

I almost threw the thing away. Now what help is that?

As I went over my own life and how I cope in the world today, I had to see that this half-and-half thing is about all you can say about it. I feel, in my own life, half damaged, half enriched by having a sister with retardation.

But, carrying the notion a step further, look at your own life, the things that happen to you in it, the people you lived with.

Don't you feel half damaged, half enriched by EVERYTHING?

Well, then.

See, I've come to the conclusion that it doesn't matter whether you keep your retarded child home with your normal children. I mean, in the long run, whichever you choose will not make or break your normal or retarded child.

If you keep the child at home for as long as you do your normal children, your normal children will be sometimes embarrassed in the neighborhood. I was embarrassed in the neighborhood when people called my sister a dummy.

On the other hand, I learned how to press through embarrassment, and I can now climb up on the stage and perform and make speeches and sing and dance because I long ago got over being embarrassed.

If your normal children are exposed to a retarded brother or sister, they will learn patience and compassion. I learned patience and compassion living with my sister.

On the other hand, I learned to feel guilty whenever I got mad at her, so I have had to learn how to deal with excess guilt.

If you send your retarded child to another place to live, your normal children

will always worry about the brother or sister that got sent away.

I worried about my sister when she got sent away for a while. But, on the other hand, I finally got more of my parents' attention when I was with them, and I liked that.

Do you see how we can go on like this all day?

I can give you the flip side of every argument for keeping or for sending away that you want to drum up. They're endless circles. Forget it. Do what is going to make you—you, the mother, and you, the father—the most comfortable. And know that you can always change your mind.

When my sister throws a tantrum and kicks walls in, I want to beat her up. When my sister comes up behind me and hands me my purse that I left on the counter while shopping, I want to hug her. When we go shopping together, she has me help her count out the money, which she is no good at; then I have her help me find where I parked the car, which I am no good at. We've learned what we can contribute to each other. We've learned when to stay out of each other's way.

My parents kept my sister at home until she was in her teens. Then she went to boarding school in California for eight years. She is now in a private apartment with a hired companion trained in behavior modification. She has lost weight (she used to be very fat) and is learning to play a guitar and cook. She seems much more at peace with herself as she gets older. I have her over for dinner with my family sometimes; other times I have her come on a vacation with just me.

Our life together as sisters six years apart (I am older) was a lot less traumatic than outsiders would imagine. In fact, I got so used to my sister exactly the way she is that it always surprised me when people discovered that she is handicapped. They would get a look of tragedy on their faces, and then I would try to match the mood; but unless someone actually dramatized the discovery, I just accepted it as a fact, like the sun coming up in the morning.

My parents made it that way. They must have had some pain and tears, but what I seem to remember are the "normal" times—going out together for dinner, going on trips, riding along the canal in Venice

(my sister singing along with the boatman), learning to ice skate and swim (she only a little slower than I).

It's as if they were saying, "This is your sister Irene. She was injured at birth. She will have a much harder time learning everything than you do. She may never read or write. She loves sports, gourmet food, and sewing. She hates dull movies, blouses with monograms, and large drooling dogs that jump on her. You, too, have likes and dislikes. You are individuals with different likes and abilities but with the same rights and purposes on this earth. Let the good times roll."

"Our life together as sisters six years apart...was a lot less traumatic than outsiders would imagine."

And we did.

If I have any advice, looking back on my years in our family, I would say that it's important to let your normal children know that it's okay to get angry with the handicapped brother or sister. Whether or not my parents meant to give me this notion, I had it. I felt guilty about ever getting angry with Irene. If they had known my guilt, they would have taken steps to help me get my anger out when, for example, she wrote with lipstick all over my dolls.

I realized this habit of mine the day she was expelled (for her tantrums) from the group home I had worked so hard to establish. Our parents were out of the country at the time, and it fell to me to help her move out and back home again. We climbed into my car, and I let loose with a tantrum the likes of which Irene herself has never produced. I yelled at her about her behavior and how she had to learn to control herself, and I found myself shaking with rage and screaming. Two things happened. I realized that for the first time in my life I had given myself permission to be angry with her (I suppose that my mind had to wait until my parents were clear across the ocean!), and at that moment she was reaping thirty-odd years of pent-up rage—not just today's grievance. And—this is the kicker—I stopped in mid-sentence

screaming and looked at her. She was observing this wild fit I was having, absolutely amazed that I too was capable of it—and we started to laugh. We concluded that perhaps she needs to cool it a bit, but perhaps too I should have had the right to a few more tantrums.

My parents are not to blame for my guilt. Perhaps no matter what they did, you see, I would have decided to feel guilty about any angry feelings toward Irene.

So I think all you can do as a parent is to give permission for the anger to show itself when it's there. The rest is up to the sibling, and no matter how you try to take

the blame for everything, you just can't engineer your children's lives and feelings. I know. I've tried it with my own normal teen-agers. They won't be engineered.

All we can do is share our experiences in life with our family members, affirm their rights to love and hate and fun and anger and frustration and growth and pain, and then relax. Let the good times roll. And they will, quite often. If we let them. Ω

Family Stress Factors

The birth of a child with a disability, or the discovery that a child has a disability, can produce stress among family members. Stress can also be caused by a number of ongoing factors, or by special circumstances. Siblings need an explanation for the tensions within the family and the cause of the tensions.

Some families are stressed by the amount of financial resources required to meet the needs of the child who has a disability. Some parents may expect nondisabled siblings to accept the brother or sister with a disability as "normal." This expectation can lead to internalized feelings of anxiety and jealousy which the nondisabled sibling

may be reluctant to voice. The parents, in turn, may fail to recognize the child's unhappiness and may deny that a problem exists.

During an interview with the Parent Advocacy Coalition for Educational Rights Center, Inc. (PACER), Beth, a young sibling, offered parents some sage advice:

"I think... I'd want them to understand that sometimes siblings are going to get jealous of the extra help and attention that a brother or sister who's handicapped receives. Parents shouldn't get mad about the jealousy or make the kids without a handicap feel too guilty about it if sometimes they resent the extra attention. Parents have to sit down and talk to the brothers and sisters who aren't handicapped about what the handicap really means. Kids don't automatically understand it by themselves" (Binkard, 1987, p.5).

Nondisabled siblings may feel obligated

Essentially, parents, other adult family members, and professionals should realize that nondisabled siblings need special understanding, attention, support and recognition of their unique contributions to the family system (Powell & Ogle, 1985).

Siblings with disabilities, on the other hand, also experience stress as family members. These common stresses include frustration at not being able to make themselves understood; unhappiness at being left to play alone; irritation over constant reminders about everything; withdrawal because of lack of social skills; low self-esteem; and anger resulting from an inability to do things as easily and quickly as their nondisabled brothers and sisters. Through it all, with understanding and support, there are usually many positive interactions and normal sibling give-and-take situations from which each learns and matures.

When parents have a double standard

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 siblings' 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.

For many siblings, anxiety-producing feelings often are not expressed in day-to-day family interactions and discussions, and are shared even less at school. These internalized feelings complicate sibling relationships, for children need to vent their emotions. Children should be given an explanation for their sibling's problems so that they will not make incorrect assumptions.

Parents and professionals need to be aware that there may be a gap between the nondisabled sibling's knowledge and actions. A nondisabled sibling may be able to rationally explain a brother's or sister's disability to inquiring friends or neighbors, but may still exhibit temper tantrums over the same sibling's actions in the home.

Most importantly, the need for information and understanding does not have to be addressed solely by the parents. A child's disability is a concern which should be shared by parents, helping professionals, and society. For example, some progressive clinics and hospitals have designed programs that include siblings from the beginning. These programs offer Family Support Groups which bring entire families together as a means of sharing information and mutual support.

It is important for educators to be sensitive to nondisabled siblings' feelings and

"...siblings generally are poorly informed about disabilities."

to compensate for the child with the disability, to make up for that child's limitations. They may be acting as a surrogate parent, assuming more responsibility than would be usual in the care of a nondisabled sibling. On the other hand, siblings may help the family by providing their parents with assistance and support, which they otherwise might not have, in the care of the child with a disability. The nondisabled child may experience jealousy because he or she may be required to do family chores, whereas, the sibling with a disability is not required to do them—despite the fact that the sibling with a disability may be unable to do them, or would have great difficulty doing them. The nondisabled sibling may resent having to integrate the sibling with a disability into the neighborhood peer group, and may experience or perceive peer rejection because of having a sibling with a disability. Finally, the nondisabled sibling may feel embarrassment because of a sibling's physical characteristics or inappropriate behavior.

for disabled and nondisabled children, conflicts can arise. Even though the child with the disability, in fact, may need and receive more parental attention, the amount given may be perceived as unfair by nondisabled siblings. Some parents, on the other hand, may tend to overindulge the normal sibling in an effort to compensate for a brother or sister with a disability. The normal rivalry between all siblings may cause the nondisabled sibling to perceive incorrectly that the parents favor or love best the sibling with a disability. Mary expressed the resentment she feels when her brother is dealt with lightly in comparison to her punishments:

"Nonhandicapped kids can get pushed aside when their brothers or sisters have handicaps. Andrew seems to get help naturally—it's like attention to his needs is 'built into the system.' I'm the bad one, but he can do no wrong. He makes all the messes, but I get into trouble if I don't empty the dishwasher" (Binkard, 1987, p.10).

needs. Educators can do much to promote positive sibling interactions as well as acceptance of disabilities in all children. During the school years, especially the early years, teachers can help to promote sibling awareness and interaction by providing opportunities for siblings to learn about disabilities. For example, conducting a "sibling day" or a sibling workshop can be an excellent way of introducing siblings to a variety of disabilities. A "sibling day" can be held on a school day or on a weekend.

On this day, activities can include a presentation by "Kids on the Block," disability simulation games, sign language instruction, and sharing positive experiences about having a sibling with a disability. Siblings who are not disabled might be interested in seeing and/or participating in some of the unique activities in which their brothers or sisters with disabilities participate while in school. For example, siblings of students with orthopedic impairments might see a physical therapy room and go through activities a student might perform in physical therapy. Siblings of students with hearing impairments might learn a song or poem in sign language.

Information puts fears into perspective. In most instances, simply knowing the facts about a 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.

Ask parent groups, social workers, therapists, doctors, teachers, or counselors about the availability of support groups and other sibling resources in your area.

The Impact On a Sibling With a Disability or Chronic Illness

Most of the sibling research has focused on the effects of a child with a disability or chronic illness on nondisabled siblings. Also important is the influence of the nondisabled sibling on the child with a disability or chronic illness. Crnic and

Leconte (1986) report that the nondisabled sibling's impact upon the child with a disability may vary across the family's

life. While very little work has been done in this area, researchers do stress the reciprocity of sibling relationships.

"I Never Figured You Were Disabled"--A Sister's Experience

In the article which follows, a sibling with a hearing impairment discusses her experiences as a sibling with a disability,

her interactions with her brother, and how she has learned to cope.

"I just don't have a picture of you being disabled," my younger brother muses as we discuss growing up. "There was never a suggestion in our parents' voices about 'your disabled older sister.'"

I am writing as a sister with two invisible disabilities: a moderate-to-severe high frequency loss in both ears, which causes my speech to slur consonants, and the functional use of my left eye to restrain my weaker right eye from producing double vision. These conditions result from my premature birth at six months.

Although my visual and aural disabilities aren't severe, they've affected the way I communicate with my brother and react to him. Since I pick up my aural information from lipreading with one faulty eye, I don't trust the information I receive. This leads to a general mistrust of all my perceptions and a dependence on others for making decisions instead of trusting my sense of inner truth.

My family refuses to think of me as "handicapped." This encourages me to challenge myself academically, but this denial doesn't acknowledge or respect how faulty communication impairs the first impression which influences so many interpersonal and business relationships. Denial colors my brother's one clear memory of my hearing loss. He remembers, "The one thing that bothered me the most was when I had to repeat things. It seemed kind of selective. If I whispered, 'There's ice cream in the freezer,' you'd hear me, but not if I said, 'It's your turn to do the dishes tonight.'"

I have other memories. My brother has a great sense of humor, which he displays in teasing with a deadpan face. I would often be furious at some "joke" and would

yell at him, completely missing the vocal inflections that relay the "humor." And other kids' reactions to my speech and hearing loss have led me, for many years, to interpret all teasing, laughter, and whistles as being directed against me.

I come from a traditional family that gave the younger son much more independence than the daughter. A greater protectiveness, beyond gender differences, belied verbal assurances that I was typical. My mother ran my Girl Scout troop to keep the other kids from teasing me. I was in my mid-teens before my parents trusted me to ride a bike, where my younger brother wheeled around at ten.

As I grew into my teens, I avoided the anger and jealousy I felt toward my brother by spending hours in my room reading. As he was three-and-a-half years younger, he constantly asked me to play with him, only to have me turn him away. But as I got used to his teasing, his wonderful sense of humor disarmed me. We hid our emotional intensity in endless arguments about politics and foreign policy.

During our conversation about growing up, my brother also adds, "When you grow up with somebody, you don't see anything different. That's the way they are—that's my sister." As I come to terms with the physical and psychological meaning of my hearing loss, I read acceptance in those words.

In thanks to my brother for our experiences growing together, I'd like to tell parents, brothers, and sisters about the strengths my disability has given me and my family.

Because a partial hearing loss forces me to fill gaps, I have developed an active sense of nonverbal cues from facial

expression, mouth movement, and shifts in vocal intensity. My brother's teasing gave me plenty of practice here! I'm just beginning to trust the truth of clues.

I am developing a sense for subtle shifts in people's responses to me that tells me whether I have picked up on the underside of their speech or whether I am way off base. What this means in families is that children with hearing loss are very acute in discerning if the verbal cue does not match the underlying nonverbal feeling or behavior. And it's very easy, if a parent or sibling is uncomfortable with the accuracy of this discernment, to say that the child didn't hear correctly.

The "selective" hearing that my brother mentions is a trait all children have! I have known kids with keen hearing to go "deaf" when dishes are mentioned. Also, it's a function of the extra "sense" that I have had to develop. People usually lower their voices or use a different pitch to say censored, pleasurable, or emotionally-laden phrases. This signals to me that something important is coming, so I increase my concentration or alertness.

My family has allowed me to educate them on the challenges facing a sister with a hearing loss. Some of these challenges are as follows: It takes an enormous amount of energy and concentration for me to listen to conversations, especially in group situations. I am most comfortable one to one, or in groups of two to four people. Unless I can see the person's lips, it's impossible for me to hear conversations in the dark. I still have to tell my family not to dim the lights for those cozy living room discussions. I find it difficult to listen to anyone with a television on or music playing. All these things come up within families.

When I am emotionally upset, I find it much harder to hear. It's necessary to slow down, rephrase sentences, and give me time to process things. This is hard to do in a fight or when someone's crying. Also, I tend to interrupt a lot because it's difficult to distinguish a phrase from a full stop.

For all families: Use your differences and your gifts to imagine the fullest life each family member can live. There is a difference between being "disabled" and "having a disability." If I am "disabled," that defines who I am. If I "have" a

disability, I have certain choices as to how this physical and psychological reality limits what I do and how I live. If other people recognize and respect that disability, we can work together to create ways to stretch those limits. Ω

Planning For The Future

Sibling Concerns

Planning for the future raises many important issues for the family of a child with a disability. Powell and Ogle (1985) note that the most challenging of these dilemmas is the care of the adult sibling who has a disability. Even though nondis-

abled adult siblings have lives (and often families) of their own, they face unusual, additional responsibilities because of their unique relationship with their brother or sister with a disability.

The amount of responsibility that adult nondisabled siblings assume for their adult sibling with a disability varies with individuals and with circumstances. It is dictated by a consideration of family and job responsibilities, personal choice, and available community support.

Perhaps the most challenging issue families face is, on the one hand, encouraging and fostering the independence and self-determination of the person with a disability and, on the other hand, facing the reality that, at some level, assistance may be necessary.

Planning for the Future...An Adult Sibling's Suggestions

The following article is written by an adult sibling who has a close relationship with her sister who has a disability. In the article she shares some ideas on how to encourage nondisabled siblings to take

responsibility for adult siblings with a disability. She also shares some of her frustrations and anger over the lack of available community services and housing for adults who have disabilities.

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.

Families are expected to care for an infant or young child who is very dependent, and to provide experiences that eventually will lead to the independence of that person. Karen tells me that she needs to be

independent through her actions. I've seen her work at a task over and over again until she succeeds, despite the bumps she gets along the way. Karen is so proud of her every accomplishment. She wants others to be proud of them, too.

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.

In looking back over my childhood, I am grateful to my mom for encouraging my independence and for being moderate in her expectations that I care for my sister. Yet, family members are often interdependent throughout their lives. The concept of interdependence is important when considering the relationships of siblings

when one has a disability.

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.

In my experience, and from discussions with other siblings of people with disabilities, I have learned that the best way to foster a positive relationship among family members and a strong commitment to each other is to let them choose the levels and intensity of involvement with each other. I have noted that for me, these levels have fluctuated over time and during various circumstances. My relationship with Karen was strengthened when I came to view my involvement with her as a collaboration. Collaboration can be encouraged, but never coerced.

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 know it’s easier to say that siblings should be involved in planning for the future care of their brother or sister with disabilities than it is to involve them. I also know that the emotional ramifications of this are sometimes subtle and not always easily recognized. With respect to financial planning, moms and dads don’t usually sit down with their kids and say, “OK, folks, I want to let you know the details of our finances now and our financial prospects for the future.” This topic is difficult for parents and children alike. But you must attend to this in some way if family members are going to be prepared to take over the care of, or responsibility for, a person with disabilities. I remember all too well the day I finally got the courage to ask my mom about her insurance provisions for my sister. Her answers were anticlimatic compared to the effort and

energy I had spent getting the courage to ask the question.

The difficulty with planning for the future is that it forces family members to deal with the inevitability of death. Sitting down and actually discussing these details can be very disturbing to everyone concerned. My mom says she’s going to live forever; that she has too many responsibilities to ever abandon them. While we both know this isn’t so, no matter how

aunt’s house to visit her, and she could plant and tend her own garden, something she loves to do.

When I moved to my new neighborhood, I did as I always do, called about community living and work options for my sister. I was told that the current waiting list for group homes was ten years long! I asked the social services worker what I would do if tomorrow my sister needed a place to live. The worker told me

“...avoid seeing the person with a disability as ‘the dependent.’”

much we wish it were, it’s hard to discuss the inevitable. As an adult, I now know how difficult it is to come face to face with one’s own mortality.

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.

When people ask me what my needs are as a sibling of a person with severe disabilities, I tell them that I need the commitment from society that every person has a right to a basic quality of life. I believe that my sister has a right to live and work in her community, and a right to lead a life of her own, with some assistance. For me to be powerful in my collaboration with Karen in meeting these goals, I need resources to make this commitment become a reality.

I’d like to have my sister live up the street, in a house with other people with disabilities with whom she can share responsibilities and experiences. If she lived up the street, she could come over for dinner, my future children could go to their

that in certain emergencies people could be moved to the top of the list, and then they had to wait only three years! When I asked what one would do in the meantime, the social services worker retorted, “I guess you’d have to quit work and stay with her.”

Until society can be mobilized to provide a continuum of services throughout life to citizens with disabilities—services that allow a person to live a quality life with some independence, no matter what the level of disability—there will continue to be tremendous stresses on family members. Families should not be expected to bear the total burden; they cannot.

Today, due to pressures from parents and professionals, we have laws guaranteeing a free, appropriate, public education to our nation’s children and youth with disabilities. But after the child has aged out of public school, he or she again becomes the responsibility of the family. A continuum of accessible and appropriate services should be available to people with disabilities from birth to death.

Just as people united for the passage of special education laws and programs for the school-aged child, we must unite to work for the adequate provision of community-based services and housing for adults with disabilities. Society must share more of the responsibility with the family for providing necessary services. I maintain a positive attitude and believe that this will happen, in time. I just want to make sure that it happens in time for Karen and me. Ω

Suggestions for Families

When planning for the future of the sibling with a disability, you should consider such things as mobility, social and communication skills, education, and the individual's own ideas about where to live and work. Even after careful planning and the appointment of a guardian or co-guardians, plans should be made for emergencies. A file should be kept in a safe place,

“Parents set the tone for sibling interactions and attitudes by example and by direct communications.”

known to all family members. The following ideas should be addressed when making future plans and the information should be included in this accessible file:

1. Develop financial plans for future care. If the family is considering establishing a trust for the family member with the disability, it should consider the incomes of the children in the family, including the sibling with a disability. Make a will only with an attorney experienced in devising wills for those who have an heir with a disability. Inheritances must be treated with caution. It is especially important to investigate the continued eligibility for certain social services if assets from an estate, pension, or life insurance are left to the child with a disability.

2. Know your state's laws regarding guardianship and independence. Do not assume that you as parents will automatically remain your child's guardian when he or she reaches the age of majority in your state. Establish whether the sibling with a disability requires no, partial, or full guardianship. This information should be in writing, and, if possible, make contingency plans in case the first-choice guardian is unable to assume that role. Be aware of the consequences in your state of not having a guardian appointed.

3. Nondisabled siblings should know where to access the needed educational, vocational, and medical records of the disabled sibling, and be ready to anticipate his or her changing future needs.

4. Families should consider the future health of the sibling with a disability with

respect to needed services and care. Parents should document where he or she can receive medical care and the financial resources and arrangements necessary for this care.

5. Families should gain an understanding of the legal and eligibility requirements of programs available to the family member with a disability. Investigate resources through government programs, such as Supplemental Security Income

(SSI), Vocational Rehabilitation, Independent Living Centers, employment services, parent and disability groups.

6. Families should discover the types of community resources available. The range of services and resources varies considerably according to place of residence. Keep abreast of any changes in the availability of these services. Consider the sibling's need for long-term care, as well as for employment and companionship.

7. Be aware that, as families grow and develop, the members within it change. Living with and caring for a child with a disability is different from living with and caring for an adult with a disability. Family members should continually ask themselves the following questions:

- What are the needs of the sibling with a disability?
- How will these needs change?
- What can be expected from local support groups in the community?
- What is and will be my level of involvement?
- Is the involvement financially, emotionally and psychologically realistic for me?
- How will the responsibility be shared with other family members?
- Are my career plans compatible with my responsibilities for my brother or sister with a disability?
- Will my future spouse accept my brother or sister?

The care of a sibling with a disability or chronic illness is, in large part, a family affair and a responsibility that should be

shared as evenly as possible. By planning effectively for the future, parents can help ease the responsibility and the feelings of stress that uncertainty about the future can bring.

Suggestions to Parents

Parents set the tone for sibling interactions and attitudes by example and by direct communications. In any family, children should be treated fairly and valued as individuals, praised as well as disciplined, and each child should have special times with parents. Thus, parents should periodically assess the home situation. Although important goals for a child with special needs are to develop feelings of self-worth and self-trust, to become as independent as possible, to develop trust in others, and to develop to the fullest of his or her abilities, these goals are also important to nondisabled siblings.

To every extent possible, parents should require their children with disabilities to do as much as possible for themselves. Families should provide every opportunity for a normal family life by doing things together, such as cleaning the house or yard; or going on family outings to the movies, the playground, museums, or restaurants. Always, the child with the disability should be allowed to participate as much as possible in family chores, and should have specific chores assigned as do the other children.

Caregiving responsibilities for the child with a disability or chronic illness should be shared by all family members. It is especially important that the burden for caregiving does not fall onto the shoulders of an older sibling. If there is an older sister, there is a tendency in some families to give her the primary responsibility, or an excessive amount of it. Today, however, more communities are providing resources to ease the family's caregiving burdens. Examples include recreation activities, respite care, and parent support groups.

Powell and Ogle (1985) present several strategies suggested by nondisabled siblings themselves for parents to consider in their interactions with their nondisabled

children. These siblings suggest that parents should—

- Be open and honest.
- Limit the caregiving responsibilities of siblings.
- Use respite care and other supportive services.
- Accept the disability.
- Schedule special time with the non-disabled sibling.
- Let siblings settle their own differences.
- Welcome other children and friends into the home.
- Praise all siblings.
- Recognize that they are the most important, most powerful teachers of their children.
- Listen to siblings.
- Involve all siblings in family events and decisions.
- Require the disabled child to do as much for himself or herself as possible.
- Recognize each child's unique quali-

ties and family contribution.

- Recognize special stress times for siblings and plan to minimize negative effects.
- Use professionals when indicated to help siblings.
- Teach siblings to interact.
- Provide opportunities for a normal family life and normal family activities.
- Join sibling-related organizations.

Children with special needs, disabilities, or chronic illness may often need more help and require more attention and planning from their parents and others in order to achieve their maximum independence. Brothers and sisters can give parents some of the extra help and support they need; the special relationship of brothers and sisters, disabled and nondisabled, is often lifelong. This special and unique bond among siblings can foster and encourage the positive growth of the entire family.

with the disability. After that, parents are consumed with coping and survival. There is so much to think about: medical treatment, another opinion, insurance, money, weariness, and wondering why it happened to you. There just is never a convenient time to consider the Mariannes of the world.

It was difficult or impossible at the time to see the situations in which the siblings were being slighted. The slights were not intentional and there was no lack of love. When Marianne and her older sister, Patricia, were four and five years old, respectively, I enrolled them in dance class. This was one of the first realizations I had as a parent that they were not getting as much time, energy, and effort as their little sister with a disability. After that, I can recall making a conscious effort to change things. I remember how important it became that their costumes for the dance recitals were all that they should be. I remember sitting the children down and saying, "Jane takes more of Mommy's time and energy. It isn't that I love her more; it is just that she needs more. You see, she needs more car rides for her doctor visits and evaluations, and more time for her programs. So it ends up that she gets more of my time."

Do you suppose that Marianne, her sister, and her brothers who were older were able to accept those kinds of ideas? I don't know.

I do know that at some point in those early years things did change. Gradually, all the children became involved in assisting with Jane's programming. It was great fun to see members of the family join in to help. When Jane began to respond to their teachings, the children taught all the harder. I remember when my oldest son, Mark, taught Jane to "give me five." I remember telling teachers that our household had become a household of speech therapists. "Watch my lips" must have been uttered a hundred times a day; everybody was trying to get Jane to continue to develop her speech patterns. All these things were done in a light and joyful way that made them lots of fun. I, however, look back and wonder if it was too much for them? "How was Marianne being affected?"

I think about other things, too. I remain amazed by the enormous difficulty of motivating normal children to do their best when so much time and effort goes into the

"Where Was Marianne?"

by Patricia McGill Smith, Acting Assistant Secretary, Office of Special Education and Rehabilitative Services, U.S. Department of Education

The following article was written some years ago by a mother of seven children, the youngest of whom was born with a disability. Having worked successfully for years as a professional parent advocate, she knows all too well how difficult

it is for parents to juggle all their responsibilities and commitments when they have a child with a disability. She has put her thoughts on paper to remind and encourage parents to set aside time for their children without disabilities.

I have a daughter named Marianne. She is 14 years old and so pretty. Marianne may giggle constantly, and then sometimes grow very somber. She is a fantastic young lady of whom I am so proud. She plays soccer and basketball; she can cook and clean; and she has sensitivities far beyond her age. Several trophies line the shelf in her room, and she recently won a scholarship for high school. Yes, Marianne can do all kinds of things, and she is in and out of love every other week. While so much she does is so normal, there are some other things about Marianne and her life that are unusual.

Marianne was three years old when her sister, Jane, was born. The next two years in Marianne's life are a blur in my memory. Yet, I can recall vividly what hap-

pened to Jane during that time. You see, Jane was born with a disability. We did not confirm her disability until she was 14 months old. Those first 14 months were filled with apprehension, concern and crying, and the fussing and fretting of a demanding little baby. The next 12 to 14 months, the months after the diagnosis, were filled with more concerns, confusion, distress, dismay, and heartbreak.

I wonder where Marianne was during those two and a half years. What was she thinking during that time and what was happening to her?

If you don't have a child with a disability in your family, you can't imagine the impact this event has upon the entire family. So much of family life—the emotion, time, and concern—is focused on the child

development of the child with the disability. What a disappointment when the grades of the siblings come home and they are not all A's. You know they could all be A's, and yet, how do you motivate the normal children to work to their full capacity? I didn't know then, and I don't know today. Then there was the overemphasis on the accomplishments of the child with the disability. Were the accomplishments of the normal siblings similarly heralded? I don't think so. Yet, my Marianne and all the rest seemed to be happy children.

What about the resentment when Jane was learning tasks? It never seemed as though she kept up. Jane, as well as the rest of the children, had assigned tasks around the house and yard. Yet, wasn't it easier to get the older kids to do a job than it was to have Jane do it? I think so. What about the time I gave to teaching the older children skills? Was equal time given? I don't think so. I remember the summer we taught Jane to clean her bedroom. It had been Marianne's job to teach Jane the finer points of room cleaning, but Marianne didn't want to do it. Do the normal siblings

become resentful? Does this resentment create other troubles? I think so. Will Jane ever catch up and be able to fully meet the family's requirements of its members? I don't think so.

Is having a child with a disability going to adversely affect the development of the children who have no disabilities? Each family needs to consider this possibility and work to avoid inadvertently hurting the ones we love.

Have I personally ever gotten an answer to this question? Indirectly, yes, for despite all the uncertainties, my children have grown and matured into adults of whom I am proud. However, Gene, my oldest son, gave me what was perhaps the most direct answer I am sure I ever got to an unasked question. When he left home for college, he wrote me a letter. In this "lonesome" letter, in which he expressed his longing for family and friends, he spoke of all his brothers and sisters. Of Jane he said, "... and Jane, well Jane is probably the greatest blessing to us in the world."

Did he mean that he was glad that she was born with a disability? Quite the

contrary. He was saying that Jane and her needs had brought us together as a family. It was true; Jane had been a focal point around which we all rallied. We worked as individuals and as a family to help her. Jane had become a total family effort.

Over the years, as a family, and as individuals we have had many successes and some setbacks. Yet, we know none of us has to be alone. We know how to pull together as a family, to love, support, and share—something we learned how to do a long time ago with Jane. Ω

A Final Word

It is important for parents, siblings, and professionals to utilize the positive resources discussed here in order to cope with a variety of special circumstances, and to adapt them to meet individual needs as they change. Together, family members, as well as professionals, must strive to accent the "abilities" of disabilities, not only for a brother or sister with a disability, but for the entire family.

Bibliographic Note:

You can obtain many of the documents listed below through your local public library. Whenever possible, we have included the publisher's address or some other source in case the publication is not available in your area. The organizations listed are only a few of the many that provide various services and information about siblings. Additional support is also available from state and local parent groups, as well as from state and local affiliates of major disability organizations. Please note that these addresses are subject to change without prior notice. If you experience difficulty in locating these documents or organizations, or if you would like additional assistance, please contact **NICHCY**, by writing to PO Box 1492, Washington, DC 20013, or by calling, toll-free, 1-800-695-0285.

If you know of a group providing support services for siblings and their families in your area, please send this information to NICHCY for our resource collection. We will appreciate this information and will share it with other families and professionals who request it.

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The Bond. A quarterly newsletter intended for siblings and adult children of individuals with mental illness. (For subscriptions, contact: Sibling and Adult Children Network, National Alliance for the Mentally Ill, 2101 Wilson Boulevard, Suite 302, Arlington, VA 22201. Telephone: (703) 524-7600.)

The Exceptional Parent. A magazine for parents of children with disabilities published twelve times a year. (For subscriptions, contact: Psy-Ed Corporation, P.O. Box 3000, Denville, NJ 07834. Telephone: 1-800-562-1973.)

NASP Newsletter. A newsletter published for service providers. (Available from: National Association of Sibling Programs, Sibling Support Project, Children's Hospital and Medical Center, P.O. Box 5371, CL-09, Seattle, WA 98105-0371. Telephone: (206) 368-4911.)

Sibling Information Network Newsletter. A newsletter for siblings, published quarterly. (Available from: Sibling Information Network, A.J. Pappanikou Center, 1776 Ellington Road, South Windsor, CT 06074. Telephone: (203) 648-1205.)

ORGANIZATIONS

The Sibling Information Network- A.J. Pappanikou Center, 1776 Ellington Road, South Windsor, CT 06074. Telephone: (203) 648-1205.

Siblings for Significant Change- 105 East 22nd St., New York, NY 10010. Telephone (212) 420-0430.

Parent Advocacy Coalition for Educational Rights (PACER) Center- PACER is a center of "parents helping parents." PACER's programs help parents and children become informed and participating members in the life of a child with disabilities. In addition to a resource listing of publications and a newsletter, PACER offers many workshops. Write: PACER Center, Inc., 4826 Chicago Ave. South, Minneapolis, MN 55417. Telephone: (612) 827-2966 (outside of MN); 1-800-537-2237 (in MN).

Siblings of Disabled Children- A program of Parents Helping Parents, offers two groups, one for ages 8-12, and one for ages 13-17. The objective is to give siblings special attention relating to their needs around being a member of an exceptional family. Their newsletter is called, *Sibling Squabble*. Write: Parents Helping Parents, Inc., 535 Race St., Suite 140, San Jose, CA 95126. Telephone (408) 288-5010.

Sibling Support Project- Children's Hospital and Medical Center, P.O. Box 5371, CL-09, Seattle, WA 98105-0371.

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