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Christine S. Davis and Kathleen A. Salkin

*Journal of Contemporary Ethnography* 2005; 34; 206

DOI: 10.1177/0891241604272066

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## **SISTERS AND FRIENDS**

Dialogue and Multivocality in a Relational Model of Sibling Disability

CHRISTINE S. DAVIS  
*University of South Florida*  
KATHLEEN A. SALKIN  
*Sara Lee Branded Apparel*

*CHRISTINE S. DAVIS, M.A., is a visiting assistant research faculty member at the Florida Mental Health Institute, Department of Child and Family Studies, at the University of South Florida. Her research interests are in the intersection of health, disability, family, interpersonal, and group communication. She is a Ph.D. candidate in the Department of Communication at the University of South Florida.*

*KATHLEEN A. SALKIN is a human resources information systems analyst for a major corporation in Winston-Salem, North Carolina, and her main interests are anthropology, communication, and research in interactions of computing technology and the disabled.*

*Journal of Contemporary Ethnography*, Vol. 34 No. 2, April 2005 206-234

DOI: 10.1177/0891241604272066

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*This article takes the reader into a journey of family dynamics, as sisters—one with a physical impairment and the other the sibling of a woman with a physical impairment—try to sort out their feelings and experiences through in-depth interviewing, interactive interviewing, co-constructed narrative, and dialogic conversation. There is little research that looks at the relationship between the sibling with a disability and his or her nondisabled sibling as it is experienced by the two of them. This article engages the siblings, and, perhaps, the readers, into a dialogic conversation that is multivocal, inclusive, and accepting of differences.*

**Keywords:** *family communication; sibling disability; autoethnography; co-constructed narrative*

## PROLOGUE

In February 1952, when my mother was 51/2 months pregnant with my older sister Kathy, she met a fortune teller. The woman put her hand on mom's abdomen. "I see dancing legs," she predicted. "Your child will be a dancer."

Two weeks later, my sister was born. She was baptized immediately. She was weighed for the first time when she was five days old; she weighed 2 pounds, 4 ounces. When she was eighteen months old, her inability to walk, muscle spasticity, and lack of response to sounds was given a name: cerebral palsy. The cerebral palsy was thought to be caused by a lack of oxygen at birth. Her cognitive functioning was fine, but she was partially deaf and moved around only by vigorous crawling. It took two leg surgeries, huge leg braces and crutches, and years of physical therapy before she was able to walk.

As the younger sister, I was born to exhausted, preoccupied parents with stored-up expectations for their children. I learned independence as I used the physical therapy workroom as a playhouse, running up and down the stairs, along the parallel bars, and over the treadmills, as Mom and the physical therapist worked with Kathy. I developed a fear of doctors as I sat alone in waiting rooms of doctor's offices, listening to

*AUTHORS' NOTE: The authors wish to thank Art Bochner for his especially helpful and encouraging responses to this article and Carolyn Ellis and Art Bochner for their support, inspiration, and encouragement. We would also like to thank Monica Casper and the anonymous reviewers for their helpful and supportive suggestions. Please direct all correspondence to Christine S. Davis, Department of Child and Family Studies, Louis de la Parte Florida Mental Health Institute, University of South Florida, MHC 2403, 13301 Bruce B. Downs Blvd., Tampa, FL 33612; e-mail: cdavis@fmhi.usf.edu.*

Kathy's terrified screams down the hall as the doctor used an electric saw to remove yet one more cast. I acquired patience when I had to wait because it took Kathy longer to do things. I gained responsibility because it was my job to pick up both of our toys; after all, Kathy is "handicapped."<sup>1</sup>

### RESEARCH QUESTION

In this article, I want to examine my relationship with Kathy. In my research on this subject, I looked for evidence that others have shared my experiences. I found research that says that siblings of people with disabilities are less well adjusted and are more likely to experience severe behavioral problems than children without a sibling with a disability; that siblings of children with severe emotional disturbances tend to feel overlooked or ignored, suffer from a disproportionately lower share of parental attention, and a disproportionately higher share of parental expectations; and experience "survivor's" guilt for their better health (Cuskelly 1999; Fisman, Wolf, and Ellison 1996; LeClere and Kowalewski 1994; Lobato and Kao 2002; Pit-ten Cate and Loots 2000; Nixon and Cummings 1999; Schulman 1999; Seligman and Darling 1997; Wolf, Fisman, and Ellison 1998). Other researchers have found, however, that siblings of children with disabilities are more well adjusted than other siblings—many show more maturity, responsibility, altruism, tolerance, self confidence, and independence (Pit-ten Cate and Loots 2000). I relate to all of those findings.

Researchers have looked at sibling caregiving—something I have never had to do for Kathy—and found that sisters are more likely than brothers to provide care for siblings with mental retardation (Krauss, Seltzer, and Gordon 1996; Orsmond and Seltzer 2000). Some siblings of children with disabilities report increased homecare and caregiving responsibilities over other children, while others do not (Damiani 1999; Seligman and Darling 1997). Kathy's disability is physical and not cognitive, and she lives independently, so this is not an experience I share. What I do share, however, is a concern about Kathy's future and an awareness as I was growing up that I might be assisting her when we got older.

Nonetheless, there is little research that looks at the relationship between the sibling with the disability and the nondisabled sibling as it is experienced by the two of them. How did Kathy's disability and impairment affect how we related to each other, I wondered? How much of our relationship was based on being sisters, and how much was based on her physical condition? And can these issues even be separated? Also, I wanted to get clues to whether her disability had in some way affected my relationship with my parents. I wanted to hear an excuse—exhaustion, stress, overload—for my experience of emotional neglect as I was growing up. I decided to use Kathy's and my relationship to write this; to together produce a co-constructed narrative, with the two of us writing and talking together, discovering together as we write, what our relationship is about. I was hopeful that as we wrote about our relationship, we could in fact enhance it.

### DISABILITY AND STIGMA

Of course, disability and impairment are not the same thing. Kathy's body has impairments—cerebral palsy and hearing impairment. Impairment turns into disability through a process of exclusion from social activities in a society that stigmatizes individuals who are physically different (Goffman 1963; Marks 1999, Oliver 1990; Oliver 1996; Shapiro 1993). Stigma has been defined as an “undesirable differentness” (Goffman 1963), and the stigmatization results not from the differentness itself but from a society that constructs disability and normalcy, one that says that people who are different are somehow “invalid” (Barnes 1996; Marks 1999; Oliver 1990, 1996; Zola 1982). The disability itself often overshadows the person's self-identity (Susman 1993). It seems to me, though, that the differentness of our family overshadowed not just Kathy's identity, but everyone's. It is the hegemonic influence of “able-bodied” society that separates people into categories of “normal” and “deviant” and therefore pushes people with impairments to attempt to behave more like “normal” people—submitting to medical procedures designed to help them “overcome” their physical impairments (Oliver 1990). This traditional “medical model” of care involves professional hegemony in which people with physical disabilities, and sometimes their families, are viewed as deficient objects,

responsible for their problems. This perspective emphasizes loss and inability and contributes to a picture of the child and family as being dependent and results in a disempowerment and marginalization of people with physical impairments (Barton 1996; Foucault 1995; Marks 1999; Oliver 1990, 1996; Seligman and Darling 1997). I suggest that to study Kathy's disability within the context of our family and our relationship—studying our collective experience of disability—yields a richness to the understanding of the social aspects of impairment and disability that has yet to be examined. I further suggest that families of people with disabilities and physical impairments also undergo a process of normalization in which they try to live up to society's image of a "normal" family. I also want to make it clear that I am not attempting to classify Kathy or myself into categories of normal versus disabled. I believe that as we age, we are all simply disabilities waiting to happen (Zola 1982). I also believe that each of us has conditions that are at times disabling and are at other times enabling. What seems clear to me is that any disability Kathy had was a "family disability," experienced in relationships between our family members. This is what I wanted to find out with this research—how was Kathy's disability experienced in our relationship, and how was it experienced in my relationship with our parents?

## METHODOLOGY

I am aware of the moral ethics of speaking for Kathy, and I am sensitive to letting the voice of people with disabilities be heard (Barton 1996). This is why, in writing this article, it was important to me that I not attempt to give my accounts of Kathy's experiences (Oliver 1996). Instead, this article attempts to let each of us give our own accounts of our own experiences. I have made a conscious effort to give both of us voice. My goal in this research was to be a "dialogic researcher" who engages dialogically with Kathy through acknowledging both of our humanities and our vulnerabilities (Czubaroff and Friedman 2000; Mizco 2003; Patton 2002; Reed-Danahay 2001). In essence, this is a case study methodology in which I study one case—my family—within the context of being a family with one member that has a physical impairment. I am attracted to a case study approach to research

because it takes a postmodern ethnographic orientation in its basic epistemology. It sees knowledge as experiential, it pays attention to sociopolitical contexts that influence the meaning within the case, it seeks to understand multiple realities, it takes a radical constructionist position that is interested in the ways that everyone involved is touched by the situation, and it focuses on interpretive knowledge from the human being who is the research instrument. Rather than generalizing to a population, case studies provide naturalistic generalizations so that readers are able to experience the case vicariously along with us. A case study looks at a situation in its contextual complexity and typically focuses on understanding actions, processes, patterns, and problems through interpretation and narratives (Lincoln and Guba 1985; Stake 1995).

Our parents are both deceased, and my other sister Kelli is much younger than us and therefore did not participate in much of our joint childhood experiences. In addition, Kathy has completed graduate work in a social science discipline and has expressed interest in my research. Thus, I decided to invite her to write this article with me. Since we live in two different cities 800 miles apart, and because Kathy is hearing impaired, we discussed these issues via e-mail and America Online Instant Messenger. We also had one in-person conversation during a trip I took to visit her. I sent her this article as I wrote it and invited her to write about her own memories, as well as comment on mine. We performed this article exchange two times. I had hoped that she would feel comfortable putting her voice forward as strongly as mine. I am aware, however, that the hegemonic influence of the academic publishing guidelines gives my academic and narrative voice more "weight" than Kathy's conversational voice and that the editorial necessities of writing such an article give more room for my voice than hers. However, I do believe that the writing is also multivocal and moving toward the dialogic. To preserve the multivocal quality of this article, I have included the exact words from each of us as much as possible. Editing only consisted of removing conversation that did not pertain to the research topic. Methodologically, this article is a combination of in-depth interviewing, interactive interviewing, co-constructed narrative, and a conversation between sisters. Practically, the reader is being taken on a journey inside our relationship.

This article presents recollections, feedback, and conversations. Thoughts constructed after the conversation are in parenthesis.

## THE CONVERSATION BEGINS

Kathy: I am the eldest of three sisters and have considered us all to be relatively close—that is, until they moved down to Florida this past year. I do miss them but my life is so full that I keep myself busy, so I don't have time to mope.

I am both excited and apprehensive at this project. Excited because it's always good to learn new things about yourself and those you interact with. Apprehensive because I'm afraid negative things will come up and I don't take criticism very well sometimes. However, this is a good learning opportunity for us and I'm pleased Cris asked me to be a part of it.

Cris: I had the exact same concerns that you did; I was concerned that we might talk about something that might be hurtful, or painful, or we'd bring something up that might insult the other person. If I said something that hurt your feelings, that might cause a problem in our relationship, and one of my goals in doing this is for us to talk about stuff and get closer. I'm hopeful, and I hope you agree, that we can agree to work through anything that gets difficult and make sure that it does make us closer.

Kathy: I don't have a rose colored vision of us as a perfect family. I tend to shy away from confrontations because I don't like them. I don't like being hurt and I don't like hurting people. I'm a little apprehensive.

Cris: One of my goals in studying this for myself is to determine how much of our "weirdness" growing up had to do with the fact that somebody in the family was disabled, nothing personal against you.

Kathy: Yeah, that's the dynamics, there's no getting around it.

## THE EARLY YEARS

I look through the family photo album until, finally, I find the picture I am looking for. This picture is the epitome of our childhood. We are dressed up, posing for pictures, pretending to be perfect. Easter Sunday. I am probably five and Kathy is probably ten. We are in the backyard of our house in California. The sun is casting shadows in front of us. The grass is green. A palm leaf peeks in the corner of the picture. We are dressed in pastels; me with baby blue ruffles running along the bodice of the dress and white chiffon skirt beneath and Kathy in a turquoise blue lace dress with a pink sash. We both have on white socks with lace tops and white Mary Janes. We are both squinting into the sun. Kathy, at



least a foot and a half taller than me, is leaning on me ever so slightly. Her feet are turned just a little bit funny, away from the rest of her body.

I wonder how many of my feelings of parental indifference and adjustment problems stem from Kathy's disability, how many stem from my place as a younger sibling, and how many stem from the combination of the two factors? It is interesting to note that research on birth order has found that older siblings have more access to parental time, energy, and engagement in their lives (Steelman et al. 2002), reinforcing my birth order hypothesis. On the other hand, other research has identified difficulties younger siblings have in adjusting to having an older sibling with a disability (Cuskelly 1999).

Cris: I remember playing dress up and I got to be the princess and you had to be the prince, you were the older sister and you had to be the prince.

Kathy: I remember that; that was a lot of fun. I remember I hated the way Mom used to always make me wear pink and you always got the blue dress.

Cris: I always hated dressing up like that anyway. Regardless of what it looked like.

Kathy: It was kind of cute.

Cris: It was so uncomfortable.

Kathy: She made those dresses; she worked hard on those dresses. She put all of her love into those dresses. She wanted the best for us. She just loved to dress us up. She loved us. That I never doubted.

(CRIS: [To myself]. I did doubt that. I guess that's why I'm on this journey; to find out that her perceived indifference wasn't about her not loving me. Throughout the years, Kathy and I have had this same conversation, and it always ends the same way, with me saying I didn't feel love from Mom, and Kathy bringing out all sorts of evidence to prove she loved us. Kathy saw her dressing us up as being about love; I saw it as being about her trying to mold us into something we weren't; proof that I wasn't good enough for her the way I was.)

More pictures of us together: Kathy posing with me at my kindergarten graduation; I'm wearing a white graduation gown, holding a white rolled up parchment. Kathy and I held safely in Dad's arms, one on each side of him, sitting on the living room couch. Posing in front of our Christmas stockings, in our matching red and blue dresses. At the beach, sitting side by side. Playing in our playhouse. Playing with our cat. Posed in matching dresses, standing side by side. Playing with dolls. Playing in the backyard. Kathy on her tricycle, me in my "Hot

Rod” toy car. On family vacations. Always side by side. Usually in matching clothes.

Kathy was my first friend, I guess. Long before I went to nursery school, long before I made friends in the neighborhood, Kathy played with me. I was her real-life baby doll and she was my big sister.

Looking back over the pictures, stories, and memories, I can see my conflicted feelings about Kathy. I loved her, and when we were young, I did not see any impact of her disability on her or on our relationship. She was my big sister, and that was just the way she was. As I got older, though, I resented having to take on additional responsibilities to make up for things she could not do. And I was jealous of the time that Mom and Dad seemed to spend with her and not me. Other siblings also seem to have these conflicts. Siblings in Pit-ten Cate and Loots’ (2000) study reported both positive and negative aspects of their relationship with their sibling with a disability. They reported love and affection toward their sibling, perks awarded to the family as a result of the disability (special holidays, going to the head of a line, etc.), and enjoyment in playing together. But they also reported difficulties in playing physical games and in communicating with each other. Part of the communication difficulty was because of the impairment itself, but part was due to the fact that the siblings, because of the impairment, had less in common, and because they were not comfortable discussing the disability itself. Inability to discuss the disability in the family may result in increased loneliness and isolation for the nondisabled sibling (Seligman and Darling 1997). I wonder if this may result in loneliness and isolation for both siblings. I wonder if Kathy ever felt isolated because we could not discuss her disability. I wonder if she still does.

Kathy: It’s interesting what you said about the family photos, for there is a family photo of us taken just before I broke my leg back in 1997. You and Kelli are in the back while Jerry, Mom, and I are in the front. I usually am in front in most group photos, as it is an “advantage” of being the shortie—ha. I realize the photographer posed us, but I think it it’s interesting that you and Kelli are together because I’ve felt sometimes that the two of you are closer together than either of you are with me. I’ve felt the outsider sometimes as we got older, especially after Dad died. However, that might be because Mom got more sharp tongued and divisive after Dad’s death, I don’t know. \*Shrug\* However, I don’t really obsess about it because it’s not really important. We’re all that’s left of the family, and we need to stick together.

Kathy: I've often wondered; somehow some of the expectations that come with being the number one child got passed on to you because of my disability.

Cris: That's interesting you say that, because I felt often that I was born the oldest child. I've often felt that from the time I was old enough to remember, I was expected to know things that I wasn't old enough to know, know how to do things that I wasn't old enough to do.

Kathy: I don't know about that. Sometimes they say the expectations of the oldest child is that you do well, they have higher expectations of the first born. That's not to say that they didn't have high expectations for me.

Cris: I always felt that their expectations for both of us were put on me to some extent.

Kathy: I think that once that Dad realized that I could do pretty much what I wanted to with my brain, he increased his expectations of me.

Cris: What I'm referring to, for instance, is usually the older sister is expected to kind of watch out for the younger sister, and I think I always felt, whether it was right or not, that it was my responsibility.

Kathy: Oh, yeah, Mom expected you to look after me. I remember I kind of fought that. That's probably one reason I'm so independent. Because I hated feeling like you guys had to watch out for me. I didn't ask to be disabled. You didn't ask to be the middle child. You didn't ask to have expectations higher of you than were normal.

As I look through the photo album, I see a picture of Kathy in her leg braces. I remember them. They were huge metal things, constructed with two flat metal slats fastened into a top thick, tan leather band that fit around her leg above her knee. At the bottom of each metal side slat was a flange that fit into a notch in the side of her specially made, huge, heavy, brown leather lace-up shoes. With the braces on, she walked stiff legged and awkwardly, lunging forward with each step. Spasticity in her legs caused her to walk mostly on her toes. She kept her balance with the aid of arm braces, a combination of canes and crutches that fit to a leather strap fitted around each arm. I don't know how she felt about walking with these braces, but as her little sister, I loved playing with them. To me, they were toys, big-sister props that she had, and I did not, reason enough for me to want to play dress up with them.

Cris: What influence do you think your disability had on all of our family relationships?

Kathy: That's kind of hard to say, because I was the center of it. Kids tend to be centrist; when you're a kid, you don't tend to think of other people's

feelings. I do know that it put a lot of money pressures on Mom and Dad. They had to worry about therapies for me, and braces. But they did have help with a lot of that stuff. From Easter Seals. But just the tension of dealing with a disabled child; finding out what schools to send her to and everything. How to get me to school, therapy, and all. I guess we were extremely lucky we lived where we did. LA [Los Angeles] County had an extremely good program for disabled kids. Lowman School was the best academically speaking that I could have gotten, as good a program as any. At least they never ever talked about sending me away. A lot of parents were encouraged to send disabled kids away to boarding school. I remember Mom telling me several times that her doctor told her that I would never be able to be educated, I would have to be institutionalized. This was when I was a baby, before they knew the extent of my disability. She said she refused to believe that. Knowing Mom, I could believe that. She said she was determined to make me be the best I could. And she did. She was the best mother she could have been. A problem with that was, I think it took so much of her energy. And dealing with a disabled child.

Kathy and I certainly had different experiences of mom and dad. I wanted to know if their seeming inattention was caused by a lack of love toward me or their preoccupation with raising Kathy. I wanted to hear evidence that they meant well and that their indifference toward me was out of their control. I wonder what evidence would change my feelings. I look through my research. Parents of a child with a disability have to contend with the loss of their anticipated familial narrative. Their narrative must be transformed to accommodate the disability, which in a systemic sense affects the entire family. Family life is normalized around the disability, as barriers are faced and overcome (Green 2002). Families with a child with a disability tend to have more stress, conflict, financial burden, maternal depression, and marital distress than do families without a child with a disability (LeClere and Kowalski 1994; Nixon and Cummings 1999). Mothers of children with a disability are more vulnerable to stress and have a diminished sense of mastery (Seligman and Darling 1997). I could say that we experienced all of that.

(Cris: The following interview [done using America Online Instant Messenger] illustrates, I think, how much sometimes Kathy and I are simply big sister and younger sister roles.)

Cris: So, do you want to finish that interview we were in the middle of, at your birthday? We could do it now if you want.

Kathy: Right now?

Cris: Uh huh. For awhile at least. As long as you have time.

Kathy: I was planning to go to bed early.

Cris: For a few minutes? Whine whine. (Sometimes it helps to play "little sister.")

Kathy: OK if it's not too long.

Cris: OK; thanks!

Kathy: Shoot.

Cris: I think I was asking you to describe your relationship with Mom and Dad, and you were in the middle of answering that when we left for dinner, so do you have anything to add about that? So, the question was, how would you describe your relationship with Mom, especially when you were younger, elementary school age?

Kathy: It was pretty good when I was a kid. Not bad at all.

Cris: What made it pretty good?

Kathy: Happy times, and so forth.

Cris: Tell me about a happy time.

Kathy: When she gave me a surprise birthday party and invited my Girl Scout troop and school mates, when I was eleven, I think. There were about ten or so girls, and we had a blast. Mom made one of her cool cakes and it was all very nice.

Cris: Do you remember if I was there?

Kathy: I think you were. You were at all my birthday parties.

Cris: Do you remember the birthday where the magician pulled the rabbit out of the hat? That was a birthday party for you.

Kathy: Oh yeah. I was about seven or eight that year; you were just two or three.

Cris: That was really traumatic for me because I got left out and didn't get to pet the rabbit; for some reason I remember that. (I was the baby; pre-school age. Everyone was so busy with Kathy and all her friends with disabilities that I got pushed to the back. I stood in the corner and cried and nobody noticed me.)

Kathy: Awww. . . . I don't remember that part.

Cris: I remember going with you and Mom to your physical therapy. What age did you start going to physical therapy?

Kathy: That was a special thing when I went to St Paul's.

Cris: What age were you diagnosed with cerebral palsy?

Kathy: Diagnosed at two; started physical therapy at three.

Cris: What was physical therapy like for you?

Kathy: I hated it!

Cris: Why?

Kathy: Because I had a mean physical therapist when I was six or so and never got over it.

- Cris: Huh! I always thought it was fun to tag along; kind of like playtime.
- Cris: What did he/she do to make him/her mean?
- Kathy: She would shake me roughly when she thought I wasn't moving fast enough and it scared me.
- Cris: Yuck.
- Cris: How much extra time as parents do you suppose Mom and Dad spent doing stuff related to your cerebral palsy as opposed to regular parent stuff they would do with any child?
- Kathy: Hard to say. I know they put a special effort into the PTA [parent-teacher association] because it was one area where they had a voice.
- Cris: Were there issues that you took longer to get dressed in the mornings and stuff?
- Kathy: They just got me up earlier, etc.
- Cris: My memories are that they were burdened and didn't have time for me, and I'm wondering how much of that was the cerebral palsy and how much of that was them and how much of that was just being a younger child.
- Kathy: I remember sometimes they'd have to hurry me up to catch the bus. Dad was a very busy man. . . . He was in PR [public relations] for Technicolor, and he traveled sometimes.
- Cris: Yeah, and my memories are that Mom was really busy too.
- Kathy: I remember Mom being there all the time.  
(Cris: For who? You?)
- Cris: Do you remember my relationship with Mom?
- Kathy: All I remember early on is that you were a cranky kid at times. You were, you know.  
(Cris: Ouch! So much for sympathy! What a big sister thing to say! I feel my old competitiveness rising up!)
- Cris: What age, in what way?
- Kathy: Well, when you were like two or three you had horrible temper tantrums. You would sit there and cry and cry because you were so mad.
- Cris: All two-year-olds have horrible temper tantrums! That's what the phrase "terrible twos" means! (I'm feeling very defensive here! I can see that after forty-five years, you're still able to push my "anger" buttons! I wonder why?)
- Kathy: I'm sure you drove Mom crazy.  
(Cris: Phew! Sometimes Kathy can be really "know it all," and even at our ages now, she can make me so mad! Why does she have to say something mean like that? As I read through this, I story myself as the little sister to her, who looked up to her, and at the same time as a sort of big sister to her, who watched out for her. Why does she have to have such negative memories of me?)
- Kathy: You were stubborn, that I remember too.

Cris: In what way?

Kathy: Always wanted to get your way. You and I used to have these fights in our room all the time, over silly things like who would turn out the lights, who would get which bed, whose stuff went where—usual stuff like that. And Mom would get fed up because she would have to come in and settle things.

(Cris: Yeah, well, it takes two to fight!)

Cris: I remember she used to say that she always wanted us to be close because she had been an only child and had missed that.

Kathy: You were a good kid, basically, but sometimes you could get stubborn and refuse to do something.

Cris: Like what?

Kathy: Oh, jeez I don't know. I can't remember a specific time; it's just a general memory, you know?

Cris: Uh huh. (It's probably time to end this interview before we get into a fight about whether or not I was a brat at age three!) OK. Let's go to bed. Goodnight. Thanks for your time.

Kathy: You're welcome. Good night. Love ya. Bye.

Cris: OK, love you! (I sure hope our relationship survives this project!)

Both: Signed off.

I feel like I am ten years old again! I feel vindicated to read that first-born siblings have been found to be less agreeable than later born siblings. Later born siblings tend to be more agreeable, partly as a strategy to minimize confrontation with their older siblings (Michalski and Shackelford 2002). Nixon and Cummings (1999) found that siblings of children with disabilities experience greater emotional distress in reaction to family conflicts and develop extra sensitivity to family conflict and concerns, perhaps even becoming negatively biased toward social cues in interactions. I wonder if that is true of me. Siblings of children with disabilities tend to use more coping (rather than avoidance) when dealing with family conflict; that is, they try to take the responsibility to "fix" the problem. I wonder if some of our conflicts are a power-resistance dialectic, in which, having both been put in an "older sibling" role, we are both resisting the other. If power in a sibling relationship is an entitlement, then which of us is entitled to it? The one first in the birth order or the one who had the primary sibling responsibility?

Cris: Part of what was up with me was that they didn't have time to teach me things, so I . . .

Kathy: I don't understand what you mean.

Cris: Like tie my shoes.

Kathy: Mom didn't teach me those things; Nana did.

Cris: No one taught me. An older girl in elementary school taught me because she thought it was ridiculous that someone my age didn't know how. No one had time to teach me. I think that I just learned to be good and keep out of the way because Mom had her hands full and didn't have time to mess with me, so I just learned to be the "good daughter."

Kathy: I always thought that before I was the age of age, Nana was the one who was the main . . . of course, Mom was there.

Cris: Why was Nana the one who did that? Was Mom not a nurturing mother?

Kathy: I don't remember. I think Nana sort of spoiled me rotten. I remember Mom used to tell me that anytime she wanted to punish me for something, Nana would say, "Don't do it! She can't help it!"

## THE MIDDLE YEARS

When Kathy was ten and I was five, she had the second of three surgeries on her legs to cut the tendons in her calves and allow her to walk more easily. I tagged along when she got the leg casts removed.

Mom helped Kathy out of the car as I waited patiently next to our black 1960 Buick Roadmaster. With the toe of my shoe, I played with a crack in the sidewalk as Mom helped Kathy pull her huge leg casts out of the car and moved her to a waiting wheelchair. I followed behind the wheelchair as Mom wheeled Kathy into the doctor's waiting room.

"Sit over there," Mom said, pointing to a seat, a middle seat in a row of black, olive green, harvest gold, and burnt orange plastic cushioned seats. I complied. Immediately behind me, in the next row of seats, were two nuns. Their eyes, nose, lips, cheeks, and chins stood out from their black starched habits and headpieces. I tried not to stare, but it was hard. I loved nuns. They seemed to be similar to angels, and I figured that they prayed all the time, so they must have more direct access to God than the average person. Direct access to God was a good thing. God could answer prayers. If He wanted to, He could heal impairments like my grandmother's blindness or Kathy's cerebral palsy. I wondered what these nuns were thinking. I tried not to stare as I stole glances at their faces.

"Kathleen Salkin." The nurse at the door called Kathy's name.



“Stay here and read your book,” Mom whispered as she handed me *Tip and Mitten*, my favorite reading book about a cat and a dog. “We’ll be back as soon as we can.”

I looked at the book. Suddenly, I heard a commotion coming from the other side of the waiting room door, echoing from far away. First, the loud whirring, whining, screaming sound of a saw. Then, almost instantaneously, the high-pitched sound of a human scream. The scream of the saw and the scream of the human merged in a disharmony of sharps and flats as my hair stood on end. I recognized that scream. It was Kathy, screaming as they were sawing off her cast. I wanted all the screaming to stop; I wished they would stop. Couldn’t someone make them stop?

Mercifully, the screaming did finally stop, the nuns were called in to see the doctor, and I got a lollipop from the nurse even though I had not had to scream to earn it.

Kathy: I only had three surgeries as a child—a tonsillectomy at the age of five and the two on my right foot at the ages of eleven and twelve, not four.

Cris: Whatever (she always has to be right!)

Cris: Talk about your relationship with Granddad.

Kathy: He kind of spoiled me too. He was an inventor. He did things that helped me increase my mobility. He built things. When I was a little kid, I couldn’t walk very well, so he built a little walker for me. You know those bar stools, he cut the seat and cut a hole in the seat and put wheels on the end of the legs. I’d pull myself up by the shoulders and then just wheel myself all over the place.

Cris: Tell me about your relationship with Mom.

Kathy: She’s my mother, and I don’t remember having any problems with her when I was a little girl; she was the quintessential housewife. We lived in this really nice house in California, beautiful house; Mom was a very house-proud woman. She loved decorating, and she was very good at keeping things neat and tidy, unlike me. Appearances were very important to her. She’d always fuss at you if you didn’t look your best. She always had this picture of what things should look like.

Cris: Let me ask you this. I agree with you, and I’m thinking as I’m doing this writing. Outward appearances were so important to her, how do you think she was affected by your disability? That’s an appearance thing.

Kathy: The thing about me is, unless you see me walking or see me in a wheelchair, I don’t look disabled. A lot of disabled kids have funny

looking teeth or funny looking features. My disability is in my legs; it's not in my face. I've been told I'm pretty.

Cris: I think so.

Kathy: It's not like she had a horrendous child to contend with. She coped with my not being able to walk very realistically. She knew I couldn't do certain things and she made certain allowances. But I will say this for her: when I was a kid, I would have to do the dishes, I would have to help with the housework. And I hated it. They didn't let me get away with murder. Now you and Kelli may have different opinions.

Cris: I do, but that's alright. (My memory is she did get away with murder!)

Kathy: I got away with as much as I could. That's kids. That's normal for a kid. I don't think, I don't remember Mom or Dad letting me slack off in school just because I was disabled. At least in schoolwork.

Cris: You were always very good in school.

Kathy: Now physically, I remember they made some allowances for me, but I remember Mom would make me help with the dishes, and she would let me help with the cooking. I cleaned rooms, but I admit I'm awful at cleaning rooms. But that's just laziness on my part; it wasn't from lack of effort on Mom's part to teach me. If I had been an only child, she might have made more of an effort with me, but when you were born and Kelli was born, she concentrated on teaching you guys how to clean the house. Maybe she thought it was less of an effort to teach you than to teach me.

## THE LATER YEARS

Kathy's series of surgeries helped, and she was able, for many years, to walk unaided. She still had a strong limp, still favored walking on her toes, and had balance problems that caused her to fall frequently, which finally convinced her to begin using crutches to help her walk.

When I was twenty-two and Kathy was twenty-seven, we went on a river tubing trip with some of my friends from the single's group at church. I didn't want her to go.

"Mom, they're MY friends! Why do I have to invite Kathy along?" I whined. They were my friends, from my church, in my life, separate from my parents and my sisters. Having her come would ruin everything! I couldn't enjoy myself if Kathy were there. I felt like a teenager whose younger sister wanted to tag along on a date.

"She's your sister! She's met your friends before and they get along great! This is a great opportunity for her to do something she's never done before! This is a church group outing. Why wouldn't you want to

take her?" Mom's logic and my guilt fused together and I reluctantly agreed to bring her along. I wasn't quite sure why I was so irritated at including her, but I was. I fought off the ominous feeling creeping into my consciousness.

The day dawned beautifully. It was a sunny July day, not unbearably hot, but hot enough to enjoy floating in the river. The outfitter guys dropped us and our big black rubber inner tubes off at the riverbank. They helped lower Kathy into the river, so all I had to do was watch fretfully as they tried to balance her in the mud and she landed in the inner tube with a plop. I watched as they drove off with her crutches.

"We'll meet you at the end in a few hours!" They waved as we set off.

The water was calm and we settled into a rhythm of lazy floating, letting the current carry us slowly along. I closed my eyes and let my hands drag in the water as I relaxed. I could hear the rest of the group chattering and laughing in the distance as the sun warmed my face and the breeze gently blew through my hair.

"Hey, look!" A shout woke me up. I looked up. Dark, black clouds filled the sky. "We're fixing to get rained on!" someone yelled. Almost immediately, big plops of raindrops fell on the water, created shiny black dots on the inner tubes, and hit our heads. "What should we do?" someone asked, just as a bright flash of lightening hit the water in front of us. "Get out! Now!"

I paddled through the crowd of churning water and flailing arms and reached Kathy. She had a look of alarm on her face. "Here," I said. "Hang on to my tube." We paddled together as I pulled her to shore. The other people were already heading for a path along the side of the river as I struggled to pull her tube and her out of the water.

"Thank you," she whispered. I brushed off the comment and, with great effort, balanced her in one arm and the two inner tubes in the other.

"Here, hold onto me," I said, as we tried to find the path the other people were following. We inched along, one step at a time, as she fought to keep her balance in the rough terrain. "Use me as the crutch," I said. I could see the heads of the rest of the group in the distance. Why couldn't they wait for us? Why didn't they slow down? Why didn't they help?

Step. The thunder cracked in the distance as the rain pelted down. Step. Our bare feet stumbled on brambles and pebbles as I fought to catch my breath while dragging the two tubes and holding up Kathy. Step.

Mercifully, the storm finally stopped, and we were able to get back in the water after a while. "Thank you," Kathy said with a hug, after the outfitters helped her back into the van.

I still get a visceral reaction in my gut when I remember that day. I was so scared—scared for Kathy and scared for me. I was scared that I would get struck by lightning helping her and scared she would get struck by lightning while I was helping her. I was angry at my friends for abandoning us and angry at Kathy for holding me back. And I felt guilty for being angry at Kathy for something she couldn't help. Still looking for research that helps explain my experiences and feelings, I continue reading. "The mere expectation of having to carry the role the parents had established with the disabled sibling throws a shadow on the relationship between the well sibling and the handicapped [*sic*] sibling. This can also be expressed in an antagonistic attitude against the caretaking parent, who is often criticized by the adult well child for overprotective handling and sometimes for further crippling the sibling" (Schulman 1999, 5). I wonder if my feelings toward having to be overresponsible for Kathy have caused antagonistic feelings toward Kathy and toward Mom and Dad. I wonder if it is time to let go of them.

## TODAY

I sent Kathy a draft of this article. I wanted her to respond to it. Days went by and I had not heard from her. I began to get nervous. I sent her an e-mail:

Hi,  
I haven't heard from you since I sent you the article, so I'm wondering if you've been busy or if I said something to upset you in what I wrote. Hope you're doing well and I'm looking forward to hearing/reading your feedback. Love, Cris

Her response came a few hours later:

Kathy: Well, a couple of things did need pondering over and I'm still trying to figure out how to word my response. But to reassure you I'm not upset, just taken aback. I'll try to get it to you tonight. Is that OK?  
(Cris: Taken aback? Oh, no!)

In the past several years, Kathy's legs and joints have become weaker and her falls had become more frequent and more serious. Finally, she had a fall that broke her leg. She has used a wheelchair to get around ever since.

Two years ago, Kathy and I went to see a movie. She drove herself in her hand-control equipped car and met me there. I was running late as usual; she was waiting patiently for me in her car. I watched as she operated the wheelchair carrier on top of her Honda Civic. The carrier looked like a white camper top. It was almost as large as the car itself and added a double-decker look to the roof of her car. The carrier was operated by a mechanical device that lowered the wheelchair to the side of the driver's door where Kathy could reach it.

She proficiently got herself in the chair and wheeled off toward the theatre. I followed behind. People in wheelchairs get in free to the movies, and so do their companions. That has always embarrassed me, and every time I go to a movie with her, I expect someone to stop me for doing something wrong. Kathy walked in the door as if she was right at home, and I just followed along behind. I pushed her chair through the door, to make it look like she needed a companion and there was a reason for my being there, especially for getting in free.

We walked through the nearly empty lobby, wheeling over the red carpet and past the whiffs of popcorn, butter, and salt. "This one," Kathy pointed to a closed door. "Here's the movie."

I opened the door quietly as she maneuvered her wheelchair inside. Since we were a few minutes late, the previews had already begun, and the theatre was dark. About halfway down the aisle, there was one row with a cutout for a wheelchair, and Kathy knew exactly where it was. She headed straight for it, rolling rapidly. I tried to keep up with her, in case she needed help stopping. She didn't. A couple sat in the two seats next to the cutout.

"Excuse me," said Kathy, touching the man's arm to get his attention. "Would you mind moving over one seat, so my friend can sit with me?"

The couple looked up. "What?" the woman said, loudly. "She wants us to move," said the man.

"It's so my friend can sit with me," Kathy said, pointing to me.

"I suppose we can move if we have to," said the woman, as they picked up their coat and made an unnecessary show, I thought, of moving to another row in the theatre.

"I'm sorry if they're upset," Kathy said to me.

"Don't worry," I said in a loud whisper so the people sitting around us could hear. "They must not know that this is the only seat for a wheelchair. They had plenty of seats to choose from. They'll get over it."

We enjoyed the movie, a romantic comedy. When the movie was over, Kathy let me push her up the aisle. "It's hard to push uphill," she admitted. I was glad to have something to do.

"I have to go to the bathroom," I said as the light in the lobby hit our eyes.

"Me too," she said and pointed me to the right direction.

Still pushing her wheelchair, I struggled with opening the bathroom door and pushing her in. A woman leaving pushed the door out and held it so we could enter. The room was long and narrow, with a line of stalls on the left and a line of sinks on the right. Kathy rolled herself down to the handicapped stall. "Oh, shoot!" she said. "The door won't close!" Despite being labeled as a handicapped stall, the door opened in, and the space was too small to allow the door to close with a wheelchair in there.

"I'll stand here and keep anyone from coming by," I offered. I stood with my back to the stall and guarded the space so no other women would walk down to that area.

"Thanks!" Kathy said, as she wheeled out.

"Not a problem!" I responded, speaking loudly so the other women in the room could hear. "It's not your fault that they don't build bathrooms to accommodate wheelchairs!"

We chatted outside our cars for a few minutes, catching up on our lives and promising to get together again soon. I hesitated in my car as she expertly put her wheelchair into the carrier, and waited for her to pull out of the parking lot. I followed her out, just in case she needed my help. She didn't. I thought about how well she has constructed a world that enables her, rather than disables her.

Kathy: The bathroom scene happened in JC Penney's bathroom, not at the theatre.

Cris: I distinctly remember it happening in the theatre!

## REACTIONS

I think back over our family relationships and the issue of normalcy versus difference. In our family, normal was the different. What was normal in our family? To me, when I was a small child, it was about falling down. Kathy fell a lot, and she was my older sister, and I fell a lot too, maybe just to be like her. It was getting angry at her friend Marilyn for cutting the hair off of my Barbie doll, and I don't care if Marilyn *was* blind. It was chasing Kathy around the house, who could somehow outrun me even with leg braces on. It was being yelled at by my grandmother for chasing Kathy. It was hating Jerry Lewis and the Three Stooges for making fun of people who were different and disabled. It was being embarrassed by having a sister who was different but fiercely protective of anyone who dared say anything against her. To my mom, it was driving Kathy to her special school, to the doctor, to the hospital, to physical therapy. It was finding sources of funding for crutches, braces, and medical care. It was finding help and support from family, friends, professionals, and other parents of children with disabilities. It was making physical therapy for Kathy as normal as ballet lessons for me, hospital trips as normal as Girl Scout camping trips. It was about accepting what life had given us and about taking that life one step at a time—just doing what had to be done, together, as a family.

Kathy: The thing that took me most by surprise (and I confess hurt a bit) was that you were embarrassed by me. I've never been embarrassed by my disability. Yes, I hated being different, but it was so much a part of me I was never embarrassed, and I've never thought anyone in the family was embarrassed because of it.

And I can't believe you still remember Patti and I cutting off your Barbie doll's hair! But Patti wasn't blind, she had a heart defect that was corrected by surgery not long afterwards, and she transferred to a "normal" school. Never saw her again.

Cris: I confess that my first reaction to your comment about your feelings being hurt was to take back saying I had been embarrassed. I'm ashamed to admit that I was embarrassed by your disability, and now I feel bad that I hurt your feelings. But then I think again. Why should I deny my feelings? If this article is about being honest with each other, why shouldn't I admit what it was like from my point of view?

Disability carries a stigma (Goffman 1963). It does. I know you experienced stigma; we've talked about how other people treated you in

strange ways. Why should it surprise you that I shared your stigma? We shared everything else! I was “family-wise,” and as such had a “courtesy stigma.” That is, I “shared some of the discredit of the stigmatized person” (Goffman 1963, 30). As your younger sister, I looked up to you, and identified deeply with you. “Every relationship implies a definition of self by other and other by self” (Laing 1961). I am who I am, at least partly based on my relationship with you. We receive our personal identity from our referent group (Goffman 1963). If there was something “discrediting” about you, then I had to have it too! After all, we were sisters! The essence of our self is always in reference to others (Cooley 1964; Mead 1934). I understand my self by seeing myself reflected from the other. Our sense of our selves occurs in community. If the self I see reflected back is different, or, in the eyes of others, “less than,” this certainly could affect my self-concept and self-esteem.

You, at least, had others you could identify with. You had all your friends at Lowman School, who were disabled also. You had people who shared your experience and people who spent a lot of time and energy helping you get over being stigmatized. I didn’t. I was out there all alone. Talk about being different! I didn’t know anyone else who had a sister who was disabled. I didn’t have anyone I could relate to, swap stories with, commiserate with. This is probably the first time I’ve ever admitted this to anyone! I’ve never had anyone with whom I could talk about this before.

Kathy: As you’ve probably heard by now, John Ritter died Thursday, It was a shock to me, as he was only fifty-four and was way too young to die. But also, it was more of a personal thing for me as his older brother, Tom, has CP and our parents knew their parents while Tom was a student at Lowman School. Since reading this article, I’ve wonder upon occasion if John had the same sort of issues with Tom as you did (and other siblings) with CP sibs like me. Tom is a success in his own right, as a lawyer in Nashville, so I’d say he’s been successful in dealing with his disability.

Kathy: Hmm . . . what do I remember? I remember being worried about you at St. Paul’s because of Nancy Spiker and her bullying you.

Cris: I can’t believe you remember that! Nancy used to terrorize me, and I didn’t know that anyone in the family even knew about it! It kind of feels nice to think that my “big sister” was in the background, keeping an eye on me. Wish I’d known it then.

Kathy: I remember going to ballet classes with you at Miss Ness’s (I was a student there, too) and going to ceramic class with you at Ollie’s. We used to go to the library together and we’d sit there and browse while waiting for Mom to come back from running her errands to pick us up.

Cris: I don’t remember the library at all, but I do remember ballet class, and now that you mention it, I vaguely remember hanging around during



your class which was either right before or right after mine. I do remember ceramics; I loved that!

Kathy: I think we had a lot of fun together—we'd play dress up and play school—I was the teacher and you were the student. I also remember almost killing Mom by shooting an arrow through the house one time—boy was she pissed!

Cris: Yeah, I used to love playing dress up. I remember that because I was younger, you would let me be the princess and you would be the prince. I also remember playing school, but my memory is that I was the teacher! The time you shot the arrow past Mom, I confess, it was great to see you get in trouble for a change!

Kathy: I'm not famous and don't make a lot of money, but I think I've done pretty well—got two degrees and have a job I really like working with good people. It's not a bad life at all! Being disabled is just a part of me and I deal with it.

Cris: As Schulman (1999, 1) points out, "Sibling relationships are the only relationships that last a lifetime." You know, your disability will always be a part of me also, and, like you, I just deal with it.

Kathy: When one has CP, one doesn't overcome it for it never goes away, one simply deals with it and does the best he/she can.

## REFLECTIONS

In the end, I think this article illustrates the difficulty both Kathy and I have in talking about our feelings. We both admitted at the outset that we were afraid we would hurt our relationship by bringing up painful memories, and one can see throughout the article many missed opportunities for candidness and conversation. We simply were not comfortable saying some things to each other directly, although I think that it is interesting that some of our disagreements were communicated with each other via the exchange of this article. I think we were both afraid that saying more, especially disagreeing with each other directly, would worsen our relationship. I wonder why, and I wonder how we can come to a place where we can disagree with love, empathy, and understanding. I think too that the ethnographic conversation creates an artificiality that makes it safer, in some ways, to say some things, and more difficult, in other ways, to be completely open.

This article ended up being much more of my story than the co-constructed narrative that I had hoped it would be. I know that my voice is more prominent in this article and her voice is more muted, possibly

subordinated to the forms of writing dominant in the academy (Ardener 1978; Orbe 1998; Wall and Gannon-Leary 1999). Even with my inviting Kathy numerous times to critique my writing, and to contribute more narratives herself, in retrospect, many of her contributions were more of an interviewee than a coauthor. Perhaps in the context of my searching for love, reassurance, and positive regard, she was afraid that any criticisms or negative stories on her part would be seen as thwarting that. Perhaps in a published ethnography, the academic voice will always be dominant. Perhaps this was resistance on her part against the hegemonic dominance of that academic voice. Perhaps this simply reflects the fact that this was my article, my field of study, my agenda, my project, and my timeline, and not hers. Perhaps she was simply and powerfully giving me my voice, something that I have felt was lacking throughout much of my childhood.

What I wanted for this article was a dialogue, a common understanding (Pearce and Pearce 2000), including creating new ways of understanding ourselves, the other, and our common world (Wood 2003). In dialogic communication, self-disclosure is not a tool but instead is a process of "co-authoring" (Wood 2003) a conversation with the other. We may not have been comfortable verbalizing all of our different points to each other, but we wrote them, read them, heard them. We may not have reached consensus, but we did reach multivocality. Dialogue requires an openness to different voices as well as different ways of enacting voice (Hawes 1999; Wood 2003). In dialogue, the emphasis is on "mutuality, community, transformation . . . and inclusiveness of contexts, perspectives, and individuals" (Stewart, Zediker, and Black 2003, 8). Dialogue does not require overcoming tension, rather it requires "engaging the tension in dialogic encounters" (Stewart, Zediker, and Black 2003, 12). This point of view acknowledges differences, accepts them, and suspends judgment on them as they understand how they create perspectives and interactions. Dialogue goes beyond understanding to transforming the issue and the relationship into something new. Dialogue explores how we think what we think (Cayer 1997). Kathy and I are not all the way there yet, but we are talking. We are listening. We are engaging in dialogue.

As I look over what we've written and discussed, I see the striking difference between the dependent person I was afraid Kathy would be when I was a teenager and the independent person she actually is. I think that much of our relationship dynamics during our lifetimes can

be attributed to a sibling rivalry tension, a big-sister/little-sister sort of thing. Maybe her disability got in the way a little bit. Maybe my jealousy got in the way. Maybe her needs got in the way. But you know, we are all mutually interdependent (Marks 1999; Oliver 1990)—that is what makes us human. And maybe it's my needs that got in the way also. And I know that Kathy would help me any way she can, such as helping me with this article. I think there will always be power dynamics at work in our relationship, as in any relationship. As the younger sister, I suppose I hold a certain power over her (remember how I "whined" my way into an interview!). I think Kathy's disability also in some ways gives her power over me—in our mixed-up who-is-really-the-older-sister dynamics, I tend to look out for and worry about her. Yet she told me in a conversation that she has always looked out for me too. When we were both very young, I really didn't see her as disabled. Her cerebral palsy and hearing impairment were simply part of the way she was. When I didn't see her as different, I think our relationship was built more on our being siblings. When I became a teenager, and saw her through the eyes of peers who saw her differentness, I think power dynamics did come into play. Now that I see her for her strengths, for what she can do and for what she has accomplished, I think we're closer, and I think that our relational dynamics are again based on our being siblings rather than on a consciousness of disability.

## CONCLUSION

Research on impairment as a family systems and relational disability is scarce but crucial. Seeing disability in a relational mode takes us one step beyond the social model of disability identified by Oliver (1996), and conducting research that is multivocal and participatory is essential to understanding the relational and systemic nature of family disability.

Identity is formed through relationships, and every identity as a person who is disabled or enabled, disempowered or empowered, is built in relation to others. In our family, Kathy's physical condition and disability was interrelated with our interactional patterns—both the result and the cause of the types of interactions we had. These interactional patterns shaped our individual and group identities. It made us better, perhaps, in some ways, and worse, perhaps, in others. In the end, I think we

probably have a pretty normal sibling relationship. We fight, like all siblings do. We make up. We watch out for each other. And, we care.

## NOTE

1. I use the term "handicapped" here purposely. Although this term is not used today to refer to people with physical impairments, when we grew up in the 1950s, it was the language used.

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