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EFFECTS OF A HANDICAPPER ON OTHER CHILDREN IN THE FAMILY

by

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ABSTRACT

EFFECTS OF A HANDICAPPER
ON OTHER CHILDREN IN THE FAMILY

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In the last twenty-five to fifty years, two social changes have touched the lives of handicappers and their families: de-institutionalization and the increase of life expectancies of the disabled. Most of the expense and actual care of handicappers has been transferred from the state to the individual families involved, and more and more people who will always be seriously limited are being saved and cared for in their own homes. This dissertation explores able siblings' perceptions of the effects of mobility disadvantaged handicappers on social relations within their families.

The research data were obtained from interviews with thirty-one siblings of from-birth or early-childhood handicappers and ten siblings of those disabled as adults. Using a process suggested by grounded theory, I developed responses to questions, volunteered statements, and topics respondents appeared to avoid into themes/categories for analysis. The analysis focuses on organization and effects of family activities (e.g., physical care), the influence of family composition (e.g., variations in family size and make-up), and the influence of family life-cycle (e.g., children "leaving the nest") on the able siblings of mobility disadvantaged handicappers.

No one seriously disputes that the presence of a handicapper influences family life, but from the evidence we now have, it appears that the effects are quite variable, and some, but not all, able siblings are at greater risk of psychological and/or psychosomatic problems. Interviews with forty-one people suggests that family composition may be crucial in determining which able siblings are most vulnerable to these difficulties. These critical factors are: size of family -- those from smaller households are more likely to experience these problems, especially if there are only two children, the handicapper and the able sibling; those from single-parent households where the remaining parent is the primary wage-earner -- older sisters are particularly vulnerable to these risks; those in households where emotions and feelings are concealed; and parents' acceptance of the disability -- children whose parents deny problems or reject or over-protect handicappers are likely to experience more difficulties. When the sibling became disabled is also important. If the disability is present since birth or early childhood, able siblings accrue power that they would not ordinarily attain if all the children were able. In this small sample, extent of the disability did not appear to have a strong impact on other children in the family.

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Chapter 1

"I think he's the greatest thing that ever happened in our family. All he knows how to do do is love. He doesn't know anything but to be happy and loved." [Interview #12]

"It sounds a little cruel, but she disrupted what I knew as a pretty decent home. Before she was born we did things. There was a family; there were a lot of good times. I remember those abruptly coming to an end and not understanding why my mother started drinking." [Interview #24]

INTRODUCTION

What are the effects of a handicapper upon other children in the family? The remarks above give some indication of how complex the issue really is. Able siblings' feelings and attitudes range from complete rejection and resentment to total acceptance and love. Most reactions are probably between those poles. It's impossible to predict how a particular sibling will be affected by a disabled sister or brother, but patterns common to able siblings can be discerned.

In this study, I do not focus on the handicapper, per se. Instead, the central concern is the social relations of the family -- as seen through the eyes of the able sibling: the effects of the handicap on sisters and brothers who share the same parents, home, and environment, and on the

social interactions and varied relationships within the family. I want to know how one person's difficulties shape, and are shaped by, the lives of other family members -- particularly those of the sisters and brothers. I'm concerned with the siblings' perceptions and interpretations about living intimately with a handicapper. How do they feel about having a handicapper sister or brother? Do they worry about the future -- their own and/or that of their disabled sibling? How are family relations affected? Does having a handicapper sibling alter able siblings' self-concepts? Do the other children in the family feel socially isolated or stigmatized? What are the factors leading to the different responses able siblings have to their handicapper sister or brother? And how do those responses affect the handicapper?

Until recently, the entire focus of research on families of handicappers was on the less-than-perfect member. Perhaps this was because researchers were attracted to the "externally different," which means in this case, that they ignored the parents and the "normal" siblings. Kew (1975) refers to this as "professional myopia" -- a distorted vision that tends to ignore other sides of the problem. Within the last few years, there has been some shift in focus. Instead of concentrating on just the handicapper, there is more attention to how the presence of a disabled member affects the entire family. This is an important area that has not been adequately addressed. Substantial numbers of families include handicappers;

exactly how many is hard to determine. Eisenberg (1982) maintains that one in every eleven Americans is a handicapper (9 percent of the population), and Gliedman and Roth (1980:15) report:

> Roughly one-tenth of all children are handicapped, one-fifth of all adults are handicapped, and at least half of all adults have a disabled spouse, child, parent, or close friend (emphasis in the original).

The estimates of the number of disabled in our society range from 30 million (Hicks,1982) to 45 million (Wright and Schwab,1979). Part of this variation is due to differences in definition of "disabled" and the fact that handicappers with more than one disability may be counted in several categories. Another factor is the extent of disability; some figures include those who are minimally disadvantaged, while in other sources they are omitted. No matter how you calculate, it is apparent that the handicapper population in our country is a sizeable group, and relevant to my study, substantial numbers of those handicappers have able sisters and brothers.

In the last twenty-five to fifty years, two social changes touched the lives of handicappers and their families: de-institutionalization and the increase in life expectancies of the disabled. Prior to the deinstitutionalization movement of the 1960s, most severely handicapped individuals were removed from their families and put in hospitals or special institutions for the disabled. With

de-institutionalization, or "community-care" as it is some times termed, the impact of handicappers upon families has grown. As money, employment, housing alternatives, staff, and programs have become scarce, the demands on the family structures have increased. Most of the expense and actual care of handicappers has been transferred from the state to the individual families involved. These policies work on the assumption that this is less costly, but this ignores the costs of care to one of the main groups of caretakers -- women.[1]

During the past half-century, there has been a tremendous change in the nature and prevalence of handicapping conditions. Today, children have a much longer life expectancy, thanks in large part to the reduction of communicable diseases. While this solved many problems, it created others. There is the paradox that while medical advances have reduced the incidence of some handicapping conditions, the same advances have enabled many with severe disabilities to survive, including those who have sustained permanent injuries as adults. More and more people who will always be seriously limited are being "saved" and cared for in their own homes.

These two social changes, de-institutionalization and the increase in life expectancies of the disabled, have particularly touched the lives of women. According to Finch and Grove:

> Both demographic change and the 'restructuring' of

> the welfare state have been grafted on to a pre-existing situation in which women have been defined as the 'natural' carers and also as the dependants of men. These alleged characterisitics of women make them especially attractive as potential providers of unpaid care, in the private domain to which they have traditionally been assigned (Finch and Groves,1983:5).

As a nation, we have moved closer to mandatory intervention to save all the handicapped. However, we have not yet come to terms with matters like quality of life, the expense to the family and society of caring for a handicapper, or the problems and emotional trauma for other family members.

Background

My original intention was to investigate the effects of a handicapper upon parents. I had a daughter who used a wheelchair her entire life. The exact nature of her illness was never determined, but apparently it was a form of muscular dystrophy. Her disability affected our family life in many ways -- some adversely and some more positively. Within fourteen months of her death, her father and I separated and eventually divorced. I wanted to see if other parents of handicappers experienced similar breakdown, emotional distress, and disruption of their lives.

When I looked at the literature, I found that the pressures and stresses placed on mothers and fathers of handicappers had been extensively investigated. Not willing

to abandon the project, I continued reviewing the literature. What I found was that very little attention was paid to the effect of the handicap on able siblings. Those were missing, but vital, voices in understanding social relations within handicappers' families.

We need to better understand the structures and meanings of sibling relationships, including those in sensitive situations. Over twenty years ago, sibling interaction was identified as a neglected aspect of family research,[2] but only recently has the topic captured the interest of sociologists. Prior to this, sibling relations were subordinate to other concerns, such as mate selection, divorce, or the mother-child bond. Children were not viewed as active participants in the family; they were usually seen as just part of a sub-group -- "the children;" they were seen as either submitting to, or defying, another sub-group -- "the parents." In truth, we know very little about the relationships of ordinary siblings, but we know even less about interaction between impaired and able sisters and brothers.

It's interesting that in the meager research on siblings of handicappers, only parents, teachers, therapists or social workers were interviewed;[3] they were asked to relate their own perceptions of the effects of the handicapper on siblings. The professionals were primarily concerned with the problems involved in having a handicapper in the family.

I use the word "problems" deliberately. Most of the

literature assumes that living with a handicapper presents difficulties and/or deprivations for the rest of the family. There is an abundance of studies about the negative impact of a handicapper, particularly the mentally retarded, on family functioning. In nearly all cases, the handicapper is reported as affecting the family in a negative way; s/he is seen as an additional stress factor. His/her presence is viewed like death, separation, or alcoholism -- as something that adversely affects the family and family life.

As an illustration of this type of thinking, the other children in the family are sometimes referred to as "a population at risk."[4] According to this view, able children in the family have unusually high rates of both physical and emotional problems. One of my objectives in this study was to explore the validity of this claim and possible explanations for it.

Another objective, and one of the main contributions of my study, was to talk directly to siblings of handicappers. In this arena, they are the experts. Instead of relying upon second-hand information, I asked the brothers and sisters about their experiences as a sibling of a handicapper. I believe it is essential to talk to them. Questioning mothers or professionals about the problems of other children in the family is often an inaccurate and/or incomplete account; it doesn't accurately reflect able siblings' own feelings and the important events in their lives. Many of the people I talked with said they had concealed their feelings from their families -- perhaps to

"protect" their parents or for fear their true reactions would open a Pandora's box of attitudes and emotions that no one in the family felt they could confront.

Another weakness of previous research on handicappers and their families is that most of it was done by professionals with little or no personal knowledge of, or experiences, in a family that included someone who was disabled. I believe that my experiences as a mother of a handicapper child made me better able to empathize and establish rapport with someone who lives, or has lived, with a handicapper. My awareness of what it's like to live with someone who is disabled gives me a special lens to help focus the analytic tools I've gained from professional training. From my insider position, I sought to broaden the focus from seeing handicappers as primarily a catalyst for family problems to trying to understand the entire dynamics of social relations in such a family. There are problems, but they may be over-emphasized in the literature.

Professionals are trained to think about feelings and human behavior, but often their distance from the problem leads them to concentrate only on the family's vulnerability, neglecting its strengths. I wanted to know if there were any benefits or positive results from having a handicapper in the family. I was interested in whether, for some siblings, the experience of growing up with a handicapper might be a positive experience -- or at least a neutral one. To date, few have explored the possible <u>benefits</u>, the compensations, that might accrue to the family

with a handicapper member. Folk-wisdom assumes that having a handicapper in the family presents unusual and difficult problems for the family -- including the brothers and sisters, but there is also the notion that it can present some valuable opportunities for attaining growth and maturity. Interacting with my daughter on a day-to-day basis certainly helped me appreciate the strengths and joys of such a situation.

Terminology and Definition of Terms

The terminology used in the literature on handicappers and their families is, unfortunately, thoroughly value-laden. This is true whether the literature is in sociology, psychology, rehabilitation, special education, or medicine. While no negative connotations may be intended, the vocabulary teems with words that label and potentially stigmatize, but the terms are widely used and accepted -- both in the professional sphere and in common, everyday usage.

Early in this study, I made a deliberate decision to eliminate biased or negative language throughout the research endeavor. I've made a sincere attempt to substitute a neutral vocabulary whenever possible. Even with that resolve, it has sometimes been difficult to use "non-ablest" language. (In this context, "ablest" is similiar in meaning to "sexist" or "racist.") The goal is to eliminate

terms that derogate or belittle a group of people.

The terms used in this study of siblings of handicapper children are defined as follows:

Mobility disadvantaged: These include people who lack full use of their limbs, who are limited in their range of movement of either their arms or legs. These conditions are relatively severe and visible to outsiders; therefore, people experiencing these restrictions are usually readily identifiable and are often singled out for differential and unequal treatment.

Handicap: Any difference that is perceived by others as making that person "less than perfect" thereby at least potentially disqualifying that individual from full social acceptance. Such a "difference" is often the basis of distinct and dissimiliar treatment.

Family: In sociology, there are many schools of thought, with overlapping definitions, in regard to the concept of "kinship" versus "household." Main line family sociologists have usually defined it as mother, father, and their biological or adopted children. Other, less traditional, sociologists see the family in terms of complex social relationships.

When I first started this study I unconsciously limited "family" to units defined by blood or marriage, especially mothers, fathers, and minor children. But as I talked with the respondents, I realized that many of them defined the family as more than just a biological or marital relationship. Five people volunteered to talk to me about their

foster handicapper sibling. Upon reflection, I decided to permit the respondents to define family. Their definitions view families as being made up of three different kinds of kinship: 1) conventional kin, where family members are tied closely to one another through blood and/or marriage, was the most common relationship among the respondents in my study; 31 of the respondents were biologically related to their handicapper sibling; 2) discretionary kin, where the ties are similiar but weaker, involved three respondents where step-siblings or half-siblings were involved. In two of those situations, the step-siblings were always referred to as "brother," but in the third instance, half-siblings were invariably termed, "half-brother" or "half-sister;" and 3) fictive kin, where the actual kin ties are imaginary, but people treat one another as if they were kin or as "non-kin kin;" in my study, five handicapper siblings were foster children of the family. Two families involved adopted handicappers; depending upon your definition, they could possibly be considered as any of these three types of kin: conventional, discretionary, or fictive; in any event, they were considered family. In this study, family refers to any of these three types of relationships. This means that people who consider one another "family" were treated as full family members.

Able Siblings: This refers to brothers or sisters who are not considered physically or mentally impaired by either the family or the larger community. These siblings are not ordinarily treated differently or unequally. Synonyms for

this term are not easy to find. "Normal" seems inappropriate and so does "well-sibling." "Unimpaired," or "non-disabled" also seem unsuitable and at least potentionally negative in connotations. "Able-bodied" is also commonly used. In this study, I have used the terms "other children" and "able sibling." The latter term is occasionally used in the literature, both with and without quotation marks. Either way, in my view, the term "able" seems preferable to "normal."

Timing of Onset: This refers to the age of the handicapper when the disability was diagnosed or became apparent. "Childhood-onset" refers to a disability that was apparent from birth or any time up until age ten. "Adult-onset" are problems that manifested themselves when the person was 17 or older. In this particular study, there are no people whose siblings became handicappers between the ages of ten and sixteen.

Selection of Respondents

Between mid-January 1985 and early February 1986, I recruited and interviewed forty-one siblings of mobility disadvantaged handicappers. I limited my respondents to this group because others have investigated the effects of a mentally retarded, blind, or deaf sibling on children in the family.

When I started recruiting respondents, I did not think

about sisters and brothers of people who became disabled as adults. My first interview turned out to be with a woman whose sister suffered an adult-onset handicap. From that point on, I recognized the importance of when disability occurred. Siblings of people who became disabled later in life are seldom discussed in the meager literature on siblings of handicappers, and this is unfortunate, since when the handicap occurs in the life cycle has important bearings on both the life chances of the handicapper and how they are treated and thought of by their able siblings.

For pragmatic reasons, including convenience, respondents were recruited only on the campus of Michigan State University. I made appeals in large classes, in advertisements placed in the student newspaper, from a display table in the student union and other campus buildings, from posters placed on bulletin boards throughout the university, and from personal references. No attempt was made to limit respondents to college students, but only six of the 41 able siblings I talked with were not enrolled in the university.

Methodology

In this research, my main objective was to learn the siblings' interpretations of events and of social relationships within their families. I wanted to learn first-hand what it is like to have a handicapper sister or brother. From the start I decided to use in-depth interviews in more-

or-less unstructured discussions to get verbatim, retrospective accounts.

Because this is an exploratory study and there is so little published information about able siblings' feelings and attitudes, I had no way of anticipating the full range of possible responses. I began with a few specific questions of general interest, but I rejected the use of a standardized questionnaire. Choice of questions is crucial, and traditional questionnaires tend to direct reactions. I did construct an interview schedule (see Appendix B) based on issues brought up in the literature, but those questions only served as a guide to ensure that the same topics were covered with each respondent. This somewhat structured the interviews, but the order was not held constant, and I had no clear idea what categories would become relevant. Throughout, I tried to follow the Glaser and Straus (1979) notion of "grounded theory," where the researcher asks questions but lets the responses and emerging categories determine the direction and content of interviews. According to Glaser:

> The goal of grounded theory is to generate a theory that accounts for a pattern of behavior which is relevant and problematic for those involved. The goal is not voluminous description, nor clever verification (Glaser,1978:93).

Using this approach enabled me to probe as seemed appropriate and allowed me to capitalize on leads offered by the respondents. I wanted to base my findings in the

everyday life experiences of siblings of handicappers. Deciding what topics to cover was influenced by my own experience with a handicapper child and my reading in the area.

The interviews lasted from slightly over a half hour to an hour-and-forty-five minutes; the average length was about an hour and twenty-five minutes. All interviews were tape-recorded, with the person's permission. Each respondent read and signed an informed consent form. (See Appendix A for copy.)

Nature of Handicaps

Knowing the nature, severity, and timing of the disability helps set the stage for analysis of my findings. It is also useful in evaluating the respondents' comments on how they feel about having a handicapper sibling. Some of the 41 respondents had more than one handicapper sibling; the total number of respondents' handicapper sisters and brothers was 46. Two major classifications emerged -- disabilities that were apparent from birth or early childhood and those that occurred in adulthood.

Childhood-Onset Problems: This includes all disabilities that became apparent sometime between birth and the age of ten. The single largest category of sibling handicaps reported by the able siblings in this study was muscular dystrophy. Eleven (23.91 percent) of the handicapper siblings were diagnosed as having it in some form.

Muscular dystrophy is an inherited disease that causes a progressive weakening or wasting away of the skeletal muscles; for most types of muscular dystrophy, there is no cure. Often the first indication is that the child stumbles a lot; the degeneration of the muscles continues over a period of years until s/he can no longer move. It is a hereditary condition which usually appears between the ages of two and six and afflicts mostly males.

The next largest reported category of handicap in my sample was cerebral palsy. which was the diagnosis of seven siblings (15.21 percent). Cerebral palsy is not a specific medical diagnosis but a name given to a group of defects that result from damage to the central nervous system and the parts of the brain that cause movement. This damage may occur before, during, or more rarely, after birth. It results in defective muscular control and/or some degree of paralysis. While cerebral palsy is non-progressive (the damage to the brain itself does not get worse), the symptoms may change over time. Children who have this condition often have other handicaps, such as mental retardation, epilepsy, or speech problems.

Three handicapper siblings (6.52 percent) had polio-myelitis. These people contracted the disease over twenty years ago, before the Salk vaccine was available. Polio often results in partial or complete paralysis.

At least one of the handicapper siblings, and perhaps a second, had osteogenesis imperfecta (one respondent didn't know the specific medical diagnosis of her younger brother,

but the description fits this diagnosis). The condition was described by a twenty-four year old brother:

> She was born with a bone disease called 'osteogenesis imperfecta.' The bones never fully developed. They lose calcium and decalcify, and they are very brittle and very easy to break. You get a lot of hair-line fractures. She's roughly two-and-a-half or three feet high. [She is now 19 years old.] She can only sit on the floor. She's unable to stand because her legs are so badly curved. Her arms are mostly functional, but she does have a bad arm; I believe it's her right. Her head and the rest of her body features are more or less normal, but they are compressed. [Interview #6]

Two of the remaining handicaps were attributed to child abuse by a parent and two had epilepsy, a disorder of the central nervous system that causes repeated seizures. One handicapper had spina bifida, a condition that results in spinal cord damage because the backbone doesn't close during development in the womb; the higher up on the spinal cord the more serious the handicap. Another handicapper was diagnosed as having hydrocephalus where too much spinal fluid builds up in the brain; this pressure may cause paralysis, mental retardation, or seizures. One had Prader-Willi syndrome, a condition where babies have very floppy muscles, and one had talipes (the medical term for club-foot.) In this sample, twelve of these siblings (26 percent) were also mentally retarded.

Adult-Onset Handicaps: These include disabilities that occurred at age 17 or older. Accidents or illnesses that caused the person to become a handicapper as an adult

accounted for ten of the handicapper siblings in my sample (25 percent). Five of these were in automobile accidents, one had a serious fall in which his back was broken, one had a diving accident and broke his neck, one had cancer of the spine, and two were victims of severe beatings.

Severity of Handicap: There is some evidence that the extent of disability interacts with the life cycle determinants, things like aging, births, and when children leave home. Some authorities maintain that extent of disability also determines, to a large extent the family's life style and that minimal handicaps have fewer effects on a family than more severe ones. Others disagree. They cite evidence that because mildly handicapped individuals are perceived as "normal," but cannot function at that level, it can be very difficult for family members to cope with the handicapper. My research supports the latter conclusion -- that severity of handicap is not the critical dimension for handicapper's families.[5]

Analysis of the Data

While this research focuses mainly on the able/handicapper sibling dyad, it's important to root this relationship within the entire family. To do this, an organizing framework which takes into account the three major sub-systems in the family is useful -- the subsystems of 1) spouses, which concentrates on husband and wife interactions, 2) parental, which centers on parent-child inter-

actions, and 3) siblings, which involves child-child interactions.[6] This study centers primarily on one aspect of the sibling sub-system -- that of able and handicapper siblings, but it is important to recognize the other relationships and acknowledge that siblings affect, and are in turn influenced by, the other two systems.

When we are children, relatively little of our lives is under our control. Our world tends to be planned and defined by grownups. A child's "truth" is created, if you will, by parents and other adults. A child's reality is socially constructed, and initially, at least, adopted almost in total. Their world is strongly influenced by what is said, and not said, about such things as the handicap. Children construct worlds, and if the disability isn't explained to them in language they can comprehend, they interpret it in ways that make sense to them, but the interpretation may be grossly distorted if they don't have accurate and full information. Often it is much later, in adolescence or adulthood, that the other children have enough information to accurately question or reject the validity of that earlier constructed reality. That means how a sibling reacts to a handicapper brother or sister is shaped, in large measure, by how the significant adults in his/her life define that circumstance -- particularly if the handicap is present from birth or early childhood.

Everyone, including parents and other family members, forms complex impressions of others on the basis of limited information, and one piece of information that is readily

available is an obvious disability. Handicappers often encounter special treatment based on stereotypes of their capabilities and interests. Unlike temporary injuries, a handicap is considered to be an integral, permanent part of a handicapper's social being and, because of the disability, they are often treated differently than other children in the family.

In this study I will discuss three aspects of the social construction of reality for handicappers and their families -- three building blocks of that reality: 1) the impact of family activities (e.g., physical care); 2) the influence of family composition and attitudes (e.g., variations in family size, make-up, and beliefs); and 3) the influence of family life cycle (e.g., children "leaving the nest"). I started the analysis concentrating primarily on family life cycle, but that did not, by itself, capture the full range of their experiences. It provides only a one-dimensional picture; family activities and particularly family composition and attitudes are also needed since all three aspects of this social construction of reality are interrelated.

All families perform essential activities for individual members as well as the larger society, but families differ in the number of activities on which they focus and in the degree to which they perform any particular one. As families move through the various stages of the life cycle, the responsiblity for performing these various activities shifts among the three sub-systems. Many of the activities

that initially were performed by parents are eventually assumed by the siblings. This may be particularly true of handicappers' families.

As an illustration, physical care is an activity of most families; it includes health-care, safety and protection, and in some families, child-rearing. In families with a handicapper, able siblings may have to assume these responsibilites, perhaps helping with a therapeutic regimen, guarding the handicapper from people who tease or might harm him/her, and serving as a surrogate parent on occasion.

The composition and attitudes of families vary considerably on a number of different dimensions, and these affect the sibling subsystem. For instance, if the family unit is small and/or the mother must work in the paid labor force, an able sibling may have to provide most of the childcare for the handicapper.

Life cycle is more than just the passage of time, and it also involves more than the individual life cycles of all the members. They interaction of these produce a family cycle of development. In addition, it's important to recognize that families at different stages of development have different characteristics and needs. The aspects of family life cycle that I'm most concerned with are: 1) the respondents' thoughts about the future and 2) what happens when, in some family's life cycles, a member is disabled as an adult.

In this study my goal was to discover the underlying

categories that the able siblings use to make sense of the experience of having a handicapper brother or sister. Using a process suggested by grounded theory, I took the responses to questions, volunteered statements, and topics respondents appeared to skirt, and developed themes/ categories for analysis. Two main themes emerged: 1) factors that produce hazards or benefits to able sisters and brothers. This includes exploring the validity of the claim that able siblings of handicappers are "a population at risk," and 2) similarities and/or differences in the experiences of those whose siblings have been handicappers since birth or early childhood and those whose siblings became handicappers later in life. This includes exploring social relations of siblings within the family and how these relations vary depending upon family composition/attitudes and life cycle.

Organization of Study

The research is organized as follows: the second chapter, the "Review of the Literature," examines approaches that have been used to study handicappers and their families, factors that influence able siblings, and common responses to a sibling's disability. Weaknesses of these approaches are also discussed.

The third chapter, "Methodology," lays out the purpose of this particular study and discusses the research procedures, recruitment process, and strategy for analysis

of the data. Chapter Four, "Toward a Sociological Understanding of Handicapper Siblings: A Conceptual Framework," provides a frame to ground the investigation. Three aspects of the social construction of reality for able siblings are considered: the impact of family activities, the importance of family composition and attitudes, and the influence of family life cycle.

The following four chapters present information from the respondents themselves; it is an opportunity to hear their authentic voices. Chapter Five, "Social Relations in Handicapper's Families," reports the most significant findings that emerged out of this grounded theory approach. Chapter Six, "Able Siblings' Reactions/Attitudes Toward the Handicapper," considers how able siblings in this sample (and their families) cope with the disability. Successful adjustment is based on a number of factors, including family composition; these are discussed along with examples of the attitudes and coping mechanisms the respondents use.

Chapter Seven, "Trials and Tribulations: Obligations and Stresses on Able Siblings," discusses family activities that able siblings often provide and the kind of expectations they feel are made on them. These are the lesser types of inconveniences and obligations they encounter. Chapter Eight, "'A Population at Risk?': Potentially Serious Effects of Handicapper Siblings" is concerned with the assertion that able siblings are the primary victims in families with a handicapper. Are the other children in the family unusually vulnerable to

assorted mental and physial problems?

The last chapter, "Conclusions," includes a brief summary of the research, a discussion of the implications of the findings and contributions of the study, and suggestions for further research and directions in which that study should go.

ENDNOTES

1
A complete discussion about the special nature of kinship obligations/costs and expectations that women will be the primary nurturers and caretakers is beyond the scope of this chapter. For additional information, see Groves and Finch (1983), Rimmer (1983), and Brittan and Maynard (1984).

2
See Irish (1964) for an early plea for the need for sibling research.

3
An exception to "experts" testifying to the effects of a handicapper sibling is a paper by Breslau and Prabucki, "Siblings of Disabled Children: Effects of Chronic Stress in the Family" (1987). In the original study of 369 families, mothers were interviewed. Five years later in the follow-up study, the able siblings were also interviewed and given the Psychiatric Screening Inventory that measures seven areas of child behavior: self-destructive tendencies, mentation problems, conflict with parents, regressive-anxiety, fighting, delinquency, and isolation. I have reservations about the inventory because it was administered by the mothers. From interviewing 41 able siblings, I'm aware they often conceal how and what they feel from their parents. But, this kind of study is definitely a step forward.

4
For more information on the notion that able sisters and brothers of handicappers are a "population at risk," see San Martino and Newman (1974), Kew (1975), and Trevino (1979). For an interesting discussion on the assumption that the entire family is "handicapped," see Fotheringham and Creal (1974), "Handicapped Children with Handicapped Families," Larcombe (1980), "A Handicapped Child Means a Handicapped Family," and Shearer (1981), "Disability, Whose Handicap?"

5
For the argument that extent of disability is not a critical dimension of how the family is affected by the presence of a handicapper, see Grossman (1972), Fewell and Gelb (1983), Skrtic, Summers, Brotherson, and Turnbull (1984). For contrary findings, see Kew (1975), Schell (1981), and Darling and Darling (1982).

6
In sociology of the family, husband-wife interactions have long been a focus of interest. As examples, Blood and Wolfe (1960), Husbands and Wives: The Dynamics of Married Living, Cuber and Harroff (1983, but first published in 1965), "Five Types of Marriage," Komarovsky (1967) Blue-

Collar Marriage, Cromwell and Olson (1975), Power in Families, and more recently, Meyers (1983) "Battered Wives, Dead Husbands."

Parent-child interactions began to capture attention in the 1970s. Examples are Wallerstein and Kelly (1976), "The Effects of Parental Divorce: Experiences of the Child in Later Latency," and Gelles (1977) "Demythologizing Child Abuse."

Sibling-sibling interactions were ignored for years and only recently have attracted researchers. An early example is Kirtpatrick (1963), "Sibling Interactions," and later Sutton-Smith and Rosenberg (1970) "The Sibling and Schvaneveldt and Ihinger (1979), "Sibling Relationships in the Family." In the past decade there have been several, including Bank and Kahn (1982), The Sibling Bond, Atkins (1984), Sisters, Handel (1984), "Central Issues in the Construction of Sibling Relationships," and Dunn (1985), Sisters and Brothers.

Chapter 2

REVIEW OF THE LITERATURE

Introduction

One of the obstacles in reviewing the literature on handicappers and their families is the profusion of approaches that have been, and still are, in use. There appears to be little consensus on how to study this subject. Each researcher has their own conception of what is important and how to investigate it.

In reviewing the literature, three basic focii can be discerned: a) the medical focus that concentrates on the disease, looking on the handicapper only as a "sick" person and upon his/her physical care, b) a focus entirely on the psychological and physical state of the handicapper, and c) attention to the family of the handicapper.

Much of the work with handicappers and their families can be termed a "change-the-patient" approach. It relies on a medical model, inferring that the individual is "sick" and needs to get well. The medical model implies that as a sick person, the handicapper is both obligated and entitled to be helped, to be cured, by medicine's technical knowledge (Conrad and Schneider,1980). This approach disregards the reality that in many cases the people will never be able to recover full use of their bodies or minds. The medical model ignores the social nature of being handicapped and the

social origins of many of the problems of disabled children. In addition, this model omits any notion of the socially learned preconceptions and reactions of the able-bodied.

Gliedman and Roth (1980) maintain that the medical model communicates a sense of stigma and the expectation that handicapper children will have no real future as adults. Implicit in this model is the notion that handicappers are a minority group. This approach almost forces the family to see a handicap as something tragic and traumatic (Cohen,1962; Aradine,1983). Because the medical model provides no insights into the handicapper's effect on other family members -- especially no information on how the able siblings are affected, I did not pursue this area.

Until recently, both the sociological and psychological research on families of handicappers concentrated on only the handicapped -- their physical condition, behavioral or intellectual functioning, progress in therapy, or psychological acceptance of the handicap (see Gliedman and Roth,1980; Thomas,1980; Pearlman;1981; and Schell,1981). Relatively little inquiry was concerned with how a physically handicapped child affects the rest of the family -- particularly the repercussions for the lives and experiences of the siblings. The few studies that have been done are mostly retrospective and descriptive; they focused only broadly on the effects of a handicapper on the family (e.g., McMichael,1971; Dunlap and Hollinsworth,1977; Marinelli and Dell Orto,1984). This focus doesn't clarify the interactive effects of the handicapper, the family, and

the social environment. Jacqueline Kowalski (1980:1) writes:

> Prior to this time the focus seems to have been on the discovery and treatment of the handicapped child, often to the exclusion of other family members. The concerns of clinics and agencies were 'child centered.' Their emphasis was on the diagnosis of the condition, the medical care required by the child, the facilities available for training and long-term care, either at home or in an institution. It was as if the child and the handicapping condition were the whole problem. In other words, if the child could somehow be changed, the problems brought about by the situation would be alleviated [Emphasis in the original].

Others agree that research on the impact of handicappers has been dominated by the handicapper-centered approach (Kew,1975; Stoneman and Brody,1984; Skrtic, Summers, Brotherson, and Turnbull,1984). It has concentrated exclusively upon the handicapper and totally neglected the handicap as a social event in the context of the family and the community. Up until recently, this approach has been the most common.

Instead of using these approaches to studying handicappers and their families, we can study the family as a group whose existence preceded the arrival of the handicapper. Increasing numbers of professionals are now focusing on the family. (See Voysey, 1975; Schell,1981; Beckman-Bell,1981; Crocker,1981; Garwood et al.,1981; Seligman,1983; Skrtic et al.,1984.) Most of these studies have almost totally ignored the role of fathers and

siblings, and when siblings of handicappers have been studied, most of the studies looked at sibling reactions to retarded sisters and brothers. (Exceptions are Kew,1975; Breslau,1982; Sktric et al.,1984).

Many authors maintain that we need to know more about the stresses and strains on the families of handicappers (e.g. Grossman,1972; Seligman,1983; Blacher,1984; Stoneman and Brody,1984; Skrtic et al.,1984). According to Grossman (1972:8):

> We must realize that the 'case' is not just the handicapped child. The 'case' is the entire social system that influences and is influenced by, the child's condition. It definitely includes the family, including the normal siblings. The entire network of family interaction and patterns is influenced by the handicapped child.

According to Grossman (1972), the presence of a physical handicap of one member of the family is an ecological event -- not just a psychological one. The reactions of the individual and of the social setting s/he inhabits determine the consequences. Until recently, it was seldom acknowledged that discrimination against the handicapped may have crucial effects on both the handicapper and their family members (Gliedman and Roth,1980; Thomas,1980).

A variation of the family focus is seeing handicappers as being particularly "at risk." There is some evidence that able siblings of handicappers have a disproportionately high rate of mental or psychological problems, higher rates of alcohol/drug dependencies, and/or need for counseling

(Grossman,1972; San Martino and Newman,1974; Kew,1975; Trevino,1979).

Some people maintain that the able-bodied siblings are often the prime victims in families that contain a handicapper (e.g., Kew,1975; Darling,1979; Darling and Darling, 1982.) Surveys have indicated that some siblings have problems clearly related to the effect of the handicap on their family and that quite a number of siblings may be likely to be emotionally disturbed (Grossman,1972; San Martino and Newman,1974; Kew,1975; Trevino,1979).

In some cases, the direct consequences of the handicap are relatively minor, but the impact upon the family may be enormous because of the interpretations and reactions of the people involved. (See Grossman,1972; Vovsey,1975; Darling, 1979; Beckman-Bell,1981; Murphy,1981; Darling and Darling, 1982.) Examples of this include families that are excluded from social activities, or who rarely go to public facilities for recreation or take vacations, because they feel "stared" at or discriminated against in some way. This is because in our society, the people with visible disadvantages -- and their families -- tend to be treated differently than the rest of the population (Thomas,1980).

Being the sibling of a handicapper is undoubtedly more difficult than having an unimpaired sister or brother. Children with handicapper siblings are much more likely to encounter stigma in the school or community. This involves the idea of contagion. People who are related to a handicapper are also labeled and "disgraced" by the connection.

They, too, may be given different and unequal treatment (Thomas,1980). They are also more likely to have heavy responsiblities at home (Thomas,1980; Darling and Darling, 1982). Gregory Schell (1981) maintains that siblings of severely handicapped children are vulnerable to difficulties in bonding, or attachment to their parents. All of this leads Kew to assert, "These pieces of evidence, taken together, do suggest that siblings of the handicapped are very much a group at risk" (Kew, 1975:11).

This is an area that needs more study, especially since most of this research on "population at risk" is based on interviews and testing of individuals who were in treatment or counseling at the time of the studies. (See Grossman, 1972; San Martino and Newman,1974; Kew,1975; Trevino,1979; Schell,1981).

Factors Influencing Able Siblings

The social interaction between handicappers and non-disabled peers has been studied (Voysey,1972), but relatively little is known about the interaction between impaired and non-impaired siblings. Hewett (1970) and Skrtic et al.(1984) argue that discovering the effects of a handicapper on the family is difficult because we do not have sufficient information about the effects of "normal" children, and we don't know how much the so-called "handicapped" child deviates from the norm. They maintain that

relationships between parents and children of families with handicappers may not be as different as we have been led to believe. Skrtic et al.,(1984) point out that there have been few studies concerned specifically with siblings of handicapper children and the ones that have been reported share a major problem:

> Literature concerned with siblings of handicapped children too often is divorced from a consideration of sibling relationships in general. Handicapped people, after all, are 'people' first and only secondarily 'handicapped.' A reviewer of this literature is frequently left with the difficult problem of determining which parts of the observed phenomena are a result of factors related to sibships in general and which can be attributed to the factor of handicap (Skrtic, Summers, Brotherson, and Turnbull,1984:218).

Caution must also be exercised about treating the other siblings as a homogeneous group. The effect on any individual child depends upon a number of variables. Some factors which may influence the effect of a handicapper brother or sister upon the other siblings include the nature and degree of the handicap, the age, birth order, and size of the family, the gender of the sibling, the influence of religion on the family, internal resources of the able siblings, structural factors, parental reactions to the handicap, and if able siblings must act as caretakers.

Some researchers (Voysey,1975; Darling and Darling, 1982) maintain that there are only minor distinctions between mental and physical handicaps and the few that exist have little bearing on the structure of sibling or parental

response. According to this view, the difficulties family members experience are shared by all families with a less-than-perfect child.

According to many authorities, there is reason to believe that minimal handicaps have less effect on a family than more severe ones -- if only because it's easier for everyone to treat the less disabled child as they would a typical child (Kew,1975; Schell, 1981; Darling and Darling, 1982). Kew writes (1975:190), "There is mounting evidence that the more mildly handicapped the child, the less his effect on the able-bodied sibling."

Not everyone agrees; other researchers (e.g., Voysey, 1975; Featherstone,1980; Garwood et al.,1981) insist that degree of the handicap determines to a large extent the family's patterns of eating, their recreational activities, and other aspects of their life style. Schell (1981) maintains that the severity of the handicap will influence the family's ability to cope. The child's "differentness" may require explaining the handicap to family and outsiders, and these differences may lead the family to reduce its social life and involvement in the community. Featherstone (1980), Thomas (1980), and Paul (1983) all stress that family members are vulnerable to one another. The pain of one child's disability is a strong influence on the family; it may reshape all the other lives in unexpected and unplanned ways. The results of my study indicate that degree of handicap is not a critical element -- at least as far as able siblings are concerned. Perhaps degree of

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disability is more crucial for parents.

Many siblings' problems may be "outgrown" as the child grows up (Kew,1975). The relative ages of the sibling and the handicapper seems to be relevant. The child closest in age to the handicapper sibling is more prone to disturbance in one form or another than children who are considerably older or younger (Kew,1975; Breslau,1982). Milunsky (1981) and Grossman (1972) report that favorable adaptation is more likely when the able sibling is older than the handicapper.

At least with retarded children, younger siblings are more likely to be affected than older ones. This is attributed to the fact that a highly dependent retarded child disturbs normal role progression in the family by always playing the role of the youngest sibling, regardless of the ages of the sisters and brothers (Darling and Darling,1982). This may be true of physically handicapped children as well. Interaction with the handicapper is a central issue. Stephen Bank and Michael Kahn (1982) maintain that narrow age spacing can force children into contact, dependence, and competition, heightening opportunities for mutual influence. But they also add that birth order research is still in a state of flux, which means we cannot be assured that the results are meaningful.

Kew (1975) agrees that the evidence is not clear or overwhelming, but he has found some support for the notion that large families may cope better. The able sibling in the small family may be under extra stress due to parental aspirations (Grossman,1972; Thomas,1980; Milunsky,1981).

The gender of the sibling may have a strong impact on adjustment and anxiety, and gender might tend to affect the way in which disturbance is experienced or expressed. There is quite a bit of evidence to suggest that siblings of the other gender are less susceptable to disturbances than same-gender siblings (Grossman,1972; Kew,1975; Milunsky,1981; Banks and Kahn,1982; Darling and Darling,1982). Certainly, there is ample evidence that daughters, particularly older daughters, often have to do more daily caretaking than sons (Kew,1975; Voysey,1975; Featherstone,1980; Beckman-Bell, 1981; Schell,1981; and Darling and Darling,1982).

Darling and Darling (1982) and Grossman (1972) have found that the older daughters of mentally retarded siblings tend to go into "helping" professions (e.g., nursing, special education, counseling) in disproportionately higher numbers that would be expected. This was not true of brothers. This finding is not surprising nor probably significiant. Because of socialization and occupational segregation, a disproportionate number of women, with our without handicapper siblings, are attracted to helping professions.

Bank and Kahn (1982) maintain that there is a problem with studying gender differences -- sociologists of the family have studied general aspects of the sibling phenomenon, but the type of research they conduct (questionnaires or interviews in non-stressful situations) do not provide rich details about "painful, conflicted areas" of people's lives.

Religious faith and ethnic background may have profound effects on how people respond to a handicapper in their family. Some people believe that a deformed or otherwise abnormal child is evidence of an offense against God (Voysey,1975). In Europe, until the nineteenth century, children with birth defects were called "changelings" and were believed to be the off-spring of demons, pixies, or fairies (Voysey,1975; Fewell and Gelb,1983). When such views changed, having such a child was not seen as a "fault" of the parents, providing they had taken precautions and guarded the child when s/he was an infant.

Voysey (1975) writes that by the seventeenth century, the Devil was seen as God's instrument; God punished parents for not fearing him, for unchastity, or bearing children outside of matrimony. The blame for having a deformed or otherwise less-than-normal child was a cause of great fear and guilt. The parents were thought to have offended God in some manner. Other people sometimes used deformity or handicap as justification for ostracising the family.

In contemporary society, there has been a general decline in the use of religion to legitimatize disability. The question of how this "terrible thing" happened is not considered relevant; the people involved are expected to "accept their fate." But the "injustice" of disability is a problem for many people; they ask, "why me?" (Voysey,1975; Featherstone,1980; Zola,1982a).

Many people believe that those involved may expect "compensation": a closer marriage, a better family life, or

the satisfaction that their child is progressing because of their efforts (Voysey,1975). Another religious element is the Biblical belief in miracles; parents often express hope that they will experience a miracle. In his research, Kew (1975) has found that some families with a handicapper may find solace and support from religion, but as yet, there is not enough evidence to prove that siblings in religious families are less likely to be disturbed than those in less religious ones (Grossman,1972).

The personality of the able sibling is important, too. Both Grossman (1972) and Kew (1975) report that some children seem to rise above all the problems of this difficult situation and come through it stronger and better off for their experience. This is attributed to the fact that some children (like some parents) seem to have more internal resources for coping with stress and adversity than do others. One such resource is the ability to communicate needs in a way that will be effective.

There is some recognition that one of the most important structural factors is social class (Grossman,1972; Voysey,1975). Other important structural features are the age and developmental stage of the other sibling when the problem became manifest, the rate of onset, and the degree of embarrassment or stigma resulting from the sibling's problem. These are influences on the other siblings' reactions to the handicap of a brother or sister (Voysey, 1975), but unfortunately few studies have been done of siblings in crisis situations.

Families vary in the degree to which they are affected by handicap and the ways in which they cope with crisis (Kew,1975; Featherstone,1980). One of the most important variables is how the parents accept the handicap and communicate this acceptance to the other children. If the parents experience guilt, anxiety, or shame, this has a marked influence upon the able siblings (Grossman,1972; Thomas,1980).

Reactions of parents to the birth of a handicapped child have been studied (Hewett,1970; Kew,1975; Featherstone,1980; Thomas,1980). These reactions range from shock, to denial, grief, guilt, and perhaps shame. Rejection and over-protection are possible responses to either the handicapper or the other siblings. Kew (1975) maintains that the equilibrium of a family is usually upset by the birth and presence of a handicapper; he maintains:

> Both the internal functioning of the family and the relations of the family to the outside environment are held in balance. In the crisis that often attends handicap, the stability of this balance is upset -- both in terms of the inner dynamics of the family life and in terms of the family's relations to the outside world (Kew,1975:1).

Siblings of handicapper children sometimes complain that they feel like parents, with heavy responsiblities at an inappropriately early age. Many parents assume the other siblings have an inherent preoccupation with the needs and progress of their handicapper sister or brother; sometimes the able children are taught that the common challenge will

increase family bonding and communication -- although there is ample evidence that this is not always the case (Milunsky,1981).

Some able siblings are burdened with heavy babysitting and child-care responsiblities that cut them off from their peers (Featherstone,1980). When other siblings must act as caretakers (particularly as primary caretakers), there is evidence this has a profound effect upon them (Grossman, 1972; Kew,1975; Voysey,1975; Cleveland and Miller,1977). This responsiblilty to care for the handicapper may result in what Bank and Kahn (1982) term the "vindictive caretaker." They write:

> Any sibling who must, in some extraordinary way, care for a brother or sister, has been to some extent abandoned by a parent. The rage of that child, adolescent, or young adult sibling feels toward the parent can be temporarily assuaged by a variety of defense mechanisms in the sibling relationship. By caring for one's siblings, one can wear a mask of responsibility and exaggerated concern and thus deny that rage. By loving and looking after a sibling, one can sublimate anger both at the depriving parent who has been neglectful, and 'outparent' that mother or father (Bank and Kahn,1982:134).

Common Responses to a Sibling's Handicap

Based upon interviews with social workers, Kew discusses responses of other children in the family to a sibling's handicap.

> Many siblings face enormous social and emotional problems in relation to handicap, even though they themselves are healthy and sound of limb. Some of their problems arise directly out of their relationship with their handicapped brother or sister; most, however, are related to changes that are wrought in the family as a whole as it tries to cope with and adjust to the birth and presence of a handicapped child (Kew,1975:2).

Able siblings may experience a number of different emotions about their handicapper sisters or brothers. Some may be negative, such as jealousy, frustration, or resentment; other emotions may be positive, such as concern, love, or protectiveness. Other responses may be curiosity, grief, and anxiety. These emotions provide the bases for the common themes in response to disability: embarrassment, identification, confusion, stress, attention-seeking behavior, anger, jealousy, and the problem of a courtesy stigma.

There is evidence that some siblings may become very sensitive about bringing their friends to the house for fear of being ostracized or stigmatized (Grossman,1972; Milunsky, 1981). Helen Featherstone (1980) agrees; she mentions that sometimes the other children handle embarrassment by putting distance between themselves and the handicapper; one way to do this is by never inviting friends into the home. Other children may attempt to conceal their embarrassment, perhaps even from their parents. Unfortunately, little of this research has been sensitive to social class or ethnicity. Most of this research has been done on white middle-class or working-class families.

Featherstone (1980) believes there is a developmental basis for feelings of embarrassment. Most children go through stages where conformity is essential to them; when this happens neighborhood and peer norms become exceedingly important. There is often a strong element of identification in such feelings of embarrassment. In Grossman's study (1972) of mentally retarded youth, those with a retarded sibling of the same gender reported more embarrassment than those whose sibling was of the other gender.

Children define themselves through their families. Siblings use one another as major influences in a search for personal identity; they seek resemblances between themselves and their sisters and brothers or they look for differences in order to find a separate or distinct identity. According to Featherstone, if one of the siblings is a handicapper this identification can create a "particular sort of vulnerability" (1980:148).

A handicap may encourage able siblings to question their own health and capability. Moreover, siblings of a handicapper are often uncertain about the extent and nature of the handicap, and they wonder about the implications of it for their own lives. They may wonder whether the disability will adversely affect their own health in some way. Identification helps other siblings see events from the perspective of the handicapper, and as they get older, they may wonder about the sibling's future (Grossman,1972; Featherstone,1980).

Grossman (1972) contends that the main task of siblings

of handicappers is to try and avoid identification with them. Many of these children attempt to maximize the differences between themselves and their handicapper sibling. Bank and Kahn maintain that "a well sibling derives a distinct and satisfying sub-identity from having a deviant brother or sister" (1982:233). Being the able sibling may force the other children to become competent and superior in the eyes of the parents. (The authors believe that the parents play a crucial role in assigning these contrasting identities.)

Featherstone (1980) points to a paradox about disability -- in the larger, outside world, children strive to fit in, to be like everyone else, but within the family, each child wants to be special. For the handicapper, the disability may confer some advantages; it may be a "passport to special attention, recognition, and privileges" (Featherstone,1980:47). This may result in many able brothers and sisters experiencing jealousy and resentment toward their handicapper siblings.

Siblings of handicappers may be seen as marginal people; they participate in two different cultures -- the world of their "normal" peers and the world of their "different" family (Featherstone,1980). Milunsky (1981) agrees that being the brother or sister of a child who is profoundly handicapped presents elements of stress.

Stress varies with characteristics of the child: the care-giving demands, behavior problems, temperament, the child's social responsiveness, and his/her rate of

development. Some siblings misunderstand the causes and outcomes of the sibling's handicap. Some younger children may wonder if this will affect their own health in some way -- could they "catch" it, too? They may not understand the potential genetic implications; some able siblings worry that their own children may also be born handicapped (Featherstone, 1980; Beckman-Bell,1981; Milunsky, 1981). Because grown-ups with handicaps are still rather invisible in our society, many children wonder about the handicapper's future. They look ahead and wonder whether they will have to assume responsibility for the handicapper sibling when the parents die or become too old to take care of them. They are concerned about whether they will be able to find a spouse who would agree to take on that kind of responsiblity (Grossman,1972; Featherstone,1980).

Another problem is that families often establish a double standard for child compliance and performance. Other children in the family may have to follow the rules, but the handicapper has a less rigid set of expectations. Along with this, significant personal accomplishments of the other children may appear to be less valued than seemingly small gains by the handicapper. Sometimes the able children experience the stress of feeling obligated to meet high parental expections about their personal accomplishments; they feel pressure to excel because all the family's hopes and expectations seem to rest with them.

Some able siblings seem apologetic about their own good health; they wonder if they should have been the victim.

This response -- which Kew (1975) and Banks and Kahn (1982) term "surviver's guilt" -- can become particularly acute if the handicapper sibling dies. Surviver's guilt can place considerable stress of the sibling, and in some cases it may be a source of lasting distress. Death of a sibling is the most extreme example of a situation producing stress and guilt. Kew (1975) maintains that a child's response to the death of a handicapper sibling differs in several ways from response to other deaths. The way in which any particular child responds to the death of a handicapper sibling depends on a number of factors. Based on his findings, he maintains that in the case of a handicapper sibling's death, the other children often experience a great deal of disturbance. Kew attributes this to the rivalry between them; he writes: "When the hostile wishes have been fulfilled by the death of a sibling, sometimes the young child assumes that the power of his own thoughts has been the cause of death" (Kew,1975: 115). These feelings of surviver's guilt may be expressed in a number of ways. Kew writes:

> Some children feel they should have died along with their sibling -- or perhaps instead of him. Some have suicidal thoughts or dwell on the bad things they've said or done in the past. Others react with depressive withdrawals, accident-prone behavior, punishment seeking, constant provocative testing, exhibitionistic use of guilt and grief, massive projections of super-ego accusations, and many other forms of acting out (Kew,1975:107).

Parents often expect other children in the family to accept the handicapper and to realize the intrinsic benefits

from his or her presence. But the brothers and sisters may experience troubled feelings, including jealousy and anger. Kew (1975) maintains that jealousy is essentially hostile in intention and its motivating force is to destroy the envied person.

In a study of 50 physically handicapped children and their families, J.K. McMichael (1971) had teachers question mothers of handicappers; the survey found that 79 percent of the siblings of handicapper children were "normal" or had only a slight adjustment reaction. In a study of 150 cerebral palsied children who remained at home, Hewett (1970) found that 33 percent of their mothers reported their other children were jealous of their handicapper siblings -- the same percentage of sibling jealousy was found in a sample of mothers of all "normal" children. Sibling rivalry is a common occurance reported in many other studies of "normal" children.

Kew (1975) maintains that not all siblings exhibit jealousy towards their handicapper sisters and brothers. According to him, in some families the rivalry system is not imbalanced and in others where it is imbalanced, the able sibling is able to get the affection s/he needs either from the other parent or from a surrogate parent figure. One weakness of Kew's study is the fact that he did not interview able siblings of handicappers; his entire study was based on interviews of mothers by social workers.

Able siblings are often angry -- angry at the handicapper sister or brother, angry at their parents, angry at

the world, or fate, or at life itself. This anger and the jealousy can create feelings of guilt. Able siblings realize that they are fortunate not to be so inflicted, but nonetheless, they may resent the special privileges and expenditures -- on braces, treatment, special equipment, or diagnosis; they may feel that the financial resources should be spent in a more equitable way (Featherstone,1980; Milunsky,1981; Darling and Darling,1982). The jealousy may be directed toward the handicapper or it may be "disguised" jealousy, where the sibling's hostility is directed toward others (Darling and Darling,1982). Kew (1975) also discusses disguised jealousy. He maintains that disguised or ambivalent feelings are the product of socialization; parents control behavior because they either don't approve of exhibitions of jealousy or cannot accept them.

Bank and Kahn (1982) point out that aggression is a major vehicle for all sibling interaction, and even when it is painful, aggression may represent human contact and interaction. It is their view that even if aggression is present between the handicapper and able siblings, this may have a constructive function in that it forces the participants to learn how to manage and resolve their conflicts. I agree. Expressing aggression against the handicapper sibling might also allow the handicapper the opportunity to ventilate. Sibling squabbles could be healthy for everyone, handicapper and able children alike. Zola (1982a) reports that there is no acceptable way for a handicapper to express anger and resentment. Because they

are usually treated with a combination of overprotection and distancing, handicappers are "socialized" out of their anger.

> With virtually no acceptable avenues for expression, those with a chronic disability are forced to turn their anger in on themselves or to blunt it. To the degree that we succeed in the latter we become increasingly unfeeling, and often so distanced from ourselves that virtually nothing can touch us... If we turn the anger inward, it is likely to take the form of depression. This depressed state is not merely a primary reaction to our losses, our dependency, our sickness, and thus something for us to 'realistically come to grips with,' it is every bit as much a socially induced defense, the result of our enforced inability to express anger (Zola,1982a:222).

Kew (1975) maintains that because most parents are thrown "off-stride" by the birth of a handicapper, their time and energy is spent readjusting. Often this means there is a corresponding decrease in time and energy spent on other children in the family. This may result in disruptive behavior on the part of other children; the disruptive behavior serves two functions for the able sibling: 1) it acts as a way of expressing feelings of jealousy that s/he is experiencing, and 2) it represents an attempt to control behavior of the parent by "blocking" the part of it that is the cause of so much pain. Kew (1975:81) writes, "It seems that the underlying pattern of neglect and response, followed perhaps by further rejection of the sibling, is almost a universal phenomenon."

Sometimes able siblings have behavioral problems --

perhaps because they feel neglected, or really are neglected. Reported behavioral problems among the other siblings may include difficulties in school, drug use, nocturnal enuresis, running away from home, or trying to harm the handicapper (Grossman,1972; Featherstone,1980; Milunsky,1981). Able siblings may engage in attention-seeking behavior, such as clinging to parents, throwing temper tantrums, complaining of psychosomatic pains, and exhibiting various disruptive behaviors (Grossman,1972; Kew,1975; Darling and Darling,1982).

David Thomas (1980) argues that family members of visibly handicapped children carry a courtesy stigma. The "disgrace" of being less-than-perfect is transferred to parents and siblings and their social position becomes ambiguous. Even though they are normal in their performance, they are considered different because of their close association with the handicapper -- who is treated as deviant in our society. The deviance not only stigmatizes the handicapper but also those in regular association with him/her. Erving Goffman describes this phenomenon as a "tendency for the stigma to spread from the stigmatized individual to his close connections" (1963:43).

Thomas (1980) believes that other people's attitudes toward the handicapped and their families constitute a social and psychological matrix within which they all must live. This matrix becomes fundamental to their socialization, and it greatly influences interpersonal behavior. This social and psychological matrix includes

sanctions imposed by the larger society, differing socio-personal distances in interactions, and laws, acts, and institutions through which public attitudes are conveyed (Thomas,1980).

According to Thomas (1980), many family members, including siblings, try to distance themselves from the stigmatized person to avoid courtesy stigma and its deeply discrediting attributes. Grossman (1972) stresses that enormous differences exist from one family to another in how members react to, and cope with, a severely handicapped child. Not all families acknowledge experiencing a courtesy stigma.

Conclusions

In the past, relatively little attention has centered on how a physically handicapped child affects the rest of the family. In particular, there has been little research on repercussions for the lives and experiences of other siblings. In the limited research available, able siblings have usually been cited as prime victims in families with handicapper children (Kew,1975; Darling and Darling,1982), but the cumulative evidence suggests that it is not invariably true that other children will be adversely affected by a handicapper brother or sister (Thomas,1980). Darling and Darling (1982) maintain that most studies indicate that in the majority of cases, other siblings manage to adjust well to the presence of a handicapper; they

suggest that perhaps those who fail to adjust have been given a disproportionate amount of attention. This could very well be true, but questions have rarely been asked of able siblings themselves. That is the purpose of my research -- to talk directly with siblings of handicappers to find out their experiences and feelings.

Chapter 3

METHODOLOGY

Introduction

The aim of this research is to understand how able siblings of mobility disadvantaged handicappers perceive, organize, and communicate realities of their lives. What are the experiences of able siblings? Do those experiences reflect and shape their lives? Are able siblings "a population at risk?" Does timing of disability make a difference in how able siblings respond to a handicapper sister or brother? Since relatively few investigators have talked directly to siblings of mobility handicappers, this is, of necessity, an exploratory and descriptive study. Information gained may be helpful to others studying and working with families of handicappers.

Life, including life within a family, is not static. It changes over time, and meanings members construct about the handicap may change, too. Most research on the family and handicappers, including this study, has the problem of dealing with this dynamic aspect. One of the problems of asking people about their feelings and behavior is that only selected incidents are related and past history is continually reconstructed. To attempt to use those few episodes to construct a theory of the effect of a handicapper on able siblings could be misleading. There is

no way people can communicate a lifetime of experiences in ninety minutes, but analyses of these interviews does reveal patterns of responses that are useful.

Almost no one has interviewed siblings of handicappers first-hand; consequently, little has been published about their opinions and daily life experiences. There is some information about what their mothers, or social workers, or therapists believe they feel, but in my opinion, this is an inadequate way of studying siblings' experiences. Instead of interviewing the "experts," I decided to find out what brothers and sisters of handicappers had to say about their own experiences and feelings. Very early in my thinking, I decided that focused open-ended interviews dealing with the able sibling's own, and family responses, would be the best way to capture information of concern to me. In-depth interviews are not new in this area of research, but the emphasis has shifted; I am focusing upon the richness of experiences of ordinary people.

Because there is so little knowledge about siblings' feelings and attitudes, I started with few specific questions in mind. I had general areas of interest, and although I constructed an interview schedule, I used those questions only as a guide. I wanted to avoid imposing unsuitable categories and becoming locked into that mode. I attempted to follow Glaser' and Strauss' (1979) concept of "grounded theory" -- asking questions and letting responses and emerging catagories determine direction and content of the interviews. I wanted to ground my findings in the

everyday life experiences of siblings of handicappers. In my effort to do that, I tried to structure the interviews to increase the opportunities for insights. Often interviews would go in unexpected directions, but unless it was far afield from the topic, I encouraged the person to continue talking about her/his own concerns and feelings. In a few conversations, as Barbara Myerhoff put it, they crossed the invisible line from informed disclosurers to inadverdent disclosure. We often digressed, and not all the questions were asked in every interview. But in each interview, I did make sure to cover issues I considered particularly crucial.

During each interview, I tried to learn something about the person's value orientation and attitudes. I tried to pay attention to what they included in their accounts (e.g., factual information), but I was also sensitive to omissions (e.g., acknowledging the handicapper sibling as a potentially erotic person who might have intimate relationships or marry). Both what was included and omitted provided clues to constraints, conflicts, and tensions they felt about the topic. Reviewing the interview material, I looked for patterns of response and developed these into themes for analysis.

Early on, I made a commitment to study how subjective social realities were created, experienced, and described by the social participants themselves. In traditional interview protocal, information is usually one-directional. The interviewer asks the questions, and the "subject" answers it. From the start of the project, I thought of and

referred to the able siblings to whom I talked as "respondents" rather than "subjects." Webster's New Collegiate Dictionary defines subject as "an individual whose reactions or responses are being studied; one that is the object of clincial study" (Woolf,1974:1159). The definition of respondent is "one who responds" (Woolf,1975: 986) -- a more accurate description of the interactive process between the able siblings I talked with and myself. The traditional interview stresses quantification, control of the interview by the investigator, detachment, and unequal exchange of information. I am not comfortable with that protocol; from the start I made an effort to establish a non-hierarchical relationship between myself and people to whom I talked. In some cases, it was a true exchange; I would talk about my experiences with my daughter or give them information. Throughout the entire project, I'm tried to ensure that respondents would not become victims by interpreting their answers in ways they did not intend. When I have discussed possible hidden meanings, I've tried to keep them on the level of speculation.[1]

Because I was so close to the data, during the interviewing process when I sensed something was missing, I could alter my strategy by dropping or adding questions. In this approach, gathering and analysis of data are not split apart, as they often are in more deductive approaches to research. As I talked with people, I found that some questions I'd originally included were not useful, and in later interviews, I would omit them. In place of those

issues, I'd include others that individuals brought up. This is one of the advantages of the grounded theory approach -- you aren't locked into an interview schedule and can pose fairly broad, general questions and pursue leads as they emerge. The method also has some drawbacks. The interview doesn't have the same amount of control as in the traditional interviewing method. You may also discover a really important relevant issue well into the interviewing process and not to be able to probe it with earlier respondents. I also found that early in the interviewing process, I seldom took the initiative to probe deeper, and I feel that would have been useful. The use of non-standardized questions means that quantification of data cannot be a major part of analysis.

Defining the Population

Originally I defined the population as "siblings of the orthopedically handicapped", but this definition presented several problems: did I want to include only those who could not walk unassisted? How severe would the handicapping condition have to be to include the sibling in the study? Should I eliminate siblings of people who have been in an accident and became physically disadvantaged? I saw these as important concerns and as issues I wanted to address. To resolve this dilemma, I decided to redefine the population to include these dimensions.

After the first three or four interviews, a new

definition emerged in my thinking. In the winter, 1985 academic quarter I changed the definition to "siblings of people who are mobility disadvantaged." By changing the definition, the questions I mentioned were no longer a problem. The disadvantage could include arm/or leg mobility, to any degree. With this definition, people I interviewed decided for themselves that they were part of my population. They, and not I, defined whether or not their sibling was a "mobility disadvantaged" person.

Late in the study, I decided that "mobility disadvantaged" is an artificial distinction. If I had it to do over, I would define the population as "siblings of handicappers." There are more similarities than differences in these groups. By defining it as "handicappers" I would include brothers and sisters of the mentally retarded, autistic children, and seriously physically handicapped.

Locating Respondents

I chose the recruitment site and age of the respondents for practical reasons. Recruitment was limited to the campus of Michigan State University, although siblings did not have to be students. I believed it would be much easier and quicker to recruit volunteers on campus, and I decided to interview siblings over the age of seventeen because they are old enough to fully enter into the reflective process. Early on, I knew that I would ask about guilt and resentment; emotions like these are probably too complex for

youngsters to conceptualize and discuss. And finally, another consideration was that gaining meaningful and legal informed consent is more difficult with children than with adults.

Because this research was designed to be exploratory, seeking new insights about siblings of handicappers, I made no effort to select a truly representative sample. In my proposal, I specified that I would interview "college-aged subjects" recruited on the Michigan State University campus. As the recruitment process continued, I found that the volunteers included some non-students who had handicapper siblings. I decided to also include them in my sample because they would broaden my research findings to a larger population.

Early in the research endeavor, I attempted to secure funding to pay the respondents. I wrote to twenty-one Michigan foundations who support research in the area of the family and/or handicappers, requesting a grant to be used primarily for paying volunteers. All of them rejected my appeal. Later, I learned that under the Reagan administration, grants to individuals are no longer tax deductable. Because I was unsuccessful in obtaining research funding, for the first several months, I did not pay the people to whom I talked. I was uncomfortable about this lack of compensation for their time and effort. The inequity of the research bargain bothered me a great deal although I realize that money is not the only potential benefit someone may gain from being interviewed. The opportunity to teach, to

tell people something, can be an important plus for some individuals. In addition, an opportunity to talk to an understanding stranger, a near anonymous listener is salient to some. Both of these probably operated in the people I interviewed. A sizeable number also mentioned a third gain -- helping someone who needs your assistance. Many of the people I talked to offered me encouragement and specifically said they hoped their information was helpful and useful in my research.

Nevertheless, when I continued to have difficulty locating respondents, I decided to pay a ten dollar honorarium to each one I interviewed. This did help reach more people, but more importantly, I felt it was then a genuine research bargain; both the respondent and I "gained" something. Because I still felt uncomfortable about seven people I'd interviewed in the beginning of the project, I looked up their addresses and sent each one a check for ten dollars. At least six people I interviewed offered not to take the money. In each case I told them I wanted to make the payment. In two instances where they were quite insistent about not taking any money, we compromised by agreeing they would give the money to a handicapper charity.

To locate potential respondents, I tried a variety of methods, with mixed success. During three academic quarters of 1985, I placed seven advertisements in the student newspaper. These ran under both the "Personals" and "Wanted" columns. Wording varied, but all were similiar to this, the last ad I ran:

> Siblings of handicappers (wheelchair users or those who experience other mobility disadvantages) wanted for interview by doctoral candidate. Information confidential (The State News, October 2, 1985).

Two phone numbers were included. Only two volunteers were located by this procedure.

I also went to twelve classes at the university and appealed directly for respondents. The instructor introduced me as a doctoral candidate in the department of Sociology. I gave a brief description of the research endeavor and then asked for siblings of handicappers to volunteer to be interviewed. I also asked them to tell any friends who had handicapper siblings about me and my research. Appealing in classes never yielded more than one respondent per appeal, and in a total of a dozen appearances, I secured only four people. I also tried an appeal in The MSU Watch, a quarterly publication put out by the university's Human Relations department, but no one responded.

A method that worked well was personal referals. Friends, colleagues, and earlier respondents told me about people who fit my population. This method resulted in locating ten respondents -- all very articulate individuals who fit the original profile of being college students who had sisters or brothers who were orthopedically handicapped.

The strategy that proved most successful for me in locating respondents was a combination of several things: first, paying each respondent an honorarium of ten dollars

was helpful in securing volunteers. If nothing else, the caption on the poster, "Will pay $10.00," caught people's attention. Several people specifically told me that the payment was the primary reason they were talking to me. I made up large yellow posters that said:

PhD Candidate
Needs to Interview
Sisters
&
Brothers
of Mobility Handicappers
Will Pay $10.00
All Information
Confidential

These posters were placed on bulletin boards throughout the campus, along with business cards that gave my name, home and office phone numbers, and the caption, "Research on siblings of mobililty disadvantaged handicappers." I located ten respondents in this way.

In addition, I also set up displays in lobbies of campus buildings that are high traffic areas. At a table, I placed two large yellow posters that said essentially the same thing as the smaller ones. I sat there ready to answer any questions and get any volunteer's names and phone number. As people passed by, most of them read the signs. In this way I was successful in locating fifteen respondents; however, this method was very time-consuming. I would stay up to five hours, usually getting between two and five people to interview each day I recruited.

In some cases, the combination of strategies seemed to

have a cumulative effect. Some people mentioned that they'd also seen the advertisements in the newspapers and/or the posters, but they hadn't responded until they saw me and the display set up in the lobby. I also noticed that some people would read the signs and then return a few minutes to an hour later to actually sign up for an interview. Perhaps they needed time to think it over.

I had not anticipated that it would be difficult to secure a sample. I thought there were ample potential respondents on the Michigan State campus and that I would be able to interview forty to fifty siblings within a three or four month period. This was not the case. From the start, I had difficulty locating people. Part of this difficulty was because I excluded sisters and brothers of the mentally retarded -- unless they were also physically disadvantaged. Later I realized that the mentally retarded are the single largest category of handicappers, so by excluding them, I had seriously limited my population. My original reason for not interviewing sisters and brothers of the mentally retarded was that they are one group of siblings that have been extensively investigated.[2]

The recruitment strategies I used may also have contributed to my difficulty in getting people to interview. Because the population is relatively small, appealing in classes was not a good method. Advertisements in "Wanted" or "Personals" columns were not productive since a great many people don't read want-ads.

One other problem was a matter of nomenclature: some

people defined "handicappers" in ways that I did not anticipate. I tried to resolve that problem by using such phrases as "wheelchair user" or "mobility disadvantaged." But a common question when I set up the display to recruit was, "How 'handicapped' are you looking for?," or "What kind of handicap do you mean?" I also found that substantial numbers of people did not know the meaning of the word "sibling." Once I discovered that, I used the words, "sisters and brothers," to be sure they understood.

As in most recruiting situations, I found that no-shows were a problem. I anticipated this and made sure that, when someone volunteered, I got both their name and phone number. Five people did not show up for the scheduled interview. I phoned each of them again, usually the following day. I never placed blame as to why they weren't there, only asked if we could reschedule. All five agreed to reschedule, but only three appeared for the second scheduled interview. I did not follow up on the other two people, and they are not included in this study.

Non-Representativeness of Sample

Since the project is exploratory, I was not particulary concerned with achieving a truly representative sample. The sampling is based on the theoretical sampling procedure discussed by Glaser and Strauss (1979) in which the reseacher collects material, analyses it for patterns,

creates new research questions, and then looks for new sources of information based on the knowledge s/he has now acquired.

With that in mind, I acknowledge that the people I talked to are not necessarily representative of larger society. Since most are college students, they may be more articulate than the general population. Certainly, they have more than average education and their parents are also better educated than the general population. In addition, people I interviewed were disproportionately from white, middle-income families. I talked to only two Blacks and no Hispanics, Asians, or Native Americans. Only one respondent would be considered to be from a lower socio-economic background.

The ratio of female to male volunteers was skewed; over 68 percent (28) were female. Also, since they were all volunteers, perhaps individuals who were ashamed or uncomfortable about having a handicapper sibling did not participate in this study. All but six of the people I interviewed were Michigan State University students. This is to be expected since all of the recruiting took place on campus. This also explains why only seven people were over the age of twenty-five. The average age of the able male siblings was 22.41 years and the average age of the able women siblings was 23.89. That the women respondent's average age is older may be partially explained by the fact that five women, with whom I talked, were not college students. While it is true that this sample is not

representative of the total population of siblings of mobility disadvantaged people, it does not diminish the findings -- although it may limit the extent to which they may be generalized to the larger American society.

I had the opportunity to interview four pairs of respondents from the same family: a mother and daughter combination (the mother also had a handicapper brother), two brothers whose sister has muscular dystrophy, two sisters whose brother has muscular dystrophy, and a sister and brother whose brother had broken his back in an automobile accident. Talking to these dyads reinforces the notion that contextual effects are important. Kew (1975) repeatedly cautions against treating siblings of handicappers as a homogeneous group. He maintains that the effect of the handicap on any individual person is dependent upon many variables. The meaning of the event to an individual is the crucial element, and from talking to able siblings of handicappers, it's apparent that meaning of the handicap is idiosyncratic. It does not have the same meaning or effect for all the able siblings. The opportunity to talk with these pairs of siblings, in particular, reinforces the idea that effects do vary from person to person, and there are differences in experiences even when they are in the same family.

Issues of Interest to Me

The types of questions I used to start my investigation were designed to explore themes that I considered to be important, but even after one interview, questions and emphasis began to shift. A prime advantage of using open, relatively unstructured interviews was that it enabled me to reformulate the problem, modify questions, and pursue new topics as they emerged.

I used the responses to questions and omissions in interviews to develop themes/categories for analysis. Basically, I was interested in three dimensions of siblings' experiences:

1) Information about the handicapper: this included a description of the nature of the handicap, its onset, and the prognosis for the handicapper's future.

2) Information about the family: the respondent's understanding of the different patterns of responses other family members made in reaction to the handicap, the influence (if any) of religion on their feelings and attitudes toward the handicap, family meanings constructed around the handicap, and a sense of whether the handicapper herself/himself is seen as somehow responsible for the impairment.

3) Information about the respondent: any "competition" for parental attention s/he may have experienced,

whether or not the respondent acted as a "caretaker" and his/her reaction to those responsibilities, guilt, or resentment, and what effect(s) (if any) the handicap had on his/her life.

The original interview schedule (see Appendix B) included the following themes: a) When did the able sibling first realize the sibling was "different"? (How did s/he feel about this? Does the family discuss the handicap? Who participates in these discussions?) b) How do other siblings explain the handicap to people? (Did they ever wish that the handicapper sibling was not around?) c) Do (or did) other children of the family perceive themselves as having a "courtesy stigma"? (If so, how do (or did) they handle it? What were the stages of handling?) d) Do the other siblings feel guilty about being able to engage in activities the handicapper brother or sister cannot? How much time do they spend with him/her? What do they do? (Play? Take care of her/him? What have been the changes over time?) e) Do (or did) the other siblings resent the time, attention, and money that the handicapper child needs? f) What do they think about the handicapper sibling's future? What will s/he do? What will be their own role (if any)? g) Are there any apparent gender differences in amount of time spent playing with and/or helping with the care of the handicapper sibling, choice of vocation, and decision whether or not to parent? h) Does birth order appear to influence the ways other sibling(s) interact with

the handicapper brother or sister? (If so, what effect(s) are found?) i) What did other siblings do when they got angry at the handicapper sister or brother? What did their parents do or say if they quarreled with the handicapper? j) How important is religion in the family? (Do they use religion to help explain or understand the fact of the handicap? Has religion affected their views of the handicapper sibling? Has the sister/brother's handicap affected their view of religion?) k) What do other siblings perceive as the primary difference(s) in their own lives of having a handicapper sister or brother? (For instance, do they believe that having a physically handicapper sibling has affected their relationship with their parents? Has it influenced their relationships with their peers? If so, in what way(s)?)

Themes that emerged as I taked to siblings were: a) things that made them particularly proud of their handicapper sister or brother, b) dreams and fantasies about their handicapper siblings, c) the importance to the respondent of the timing of the disability, and d) altered social relations in the family, including the development of asymmetrical power relations among the siblings.

Nature of the Interviews

For practical reasons, I tape-recorded the interviews (the informed consent sheet included permission to tape). My rationale was that recording would free me to pay

attention to responses and allow me to do more active listening. This undoubtedly occurred.

Especially in the first few interviews, I relied on the interview schedule to guide me through issues I wanted to explore. As time went on and I interviewed more people, I eliminated many of the original questions and used the time to probe in more depth the remaining issues. This also allowed me to spend time on topics that were most relevant to the sibling. If the person talked freely, I made no attempt to use the interview schedule. On more than one occasion, the respondent would apologize for "getting off the topic," but I would reassure him/her that it wasn't important and didn't matter. However, this did mean that I had additional problems trying to code and analyze information.

Interviews tended to be fairly uniform in length; most averaged about an hour and twenty-five minutes, but one was only thirty-five minutes and another ran well over an hour and a half. In most cases, I met the respondent in my office and we walked together to an empty room where we had the actual interview. This location had the advantage of complete privacy; we were never interrupted. Three interviews were in the respondents' homes. This was convenient for them, but interruptions were a recurring problem, especially when small children were present.

Because this population is relatively small and respondents are difficult to locate, I did not attempt to conduct more than one "pre-test" of the interview schedule.

My pre-test interview was with a man whose sister was handicapped as a child, but I did not include that information in this report.

The interview schedule also included some standard demographic questions such as respondent's age, size of family, his/her position in the family, nature of handicap, his/her academic major or occupation, educational levels of parents, and religious background. I believe this type of information may be useful in drawing conclusions, particularly in regard to how and why some families are able to respond to misfortune in positive ways, while others, in essentially similiar circumstances, are devastated.

Analysis of Data

A difficulty in studying attitudes and feelings of siblings toward handicappers is the multidimensionality of disabling conditions. Handicaps vary widely in their age at onset, extent of visibility and/or disfigurement, limitations upon physical and/or cognitive functioning, and associated pathology or prognosis. This includes things like the seriousness of condition, prospect of recovery, amount of pain or trauma, and degree of threat posed to life. These differences make it more difficult to compare attitudes and feelings toward the handicapper sibling.

Another difficulty in analyzing results is that my sample has three distinct groups of respondents: twenty-six biological siblings of people who have been handicappers

from birth or early childhood, ten who were able siblings of those who became handicappers as adults, and five were foster or adopted siblings of handicappers. Each group had different responses to having a handicapper in the family.

At the start, I tried to transcribe interviews as soon after the conversation as possible. As time went on, and I was recruiting and interviewing extensively each week, I fell behind in transcribing. If I'd been successful in gaining a small grant, this task would have been done by someone else.

I typed up partial transciptions of each interview, including all the portions that I thought might be relevant. I also added my own notes and comments. After the first seven interviews, I started analyzing the data. Many categories overlap; to separate this material into absolutely discrete groups was impossible. There were many interconnections and complexities that were difficult to label in just one way. Throughout the whole data collection period I tried to identify significant patterns and variations in siblings' experiences and avoid making over-generalizations. Throughout the entire process, questions and categories were revised and changed, which is a benefit of the grounded theory method.

Unanticipated Problems

In this endeavor, two problems came up that I did not anticipate -- the potential for intense emotional reactions

on the part of respondents and/or me, and the difficulty of finding, and using, a neutral vocabulary in place of ablest language. Early in the interview process, I was asked if it wasn't difficult to talk to people about such a "sad" topic. I quickly, and with no hesitation, said that it wasn't a problem. Nor was it, for quite awhile.

Under the traditional research model, emotionality would never be an issue for the interviewer. Under that positivist philosophy, the researcher is assumed to be neutral and detached. But in the approach I took, information is shared and complete detachment is seen as a barrier to communication. When I was first asked, "Isn't it difficult to talk to people about such a 'sad' topic?," I'd only interviewed four or five people, and the interviews were spread over a period of time. But during the fall, 1985 term, I talked with three to six people every week. Then I found that, on some occasions, the interviews did "get to me." The impact of discussing a handicapper sibling for several hours a week, and hearing about someone who often had no hope for living a "normal" life, began to weigh on me. I began to feel depressed, but for the most part, I was able to suppress it.

The only time my emotions threatened to get the better of me was when I interviewed a woman who had lost an older brother to muscular dystrophy; her younger brother also has it [Interview #25]. She mentioned that when she visits her remaining brother, and he is in bed for the night, he asks her to put his arms around her so that he can give her a

hug. Somehow, the image was so immediate and powerful and tragic in its meaning, that I got tears in my eyes and a lump in my throat. Of all the comments I heard, this one evoked the most memories of my daughter.

On only one occasion did someone I interviewed have similiar problems. It was a woman discussing her brother, who also has muscular dystrophy [Interview #37]. When I asked, "What do you think about his future?," momentarily she could not go on. She started to cry and apologized. I told her that I understood how she felt, and I briefly talked about my daughter, who also had a form of muscular dystrophy. This digression gave her a few minutes to compose herself, and then we went on with the interview. I felt comfortable sharing my own problems and emotions, and I think it lessened the barriers to communication.

One of the early and recurring problems I encountered was avoiding discriminatory "ablest" language. Both in common usage and in the professional literature, the terms used are value-laden. Supposedly no negative connotations are intended, but the terms do at least potentially stigmatize. The use of ablest terms functions as a form of social inequality, and such words certainly have the capacity to hurt. In his moving book, Missing Pieces, Zola writes about the word "invalid."

> In the Netherlands, the pronounciation for a handicapped person, someone we Americans call an 'invalid' was enuniciated in accord with its derivation -- from the word 'valid.' To them this was the only natural way to refer to a reality --

> the difference between healthy people and the handicapped lay in the latter's invalidity. Every time I heard it...it made me shudder (Zola, 1980a:3).

Throughout the dissertation, I've made a sincere attempt to use non-ablest language. Even with the best of intentions, it isn't an easy undertaking. Part of the trouble is that there are few alternative, non-perjorative terms in common usage. Both in the literature and in popular usage, individuals labeled as "handicapped" are generally referred to in one of three ways. Comparative adjectives, such as "disabled," are used as nouns, e.g., "the disabled," or as modifiers, e.g., "disabled individuals" or as qualifying characteristics, e.g., "individuals with a handicap." Other adjectives used in this manner are: impaired, limited, exceptional, invalid, disabled, defective, malformed, deformed, afflicted, and of course, handicapped.[3]

What I've tried to do is eliminate or reduce the negative vocabulary by substituting words that are positive, or at least neutral, in connotation. The best example of this is using "handicapper" instead of "handicapped" -- which infers inability to do everything. An equally troublesome problem, not as easily resolved, is what to call non-disabled people. People who aren't handicappers are usually classified by such terms as "the able-bodied" or "the non-handicapped." The comparative adjectives used are usually limited to two: "normal" and "able-bodied." None of

the these terms seemed desirable, but there are few ready substitutes. This research has made me aware of the lack of neutral terms. Gentile and Taylor (1976) suggest that the non-handicapper population be referred to as "temporarily able-bodied" indicating their potential to become handicappers. Sawisch (1978) concurs, but he suggests the acronym "tabs" be used, for "temporarily able-bodied souls." I don't feel comfortable using either of those terms. My compromise is to use the word "able" when talking about people who aren't handicapped, but it isn't a totally satisfactory solution. Prospects for changing the use of language aren't bright, but as Martyna said in reference to sexist terms, "language change may be difficult, but it is not impossible." A switch from ablest language is one move toward a non-biased ideology toward handicappers.

Conclusions

Through retrospective analysis, this study explores the experiences that able siblings encountered. Their pressing questions and problems are investigated. I wanted to learn the sibling's interpretations of events and social relationships, and to do this, I needed to discover and interpret the dimensions of their social reality and understand what able siblings of mobility disadvantaged handicappers feel about their own lives and experiences.

I looked at how the presence of a handicapper sister or brother affected other children in the family. How do their

experiences reflect and shape their lives? Does a handicapper alter the social relations of the other siblings? What are the effects and what are the factors responsible for the differential responses they make to their handicapper brother or sister? Questions like this have received little attention in the sociology of the family. In my view, these are not irrelevant or inconsequential but are important considerations.

My study is unique in that virtually no previous research actually interviewed sisters and brothers of handicappers. Instead, earlier studies relied on reports of "experts" -- doctors, psychologists, counselors, or mothers. I've asked a different set of experts -- the siblings of handicappers. I believe what they say is worthy of notice. The goal was to understand able siblings' lives and experiences. As often as possible, I have included verbatim accounts. Rather than simply present a generalized overview of the sample, I include the voices of many individuals; this permits respondents to emerge in their fullness and distinctiveness. To assure privacy, I have changed all the names of the people mentioned here. Examples and quotations that I provide are not intended to be in any sense "typical" but only illustrative of experiences of some able siblings.

ENDNOTES

1
In my interviewing protocol, I was strongly influenced by an article by Ann Oakley (1981), "Interviewing Women: A Contradiction in Terms."

2
For research on siblings of the mentally retarded, see Grossman (1972), Voysey (1975), Darling (1979), Darling and Darling (1982) and Seltzer and Krauss (1984).

3
For interesting and enlightening discussions on the use of non-ablest language, and its implications, see Gentile and Taylor (1976) and Sawisch (1978).

Chapter 4

TOWARD A SOCIOLOGICAL UNDERSTANDING OF HANDICAPPER SIBLINGS: A CONCEPTUAL FRAMEWORK

Introduction

Discovering and understanding the effects of a handicapper sibling on other children of the family is not a simple undertaking. There are no typical responses; a variety of factors influence the outcome. Even though there is no uniform effect, there are useful patterns for understanding able sibling-handicapper sibling relations. One of my tasks is to identify and lay out these patterns and consider how they interact. The project is complicated by the fact that research on siblings is both meager and contradictory, and studies on brothers and sisters of handicappers are particularly flawed.

To determine effects of a handicapper on other children in the family, it is essential to ground the investigation in something beyond the sibling dyad. Understanding family relationships and dynamics are crucial to finding out how a handicapper will affect other children in the family. A framework is needed to locate able and handicapper siblings within the family and to place this study within the broad context of sociology of the family. To help achieve these goals, I have done two things: 1) drawn upon an organizing framework this takes into account a trio of subordinate

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family sub-systems: spouse, parent-child and sibling and the interactions on these sub-systems on family activities, family composition and attitudes, and family life cycles and 2) laid out the concepts, basic functions, and framework I have used; this helps locate the study within the larger discipline.[1]

Dominant/Minority Relations

It's useful for this discussion to consider the disabled as a minority group that experiences discrimination, both in the larger society and in the institution of the family.[2] To understand dominant/minority relationships, we must recognize that the inequity isn't caused by personal characteristics, nor is it simply a question of prejudiced attitudes (although they are certainly part of the problem). It is a structural problem.

Minority groups are made up of individuals who possess a common characteristic which sets them apart. This attribute is used by others to place them low in the social order. In the case of handicappers, the common characteristic is their disability -- particularly if it's something that is readily visible or easy to recognize. To reiterate, the trait that puts them at a disadvantage, that causes them to be placed low in the social order, is not the common characteristic -- in this case, the disability -- it's the fact that others define that quality as less worthy

or desirable.

Minority status for handicappers arises from two important sources: socialization that discourages improvement of their position and a political and economic order that does the same. From-birth handicappers are too often socialized into inequality. Socialization is an interaction process whereby a person's behavior is modified to conform with the expectations held by members of the groups to which s/he belongs. Socialization includes not only the process by which the child gradually acquires the ways of the adults around her/him, but also the process by which an adult takes on behaviors appropriate to expectations associated with her/his position in the family and society at large. This socialization includes the idea that those with handicaps are expected to play restricted roles. In a sense, many from-childhood handicappers are taught to play the role of sick person and not aspire to "normal" roles. These possibilities become closed to them. Instead of being evaluated on their individual merits, these handicappers encounter special treatment based on stereotypes of their abilities and interests.

There is ample evidence that able and handicapper children are differentially socialized (Burton,1975; Zola, 1980, Schell,1981). By the time handicappers reach adulthood, many of them have been damanged by the socialization process; they have been systematically trained to accept second-best, not to strive, and to accept that they are unworthy of anything more. Many from-birth

handicappers are taught by their parents, by their siblings, the schools, the medical establishment, the entire society, that they must be passive. They should be grateful for the things people do for them; they ought to be cheerful and not expect too much. Over time, they learn independence, autonomy, and self-determination are not in their futures. As I talked with the respondents, it became apparent that these expectations are also learned by many of them, although there were at least two exceptions: one was a man whose brother has spina bifida and is also somewhat retarded. This respondent is actively supporting his brother's attempts to be as autonomous and independent as possible, but it has been difficult for their parents to accept the handicapper's potential [Interview #8]. The other exception was a man whose sister has osteogenesis imperfecta. Although she cannot stand or walk, she attends college alone in a distant state and the family encourages her efforts to be independent [Interview #6].

From evidence in the literature and from talking to 41 able siblings, I believe that most family members, including able siblings, consciously or unconsciously define the handicapper as someone who is different, someone who is "not normal," someone who is less than they. This attitude is both a reflection of the larger society and of family relations. The dominant group often demeans minority group members, tries to exclude them from power positions, discriminates against them, and attempts to prevent them from taking part in the general life of the society --

including, in the case of handicappers, from full participation in the family. Their distinguishing difference means it isn't necessary to emphathize or try to understand what they feel. Most handicappers have so little influence in the family and the world, so little power, that their feelings can be safely ignored or never considered as crucial or important. If the past is any guide, the handicapper won't be able to find adequate employment ("Hire the handicapped" campaigns to the contrary), will have difficulty making friends and establishing intimate relationships, and large numbers of these people won't have opportunities to live a full life. At least this is the likely future of those who have been handicappers since birth or early childhood. The handicapper has little power vis-a'-vis the able siblings and the entire society. There are exceptions to this pattern and further study is needed to determine why a few people who have been disabled since early childhood do have the opportunity to achieve and compete to the fullest extent of their potential, but most do not.

From-childhood handicappers fit Louis Wirth's classic definition of a minority:

> A group of people who, because of physical or cultural characteristics, are singled out from the others in the society in which they live for differential and unequal treatment, and who therefore regard themselves as objects of collective discrimination. (Wirth, as quoted in Berry and Tischler,1978:40).

Not all handicappers regard themselves as objects of collective discrimination, but they certainly have characteristics that parallel other minority groups:[4] 1) they possess some quality that distinguishes them from others in the society and makes them objects of ridicule. The physical disability sets them apart from the able part of society, and while they may seldom be called names to their faces, able people are sometimes called things like "retard" or "crip" as a put-down. 2) Minority members have few privileges, scant economic resources, lesser life chances, and they are frequently the object of discrimination, segregation, and occasional violent attacks. In the case of handicappers, there are very few perks that come with the territory -- perhaps free tickets once a year when the circus is in town and specially marked parking places that are frequently usurped by able drivers. It is very difficult to get the education and training to get an adequately paid job -- even assuming that someone would hire them. Certainly there is ample evidence they are discriminated against and segregated. Mainstreaming in schools has been mandated, but they are still unable to fly in aircraft unattended or live in some apartment buildings, and 3) minority members are often powerless, dependent, and exploited, and this is true of handicappers, too. Many from-birth handicappers rarely have the opportunity to even participate in decisions that will influence their own lives.

Analysis Framework

In this study, I employ a conflict perspective and the notion that most from-childhood handicappers are treated like a disadvantaged minority. Starting from that point, I discuss three aspects of the social construction of reality for handicappers' siblings and their families -- the stone, brick, and mortar that create their own reality: 1) impact of family activities: socialization and childcaring, 2) type of family composition: one or two parent household, number of children, whether one or both parents work in the paid labor force, and 3) influence of family life-cycle: who assumes responsibility for the handicapper as parents inevitable age and when in the life cycle the disability occurred.

By way of background, in the Sociology of Marriage and Family, many conceptual frameworks have traditionally been employed: structural-functional, interactional, social-psychological, and others. For over two decades the most commonly used was "structural-functionalism," which many people term "functionalist." Emile Durkheim, Talcott Parsons, Robert Merton, and Robert Bales are particularly associated with this perspective. When you read about society's need for stable family life or the orderly replacement of one generation with another, these are part of this model of society. Functionalism tends to focus on social equilibrium (rather than social change) and views consensus as the glue that holds society together; human activities are seen as organized to assure the continuity

and stability of society. Sociologists who follow this model tend to see all human groups, including societies and their subsets, social institutions, within an organic perspective. Component elements of a given society are analyzed in terms of their specific function in system maintenance. They see them as systems made up of independent parts which tend toward stability. If conflict arises, it is seen either as abnormal or as a means by which temporary strains between elements are being reduced in a move toward greater equilibrium. According to Lehmann and Young (1974):

> Parsons viewed conflict as primarily disruptive, dysfunctional, and a kind of social disease which should be dealt with therapeutically... We find a substitution of system language couched in medical metaphors using such labels as tensions, strains, psychological malfunctioning, disequilibrium and disintegration (Lehmann and Young,1974:205).

Functionalist theorists view society as structured by the function of its parts, i.e., an organization of related institutions whose functions tend to preserve the order/ equilibrium of the whole (Parsons,1964; Merton,1968). Most structural-functionalists see society as maintaining a dynamic equilibrium; it isn't seen as totally static but changes are adjusted to smoothly and they come relatively slowly and infrequently. This approach has produced an image of the family as an adaptive unit, flexible and responsible to the demands on it by the economy and society. Adherents of this perspective, such as Parsons, believe that

maintainence of the status quo is important and that any drastic changes in gender roles or sharing of responsiblities with other institutions may prove dysfunctional to the stability of the society. I don't agree with functionalist theorists that social institutions, such as the family, must maintain social stability and concensus.

Structural-functionalists see family as a crucial institution for the maintainance of order in the society as a whole. They believe families perform needed social/societal functions: socialization, physical care and protection, meeting emotional needs, and providing a place of respite and rest from the more impersonal and bureaucratic outside world. Much of the emphasis of these theorists is upon the internal relationships within a family, especially the division of labor between genders and how this division is functional for families. According to Ann Oakley (1976):

> The functionalist school of sociologists argues that families produce people in two ways. First, there is the upbringing of children to perform adult roles of the kind accepted and expected by the social group they live in. Second, the family acts to stabilize adult personalities in the socially steretoyped roles of husband and wife. In their roles as wives and mothers, women's main occupations are domestic ones; their interests are home-centered, and the emotional well-being of the family their concern (Emphasis in the original; Oakley,1976:75).

Another common way to study families is from an interactional framework. Here the primary focus is with the

action of family members. Internal processes, such as role-playing, status relations, communication problems, stress reactions, and socialization processes are the areas of interest. Willard Waller and Reuben Hill (1951), and more recently, Mirra Komarovsky (1965, 1967) often use an interactional approach to studying the family. Probably the greatest impact of this model on family theory has been to shift the focus from a broad institutional approach to the internal workings of families as individual family members interact.

I appreciate the change in focus to interaction, but as I continued working with the data, I realized this approach did not capture all I was seeing. Many of the respondents were essentially telling me about problems and conflicts they, or family members, experienced. No matter how much the handicapper was loved and accepted, his/her presence "cost" the others something: energy, time, patience, money, peace of mind, guilt. To get at these dimensions, another model is needed -- the conflict framework.

The conflict model of society is based on the notion of constraint. Rather than being held together by consensus, societies and other social organizations are perceived as based on coercion of some individuals/groups by others. Ultimately, constraints lead to conflict and inevitably, conflict leads to change. Conflict theorists see change and conflict as an inevitable part of social life and as the principal means by which groups achieve change; in this view, constraints in society are not maintained smoothly or

without cost (Simmel,1955, 1959; Coser,1956).

Conflict theorists see constraints upon the twentieth century American family as simply too great and, because of that, families are structured to fail. The isolated nuclear family, promoted by the functionalist model, has positive benefits for the economic system (capitalism) but benefits are far fewer for individuals. Certainly that seems to be true of handicappers' families. With deinstitutionalization, the responsibility for caring for handicappers has been transferred from the state to the individual families involved, but few resources have been provided to make that task easier. Deinstitutionalization, plus the increased life expectancies of handicappers, puts additional stress/conflicts on those families involved (Oakley,1976; Baldwin and Glendinning,1983; Baldwin,1985). Clearly, contemporary families must come to grips with many basic contradictions. Functionalist theorists have traditionally viewed these conflicts/strains not as general or widespread problems, but as something that may occur in some families some of the time.

As the project progressed, increasingly I began to see the relevance of a conflict perspective to this discussion. It was painfully apparent that conflicts -- what functionalists theorists term "strains" and "tensions" -- are common in families of handicappers. Rather than consensus gluing society together, I see modern conditions ungluing family ties at the same time they make them even more needed. Family members often <u>do</u> have conflicting

interests, and no where is that more apparent than in families of handicappers. Probably all families have problems, but many of these families have problems to the nth power.

Pruitt and Rubin (1986) identify five types of strategies to deal with conflict in families or in other arenas; these are: 1) contending -- trying to impose one's preferred solution on others, 2) yielding -- lowering one's own aspirations and settling for less, 3) problem-solving -- pursing an alternative that satisfies the aspirations of all, 4) withdrawing --leaving either psychologically or physically, and 5) inaction -- doing nothing, which is usually a temporary move. As you would suspect, rarely does someone employ only one of these; usually one or more are used in combination. The respondents mentioned all of these strategies, without being aware that they are "strategies," of course.

In this research, my specific goal was to identify how able siblings perceive the experience of having a handicapper brother or sister. Using a grounded theory process recommended by Glaser and Strauss (1979), I used respondents' replies to questions, their spontaneous statements, and subjects they appeared to evade to generate concerns/categories for analysis. Two main themes emerged: 1) determining what effects family life-cycle, composition, and who performs the necessary activities have on producing distress or consolations for able sisters and brothers. This includes exploring the accuracy of the assertion that

able siblings of handicappers are "a population at risk", and 2) comparing experiences of two distinct groups who vary primarily by when the disability occurred -- those whose siblings have been handicappers since birth or early childhood and those whose sisters and brothers became disabled later in life. This includes portraying power relations of siblings within the family and how these relations vary depending upon family composition and life-cycle.

Briefly, I'll describe each of the building blocks -- family activities, family composition, and life cycle of the family -- that comprise able siblings' socially constructed reality. In various combinations, they explain how other children in the family respond to a handicapper sibling and help account for that particular reaction.

Family Activities

All families undertake basic, necessary activities for individual members as well as the larger society. Elina Haavio-Mannila (1977) follows Duvall and Hill in calling these activities "necessary developmental tasks." She writes:

> As a social group, a family must come to terms with certain basic conditions, functional prerequisites, essential for its survival, continuity and growth. Reproduction, physical maintenance, protection, education and socialization, recreation, status-conferring, and affection-giving have been listed as core tasks which all families can be expected to undertake (Haavio-Mannila,1977:117).

Families differ in the number of activities on which they focus and in the degree to which they realize any specific ones. As families move through various stages of the life-cycle, the obligation for doing these various activities shifts among the three sub-systems. Many things that initially were performed by parents are eventually assumed by siblings. This may be particularly true of handicappers' families.

Two important family activities geared toward physical maintenance are production and consumption. Most families are probably both economic producers and consumers, although it varies somewhat by urban/rural background and by social class. A handicapper in the family may increase the family's consumption because of additional medical and care expenses. In addition, s/he may decrease the amount of money earned by family members, because someone (most frequently the mother) may remain at home, out of the paid labor force, to provide necessary care. In addition, as children grow older and parents inevitably age, the responsiblity for financial support and/or physical care of a disabled sister or brother may shift to able siblings. There are class and race distinctions about which family members do what kind of activities, but in my study, these are not really addressed since the able siblings in my sample are so similiar in background; they are almost exclusively white, middle-class individuals.

Another important family activity is physical care of members (Caplan,1976; Crocker,1981). To some extent,

physical care and economic activities overlap. Definitely such things as feeding, clothing, and providing for physical needs of members by purchasing necessities are related to economic productivity. But physical care goes beyond these basics. Even though there is ample evidence that not all families are happy and harmonious, there is the notion that, ideally, physical care would entail things like rearing children, caring for the health of all family members, and protecting and keeping them safe from all kinds of harm -- physical, emotional, and psychological. In many families, siblings probably provide some of these activities for younger sisters and brothers, although there my be class, race, and cultural differences (Grossman,1972; Voysey,1975). For instance, siblings may help one another with household tasks, perhaps loan each other money or clothes, or provide each other with protection from neighborhood bullies or an abusing parent. Especially in large families, or when both parents work, or in one-parent families, older children may be required to help with child-rearing. In particular, oldest daughters may be pressured into sharing childcare tasks. In families where one of the children is a handicapper from birth or early childhood, it is even more common for able siblings to assist (Grossman, 1972; Kew,1975; Voysey,1975; Darling and Darling,1982). Sisters and brothers may also feel the necessity to do such things as protect their handicapper sibling when strangers gawk or say unkind things. Bank and Kahn (1975) refer to this propensity of siblings to help one another as the "Hanzel

and Gretel syndrome."

Socialization is another activity of the family; this involves acquiring the values, attitudes, and beliefs of the culture. In every society, the family is considered the basic agency for socializing children and for continuing that socialization throughout the lifetimes of the members. Siblings are integrally associated with this socialization function. Sisters and brothers teach by example and provide role models for one another, both for what to do and, perhaps, for what not to do. A handicapper sibling can influence socialization either positively or negatively or perhaps, in some aspects, in both ways. Because of interacting with a handicapper, some siblings are mature beyond their years; they readily accept differences, are more tolerant, and are more helpful to others. For others, the outcome is less desirable. They may become self-centered and aloof (Voysey,1975; Featherstone,1980; Darling and Darling,1982).

Families also provide self-definition to individual members. Many families provide a support system that gives members opportunity to better understand themselves. Membership in a family helps everyone establish boundaries and create a distinctive individuality; it helps them identify their own place in the community. Siblings help in this process. In fact, siblings may identify with each other to a greater extent than with parents, not only because they are members of the same family, but also because they are peers within that family. This

identification process can cause particular problems for siblings of handicappers, especially younger ones. They may question whether, in some way, they are also handicapped, worry that they will become disabled, or wonder why they escaped that fate (Grossman,1972; Kew,1975; Bank and Kahn,1982). Some people call this "survivor's guilt." Or the parents may put pressures on their able children to assume responsiblity for achieving and making up for the handicapper's limitations.

In our society, we tend to accept the ideology that families provide affection and help members achieve emotional mastery. At its best, family life probably can provide a sense of acceptance, companionship, and a milieu that encourages nurturance, comfort, and support. The family can teach members to express positive emotions such as tenderness, joy, and love and to learn how to cope with, and handle, negative feelings of anger, guilt, or jealousy. Unfortunately, this ideal type, benevolent family is not in everyone's experience (Kanter,1974). The literature on handicappers' families is nearly silent about the darker side of family life. Until I started this research, I'd never considered that some handicappers <u>become</u> disabled at the hands of a family member. At least two of the handicapper siblings in this study (foster siblings) were apparently born normal and became disabled because of child abuse and two of the adult-onset handicappers were disabled by beatings. That is 8.69 percent of the handicappers in my sample.

Ideally, the family serves as a control group for its members, providing feedback and helping everyone in solving day-to-day problems. That undoubtedly happens in some families. In families with a handicapper, some able siblings provide guidance and direction for their disabled brother or sister or they may also serve as a sounding-board for parents about the care and protection of the handicapper. But in other families, able siblings ignore the handicapper, or tease him/her, or flee the household as soon as they are able (Voysey,1975; Featherstone,1980; Zola, 1982a).

Ideally, too, family members educate one another. This education has two dimensions: 1) the family receives information to help fulfill its various activities (e.g., knowledge and skills about child rearing) and 2) families educate individual members (e.g., teaching and sharing information with each other). In a family with a handicapper, able siblings need to be educated on a variety of issues, including the genetic implications of the disability, future plans for the handicapper's support, and explanations of the nature and cause of the handicap. They need this information to better deal with questions from friends and other outsiders. This process goes two ways because younger members of a family often provide information and insights to older family members. In addition, siblings are an important resource for educating their handicapper brothers and sisters. Some disabled siblings "educate" their able sisters and brothers. Three

or four of the respondents specifically volunteered that interacting with their handicapper sibling provides them with valuable insights on human behavior and motivation.

Another possible activity of at least middle class families is vocational guidance, including development of a work ethic and assisting children in choosing a career. There is ample evidence that the feeling of identification with a handicapper and a desire to understand his/her problems often leads some able siblings to choose careers in education and human services. In particular, older sisters who share caretaking responsiblities are reported to be particularly likely to enter helping professions.[5]

Family Composition:

Families in our country differ considerably on a number of distinct dimensions. Many features of family composition affect the sibling subsystem, including if both parents are present, if both mother and father work outside the home, and how many children there are. If the family unit is small and/or the mother must work in the paid labor force, an able sibling may have to provide much of the childcare for the handicapper.

Family composition varies on a number of dimensions, including ethnic or racial background and religious beliefs, customs, and traditions of the family. Based upon the family's unique background and experiences, these factors influence parental and sibling acceptance of the

handicapper. Ideological style of families is another element -- especially the family's notions on how to raise children and their attitudes toward the work ethic, the disability, and open versus closed communication. Every family is different in just how these beliefs are reflected in their everyday behavior. These are all important because the ideological style of a family creates parental attitudes toward the handicapper, and in turn, these influence able siblings' acceptance, guilt, or tendency to overprotect the handicapper (Darling,1979; Wright and Schwab,1979; Featherstone, 1980, Thomas,1980; Darling and Darling,1982; Paul,1983).

Family composition may also influence power relationships within the family. Within families, power and influence is usually related to age and gender, but a from-birth or early childhood handicapper may be denied the privileges that s/he might ordinarily achieve from birth order position (Darling and Darling,1982). Family composition also influences which, if any, able siblings are potentially at risk for emotional or behavioral problems. In my sample, I found those especially at risk were from single parent households, or small families, or from families where the disability is denied and/or the handicapper is rejected.

Family Life-Cycle:

Like individuals, families have a life-cycle.[7] The stages start with marriage, usually followed by bearing of children, their rearing through school years, departure of adult children from home, and termination of the cycle with the death of parents. The notion of family life cycle is more than individual life cycles of all the members; it is the interaction of these that produces a family cycle of development. Moreover, it's important to recognize that families at different stages of development have different characteristics and needs.

Because the family is a complex structure that includes both genders and different age categories of our society, there are continuing changes throughout the entire life cycle. These transformations are structural; they affect the balance of resources and authority, and as such, they may create competition and conflict.

The preschool years of children can be a particularly traumatic period for parents as they come to terms with the birth and diagnosis of a handicapper child. The school years of the children bring new dilemmas. For able siblings who are younger than the handicapper, those years may be the period when they catch up and perhaps developmentally surpass their handicapper sibling. Adolescence can present additional problems; able siblings may increasingly be embarrassed by stares or questions about the handicapper and perhaps feel a sense of loss for what-will-never-be. Launching into adulthood may mean that able siblings must

acknowledge implications of their sibling's handicap for their own lives: career decisions shaped by experiences with the handicapper, the possiblity of having a handicapper child themselves, or fear of future responsiblities for the handicapper's care. For families of handicappers, maturity and old age present new crises and questions; it is a time when the basic structures of the family changes irrevocably (Sktric, Summers, Brotherson, and Turnbull,1984). When parents are older, or perhaps dead, who will be responsible for the handicapper?

Another thing in handicappers' family life cycles that I'm very interested in is timing of disability -- childhood-onset versus adult-onset. Almost by definition, adult-onset disabilities occur later in the life cycle of the family. As I coded and made memos about the interview data, I realized that timing is a critical dimension. If the ten siblings I interviewed are in any way typical, in many ways it is more difficult for the able sibling when your brother or sister becomes disabled as an adult. Perhaps when you've grown up with the reality that s/he is a handicapper, it is more difficult to picture how his/her life would be if s/he was "normal." With siblings who become handicappers because of a serious accident or disease, assumptions about what his/her life would be like are abruptly and drastically changed. It may be easier to speculate, "If this happened to him/her, it might happen to me, too."

Conclusions

This framework I've suggested, permits us to examine handicapper/able sibling relationships from within the broad context of the family. It does not obscure the fact that siblings affect, and are affected by, husband-wife interactions and parent-child interactions. This model also allows us to view these three family subsystems from the perspectives of family activities, family composition, and family life-cycle. This is an advance over much of the earlier research where one or the other of these three factors has been used to explain family interaction. In this study, the most important of these three factors is family composition; these appear to make a significant difference in which siblings are assigned (and accept) heavy responsibility for taking care of a handicapper sibling and which able siblings are potentially most "at risk" for physical or psychological problems.

Using a conflict perspective and the notion of minority status for handicappers permits us to explore and capture able siblings' reality and see issues that tend to be ignored or pushed aside by other models. Conflict theorists (Sprey,1969; Steinmetz and Straus,1974) and many feminists (Oakley,1976; Bridenthal,1982) argue that society should be restructured so that personal fulfillment, identity, and other individual needs are also met by other institutions. The institution of family tends to socialize children to accept the inequalities of society as natural and unchangeable. The family is a social institution whose

agents tend to perpetuate the existing system of social stratification, gender inequality, and bias toward the able. Certainly, the American family has done little to challenge racist, class, sexist, or ablest attitudes. Using this framework enables us to see more clearly that all knowledge is socially constructed and this "reality" is what determines how able siblings react to having a handicapper sibling and help account for that particular reaction. To do this, I show how family actitities, family composition/ attitudes, and the life-cycle of the family affect able siblings' lives.

ENDNOTES

1
For clarity and to avoid confusing my meanings with those of structural-functionalism, I prefer to use the words "activity" and "composition" instead of "function" and "structure." Some sociologists, like Ogburn and Nimdoff (1955), use the term, "functions" in the sense that I use "activity." Others, such as Sktric, Summer, Brotherson, and Turnbull (1984) use the term "structure" in the sense of family composition and make-up.

2
The notion of handicappers as disadvantaged minority group is not new but, in my view, it has been underutilized. Nor has much been done to focus on the family's role in helping to create minority status or how power relations within the family reflect and perpetuate the discrimination and prejudice of the larger society. For a more complete discussion of handicappers as a minority, see Gliedman (1980), Eisenberg (1982), and Roth (1983).

3
In 1978, 60 percent of the disabled in the United States were unemployed, and in a study in California, even after vocational rehabilitation, less than 45 percent were reported as remaining in employment one year after receiving training and job placement. For a more complete discussion of employment of handicappers, see Hingson, et. al. (1981).

4
A complete discussion of the parallels between prejudice and discrimination against racial or religious minority groups and that experienced by some handicappers is beyond the scope of this chapter. For illustrations of the type of behavior and attitudes I discuss, see Myrdal (1962), Simpson and Yinger (1972), Vander Zander (1972), Berry and Tischler (1978), Gliedman and Roth (1980), Brown (1982), Eisenberg (1982), and Zola (1982a).

5
For more information on sibling relations in general, see Sutton-Smith and Rosenberg (1970), Bank and Kahn (1975 and 1982), Arnstein (1979), Schvaneveldt and Ihinger (1979), and Pollak and Hundermark (1984).

6
My study does not support this notion, but for findings that older sisters of handicappers are disproportionately likely to pursue careers in the health or social services, see Grossman (1972), Featherstone (1980), Darling and Darling (1982), and Skrtic, Thomas, Summers, Brotherson, and Turnbull (1984).

7

A complete discussion of the concept, family life cycle, is beyond the scope of this chapter. For more information, see Carter and McGolrick (1980), Foster, Berger, and McClean (1981), Fewell and Gelb (1983), and Skrtic, Thomas, Summers, Brotherson, and Turnbull (1984). For information on the life-span approach to siblings' lives see Goetting (1986).

Chapter 5

SOCIAL RELATIONS IN FAMILIES OF HANDICAPPERS

Introduction

My original research question was, "What are the effects of a physically disadvantaged sibling on other children in the family?" An effect that I had not anticipated -- nor have I seen reported in the literature -- emerged from the grounded theory method. In families where there is a from birth- or early-childhood handicapper, different types of social relations are created.

Granted, there are no typical families, but in our society, most of us unconsciously hold notions of what relations in the "typical family" are like -- or should be like. This picture of family life is useful as an ideal type and, perhaps, even as a necessary social myth. But talking to respondents, I found a half-dozen things that don't fit the ideal type of typical family social relations. Their lives are different from families where everyone is able. Not all of these differences are found in any one family, but at least some were apparent in the experiences of each of the respondents who had a from-childhood handicapper sibling. The deviations were particularly noticeable in families where the handicapper has been disabled since childhood. Differences in socialization in these families

probably accounts for most of the variations.

These variations from the myth of family concensus and harmony include: 1) some siblings accumulate power and influence at the expense of others; 2) a subordinate/super-ordinate status among the siblings may develop; 3) these two factors may create what Kanter (1974) terms "intimate oppression," whereby some individuals are socialized to be dependent, conforming, asexual beings; 4) some family members disaffiliate, leaving the household physically and/or emotionally; 5) gender-neutral or androgynous socialization of the children occurs -- with the possible exception of the oldest daughters; and paradoxically, 6) gender-expectations about who is responsible for caring for those in need are intensified.

(Unintententially), and unknowingly, the people with whom I talked gave me numerous illustrations of these changes. As I reviewed the transcripts, I perceived common patterns, although on the basis of any one interview, I would not have noticed it. Being sensitive to the material, and in particular, to the topics that respondents tended to avoid, helped me see the shadowed parts of able siblings' experiences and be aware of these altered family relationships.

The common patterns that emerged from the able respondents' experiences included these dimensions: the total omission of certain topics, use of ablest language, absence of anger in dealing with their handicapper sister or brother, expectations that handicappers will always be

cheerful and good-humored, regimented and unspontaneous lives for the handicappers, the objectification of handicappers, including a failure of respondents to see handicappers as capable of friendships and/or sexual relationships, less gender-specific socialization for the children -- with the possible exception of oldest daughters, and paradoxically, gender expectations that women will assume the caretaking chores are reinforced and intensified. All of these are illustrations of altered social relations in families of handicappers.

Power and the Creation of Intimate Oppression

One of the primary differences I discovered is the distribution of power and authority among the siblings in these families.[1] Power in families has been studied, but most of the research centers upon two issues: 1) power relations between spouses -- especially bargaining behavior and conflict in decision-making (Cromwell and Olson,1975; Olson and Cromwell,1975), and 2) overt violence between and among family members (Sprey,1969; Goode,1974; Lystad,1986; McCall and Schields,1986; Steinmetz and Straus, 1986). Originally the latter topic focused on wife-beating, but increasingly it includes any spouse violence, child abuse, elder abuse, and violence between siblings. The last topic, power and influence relations between and among siblings has been relatively ignored until recently.

In one of his several articles on the subject, Jetse Sprey writes:

> Family power structure is a theoretical concept, not an empirical fact. Its relation to the real world of the family thus lies in its potential to make sense of that which we observe: the ongoing processes of decision making, bargaining, and negotiation between its members (Sprey,1972:236).

Power is an intriguing concept; it is defined in a variety of ways. I prefer: "Power is the capacity of some person (or persons) to produce intended effects on other persons" (Wrong,1976:17Ø). Power is a part of all social relationships and exerted whenever an actor attempts to achieve some end that involves others. It is exerted, or implied, only in relation to other people. They may try to resist or exert their own power, but success or failure depends upon both parties. If power is successfully exerted or implied, the actor achieves his or her will and has power in relation to others. The opposite of power is powerlessness, dependence, or an inability to resist the power exerted or implied by others.

Power has at least three major dimensions: 1) the ability to control options available to others, 2) the potential to demand a price for one's compliance, and 3) frequently it becomes an end in itself, rather than a means to a desired outcome. Then it becomes a resource -- either authority or privilege. All three aspects interact in family dynamics.

In most societies, including ours, the family is an institution with unequal power distribution. This asymetrical distribution reflects the power stucture of the larger society where gender, age, and class determine who has the most access to power and scarce resources (Sprey, 1972; Hartmann,1979; Brittan and Maynard,1984). Within individual families, everyone has essentially the same status as far as class is concerned, but gender and age are still critical variables. Within individual families, adult males have the most power, which is also true within the larger society. In most of the world, including in our society, there is still a caste/class system whereby males enjoy more power, authority, privileges than females (Zaretsky,1976; Hartmann,1979). In the political/economic system males have traditionally had the most power and influence, but this is also buttressed in some families with males greater physical strength and prowess, to say nothing of males usually having more financial resources. In most families, fathers have the most power, privilege, and influence (unless they are quite infirm or aged, which most typically occurs late in the family life-cycle. In that case adult sons, or more rarely, adult females, may assume power). This power of fathers includes all three dimensions of power: the ability to control other's options, the potential to demand a price for compliance, and the possession of power accords them additional authority and/or privilege. (In French and Raven's terms (1959), adult males' power is legitimate, expert, and includes reward and

coercive connotations. It may also include referrent or informational bases, depending upon individual situations.)[2]

In our society, usually, next to fathers in power are adult females -- the mothers. They have power over minor children and aged parents (if they are present). Some of this power is referrent power, transferred to the mother by the temporarily absent father. To a lesser degree than fathers, mothers typically have all three dimensions of power we've mentioned, too. In mother-headed households, of course, mothers usually have more power than minor children.

Typically, minor children have relatively little power, but oldest children have more than younger ones. Much of this power is referrent and legitimate power given by the parents to be used in their absence. Gender differences in power don't appear in most families until the teen years when brothers begin to accrue additional power, in all three aspects, vis-a'-vis sisters.

In handicappers' families, I found that sibling power was not distributed on this typical hierarchy based upon age and gender. Most, if not all, able siblings who had a from-childhood handicapper sister or brother, accrued power in comparison to the handicapper. This was true of even younger sibings, including sisters. Lowest in power are from-birth handicapper no matter what his/her age. Most from-birth handicappers are in this position of being dependent and powerless. In relation to other people, including even younger able siblings, the handicapper is often unable to achieve her/his will because s/he is low in

power, lacking resources to effectively support their own interests. This inequity is a reflection of the relative status of able and handicapper siblings. The near-total lack of options for handicappers to leave their families of orientation is the prime sociological reason for their relative lack of power at home.

Intimate oppression is one of the products of altered social relations and this serves to reinforce handicappers' passiveness; they soon learn that everyone expects less of them. Even the mass media supports the ideology that handicappers are submissive, lesser human beings. This notion is further buttressed by their economic position and the jobs that are available for them. This is not true for handicappers who became disabled as adults.

There is a vast difference in the power of from-birth handicappers and the ones who became disabled as adults. Those who were disabled from childhood have an ascribed status of "disadvantaged handicapper," but those who became disabled later in life may -- or may not -- have this status. It isn't a given. Most adult-onset handicappers don't lose their status as a social adult. In addition, they often have resources. In my sample, with one exception, these disabled as adults have power and say-so over their futures. Unlike from-childhood handicappers, many have options. Often, those disabled as adults often don't learn to be passive, grateful, and cheerful, and perhaps most importantly, they have some economic power. The source of money is not crucial; it can be either a

disability pension or wages. They aren't so dependent upon family members for their care. Money gives them power -- power to choose where they will live, power to decide how they will live, and power to reject a status of second-class citizen. In a society in which money determines value, handicappers who have access to money have value. In my sample, two of the men who became handicappers later in life have military disability pensions and seven of them hold jobs. Even if they weren't educated or trained for the position they now hold as a handicapper, they weren't socialized to have low expectations. An exception to this independent-handicapper status of those who became disabled as adults is a woman who was severely beaten, but a case can be made that she has been resocialized into a dependent role. She was unable to walk, bathe, or feed herself for over a year, and during that time her family impressed upon her that her accident was God's punishment for her "evil ways" [Interview #1]. Nor does she have a disability pension or adequate income to give her any power or equity in her relationship with her family. This makes it more difficult for her to reject the status of "handicapped." Gender may also play a part; she was the only sister, in my sample, who became disabled as an adult.

In families, and in the larger society, power -- or the lack of it -- is not the result of individual contributions and resources. Intimate oppression is not the result of any kind of conspiracy or ill-will on the part of family members. Family roles and relationships are embedded in a

larger community content, and their views, only reflect society's values. In an article on marital power, Dair Gillespie writes:

> Power, then, is clearly not the result of individual contributions and resources in marriage, but is related to questions of social worth and the value of women and women's work (Gillespie,1971:456).

If we substitute "handicapper" for "women" and "family" for "marriage," the paragraph is just as true.

Kanter (1974), too, reminds us that oppression can occur so close to us that we do not even notice it. She warns us that "the happy family" is largely a myth that can "mask sorrow and destruction" (1974:314). In my sample, I found that nearly all the respondents thought of their sisters and brothers who had been disabled since childhood as dependent people; the able siblings seem to believe the disability makes their handicapper sibling incapable of autonomy and self-determination. This notion is the root cause of intimate oppression and altered family social relations. According to Kanter (1974:306):

> The family socializes people to conforming, deeroticized, dependent relationships. The family deprives us of our spontaneity and filters out much of the human in human experience.

This is particularly true for families that include a from-childhood handicapper. Intimate oppression contributes

to making handicappers a disadvantaged group. The respondents probably don't consider their behavior to be coercive or even callous or undesirable. The term, "intimate oppression," is appropriate; it describes the way power, exchange, and socialization can rob the from-birth handicapper from independence, autonomy, and self-determination.

Emotion Management in Handicappers' Families

An illustration of altered social relations and its manifestation in handicappers' families is anger -- who gets angry and the target of that emotion. In our culture, anger is pandemic, and it's especially common among siblings. But people rarely show resentment or irritation toward handicappers; in a sense, there is a taboo against anger exhibited toward handicappers (Zola,1982a). This is true for professionals, the general public, and family members -- including the able siblings. They repress or inhibit their anger; as a group, they simply don't get angry at handicappers, even when it is justified. It is a very protective attitude, but powerful people often treat subordinates paternalistically.

I asked the respondents, "What do you do when you get angry at your handicapper sibling?" Most of them said they never got angry. Probing further, many conceded that sometimes the handicapper "got on their nerves," but they

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never permitted themselves to lose their temper or label their feelings as anger. When I asked a woman what she does when she gets angry at her physically and mentally retarded sister she replied, "I leave; I try to get out of the room" [Interview #15]. Another sister said, "usually I just walk away from it" [Interview #35]. These respondents were unknowingly following a strategy that Hochschild (1983) reports that airline attendants are taught in training -- "Fall back on the thought 'I can escape' [leave]" (1983: 113). Another respondent replied, "I don't think I've ever got mad at Brad." [He's her eighteen year old brother who is both physically and mentally handicapped; Interview #41].

This denial and/or refusal to deal with it may be one explanation for the disengagement from their families of four fathers and two brothers in my sample. Consciously or unconsciously, they followed the strategy of "withdrawal" (Pruitt and Rubin,1986). They left their families completely. Withdrawal is a unilateral strategy that can be followed without consulting or considering the others involved. The respondents agreed that these individuals did not interact much with the handicapper when they were in the household. For the most part the respondents appeared to be ignorant of why these people left -- or they were unwilling to talk about those reasons to me.

What impact does a facade of calm restraint have on the handicapper? According to Zola:

One of the greatest put-downs one person can

> inflict on another (as the feminist movement has pointed out) is contained in the phrase, 'I'm afraid that you won't be able to take it.'... To be denied their resentment is to be taken unseriously and to be deemed unworthy of response (Zola,1982a:224).

Bearing that in mind, the woman who has an older brother with muscular dystrophy may have paid him a compliment by treating him exactly like she would have any other brother. When asked, "What did you do when you got mad at Tim?," she answered, "He wouldn't really fight because he was so easy going, but I'd get mad at him, and I'd hit him a lot. But it never hurt him and that would make me even madder" [Interview #30]. She was one of the few respondents to admit showing anger toward a handicapper sibling.

But denying anger may have an effect on the able siblings, too. Repressed or inhibited anger has also been linked with behavioral and psychological disorders.[4] Perhaps some of the able siblings who have been identified as at risk for increased emotional or psychological problems are those who feel anger toward the handicapper in their lives, but who for one reason or another, cannot express that emotion. Anger may be inhibited for a variety of reasons, including fear of retaliation by parents who may overtly or covertly give the message, you cannot get angry at your handicapper sister or brother, or it may be repressed because of empathy with the target.

The issue of anger goes beyond people refusing to show

irritation at handicappers. A large proportion of handicappers are unable to express anger or resentment toward others.[5] In my sample, only one person talked about her handicapper sibling getting angry, and in her opinion, his anger was often inappropriate [Interview #35]. Instead, handicapper's anger is often turned inward or blunted by distancing. Neither of these is a healthy, desirable response, but for them to get angry or show impatience is a big risk. Repeatedly the message comes through -- to deserve help means making it easy for people to give it. This means that the handicapper must not only be grateful for assistance but cannot exhibit annoyance or irritation when the help is tardy or incomplete or is available at an inconvenient time. This strategy is "yielding" -- lowering one's expectations and settling for less (Pruitt and Rubin, 1986). This type of emotion management is characteristic of many disadvantaged groups or minority members, not just handicappers.

Another experience of handicappers is that they defined as always "sweet" and "good-natured." Many of the respondents brought up how happy and patient the handicapper sibling is/was; in point of fact, only two or three respondents volunteered instances where their handicapper sibling was grumpy or difficult. (This was not a question that I thought to ask.) The respondents who commented on how happy and patient their handicapper sister or brother is/was, saw it as an individual characteristic, and no one speculated about <u>why</u> the handicapper is so genial and easy

going. Each respondent apparently saw it as some admirable personality trait of his/her handicapper sister or brother. Geniality and cheerfulness are found among other powerless groups, including women.[6]

My data included various realities in the lives of able siblings of handicappers, including numerous examples of respondents' stereotypes/denial: one respondent volunteered about her brother who has musucular dystrophy and is a wheelchair user, "He can't even walk, but he's very happy, never complains" [Interview #30]. Another woman described her sister, who has cerebral palsy, "She's a very happy-go-lucky person" [Interview #9]. Another, describing her brother Ted who died of muscular dystrophy, "People liked him; he was a cheerful person" [Interview #21]. A man talking about his younger sister who is a wheelchair user and has muscular dystrophy, told me, "She usually has a smile on her face" [Interview #23]. A woman talking about her brother who is retarded and completely disabled by probable osteogenesis imperfecta, "He's a very happy child, definitely. He's real happy. He laughs and smiles a lot" [Interview #41]. This "happy child" is eighteen years old.

Zola (1982a) discusses this phenomenon of handicappers being pressured to be perpetually cheerful, happy and grateful. He says that handicappers internalize a patronizing attitude toward themselves; they feel they must be grateful for everything they have and for everything that is done for them; he writes, "I wanted people to do things for me because they liked me rather than because they pitied

me ... for me, it became a key to survival" (Zola,1982a: 220). He points out that this gratitude serves as an effective silencer, and it protects the able people who interact with the handicapper from resentment or envy. He writes:

> In a sense we were taught we had no right to complain. Everything that could be done was being done, everyone was busy and overworked, and besides, 'weren't we grateful?' This gratitude has been our curse. In the first place, being sick made us by definition so dependent that any expression of anger or dissatisfaction became a threat to the continued care which we could not easily get elsewhere and in some sense did not really deserve. In the second place, our anger was regarded as demeaning because it indicated we weren't sufficiently grateful for all that was being done for us. And yet the act of being grateful can in itself be both humiliating and invalidating (Emphasis in the original; Zola, 1982a:221).

Some handicappers do resist, protest, and manifest anger at their situation, like members of other disadvantaged groups, but many -- perhaps most -- make a valient effort to remain happy and grateful for any small favors.

Objectification of Handicappers

One of the interesting anomalies about the interviews was that respondents could tell me how they were affected by having a handicapper sibling and give informed guesses as to how their parents were influenced, but they seemed to have little awareness or empathy about how the handicapper feels/

felt. As I reviewed the transcripts, I was struck by how respondents discussed the handicapper sibling; it was as if the handicapper was an object -- in most cases, a well-cared for object, but an object nonetheless, e.g., "We went camping a lot, and we took him along" [Interview #19] and "Everyday we exercise him" [Interview #30]. Obviously, the respondents were unaware of this objectification, but it was a common thread among the interviews.

This objectification is not uncommon in our society. Bredemier (1978) discusses this phenomenon in terms of power and coercion. He observes:

> Coercion is not, strictly speaking a social mode of relationship... Pure coercion involves treating a person as a 'thing' rather than as a cultural creature with his or her own definitions of the world, definitions which must be taken into account by the actor. It consists of treating a person by the laws of physics rather than the laws of sociality. One coercively gets a person to leave the room in the same way one gets a bag of garbage to leave the room, by picking it up ('it' is appropriate here) and carrying or throwing it out (Bredemeier,1978:439).

Another illustration of the objectification of handicappers is the total obliviousness on the part of able siblings to how unspontaneous and regimented the life of their handicapper sibling actually may be. Handicappers who are seriously disadvantaged physically, who have severe or complete physical involvement, are frequently very limited in what they can do for themselves. They must rely on other people to do the type of things that most of us take for

granted, such as getting up unassisted in the morning, bathing, getting dressed, turning on the television or changing channels, and going to the bathroom. Because they cannot do these for themselves, many handicappers find themselves on a schedule. They find their whole life becomes a long series of arrangements, with little chance to do anything spontaneously.

Like members of all dominant groups, the able siblings I talked with did not put empathetically put themselves into the position of the subordinate group. They were unaware of these constraints on the handicapper. There was an attitude of "this is the way the world is." On the other hand, they are very aware of the need to do things for the handicapper -- even quite trivial things: a man talked about his sister who has muscular dystrophy, "She needs help with everything, really. Like when she's trying to do homework, or something, she'll need pages turned, you know" [Interview #26]. A woman talking about her older brother who has muscular dystrophy, "Everyday we exercise him. That requires a little bit of time. And then we have to bathe him and get him dressed, help him when he needs to go to the bathroom" [Interview #30]. Some able siblings did mention that family life became less spontaneous after the birth of the handicapper (or after the accident), but they showed no awareness of or interest in how this affects the handicapper.

Socialization Creates and/or Reinforces Minority Status

Another illustration of how socialization contributes to altered social relations is the language used to discuss the handicapper and the disability. Examples of this are illustrated by how the handicap is discussed (or not discussed) in the family. In this area, a conflict approach is particularly useful. Concepts like secrecy, privacy, and the lie are tools to help explain both strengths and weaknesses of families. Within my sample, in many cases it involved a "vocabulary of silence" -- the family avoids mentioning it or if they must talk about it they use some euphemism, e.g., "the accident" [Interview #1] or "you know" [Interview #24]. In most families children are taught that certain topics are secrets and aren't suppose to be divulged to people who aren't family members. But when that forbidden topic is the handicap or how it happened, the very silence increases its significance -- particularly to the handicapper. Is it so shameful it cannot even be mentioned? When they talked with me, able siblings never expressed any awareness of this. Being silent on the topics, or using euphemisms enables family members to avoid a painful topic, but it also lessens opportunities for negotiation and carefully considering options.

In addition to the vocabulary of silence, often minority group members are demeaned by derogatory or belitting language. Because I had become sensitive to the use of ablest language, at the end of each interview I asked

the respondents, "Do you feel strongly about the use of some words, like 'handicapped'?" Almost a fourth of the respondents told me that they had never thought about language. Those whose siblings were also mentally retarded usually mentioned that they dislike the word "retard", but other than that, able siblings I talked with are no more aware of potentially disparaging connotations than the general population. It's an indication that they, too, consciously or unconsciously consider handicappers as different.

All of the people I talked with seemed more aware of derogatory references to the retarded than to the physically handicapped. The respondents mentioned the following as terms they found objectionable: "retarded" or "retard", "Beekman" (the name of a local school for the mentally retarded), "Beek" (another reference to the local school); and "speds" (for special education students). The twelve people whose siblings were also mentally retarded were much more sensitive to these terms than the people whose sister or brother was only physically disadvantaged, but many of the latter group also commented on their dislike of these terms.

Other expressions mentioned that did not refer specifically to retarded people were: "crippled," "confined to a wheelchair," and one person mentioned "invalid." She said, "It means too much; it says you can't do anything" [Interview #40]. Interestingly enough, one woman objected to the word, "handicapper" -- which is the one used by

handicappers themselves, at least in this region. She said, "I don't like the sound of 'handicapper.' It sounds like a 'capper' [sic]" [Interview #9].

In their conversation, the majority of people used the word "handicapped" instead of "handicapper." The latter word is the one chosen as the most appropriate by handicappers; it was mandated for offical use by the Michigan Handicappers Civil Rights Act of 1977 (Sawisch, 1978). Other terms used were: "ill," "the disease," and the specific diagnosis or cause of the handicap.

About a third of the way through the series of interviews, I started asking people what term they would suggest for the part of the population who are not disadvantaged. Many respondents used the word, "normal" -- sometimes taking themselves to task after they said it. One person suggested "temporarily able bodied," which is the one Gentile and Taylor (1976) recommend. Other suggestions from the respondents include: "able-bodied," "special," and "non-handicapper," but it was apparent that most respondents considered it a non-issue. Most agreed that something other than "normal" should be used. Definition/redefinition of what it is to be "normal" or "disabled" involves complex politics that as a society we are just beginning to explore.

Another example of altered social relations is how the able siblings conceptualize the future of their handicapper siblings. This involves projecting ahead in the life cycle of the family and trying to anticipate what the handicapper's life will be like as the parents age, and perhaps

die. As I mulled over the responses to the questions, "What do you think about the handicapper's future?", I realized that almost no one discussed from-childhood handicappers as having deep friendships or relationships, getting married or having a family. It was as if that was impossible -- even when many of the handicappers were objectively not all that disabled.

According to Milton Diamond (1984) and Wendy Greengross (1976), the family is often quite ambivalent about their handicapper's sexuality. While they may recognize that sexuality is a valid issue, they often wish the sexual concern could be ignored. It's as if they believe that if sex is not discussed, it won't come up in the person's experiences. Perhaps they don't wish to raise expectations and hopes. Yet we know that sex is one of the primary human drives. Roberta Trieschmann writes, "We must recognize that the onset of physical disability does not eliminate sexual feelings any more than it eliminates hunger or thirst" (Trieschmann,1984:222).

Most able siblings took it for granted that the future of the handicapper only involved vocational possibilities. Even this is progress of sorts. A generation ago, handicappers were not seen as potentially productive human beings.[7]

When I asked about their thoughts for the handicapper's future, typical of the answers was a respondent talking about his brother, "He's really smart. He needs the right job. He's thinking about history education. I think he'll

be a teacher" [Interview #7]. Not once in the interview did he ever allude to the possiblity that his brother might want to marry or have a serious relationship. His handicapper brother has a less severe form of muscular dystrophy and he can walk with Warm Springs' crutches [similar to canes]. In all probability he would be able to support himself and a family.

I also talked to a man who has two handicapper siblings, a brother with a clubfoot [minimally handicapped] and a sister who is both retarded and epileptic [moderately handicapped]. When asked about their futures, the respondent considered it only in relation to their ability to function on their own, without his assistance. He replied, "I don't know if I'll have to look after them or not" [Interview # 36]. He never mentioned the possibilities for them for love, marriage, or friendship.

In contrast, siblings of handicappers who became disabled later in life did consider marriage or a serious relationship as a possibility. I believe that is because they weren't socialized to see the sibling as a minority group member with limited life chances. In these cases, "handicapped" is not an ascribed status; their disabled siblings retained options. For instance, when I asked the sister of the young woman who had been severely beaten, "What do you think about the future of Susan?" she replied:

> We do anticipate that she can go back to school and get a job, but I'm worried that she's going to be limited in what she can do. Before, she had so

> much going for her. Her doctors express concern about her brain damage; she can be persuaded to do something so easily. She's susceptable to being taken advantage of by someone. I suppose she will marry, but I worry about her getting involved with someone. What would happen if they broke up or something? But that's still a long ways away. [Interview #1]

Another woman discussed her older brother who was seriously and permanently injured in a diving accident; he will be always be a wheelchair user. When I asked her if she'd considered his future, she replied:

> It's good. Career-wise, he'll probably eventually take over my dad's business [he works for him now as a salesman]. So that's really good. He's really a social person, so he always has lots of friends. His future looks really good. I guess eventually he'll settle down, get married. [Interview #39]

Another person I interviewed has a brother who has cancer of the spine and will probably use a wheelchair for the rest of his life. When I asked the respondent, "Do you think you have a role in his future?," he replied:

> I think being his brother is the role, being supportive and helping him somewhat recover. I really don't know what lies in store. He gets tremendous support from his girl friend. They started seeing each other when he first had it [the cancer], and she always knew him as having this problem. I kind of stepped out of the picture when she started stepping in. [Interview #32]

This same type of acceptance was <u>not</u> present in most of

the able siblings of people who had been handicappers from birth, or early childhood. In that regard, these handicappers were treated like we do small children and elderly adults -- like non-sexual beings. Their ascribed status as low-ranking minority members supports this kind of behavior. One exception to this, was a woman who had two brothers with muscular dystrophy. The oldest brother died of the disease a few years ago. Chris, the younger brother, now twenty-one, uses a motorized wheelchair and attends the university full time. When I asked her, "What do you think about the future of Chris?," she replied:

> I've given that a lot of thought. If something happened to my parents, either my sister or I would have him come to live with us. I'd have no problem with that. He's dating a woman now, a non-handicapper, and they are talking about marriage. I know he'd like to get married and have a family, and I hope it happens for him. [Interview #25]

Contrast this attitude with that of a respondent whose brother has cerebral palsy. By any objective standards, he is only moderately disadvantaged. When I asked her the question about the sibling's future, she answered:

> He is moving into an apartment by himself. He's going to work for my aunt and uncle doing maintenance in their apartment complex.... As far as him getting married and having kids and things like that, I really think it's to be discouraged. He's twenty-one years old and he's never really been with a girl. He'd never even kissed a girl until he moved into an apartment complex with those guys [a residential home for the mildly retarded]. There's a girl that lived upstairs.

> They all work at the same building [a sheltered workshop], and that was a real problem. She'd invite him up there at 3:00 in the morning or 6:00 in the morning...my brother confided in my aunt... She said, 'Gary, you haven't had sex with her, have you?' And he said, 'Well, we've come close to going all the way.' My brother doesn't have any concept of that. My aunt tried to explain to him, 'You know, Gary, you don't know where this girl's been. Do you understand about diseases? Do you know how a girl gets pregnant?' He really doesn't have any concept of that. As far as getting married and having kids, I don't think he'll ever do that. I think he'll always be one-hundred percent dependent, indirectly. [Interview #35]

This young man lives alone, has left the sheltered workshop and holds a full-time job, enjoys talking with people, and can, in fact, do almost everything that most people do except drive a car. (He gets too nervous to pass the driving test; he does pass the written portion.) He can read and he's unusually good at repairing and building electrical appliances. But at twenty-one years of age, he's still treated as an irresponsible child who cannot date or be interested in an intimate relationship. Like many other minority groups, handicappers are often denied self-determination and autonomy. "Problem-solving" (Pruitt and Rubin,1986), as a strategy for dealing with conflict, may not be a viable option for many of them.

In the interviews I found a number of illustrations of cavalier attitudes toward their handicappers sister's or brother's future. Most took a "Scarlett O'Hara" approach toward the handicapper's future -- they'll worry about it tomorrow. As an example, a respondent whose sister has

muscular dystrophy, said, "I haven't thought about that [her future] really. But, yeah, we'd do something [to take care of her]" [Interview #26]. Another woman whose older brother is severely disabled with muscular dystrophy said, "I never really thought about that [his future]" [Interview #30]. Are these also examples of denial?

In the case of siblings with muscular dystrophy, there's the spoken or unspoken knowledge that people with that disease don't live past the mid- to late-twenties. However, respondents whose siblings have less life-threatening handicaps say similiar things. A respondent whose half-brother will always be a wheelchair user as a result of a fight said, "I haven't thought about his future" [Interview #40]. Another respondent whose brother was originally diagnosed epileptic and was later paralyzed by a too heavy dose of a drug, answered the question, "Have you ever thought about Edward's future?" by saying:

> No. I've never really [thought about it]. Especially considering they [the doctors] never thought he'd live past twenty. [He's now 44.] There's no future for him. He's really in a semi-vegetative state...he does have a workshop he goes to on a daily basis. He does go out. But without feelings, one may sound cynical, [but] I just feel that he's been just a tremendous burden to the state. [He's lived in state hospitals and homes for the past 32 years.] You know, I guess that's a value judgment, but it's such a sad life to have it prolonged for such a long time. I really don't think about it. I guess what I'm saying is that I hope the future doesn't go on too much longer. [Interview #31]

A woman whose sister has a relatively moderate dis-

ability from cerebral cerebral palsy had at least considered her sister's future, but she sees no need to put herself into that future. In answer to the question she said:

> I used to think about her future. When she was living at home I wondered what would happen when my parents were gone and who would take care of her. Then she moved into a group home, and from there she moved into her supervised apartment that's supervised every single day. Eventually she'll move into a place that's supervised once a week. So she's got her own life. [Interview #9]

Presumably, her sister's future lies there, in the group home, and therefore the respondent doesn't have to consider it -- it's not her problem. She deals with the potential problems by withdrawing -- which tends to be a permanent (although not necessarily the best) solution.

Socialization and Respondents Thoughts About Their Own Futures

In an effort to get some insights into gender-specific socialization and some notion of how stressful having a handicapper sibling really is or isn't, I asked each respondent, "What role, if any, do you see for yourself in _____'s (the handicapper sibling) future?" My rationale was that if their socialization was typically gender specific the women might feel a compulsion to enter a helping profession and men would not.

Several of the respondents, both men and women, told me their parents do <u>not</u> see the handicapper sibling as their

responsibility -- or at least, not yet. The respondents are still in the stage of the family life cycle where parents are healthy and able to carry on the responsibilities of caring for the handicapper themselves. One woman, discussing her brother who is epileptic and mentally impaired at the severe level, said:

> We've already been told, my older sisters and I, [that] until we are at a stable point in our lives, we cannot take care of him. My aunt and uncle will be his guardians [if something happens to the parents]. It's up to them to decide when [we'll get him] if we want to take care of him -- when we can have him. [That's because] my mom doesn't want us to be tied down at a young age. She has been through this for fifteen years now. She realizes how much you have to give. So she's saying [if something happens to her and my father], until we're ready, my aunt and uncle would take care of it. [Interview #14]

A man said something similiar about his family's attitude about taking care of the handicapper daughter. The respondent is the oldest child of a family of eight. His eighteen year old sister has muscular dystrophy and is a wheelchair user. He told me:

> I've talked to my dad about it [taking care of the sister if something happens to the parents]. He says, 'Hey, you're out of here; it's none of your responsibility.' I guess the attitude I've taken is, if she needs help, I'll be there. [Interview #23]

Pruitt and Rubin (1986) term this "inaction," a temporary strategy. If the situation changes, so perhaps, will their

way of dealing with it.

Another respondent talked about the future of her brother who is both severely physically and mentally handicapped. She has considered changes that may occur as the family life cycle progresses and her parents can no longer physically care for her brother. She told me:

> My mom and dad are a long way from dying, I hope, but who's going to take care of him? I don't think my little sister would; it would probably be my responsibility. My mom is the type of person who can take care of somebody like that [a severely disabled child who can do almost nothing for himself] As far as I'm concerned, it's not that I would really mind having him there in my home, but I'm going to have a career and I don't think I'd be able to give him enough attention. I would probably put him in a home. [Interview #41]

This solution combines strategies; it includes both psychological withdrawing and contending -- imposing her own preferred solution. Later in the interview she talked about the possibility of having a handicapper child of her own and said:

> I don't want you to think this sound inhumane or whatever, but I don't think I could keep them [a handicapper] at home. Certainly I would love them and make sure that they got the best care, but I think it would be really hard for me to have to spend so much time, like my mother spends with my brother. [Interview #41]

Activities, like physical care of a handicapper, are something that she does not see as her particular responsiblity.

Literature on siblings of retarded children stresses

that a disproportionate number of sisters (particularly older sisters) go into the helping professions. To find out if this was the case in my sample, I specifically asked each respondent if the handicapper sibling had any bearing on their vocational choice. Most denied that it had. In fact, for the most part, the women respondents are not going into traditional helping professions. Instead they are majoring in engineering, business, pre-law -- a trend among many American women who have become sensitive to gender salary inequalities, especially for women who remain in traditional female occupations (Ciabattari,1987; McCrum and Rubin,1987). Even those who were going into medical technology or nursing questioned whether the disability influenced them in any significant way.

There were a few exceptions to this. One woman I interviewed is from a family where all nine children are, or were, handicappers. Only one is a natural child; the others are either adopted or ~~foster~~ children. The respondent had a severe vision problem when she was adopted into the family, but it has been corrected. [In the interview, we only talked about three of her handicapper siblings, and only these three are included in the data.] When I asked her, "Do your parents like you to spend time with your brothers, or do they leave it up to you?," she replied,

> They leave it up to me, but it's so natural to play with the kids. I've always loved the kids. In fact, I'm in pre-med. I want to be a pediatrician. [Interview #28]

Three male respondents related that the handicapper sibling had influenced their vocational choice. One man, whose brother is mentally retarded and seriously handicapped with cerebral palsy, volunteered information early in the interview:

> I've worked at the school where he goes [a developmental center]. That was probably the best experience of my life. I was a teacher's aide there. I really enjoyed it, so consequently, I changed my major to special ed. [sic]. [Interview #11]

Another man, whose sister has muscular dystrophy, told me, in answer to the question, "Did her handicap have any bearing on your vocational choice?":

> Yeah. Originally I was interested in biomedical engineering, prosthetics and things, but Michigan State turns out to be not that good of a school for bio-med, and I'd have to end up transferring, so I just went for straight mechanical engineering. I concentrated on controls, computers, and things. Right now I want to apply it to this problem, but I don't think I'm going to make it my career... A lot of my work is related to her handicap. I'm working on a robotic arm that's going to be attached to wheelchairs. A lot of people don't have the full use of their arms. [Interview #23]

A medical student talked about his brother who has spina bifida. When I asked him, "How has Tony affected you?," he replied:

> I wanted to be around people. I wanted to deal with people. I was in some way rebellious against

business and profits. I decided I was going to be people-oriented. I went to Wayne State, where I got certified in special ed. [sic]. I'd gotten into that originally because of Tony and my experience in the Special Olympics. [He taught gifted children for several years and then became a medical student.]

Q: What made you decide to change careers?

A: I needed something more challenging. Being a physican gives me more choices. I can do anything I want. [Interview #8]

I noticed in this group of respondents that many of them did not have the "typical" gender-specific career goals. A disproportionate number of the women were planning to go into various professional careers and several of the men were aiming toward the so-called "helping" professions. The shift for women to pursue non-traditional occupations is also occuring in the larger society, but the trend appears to be accentuated among families of handicappers -- at least in this sample. I have no hard evidence about what proportion of males go into helping professions, but I believe that in this sample, at least, there are definite differences in gender vocational goals. I see this as another example of the altered social relations in the families of handicappers. In my opinion, the gender-specific socialization of these people is not as complete or as effective as in the average/typical family. In handicappers' families, able sisters, of necessity, often take on additional responsiblity. From a relatively early age they flaunt gender stereotypes of what is, or is not, proper for females to do. By the same token, able brothers in some of

these families assume a more nurturant role than is common in our society.

Conclusions

Findings that emerged from the grounded theory approach advocated by Glaser and Strauss center about the altered social relations in families of handicappers -- particularly those families where the disability has been present from birth- or early-childhood. For the most part, these changes are not particularly desirable. Only one could be considered a "plus," and traditionalists might debate that.

In my opinion, the only non-adverse change in family social relations is that gender-specific socialization of the children is less complete and successful than in the average or typical family. While most of the respondents denied any connection between their career choices and having a handicapper sibling, I perceive a different pattern in families of handicappers. In these families, daughters are disproportionately attracted to non-traditional vocations and a higher proportion of brothers indicate an interest in the helping professions. This is particularly true of smaller families.

On the less desirable side are five other alterations/ changes in social relations in handicappers' families: 1) the development of minority status for the handicapper sister or brother, 2) able siblings accruing power at the expense of their handicapper sibling, 3) these two factors

produce an environment of intimate oppression for the handicapper, 4) the reinforcement of gender expectations that women will be the ones to care for children and those in need -- in this case the handicapper, and 5) divisiveness occurs in some families where someone, usually the father or brother, disengages and withdraws from the family.

While it is true that most families care and protect their handicapper members and try to meet their emotional needs, it is equally true that these additional demands place a burden on the other members of the family (Thomas, 1980; Darling and Darling,1982). Perhaps (unintentionally,) but almost inevitably, psychological, legal, and social blocks are placed in the way of handicappers. This alters the distribution of sibling power in the families of from-childhood handicappers and the relationship may become asymetrical. Many from-childhood handicappers are blocked from achieving as much power as their able siblings. Socialization, financial resources, freedom to participate in the larger society, and the ability to physically coerce the handicapper, alters the power distribution in these families. I believe that differences in sibling power are not due to individual resources or the personal competence of the siblings but to discrimination -- in the broadest definition of the term --against handicappers.

On the basis of my sample, I believe siblings of those disabled from birth or early childhood accrue additional power in the family and those handicappers become the primary victims of the family's altered social relations.

This is particularly in small-sized families of from-birth or early- childhood handicappers. This asymetrical power often results in intimate oppression for the handicapper, which in turn helps create a minority status for them. None of this is necessarily deliberate on the part of able family members -- in fact they might attempt to avoid it if they realized what was happening. But because the handicapper needs so much attention and has so little power vis-a'-vis other family members, it does occur. The handicapper is socialized into minority status. In my sample, this did not happen when the disability occurred to an adult, no matter what the size of the family. If the sibling was raised as "normal" and socialized to those expectations, s/he may continue to have power, options, and autonomy even if s/he is incapacitated later in life. But if the disability is present from birth or early childhood, the handicapper tends to internalize the views of others who consider him/her less capable than a "normal" person. Many become dependent and powerless.

In regard to predicting handicapper sibling's futures, what is interesting is that degree of handicap is not a critical variable in whether or not the able sibling thinks the handicapper can marry or be in a serious relationship. The significant difference is when the sibling became disabled. Those who were disabled later in life had the opportunities to think of themselves as a contributing people and they had a variety of life experiences that enabled them to learn about their interests. Handicappers

disabled from birth often do not have those same opportunities due to accepting their ascribed status.[8]

In contrast to the lot of most handicappers, the able sibling is "normal," with all the advantages that entails. In all likelihood, the able siblings will find jobs, friendships, special relationships and/or marriage -- in short, they will have the opportunity to lead a complete life. But because power is a reciprocal relationship, the able siblings who exert power over the handicappers don't escape obligations or commitments to the less powerful sibling. Handicappers can, and do, have some ability to influence, which means that able siblings' own freedom of action may be limited, too, but in comparison to the handicapper, able siblings maintain a great deal of power and independence.

Among the people I interviewed, the altered social relations and the lack of empathy with the disabled sibling was widespread, particularly among respondents whose siblings had been handicappers since birth or early childhood. Only the sisters and brothers of those who became disabled as adults seemed to have some sense of the <u>randomness</u> of tragedy -- that it might have been them, instead of their sibling. It's tempting to speculate that perhaps the very abruptness and traumatic nature of the injury or disease enabled the able siblings to empathize better with those injured as adults. Since prior to the accident or illness they had know that sibling as a complete person, perhaps it's more difficult to objectify them. Maybe not viewing them as an object allows them to visualize

that life better than trying to imagine what it would be like to have always been a handicapper.

Another change is the reinforcement of traditional gender expectations about who cares for children, the sick, and others in need. In most families there is a presumption that women will do this -- usually mothers, but in the case of from childhood handicappers, this notion is magnified and expands from a relatively short-term prospect to a life-time commitment. In England, the state has made efforts to provide respite care for the family (Kew,1975). This particularly benefits women -- mothers, sisters, daughters, aunts. We've made no such arrangements in this country. With deinstitutionalization, the entire burden of care has been shifted from the state and care in relatively large-scale operations to the individual families involved. There are undoubtedly some genuine benefits from this transfer of responsibility, including more personalized care of the disabled, but the disadvantages outweigh the potential gains. If this additional burden were just financial, it would be bad enough, but probably the worst is the increased physical and emotional costs involved. When no respite care is provided, nor funds to provide it, that means that many -- if not most -- families are totally dependent upon members to provide the needed care and regimine. This places particular burdens on female-headed households or homes where the mother must, or choses to, work fulltime in the paid labor force and a sister elects, or is selected to, become the primary caretaker.

One additional undesirable alteration of social relations is the fact that in some families such a premium is put upon not "rocking the boat" that there is no provision or opportunity for dissent. If someone resents the time and attention the handicapper demands, there is no safe arena to voice that objection. Their feelings/concerns are expressed only by a "vocabulary of silence." The conflict/stresses escalate and the hostility, guilt, resentment reach the point where the individual abandons his/her commitment to the family. This occurs most frequently in the mid-point of the family life cycle, when the children reach young adulthood and in families where there is a strong ideology that it is inappropriate to argue and complain. In this sample, four fathers and two brothers did just that; they were considered deserters by the respondents.

ENDNOTES

1
In the late 1960s, a number of scholars became interested in the area of family power, particularly the measurement and outcomes of power relations between spouses. David Olson is one of the best known proponets of this approach. This approach presents a number of nearly insurmountable problems; I prefer Jetse Sprey's approach. He focuses on the mutuality of power and the concept of "bonding" and "threat." This includes the notion that the closer the bond, the greater the vulnerability and its strength. In such a situation threats can be very useful in successful management of familial and marital conflict, but of course, the threat must be understood by both sender and receiver and they must recognize the consequences to both parties if the threat is carried out (Sprey,1971).

2
A complete discussion of power in families is beyond the scope of this chapter, but for exceptions to this ommission/ignoring of power and influence relations between and among sibings, see Sutton-Smith and Rosenberg (1970) who studied sibling sex status and power and Schvaneveldt and Ihinger (1979) who investigated sibling relationships, including power dimensions. For studies of power relations between members of parental-spousal subsystem, see Safilios-Rothschild (1970b), Gillespie (1971), Olson and Cromwell (1975), Sprey (1972, 1975), and Turk (1975). For information on power/control as a variable in parent-child relations, see Rollins and Thomas (1975).

3
In this chapter, I don't have space to discuss the notion that the family constitutes the foundation of women's oppression. For excellent discussions on this topic, see Firestone (1972), Zaretsky (1976), Hartmann (1979), and Brittan and Maynard (1984).

4
In a classic work, French and Raven (1959) identified six bases of potential power or influence in social relationships: 1) reward, based on ability to provide rewards; 2) coercive, based on ability to mediate punishments; 3) referrent, based on identification; 4) legitimate, based on belief that the individual has the right to control behavior or opinions; 5) expert, based on perception of superior knowledge or skills; and 6) informational, based on ability to use explanations and other persuasive communication to modify behavior. Any of these provides power which can vary from a small to a large amount.

5

Repressed anger has been postulated as an etiologicl factor in a wide variety of disorders. For a more complete discussion of repressed anger and what may happen to people who inhibit the expression of anger, see Frost and Averill (1982) and LaBier (1986).

6

A complete discussion is beyond the range of this chapter, but for a more complete treatment of the topic of handicappers inability to express resentment or anger toward caretakers and those with whom they interact, see Zola (1980a) and McDowell, Coven, and Eash (1984).

7

In her book, The Managed Heart, Arlie Russell Hochschild (1983) discusses emotion management of women in our society. She maintains that emotion work is more important for women because they are a subordinate social stratum with less independent access to status, money, power, and authority than men. As an example, flight attendants are taught to be cheerful and happy. Hochschild reports that in training the women were told, "Now girls, I want you to go out there and really smile. Your smile is your biggest asset. I want you to go out there and use it. Smile. Really smile. Really lay it on" (Emphasis in the original; 1983:4).

8

Even today, some family members impede rehabilitation efforts. For a more detailed report on this phenomenon and rehabilitation methods, see Wright and Schwab (1979). They write, "This hindering attitude was one of non-belief. This attitude assumed that because the person was different, that is, handicapped, that he or she was not subject to the same development as people who were not handicapped" (1979:278).

9

A complete discussion is beyond the scope of this chapter, but see Wright and Schwab (1979) for a comparison of handicappers who were employed versus those who were not and the significant differences between these two groups. The authors did not single out timing of disability as critical, but the importance of timing is consistent with their findings.

Chapter 6

> My mom believes God wanted her [sister disabled by a beating] to 'Stop her evil ways'.... my parents think the accident was sort of a punishment. [Interview #1]

> How could God permit something like this? [an automobile accident where her brother was permanently injured]. [Interview #20]

> God doesn't make mistakes. There's a purpose in this [having a brother and two sons with muscular dystrophy]. [Interview #21]

FAMILY COMPOSITION AND ABLE SIBLINGS' REACTIONS/ATTITUDES TOWARD THE HANDICAPPER

Introduction

As the above quotations illustrate, a handicapper in the family can be interpreted or understood in a number of different ways. No two families are alike. Every one is unique, with its own particular needs and resources, and this is particularly true for those with a handicapper. As I've mentioned before, there are no typical handicapper's families. Each varies in the degree by which they are affected by disability and the ways in which they cope with crisis/conflict. Able siblings and parents can -- and do -- have a variety of different responses to a handicapper sister or brother. The differing views on God's role is just one illustration of those different reactions.

Family meanings are constructed about how and why the disability occurred and these understandings evolve from a variety of sources. Some family members internalize the supportive values and explanations of institutions, such as religion or medicine, to help them accept and cope. Some parents develop secular attitudes and philosophies about the disability. These views are passed on to the children who usually learn and accept these attitudes -- at least initially. These notions are part of the family's social construction of reality, which is influenced by family composition and attitudes.

Influence of Religion as a Way of Coping/Understanding

Throughout this chapter, importance of family composition on able siblings' reactions to handicapper sisters and brothers is stressed. Two important dimensions of family composition are the presence, or absence, of religious faith and the extent of that belief. For many people, religion defines and reinforces heartfelt values, and their religious faith is used to explain why this tragedy happened (Voysey,1975; Fewell and Gelb,1983). However, for most able siblings in my sample, religious faith was not germane. When I asked, "Have you or your family ever used religion to help explain or understand the fact of the handicap?," the majority said, "No." As an illustration of this view, one respondent whose brother has cerebral

palsy replied, "No. My father says, 'This is life.' He's never said, 'This is the way God wanted it'" [Interview #10].

For other families, religion enables them to be grateful for small blessings and/or seek logical explanations for why the disability occurred. As an example of this, one respondent told me, "Sometimes we say there's a reason that God had him like that [brother who died of cerebral palsy]. He had such an influence over other people's lives. Whereas if he wasn't handicapped ... [he might not have affected them so much]" [Interview #19].

For some respondents and their families, religious faith provides other solace and comfort. Many people mentioned that they, or their parents, believe that religious faith enables them to better cope with the handicap/accident. As an example, a respondent whose brother has cancer of the spine told me, when asked, "How important is religion to your family?:"

> Our faith in God was probably the primary reason for us getting through this and handling my brother's handicap. We just accept it. We don't believe we're being punished in any way....that doesn't coincide with our faith. That has kept us close together, and it has helped our family grow. [Interview #32]

In a similiar vein a respondent, whose brother died of muscular dystrophy and who had two sons with it, told me:

To me, religion is very important to my

> acceptance. That's been the very basis of my dealing with it [having three family members afflicted with muscular dystrophy].... I know that's why I've been able to accept it. God doesn't make any mistakes. There's a purpose in this for me. I don't know why, but still I can accept it....not that during some hard times I don't say, 'Why me?' It's hard sometimes. Especially when I had two of them [sons in wheelchairs]. [Interview #21]

Another woman (whose brother is almost totally incapacitated with probable osteogenesis imperfecta) answered the question, "Have your parents ever used religion to help explain or understand the fact of Brad's handicap?," with "Yeah. My mother, definitely ... [she feels] this is what God wanted; this is suppose to happen. It's her way of explaining things" [Interview #41]. The respondent made it clear, that it was not her own solution; she discussed genes and heredity.

Even though there has been a decline in religiosity to legitimate disability, for some people there is still the notion that God will compensate the family (Kew,1975; Voysey,1975). Talking about her younger brother who is very disadvantaged (he is retarded, epileptic, and cannot talk), one respondent volunteered, "I think he's the greatest thing that ever happened in our family. All he knows how to do is love. He doesn't know anything but to be happy and loved" [Interview #14]. She added that she would like to have a similiar child of her own; she was the only person who expressed a desire to parent a handicapper.

A "compensation" that many respondents mentioned is the

belief that the family became united. As an example of this, one respondent said, "I think it draws the whole family a lot closer together; you really have to help each other out" [Interview #14]. Still another volunteered, "I think our family unit together is really strong. We came through this, and are still coming through it, with flying colors. Our family has become really, really close" [Interview #32]. However, for some families, the disability at least contributed to some family members leaving [Interviews #6, 15, 21, 24, 33, 35, and 36].

Other able siblings looked for, and found, something positive in the situation. The majority of respondents mentioned that one of the fringe benefits, as it were, of having a handicapper is realizing what is truly important. With this knowledge, everyday trials and tribulations are put in proper perspective; they are seen as unimportant and insignificant. One woman said:

> I think my sisters and I perhaps value life -- not more than someone else, but in a different way. There is a lot of potential that never would have been developed in our family had it not been for that [the handicapper sister]. [Interview #24]

Another respondent volunteered, "His accident has made me aware of how lucky I am not to be disabled in any way" [Interview #14]. Another woman mentioned, "It's made me appreciate good health more" [Interview #17]. Another said, "Probably one of the biggest effects it's had on me is tempering my own perspective -- what's important in day-to-

day things" [Interview #23]. The brother of a young man who is retarded and has spina bifida told me:

> His condition has tempered our attitude toward things. Nothing that people do is embarrassing, especially people who can't control it, who have no choice in the matter. How can that be embarrassing? You take that attitude into everything. You try not to judge people on how they look or anything. [Interview #8]

Another respondent, a foster sister said, "I think I've got a wider perspective, more of a sensitivity. Maybe more of an appreciation of the talents you have, even eating. People don't realize what a wonderous gift that is" [Interview #4].

Still other families cope by finding some positive aspects for the handicapper. In my sample, several able siblings come to see positive value, some desirable "good" for the handicapper, that came out of the tragedy of an accident. A sister commenting on her brother who became a quadriplegic wheelchair user after an automobile wreck:

> He's a lot stronger person than he used to be. When he was in the service, he was really wild. He was really crazy. After the accident, it made him more mature, more responsible. [Interview #20]

Another respondent said almost the same thing. As a result of a diving accident, her brother also became a quadriplegic wheelchair user. She said in answer to the question, "Can you think of anything good that has come out

of this accident?"

> Yes, I think maybe it might have [helped] put the pieces together more for my brother. He really didn't know what he wanted to do... He was just too wild; he was really wild. He might have killed himself if this hadn't happened. [Interview #39]

Perhaps these are also illustrations of denial. Both these men sustained serious, life-time injuries and were near-death. By minimizing the extent of the loss, the able siblings may deal with it easier.

For some siblings, the disability raises doubts and challenges their notions about religion and God; it contributes to a "crisis of faith" (Voysey,1975; Featherstone,1980; Zola,1982a). I asked a respondent whose older brother was seriously and permanently injured in an automobile accident, "Have you ever used religion to help explain or understand the fact of Fred's accident?" She replied:

> I don't feel I'm a very religious person. It [the accident] convinced me. How could God permit something like this? You've destroyed someone's life. And when you start really looking at the world! It's not fair to put people through this. [Interview #20]

When I asked another respondent whose sister is somewhat mentally and physically handicapped from Prader-Willi syndrome, "How important is religion to your family?," she answered:

> We were brought up in a very conservative, strict, Catholic home... I think part of my mother's problem [she became an alcoholic] was if you grew up in an era where you believe that if you were good, God did everything for you, rewarded you. The other was a punishment. And she saw that [the birth of a retarded, handicapper] as a punishment ... I think my mother blamed the nurse, I think she blamed the physican, she blamed God. [Interview #24]

This illustrates that even today, some people believe that disability is punishment by God. The disability is seen as a punishment for sin -- God's retribution (Voysey, 1975; Fewell and Gelb,1983). The disability is seen as punishment for "evil" acts. Either the victim or his/her parents are blamed for their fate; they are seen as responsible for what happened -- they "got what they deserved." Among the people I talked with, I found two examples of this belief -- the mother just mentioned and one other. When I asked a woman whose sister had been severely beaten by two men, "Have you or your family ever used religion to help explain or understand the fact of Susan's accident?," she replied:

> My mom talks a lot to Susan about it [the beating]. My mom believes God wanted her to 'Stop her evil ways.' Before her accident, Susan was drinking and smoking pot -- things a lot of kids do -- but my parents think the accident was sort of a punishment. It gave Susan another chance, but God is making her work extra hard. She's still got her intelligence and her senses, and a lot of kids don't have that. A lot of kids are killed. They [my parents] talk about that a lot. [Interview #1]

This respondent expressed conflicting notions about the relationship between the handicap and religion, which is understandable. Opinions and beliefs aren't necessarily consistent or constant. To the question, "Has religion affected your view of the accident?," she answered:

> Yes. My parents understand it more than me. I'm starting to have a difficult time understanding it. I've never lost anyone close to me. I hear about other young kids dying, and death is really a bizarre thing to me. Maybe I'm having more of a conflict with it than my mom and sister have. I started going to church a lot after the accident, and we all prayed a lot. It made me think a lot about death, and I still have a real problem with that. When someone dies and they're just not there, how do you deal with that? [Interview #1]

Her family's life-cycle is at the stage where children are ready to leave the parental home. Her sister's disability has forced her to come to grips with a lot of things, including the reality of death.

Talking with a respondent whose brother is retarded and has spina bifida, I asked, "Has Tony's handicap affected your view of religion?" He replied, "No, no," but earlier in the interview, he volunteered:

> The whole thing bothers me. I look at Tony and think, 'Why was it Tony instead of me?' Was someone being fair? You've got to be kidding. I hear people say, 'This is a test.' Why am I being tested? Why do I need to be tested? Watch how I act. You don't have to make me paralyzed. It's ridiculous. [Interview #8]

Other Ways Families Cope

Religious faith is not the only way families of handicappers cope. For some respondents, religious faith is not a strong element in their family composition; their family's ideological style may be more secularly oriented. For instance, relatives cannot depend on their handicapper's life following a typical, predictable course. Instead of looking toward the future, able siblings learn to wait and see. They adopt a philosophy of "one-day-at-a-time." They say such things as, "No one in our family has ever planned long-term [about the handicapper sister]" [Interview #23]. Another respondent talked to me about her brother who was seriously injured in an automobile accident. He's had a series of difficult and life-threatening operations. She told me, "He looks real good, [but] you don't know just how much his body can take" [Interview #20].

Other respondents cope by redefining good and evil. They see everything as relative, or think in terms of "it could be worse." The respondent whose brother has spinal cancer was grateful that Walt was still able to work and earn a good living. If his brother had to have spinal cancer (an evil) it was good that he could at least work. The respondent told me:

> Luckily, he was able to pick a career, electrical engineer, that as long as he can push a button, he's going to be pretty safe. He's still able to control his movements, and it's within the ball park, anyway. And he's still got a pretty firm handshake. It's really a blessing that he did choose electrical engineering. [Interview #32]

Some respondents redefined death, which in our society, is usually seen as something undesirable and to be postponed until old age. Now they see death as a blessing. A woman whose older brother died of muscular dystrophy and whose two sons also had it, mentioned that when her older son died, it was much easier for the family [Interview #21]. This so startled and unnerved me that I failed to probe further.

Family members' attitutes toward the disability vary considerably. The attitudes held are exceedingly important, both for the handicapper and the able siblings. (Perhaps to the parents and extended family members, too. Additional research is needed in this area.)

Attitudes Toward the Disability

Parental attitudes toward disabled children can be classified into four, sometimes overlapping, categories: realistic acceptance, denial, benevolent over-protection, and disguised or open rejection (non-acceptance).[2] In some cases, attitudes shifted over time. Obviously, these are not value-free descriptions, but they are useful to describe the most common attitudes of family members toward the handicapper in their household. In my study, I found all four attitudes exhibited by able siblings.

"Realistic acceptance" refers to approval and total intergration of the handicapper into the family, both socially and psychologically. This acceptance goes beyond

resignation to the inevitable. Family members may still have negative feelings, but they balance attention and opportunities for the handicapper with a realistic place for him/her within the family. In my sample, an example of realistic acceptance and integration into the family was given by a respondent whose sister has osteogenesis imperfecta to the degree that she cannot stand or walk. When I asked, "Is there anything you'd like to mention that we haven't covered?," he said:

> One thing you haven't asked, 'Are you proud of your handicapper sibling?' Yeah, we're pretty proud of her. Considering what she's had to overcome, she's done pretty well for herself. Whatever job she can do -- and I'm sure she can find some work, I think that eventually that will work out... Cathy is not that much different than the rest of us. [Interview #6]

There were many other illustrations of realistic acceptance in the interviews. Among the people I talked with, it was a common response to a handicapper sibling. For the majority of respondents, the handicap and altered family social relations have been a part of their reality since their youth. It was an element in the early era of the family's life cycle, and they've grown accustomed to having a disabled sibling. It is accepted as part of their family's normal life, but even among these families, at least some family members could not accept it. These include family members who left the household and no longer communicate with family members and the mother who fled in

another way -- she became an alcoholic. These people followed the strategy of "withdrawal" (Pruitt and Rubin, 1986) -- they left either physically or psychologically.

In the case of respondents whose sister or brother has an adult-onset disability, realistic acceptance is the most common attitude, although initially the family and able siblings may have denied it or tended toward over-protection, but ultimately they accepted the reality of the situation. None of the ten siblings of adult-onset disability in my sample rejected the handicapper, nor apparently, did any of their family members.

A second common attitude is "denial;" here family members reject the notion that the handicapper has real problems or unusual difficulties. Denial may take the form of undue pressure to achieve high, and perhaps unrealistic, goals. According to Thomas [1980], this attitude is relatively rare, but where it exists, it can be very detrimental to the handicapper. It can lead to frustration, regression, or some other form of maladjustment, and potentially, it can be more tragic for the handicapper than the physical disability itself.

An example of denial is illustrated by a woman talking about her adopted handicapper brother, age nine. He has cerebral palsy and is spastic. Following the adopted mother's example, the family insists that he be treated like an able child. He must do everything the other children do. According to the respondent:

> Sometimes when Bobby is screaming, usually because he's frustrated and wants us to do something for him that he can do himself, we hold a wet washcloth over his face. That works really well. Banishing to his room works if he's crabby or obnoxious... He's treated exactly like everyone else. He's not allowed to use the wheelchair in the house. He's not allowed to at all. The only time he's allowed to use his wheelchair is when he's going to school [Emphasis in the original; Interview #18]

This family refuses to acknowledge the handicapper has real or unusual difficulties and they have set an unrealistic goal for this boy. It is unlikely that he will improve sufficiently to ever walk on a day-to-day functional level, and yet he is required to move about his house unassisted, even when it takes him a great deal of time, energy, and high levels of frustration to do so. I neglected to ask if the physican wants him to move about as a form of therapy. The respondent did mention that school officals insist he use a wheelchair when he is there. This family composition includes two adopted handicappers; the other boy is less seriously disabled. According to the respondent, the father is absent on business a great deal, and the mother takes near total responsibility for raising the children. The mother came to the attention of the courts for alleged child-abuse in disciplining the other handicapper child, but the judge ruled there was insufficient evidence to convict. The respondent, another self-defined "hard-to-place" adopted child, embraces whole-heartedly the philosophy of her adopted family, the parents' notions on how to raise children, and their attitudes toward disability and

discipline. She feels these are appropriate and proper.

Another example of denial was provided by a respondent whose brother and sister had polio when they were young; she told me, "My mother is an advocate of not treating a handicapped person like one [a handicapper]" [Interview #3]. This was a theme throughout the interview -- how "normally" the children have been treated. The respondent talked about her brother. He walks unassisted, but he cannot run and he isn't very coordinated. However, he was never treated as disabled, and this pretext of being like everyone else presents frustrations for him. The respondent volunteered:

> Rob wanted to be an athlete, but he couldn't. Instead of going into something like dentistry, or becoming a lawyer, he tried in vain to do things he couldn't do. Even though he can't run, he tried out for football. He can't run, but he'll go out and buy the most expensive tennis racket. I feel he's never really accepted it [the physical impairment]; he's very short tempered. I think he's really angry. [Interview #3]

As she gets older, the respondent is rethinking her own position toward her family's ideological style. She no longer accepts all of these views, but she hasn't reached a total restructuring.

Among the group whose siblings became disabled as an adult, only one woman initially denied the handicap. Her brother became a quadroplegic in an auto accident. For quite some time she and her parents persisted in thinking he would ultimately recover. Eventually the reality of the

situation convinced her that it was wishful thinking and he was not going to improve [Interview #20]. This acceptance has been difficult for her and she still grapples with resentments at God, fate, or whatever is to blame for the situation.

Another attitude of parents/family members is "over-protection." Kew (1975) discusses benevolent over-protection and maintains that it is common in families of handicappers. That may be so, but over-protection is a difficult dimension to objectively assess. How much attention is too much? According to Thomas (1980), if the handicapper receives a lot more attention, either emotional or physical, than the disability requires, and/or if this is much more attention than other children in the family receive, this is over-protection. With over-protection, emphasis is on the disability, not the person. This is not desirable; according to Thomas:

> Over-protection limits the child's opportunities for learning independence in habits and ways of thinking, restricts his social interactions and leaves him with little or no chance of coping with feelings of failure (Thomas,1980:112).

An example of benevolent over-protection, at least in the eyes of other siblings, can be found in comments of brothers I interviewed about their sister. She has muscular dystrophy and has been a wheelchair user for many years. Her eighteen year old brother said:

> She gets away with more. She can scream at my parents more than we [the other seven children]. My dad doesn't do anything to her; he just takes it in stride. Whereas, if we [the rest of us] do something naughty, he'll blow up. [Interview #26]

Her twenty-three year old brother, whom I also interviewed, said:

> All through high school, she was never forced to really try. She's just as bright as you or I. A lot of times, because of her handicap, I think they didn't expect as much from her. Since they didn't expect as much from her, she got passed through high school, not really understanding a lot of it. [Interview #23]

Both brothers exhibit some resentment that she "gets away with more," but it is apparently a minor problem for them.

Another respondent discussed her family situation and the over-protection of her handicapper sister, who has cerebral palsy. Physically the disease has not been as damaging as for some people; she can get about with aid of a walker and she has no verbal or mental disabilities. The respondent volunteered:

> When she was first born, thirty years ago, people with cerebral palsy were automatically thought to have mental problems -- couldn't learn. So she went through all kinds of schools where they blew her nose and did everything for her. And now my parents recently found out that she was totally capable of learning. She could have learned if she'd gone to a normal school. She's probably got about the fourth grade level when she'd be capable of a lot more. [Interview #9]

I asked, "How has Grace affected your family as a whole?" She replied:

> It causes a lot of tension in our family, especially when she got older. She wanted to get out [move out on her own]. My mom would treat her like a baby, and I would get upset.... There was a lot of problems. She didn't want to be treated like a baby; she wanted to get out. She didn't want my parents to say, 'No, don't do that.' It was really bad for awhile, until she got out it was like a big cloud in the sky. She was twenty-six when she moved out. [Interview #9]

This respondent exhibits much more resentment toward her parents and, particularly, the handicapper than most of the people to whom I spoke.

Among the group whose siblings became disabled as adults, only one respondent over-protects the handicapper. The younger sister was severely beaten and will be permanently disabled to some extent and she worries that people will take advantage of her handicapper sibling [Interview #1].

A fourth attitude toward handicappers is "rejection" or non-acceptance of the handicapper. With rejection, there is conflict between intellectual and emotional acceptance of the handicapper and his/her disability. Seven of the handicapper siblings (15.21 percent of the respondents) were totally rejected by their natural mothers or families. (Two of these children became handicappers as a result of physical abuse by the mothers.) These children became the foster or adopted siblings of the people I interviewed.

It is possible to reject a handicapper without actually abusing the child or putting him/her up for adoption. Rejection can take the form of emotional retreat or the withdrawal of love and affection. Grossman (1972) suggests this type of rejection may be caused by guilt, anxiety, or shame. When it occurs, this emotional withdrawal/emotional abandonment may have a profound influence upon other children in the family, too. I talked to a woman whose parents refused to keep their son [now forty-four] because they were ashamed that he had epileptic seizures. Until he was ten or eleven, he had occasional mild ones, but when he was twelve, he had a grand mal seizure. According to his sister:

> They wrapped him in a blanket and took him away. That had an impact on me. It was the last time I saw him at home. [He was taken to a boys home and eventually to a research-type hospital.] ... My parents were very old fashioned. Of course, thirty years ago this was something to be hidden, to hide in the closet. They were ashamed that this terrible thing happened in the family. [Interview #31]

This example of non-acceptance had tragic consequences. When the boy went to the institution, doctors told the parents about a new "miracle" drug that cured epilepsy. The parents signed permission to use it, but the dose was much too strong, and it left him totally paralyzed from the waist down and partially paralyzed from the waist up -- a much worse predicament than the original malady. According to the respondent, for years her parents carried this

"tremendous guilt, as if it was their fault." Even after he was institutionalized, a type of rejection continued; the family visits him only a few times a year, despite the fact he lives within an hour's drive. The parents also made the state his legal guardian. According to the respondent:

> At different times in the past, the homes and hospitals that he's been in have asked my parents, 'Will you take him home for a weekend?' 'Will you take him places?' But my parents never could. They kept thinking that if they brought him home for a weekend, it would make him want to come home all the more. It made it hard for my parents whenever they did go to visit him. He would, at the beginning, always beg them to go home with them. Eventually he did stop asking. [Interview # 31]

When I asked, "Do you think this had an effect on you,?" she replied:

> Oh, yes, but very subtle since I was so young when he was taken away. Not only were they very ashamed that this happened in the family, they began to have this terrible, terrible guilt of signing the release which paralyzed him. They never wanted to talk about it. When I was very young, visiting him in the state institutions gave me nightmares. To visit was very terrible, very traumatic. [Interview #31]

In some instances, the handicapper was not so overtly rejected. Instead, non-acceptance was disguised or concealed, parents showing outward signs of care and concern. An example of both overt and disguised rejection was presented by a man, who talked about his mother and father. His younger brother limps and has coordination

problems from cerebral palsy. This rejection includes both sons, able and handicapper. The respondent volunteered:

> He [the handicapper] required a lot of attention, and she [the mother] was unable to give this.... When he was younger, my mother waited on him hand and foot, because she had to, and she made sure that he knew that... She was over-abusive and just played games. We've both spent all thirteen years going to school in tears. I remember once she hit him and he got a scar over his eye.
>
> Q: What effect, if any, did this have on your father?
>
> A: If he had a hard day at the office, he'd take it out on us. My Mother would sit there and laugh. He [the father] is very passive. If something happened and my brother got a cut eye or a broken tooth [from being hit by the mother], he'd pretend it didn't happen. [Interview #29]

The respondent expressed hostility toward his mother, father, and younger able sister, and he admits that his relationship with the handicapper brother is based upon guilt.

Another example of non-acceptance was given by a woman whose sister had Prader-Willi syndrome, which left her somewhat physically disadvantaged and mentally retarded. The mother never adjusted to the fact of the handicap and for twenty years after the birth, she was an alcoholic. The mother could never bring herself to even pronounce the words "mentally retarded" or "handicapped." She always referred to the problem as "you know," as in, "Better not have a baby when you're past thirty-five or you might have a 'you know'." The three able sisters were not so devastated as the mother, and they've come to terms with the labels, but

it's still a larger-than-life issue in their lives [Interview #24]. In answer to the question, "How has your sister affected you?," she replied:

> It sounds a little cruel, but she [Barbara, the handicapper] disrupted what I knew as a pretty decent home. Before she was born, we did things. There was a family. My grandmother and my aunt lived with us. I was in an extended family. There were a lot of good times. I remember those abruptly coming to an end [with Barbara's birth] and not understanding my mother's drinking problems...I think I was in the seventh grade, and I had to do the Christmas shopping for the entire family, and I remember resenting it, and looking at Barb and thinking, 'This is why, this is why.' [Interview #24]

Several respondents brought up other behavior that could be also be seen as rejection, or non-acceptance. As an illustration, three respondents mentioned able brothers leaving home as soon as they graduated from high school [Interviews # 21, 33, and 37 (the last two respondents are sisters)]. The sisters saw this as deserting the family and the responsibility of caring for the handicapper. Perhaps it was withdrawal based on "survivor's guilt." Their brothers had muscular dystrophy, which is a death sentence. The disease continues to progress, muscles atrophing, and the person usually dies by their mid- to late-twenties. It must be hard to be the able brother in such a situation. Where their families were in family life-cycle may have been influential, too. During adolesence, siblings are particularly embarrassed by stares or questions about the handicapper, particularly same-gender siblings.[3] Able

siblings may feel loss and/or guilt as they begin to understand the full implications of the disability. Once they left the family, a number of factors may make it difficult to mend the breech, including guilt at leaving in the first place, embarrassment, or anger. I did not have the opportunity to search these people out, but it would be useful to interview able siblings in similiar circumstances. In none of the cases of those disabled as adults was rejection or non-acceptance displayed.

Conclusions

Most families adjust and learn to cope with the frustrations and sorrow of having a handicapper, but not all families are equally successful. A crucial element is how parents accept the handicap and communicate that acceptance to the other children. Families with the best adjustment develop understandings (or rationalizations) about why a handicapper was born into the family (or why one of the children had a serious accident).[4]

In reviewing respondents' comments on family attitudes toward the handicapper and the disability, it is obvious that the attitudes not only affect the handicapper but they also color the lives and emotions of the other children in the family. These attitudes can instill stress, guilt, anxiety, and resentment, but some attitudes promote pride and admiration toward the handicapper and empathy. Only among the siblings who fully accepted the disability and the

handicapper were no signs of psychological or emotional problems present.

In my sample, all four attitudes that Thomas (1980) discusses were present. However, simply because parents possess certain attitudes does not mean that able siblings automatically feel the same way. In particular, many respondents were critical about what they perceived as benevolent over-protection of the handicapper. Nearly half of the people to whom I spoke said that if they had a handicapper child, they would try not to over-protect him/her and would make sure the handicapper lived up to his/her potential.

Only a few respondents (and/or their families) used religion to "explain" the fact of the disability, although some found solace through their religious beliefs. Others found positive value in the disability for their handicapper sibling or redefined good and evil.

The respondents in my sample whose sibling become handicappers as adults, expressed more positive aspects or clearly defined benefits from the situation than those whose sister or brother has been disabled since birth or early childhood. Perhaps family life cycle is part of the reason. If the handicap was apparent from early-on, the respondents were either too young (or not yet born) to hear and remember the types of rationalizations and explanations their parents may have expressed at that time. They grew up knowing the sister or brother as a handicapper, and needed no explanations for the disability or coping

mechanisms were needed by them. On the other hand, when confronted later in life with a sibling whose status changed from able to handicapper, they need to account for this tragic new reality. Interestingly enough, questions or stares by outsiders did not have the same personal impact on these siblings as it did on those whose sister or brother had been disabled since early childhood. The reality of the situtation had been incorporated into their definition of the situation, and they had less trouble dealing with it. For those where the disability was a more recent occurrence, indignation, anger, embarrassment were all present.

Within my sample, as a group, males reported themselves to be much less involved with the handicapper than females. Perhaps this is to be expected since "emotional work," as a family function, is much closer identified with women in our culture, than with men.[5] Whether this produces aloofness as a form of non-acceptance/rejection, I don't know. It wasn't until I was coding and memoing the transcripts that I considered this possibility so I didn't have the opportunity to follow up on it.

ENDNOTES

1
For a more detailed discussion of the notion of social construction of reality, see Berger and Luckman (1967), Whitehurst (1977), Roth (1983), and Brittan and Maynard (1984).

2
Attitudes toward disability have been studied by a number of people. For the most part, I've relied on Thomas (1980) because he provides a typology that is particularly useful, but see Hewett (1970); Grossman (1972); Kew (1975); Wright and Schwab (1979), Featherstone (1980), Darling and Darling (1982), and Paul (1983) for additional information on parental and family attitudes toward the disability and the handicapper.

3
For a more complete discussion about embarrassment of able adolescent siblings see Grossman (1972), Kew (1975), Voysey (1975), Featherstone (1980), Milunsky (1981), Banks and Kahn (1982) and Darling and Darling (1982). Note that unlike my research, most of the work on siblings' attitudes toward a handicapper sister or brother -- including gender differences in embarrassment -- relies on the opinions of parents, teachers, and therapists.

4
It is beyond the scope of this work to fully go into the difficulties and problems that family members -- particularly mothers and fathers -- have in adjusting to a handicapper in the household. For more complete information, see Grossman (1972), Voysey (1975), Featherstone (1980), Thomas (1980), or Darling and Darling (1982).

5
A complete discussion of the expectations that women will assume responsibility to be the nurturers and childcarers of the family is beyond the scope of this chapter. For additional evidence and arguments, see Oakley (1976), Levande (1980), Groves and Finch (1983), Rimer (1983) and Brittan and Maynard (1984).

Chapter 7

> If someone was at fault, you could blame them and say, 'You take care of it.' But it's nobody's fault [that the brother has muscular dystrophy.] We're there. We have to do something about it, whether we want to or not. [Interview #30]

> I had to be good. There wasn't time for me to be sick. There wasn't time for me to misbehave. I was an extraordinarily good kid. Nobody told me to be good and helpful, I just sensed that it was necessary. [Interview #3]

> I've always thought that I have to make up for Vicky [the handicapper sister]. She hasn't been able to go to school. [I feel I must] make up to the [whole] family. [Interview #15]

TRIALS AND TRIBULATIONS: OBLIGATIONS AND STRESSES ON ABLE SIBLINGS

Introduction

The above are examples of what Schell (1981) terms "trials and tribulations" -- the misfortunes or annoyances or tests of patience or stamina that able children may experience. In many cases, it's difficult to determine if a certain example is a "trial/tribulation" (a minor inconvenience) or an indication that the able sibling is truly "at risk" (potentially a serious problem). I have made arbitrary decisions as to which section the example best fits, but I could well be mistaken for any particular

able sibling. Both "trials and tribulations" and "risks" are on a continuum from relatively mild to quite severe. Where a given sibling is along these continuums depends on a number of factors. An analysis of the interviews reveals that not all able siblings are equally vulnerable to trials and tribulations or being at risk for various emotional or behavioral problems. Differences in family composition and family life cycle impinge upon who does what activities. Also, bear in mind that no one who totally rejected the handicapper sibling volunteered to talk with me. That means that the findings of this study must be limited to those who do, or did, interact/assist with their handicapper sibling.

Sociologists who subscribe to a functionalist perspective, tend to assume that all family members willing assist their less advantaged members -- in this case, handicappers. According to this view, parents (especially mothers) and able siblings (especially sisters) provide the necessary physical, emotional, and psychological support. This does happen in some families but definitely not in all. The conflict perspective acknowledges that to provide these services/activities entails a cost -- a cost in time, patience, energy, and lost opportunities. Not all family members, and not all families, are willing to pay the price.

Some able siblings do undertake family activities that don't ordinarily fall upon children of that age. These may include heavy care-taking responsibilities or the need to protect the handicapper from physical or psychic harm. Some able siblings assume a surrogate parental role or feel the

necessity from an early age to always be reliable and dependable. Some may have strong pressures to excel -- or conversely -- not to surpass the handicapper (McMichal, 1974; Dunlap and Hollinsworth,1977; Marinelli and DellOrto, 1984).

Caretaking Responsibilites

In the literature, caretaking responsiblities are the most emphasized activity of able siblings (Grossman, 1972; Kew,1975; Voysey,1975; Cleveland and Miller,1977; Featherstone,1980). Because it is stressed so often, I specifically asked every respondent about their responsibilities for the care of the handicapper.

In intact families where both parents work outside the home, a sister is most likely to assume primary care for the handicapper. Someone must look after the handicapper and because of gender divisions of labor, often this responsibility falls on an able daughter. In Western families, the gender division of labor places the kind of emotional work and caring upon females -- mothers, wives, daughters, sisters, aunts.[1] For the most part, males are excluded from the necessity of doing that type of labor. Certainly among the respondents and their families, mothers and sisters did most of the caretaking activities of the handicappers. This expectation is so accepted in our society that no one I talked with seriously questioned the logic of it, although occasionally someone would mention it

as "too bad" or "unfortunate" that their sister or mother had to do it. Perhaps significantly, siblings who are, or were, the primary caretaker of their handicapper sibling did not volunteer to take part in the study. (I succeeded in interviewing one such sibling, but she did not volunteer and in fact, was somewhat reluctant to participate.)

An example of the reinforcement of gender-specific divison of labor and the early caretaking duties of some able sisters was given to me by a respondent. He is the oldest of six children. His sister, Jenny, is the oldest girl in the family -- ten months younger than he. She assumed care of the handicapper brother (who has spina bifida and is also somewhat retarded) before she was ten years old. When I asked him, "What effect (if any) did Tony's handicap have on your sisters and brothers?," he replied:

> Jenny was the one who had to be the mother. [Their mother worked full time as a scrub nurse.] She had the hardest time 'doing her own thing.' By the time she was nine or ten, she was starting the care of Tony. She gave him baths and changed the sheets, took care of him, put the [stoma] bag on him. [A stoma is an artifical opening in the abdominal wall for the urine to come out.] Interview #8]

That seems an extraordinary responsibility for a youngster of nine or ten, someone in upper elementary school. When I asked how she felt about having all the caretaking duties, he answered, "I don't know how Jenny felt about [having to help] Tony" [Interview #8]. I attempted to talk with this

woman, but for various reasons, including that she lives out of state, I was not successful.

I did interviewed one caretaker sister, but she did not come forward on her own. Her younger sister was a respondent and when we talked she mentioned what a "heavy burden" had been placed on her sister and suggested I speak with her, too. I got her name and telephone number. When I called to request an interview, she hesitated, but did agree to talk with me. Interestingly enough, she glossed over the heavy obligations; when I asked her, "Did you have a lot of the day-to-day care of Tim?," she simply replied, "Yes." When I followed up by asking, "Did you resent that?," again she answered only, "Yes" [Interview #37]. She was exceedingly reticent. All of her comments were brief with little elaboration. But from talking to both her and her younger sister, I had the sense that she did feel trapped into assuming the major responsibilities for her brother's care, deeply regretted the necessity of doing it, and was ashamed of her resentment.

This respondent had been the primary caretaker of her brother for over twelve years; she is an example of a conscripted caretaker -- someone who was pressured into taking the role. Bank and Kahn (1982) term this role, "vindictive caretaker" -- someone who "outparents" the real mother or father. I don't believe "vindictive" is a good term; for most people it carries a meaning that includes being unpleasant or mean. "Conscripted" is more accurate, indicating that the individual was elected, or self-

selected, into the role by genuine or emotional reasons. Most, or certainly many, conscripted caretakers provide good and tender care. According to Bank and Kahn, these caretakers feel abandoned by their parents and are enraged that they must assume responsibity for the major care of their handicapper sibling.

> By caring for one's siblings, one can wear a mask of responsibility and exaggerated concern and thus deny that rage. By loving and looking after a sibling, one can sublimate anger both at the depriving parent who has been neglectful and 'out-parent' that mother or father (Bank and Kahn, 1982:134).

This provides one rationale of why some women elect, or permit themselves to be selected for this caretaker role. There may be others. Clearly, complex reasons are involved including, quite likely, guilt and anger.

This respondent who played the conscripted caretaker certainly seemed to have these characteristics; she assumed near total responsibility for her brother's care, looking after him for over a dozen years. In so-doing, she "out-parents" both mother and father, but she seems angry and resentful about having to do it all. She took over the primary care for her handicapper brother for over half of her adult life.

There are probably some positive outcomes from filling the caretaker role, e.g., self-satisfaction from helping someone less fortunate and achieving a feeling of worth, but on balance, the potentially negative consequences outweigh

the positive ones, especially as in this case, when the role is of long duration. Family composition encouraged her selection as primary caretaker. The family consisted of divorced parents. The mother worked full time to financially support the family; the father could not, or would not, help in any way. For eight years the respondent had near-total responsibility for her brother. An able younger brother seldom helped. As soon as he graduated from high school, he left home and the family has almost lost touch with him. The fall after she graduated from high school, the younger sister (who was also a respondent) went to college. In a few years, she married and left the household. It has only been within the past year that the problem of the handicapper's care was resolved by securing a live-in male attendant. Finally, after twelve years, the older sister has been able to go to college, at age thirty-two -- but both sisters expressed anxiety and concern about what would happen if the attendant quits. My impression is that both sisters believe the older one would return, if necessary, to care for the brother.

In my sample, in all but seven families, the primary caretaker was the mother. The exceptions were: the woman just mentioned, where the single-parent mother worked to support them, and the eldest daughter inherited the caretaker role and, in effect, became a surrogate parent [Interview #37], a situation where the handicapper son was placed in a state institution and no family member was responsible for his physical care [Interview #31], a situation where the

handicapper daughter was placed in a foster home and returned home only for brief visits during which time her mother and able sister share in her care [Interview #15]. In four families where both parents are present, fathers also cared for the handicapper. In one family, after the birth of the handicapper, the mother became an alcoholic, other family members, including the father, shared all household duties and care of the child [Interview #24].[2] In another family the father assumed primary care for a son with celebral palsy [Interview #19] and in two situations, the fathers assumed near-equal responsibility for their children who had muscular dystrophy: a daughter [Interviews #23/#26 (brothers)] and a son [Interview 25].

To return to the respondents I mentioned earlier, the older sister was taciturn; in contrast, the younger one was very talkative. In answer to the question, "Have you participated in Tim's care?", she said:

> Oh, sure. Unfortunately most of that fell on my older sister. Every day we exercise with him. That requires a little bit of time. And then we have to bathe him and get him dressed. [We] help him when he needs to go to the bathroom. Until I was about sixteen, I didn't really help too much with that because my older brother and sister were there. But from then until six months ago [a period of seven years], I, probably more so than anyone else, was helping him. [From other things she said, this is probably doubtful on a day-to-day basis. Most of that time the oldest sister was still there, taking on the lion's share of the responsibilities.] But then I was married and moved out of the home. [Now] we had another person hired to help.

Q: Did your parents encourage or discourage you taking care of Tim?

A: My parents are divorced. They were divorced when I was going into the seventh grade; my father just moved out. I never regretted doing it [helping]. We weren't blatantly asked, but I think maybe we were expected to do it. I didn't feel like I was expected to do it, but if there's no one else there to do, of course, I have to do it. My older sister had the burden of his care -- much more than she should have. And I think after a few years, she started feeling like she shouldn't have that.

Q: Am I hearing you that there was some resentment?

A: Oh, yeah, but not toward Tim, never toward Tim, because we realized he had no [voice trails off]. It wasn't really toward my parents either. It was just that we realized we were in a Catch 22. We couldn't not care for him. We just sometimes felt, 'Why should we?' It's not our fault he's like that. It's not his fault. It's nobody's fault. I guess that's the hard part here. If someone was at fault, you could blame them and say, 'You take care of it.' But it's nobody's fault. We're there. We have to do something about it, whether we like it or not... I think the emotion [of resenting a handicapper brother] definitely scarred my sister. Just because she felt guilty because sometimes she would get angry or upset because she had to take care of him...My other brother had moved out and it was like she was the oldest, she was the first [born], and yet she was still there, at home, and we were going on with our lives. And she felt guilty because she realized, well, 'Here Tim is. He can't even walk. And he's very happy, never complains.' And then she'd start feeling guilty because she was mad at him or mad at herself, or whatever. Mad at the situation. And she'd start feeling guilty because, why should she be mad?

Q: Did you ever talk about this?

A: Sort of, I guess. [She shakes her head "no" as if to contradict herself] We don't really. We kind of always sensed what's going on with the other person without talking. And when we do verbalize, it's not always in a constructive manner. Being upset, or crying, or getting mad [isn't con-- structive]. One thing I wish we would have done differently was to sit down and talk it out. We all knew the situation, and we knew there were no alternatives so it was never talked about. But even though there wasn't really anything we could do about it, I think we still should have talked

about it. [She choked up a little here.] Emphasis in the original; Interview #30]

The younger sister also exhibited some of the features of the conscripted caretaker. She expressed anger and indignation at her parents and obviously resented deeply that she had to assume partial care of her handicapper brother. Late in the interview she volunteered:

> I don't blame anybody for his handicap, and I don't blame my parents for having him, but sometimes I get mad because I say, 'Hey, I didn't make this decision to have this child.' And even though there was no reason for them to suspect them of having a handicapped child, I still feel like it's my parents' responsibility to take care of him or to get someone to take care of him. [About the time he became a wheelchair user, the father moved out of the home and later got a divorce. Not until the past few months have they looked for and found a live-in attendent to help with the brother's care.] Because it was their decision to have a child. I had nothing to do with it. But then, I can't reason that out either, because I know the strain it is on my mother. And it's not her fault. [Interview #30]

This is a double-bind, what she referred to in another part of the interview as a "Catch 22." She'd like to blame someone for this situation, to allocate responsiblity, but there's no one to logically blame. It's an extremely frustrating situation for everyone involved.

Both these respondents see caring for this handicapper for years and years as a serious trial/tribulation and both exhibit indignation that the able brother left the household and refused to assume part of the responsibility for this

essential care. In their eyes, he is a deserter, guilty of dereliction of duty -- a military term for abandoning his post. Simmel terms a group member who leaves the group a "renegade" and renegadism is always a serious threat to the group (Simmel,1955; Coser,1976). A deserter, someone who leaves the family, threatens the group and its unity because s/he puts into question the values and interests of the group.

In my study, it was only men, brothers and fathers, who withdrew and physically deserted/left the household. I didn't inquire into family dynamics prior to the birth of the handicapper, and in most cases, the respondent was either to young or born after the handicapper, but there is a strong possibility that in these families a premium was put upon smooth relationships and little overt conflict. Many people are threatened by displays of anger or hostility and yet we know that no group can be entirely harmonious all of the time. A certain degree of conflict is an essential element in group formation and the persistence of group life. When the social structure stiffles or inhibites the expression and acting out of hostile feelings, then those feelings are likely to be expressed in some other way. In addition, in any relationship where the participants are deeply involved, there will probably be feelings of both love and hatred and if these aren't allowed expression, a severe strain is put on the group. One way to end that stress is to simply withdraw -- in this case, leave the family. That strategy can be unilaterally accomplished.

An expression of hostility can serve positive functions. It permits the mainenance of relationships under conditions of stress and this can prevent the group from totally breaking down. Conflict can perform group-maintaining functions by regulating the system of relationships. This might permit the strategy of "problem-solving" (Pruitt and Rubin,1986) -- pursuing an alternative that satisfies everyone. In this situation, being free to discuss ambivalent feelings about taking care of the handicapper could, in a sense, clear the air; it could prevent the accumulation of blocked and balked hostile feelings and frustrations. Certainly there are ample opportunities for frustration in the situation of having a handicapper in the family.

In this sample, only males withdrew and left the household, but there is a possibility that gender expectations restrained some women who would liked to have left. Notions of what is appropriate or inappropriate are so strong and widely accepted in this society that women find it much more difficult to leave the household to be on their own at a young age or to totally reject expectations that they will be nurturing and supporting. But psychological withdrawal was a strategy for some women, e.g., the alcoholic mother [Interview #24] and a younger able sister [Interview #41].

To return to the respondents, a handicapper who did not require much assistance was Grace, a thirty old woman who has cerebral palsy. Grace now lives alone in a supervised apartment in "independent housing" a project for

handicappers. She is only moderately handicapped; she gets about with a walker and can read and write at a functional level. Because she was born much later, the respondent wasn't required to assist her sister, but nonetheless, she shows resentment. There is a big gap in their ages. The parents both work as professionals, and after their handicapper's birth, they waited until they were better established in their careers to have the rest of their family -- three other children, relatively closely spaced. During the handicapper's first eight years, her maternal grandmother assumed primary care for her. In answer to my question, "I know eight years is a big difference, but did you spend any time with her when you were growing up?" She replied:

> I don't remember, but one thing I wanted to say is that because she's handicapped, and because I came eight years later, she'd say, 'Oh, if you get me a bowl of ice cream, I'll give you something.' And I'd go to the kitchen and get it for her, and she'd give me a kiss. When you're a little kid, five or something, you think you're going to get a 'thing'. That's the kind of relationship we had. It wasn't real. We weren't close. [Interview #9]

To me, this comment reveals anger and resentment, but anger with no socially legitmated outlet. Getting a bowl of ice cream (or some other equally trivial task) doesn't seem an unusual demand from an older sibling, handicapped or not. Nor does the reward -- a kiss. It's the type of thing that happens in many families, perhaps related later with

amusement and fondness.

Contrast that resentment for minor assistance with the attitude of a woman who helped care for her older brother who was seriously disabled with muscular dystrophy. Family composition helped dictate that the able sister participate in his care, but she did not resent that need. There were three children in the family: an older able brother who fled the household as soon as he was old enough to be on his own, the handicapper brother, and herself. The father was an alcoholic, who nevertheless managed to work two or three jobs at a time to pay for the high medical bills. She volunteered:

> My mother had almost total care of my brother. I helped. I had to help her carry him to the bathroom and carry him to the wheelchair for the day. In the evening, I'd carry him to bed. So I took on part of the care. [Interview #21]

From her entire manner it was obvious that she felt no resentment whatsoever about assisting with his care. When I asked her, "What did you think about Ted's future? Did you ever worry about that?", she replied, "I knew I'd take care of him if something happened to my parents. I knew that would be my responsibility, but I wasn't burdened [by the thought]" [Interview #21]. It seems like one of life's sad ironies that when she was a teenager, her brother died of muscular dystrophy, and later she had two sons with the same disease. Years ago it was not recognized that able siblings can be carriers of the defective genes that cause muscular

dystrophy. Her eldest son died several years ago; the younger has been a wheelchair user for many years.

Another woman mentioned that her assistance to her older brother (who was seriously disabled with cerebral palsy) involved only helping with general things like turning the lights or radio on, "little things he couldn't do for himself" [Interview #19]. Family composition played a role since she was thirteen years younger than him and he died when she was only sixteen. In this instance, the more basic care, like feeding and bathing, was always done by one of the parents, most frequently, the father. This was atypical behavior in my sample and, according to the literature, rare conduct in any handicapper's family. There is a wealth of evidence indicating that men seldom provide much of the day-to-day care of children, including a handicapper child.

My sample was typical as far as gender differences in who care of the handicapper. Fathers rarely assume that responsibility, nor are brothers usually required to assist -- even if the handicapper is a male. In my sample, there were two exceptions to this: 1) the twenty-four year old brother of a young woman who has osteogenesis imperfecta and 2) a twenty-two year old brother of a man who is mentally retarded and severely disabled with cerebral palsy. Family composition may explain why they assist. In the first situation, the respondent is the oldest of five children and the only son. For years he has been the physically strongest sibling, and this attribute probably explains why

he does lifting/carrying tasks. When I asked, "Did your parents encourage or discourage you taking care of Cathy?", he replied:

> I'd have to take her to the bathroom a lot. Considering her size, right now she weighs between fifty and sixty pounds, I got stuck with that a lot. Put her in the bathroom, get her a drink. It was nothing real heavy duty. [Interview #6]

"It was nothing real heavy duty," indicates that he does not perceive this as a "trial or tribulation." In the other instance, the respondent is the only able child [Interview #20]. There are no sisters to assume responsiblity for caring for the handicapper.

This assistance was atypical. In my sample it was more commonly the daughters who helped. If a sister is likely to assume this responsibility varies by family composition. In families where the father left the household (or had died) an older able sister often served as the primary caretaker, especially if there were only two children in the family -- the handicapper and the able sister. In my sample, this particular family composition was not present. In the other two instances where the able sibling was a brother, the handicapper's disability was such that he (in these cases) did not need much assistance, and what was provided was provided by the mother. In the one instance where the father was not present and the only able child was an older sister, the handicapper lived in a foster home and returns only occasionally for a weekend -- at most, that is

once or twice a month. When she comes home, mother and sister share responsiblity for caring for her. The father left the family when the handicapper's physical problems became acute. In response to the question, "Do you have to dress her completely?," she replied:

> Basically, 'Yes.' She's learning that in school. Now after she goes to the bathroom, she can pull her pants up and turn around and flush the toilet. That's a big accomplishment (she's learned) in the past few years. [The handicapper is now in her early twenties.] We have to get all the clothes out, and tell her to put her arms up, and she can do the rest.

Q: Can she eat okay?

A: No. She always has to have an apron or something on. She spills down the front of her. She usually uses a spoon 'cause she can only scoop. We have to cut up all the food into little pieces. She likes to go to McDonalds and we usually break the sandwich into bites or else we'll hand-feed the sandwich to her. She can do the fries okay as long as we give her only a couple at a time [Interview #15].

Family composition can also determine who helps people disabled as adults, although, for most of the people who became handicappers as adults, rehabilitation taught them basic things they needed to take care of themselves. One exception was a young woman who was severely beaten by two men. When I asked her older sister, "Did your parents encourage or discourage you taking care of Susan?", she replied:

> For a long time she couldn't care for herself. Someone had to feed her for quite awhile, take her

to the bathroom, dress her, and help her take showers. I used to help her with that a lot. Now she's able to do a lot of stuff for herself, but she still needs help with showering and buttoning her clothes.

Q: Did it bother you to have to help?

A: Yes, sometimes. It gets to be real tedious. [Interview #1]

Early Expectations to be Reliable and Dependable

In the meager literature about siblings of handicappers, the issue of reliability/dependability is stressed, but family composition has little influence upon which able siblings exhibit unusual "responsiblity" in the family. According to Seligman (1983), the extent to which an able sibling feels they must be dependable and reliable depends upon a number of other factors, including the fact that most parents are probably thrown off-stride by the birth of a handicapper, and their time, energy, money, and emotional resources are spent readjusting to that. Often this means there are correspondingly fewer of these resources available to be spent on the other children in the family. Certainly some of the able siblings in my sample believe that. A respondent whose older sister and brother had polio talked about this need to be always dependable:

I had to be good. There wasn't time for me to be sick. There wasn't time for me to misbehave. I was an extraordinarily good kid. Nobody told me to be good and helpful, I just sensed that it was necessary. At last my mom had a baby she could

> leave alone. Karen took so long to get dressed, so I had to get dressed by myself. I learned to clear the table and carry heavier things. I could sense something was going on even though nobody told me. [Interview #3]

Often the able sister assumed this responsiblity at a particularly young age. One of the respondents talked about this necessity to be responsible/dependable at an early age. She's a year younger than her brother who has cerebral palsy and epilepsy, at a moderate stage. The respondent said:

> I always knew that he was sick because I'd always have to get rushed over to the neighbor's house when they had to take him to the hospital when he had seizures. There were nights when I'd wake up, and I'd be screaming, 'Mom,' because he was having a seizure. I knew exactly what to do, I had to get a washcloth and a tongue depressor. [Interview #35]

Other trials/tribulations of able siblings of handicappers include pressures to excel -- to help compensate or make up for their handicapper sister or brothers inability to compete (Kew,1975). Sometimes this is referred to as the "Kennedy syndrome" since Joseph Kennedy apparently pressured his children to achieve a great deal to make up for what the older dead children (and a handicapper) could not accomplish. An example of this pressure to excel was given by the woman whose sister has tubulorous scorosis and is severely mentally retarded. The respondent volunteered:

> Through school, I've gotten pretty good grades, and I've always thought that I have to make up for

> Vicky. She hasn't been able to even go to school. [I feel I must] make up to the [whole] family. [Interview #15]

There is also the reverse of this -- pressure <u>not</u> to surpass the handicapper sibling in any way -- as if it would be unfair to achieve more than they. The woman whose older sister and brother had polio before she was born said:

> I'm a real underachiever, and I know I am. I'll get sick if I know I'm doing well. I can't take compliments. I've thought about this. I can say a lot of this is because of my brother and sister, and I knew I could be better than they could. They are older than me so what right do I have to be better than they are? I still feel that. Rob never graduated from college, and I'm twenty-two-and-a-half and only a sophomore, and I'm having the damnedest time staying in college. I don't feel I have a right to succeed....and to think I could make more money than my older brother. I'm getting a headache right now just thinking about it. [Interview #3]

In addition to these stresses, some families seem to have a double standard for their children. The able children have to follow the family rules, but the handicapper has fewer and less rigid expectations and any transgressions of those rules are overlooked. This can result in resentment. In answer to the question, "How do you feel toward your parents?":

> I resent them a great deal -- especially my mother. She doesn't treat us alike at all, and it's getting worse instead of better. Max [a sister who had been a handicapper as a young child] notices it too, so it isn't just me. When I was chosen senior queen, Mom said, 'Oh, that's

> nice, dear.' When my sister was chosen sophomore princess, it was the biggest thing that ever happened. When I'm home from school [college], Mom nags me to pick up my coat, etc. while she'll wait on my sister hand and foot [even though the sister is now "normal"]. [Interview #2]

Another example of the double standard and the resentment it can cause was related by the woman whose sister was severely beaten two years ago. This resulted in a head injury, partial paralysis of her left side, and some brain damage. In the nearly two years since the beating, she's moved from being a wheelchair user to the point where she can use a walker and take a few steps unaided. When I asked the respondent, "How do you feel toward your parents?" she answered:

> I think there was a time when I resented the time and attention they gave Susan. There were times I felt like I wasn't getting enough attention, but I got over it real fast. But I still resent that when I got the chicken pox, and I was really sick, I was ignored. They didn't realize how sick I was, and my mom was mad at me for not doing the house work. They weren't paying attention to my physical problems. Susan was getting all the attention. [Interview #1]

Courtesy-Stigma, Embarrassment and other Trials/Tribulations

Because illness is seen as so threatening to our everyday world, physically-based incapacity becomes central in restructuring not only the life of the handicapper but also the lives of people who interact with them. Able

people become concerned that close contact with the handicapper may result in their being treated differently than "normal" individuals. This is termed "courtesy stigma."[3] Courtesy stigma involves fear of social exclusion and the notion that siblings of the handicapper, or other close associates, are guilty by association.

Because courtesy stigma is mentioned frequently in the literature (Birenbaum,1970; Thomas,1980; Shearer,1981; Sensky,1982), I was particularly interested in whether or not the able sibling felt that s/he was ostracised or treated differently. I asked the first few people I interviewed if they felt they were treated differently because they had a handicapper sibling. All said they were not. This may be true, but there is also the possibility that they feel this is the morally correct answer. To see if the able siblings do feel stigmatized or disgraced by their close association, I dropped the specific question and tried to learn their feelings from other responses.

My first interview was with the woman whose younger sister was permanently injured by an "accident." The entire incident was never really explained. After much probing I found out that the night of the accident Susan had taken her brother's moped and gone to a party, against her parents direct orders. When I asked the nature of this accident, I was told that Susan had been severely beaten by two men. This resulted in a head injury, brain damage, and mobility problems on the left side of her body. She's had surgery on her foot to lengthen the tendons and extensive therapy, both

at a special facility for brain injured young adults and at a local hospital. She was in a wheelchair for awhile, and now she uses a walker. She can use crutches for a limited time, and now she can take a few steps unaided. Several times I tried to probe for more of the details, and each time the respondent skirted the subject. I don't know if her sister was raped or if the two men were ever found and arrested, but my sense is, they were not [Interview #1]. When I asked, "Has Susan's handicap made a difference in your life?," the answer indicates that the respondent does feel the stigma. She told me:

> Yes, I get tired of the questions from people. I find myself avoiding people I don't know that well. You get sick of them asking about her -- especially those who were supposedly her friends. [Interview #1]

I also asked "Do people stare at you when you're out with Susan?" "Yes. It was really hard to overcome at first. We've dealt with all the looks. It seems like everyone stares." Later, she volunteered, "When we were all home, we went to church two or three times a month. Now it's hard to get Susan to church." Perhaps there are a lot of steps at the church, but in other parts of our conversation she's mentioned that they do manage to take Susan to the beach, shopping, and other public places. Are they sensitive to the reactions (real or imaginary) of the rest of the congregation?

Another way I tried to get at courtesy stigma was by

asking about embarrassment. I asked a twenty year old woman, "Think back, was there any time that being with Gary was embarrassing to you?" (He has cerebral palsy at a moderate handicap level.) She replied:

> Church was real embarrassing to me, especially when we were younger. I'd go downstairs to Sunday School, and sit with my friends, and five minutes later he'd walk in like he does [clumsy and slow], and he'd sit all by himself. I look back now, and it's really selfish of me to do that -- not sit with him. [Interview #35]

It's interesting that both these respondents singled our church as a place where embarrassment was particularly acute.[4] Certainly, embarrassment is a common response to a sibling's handicap. One form this embarrassment takes is reluctance to invite friends to the house. The reluctance may be because of the social stigma of having a handicapper, or perhaps, fear of what that handicapper may or may not do. In an effort to find out about feeling about social isolation and reluctance to have friends over, I asked a respondent whose brother is retarded and has spina bifida, "Was there any time you were embarrassed by your handicapper sibling?" He said:

> When Tony was younger there was a great deal of embarrassment because he had this stoma. The glue that was holding it on would break open and the urine would spill out. At first we were scared to bring people home because of Tony and the way we lived. [He felt the housekeeping standards were not equal to that of his friends' homes. Interview #8]

The phrase, "and the way we lived," is important. Children, particularly adolescents, are embarrassed at any deviation from the norm. They strive to fit in and be like their peers. Some of the reported embarrassment of able sibings may be only peripherally related to having a handicapper in the home.

Other trials and tribulations mentioned in the literature were also brought up by at least one or two of the able siblings I interviewed. These included: diminished resources available to spend on the other children (because of the extra expenses of a handicapper), less time and/or energy spent on leisure and recreational pursuits, social isolation from friends, relatives and neighbors, and general feelings of pessimism about the future of the handicapper. These were also reported by mothers, social workers, and counselors. In my sample, none of these were defined as key issues by respondents. I asked each of them about it, but almost to a person they indicated that as far as they were concerned, these were minor inconveniences and not "trials and tribulations" for them. Since in my sample I directly asked siblings and the published reports rely on second-hand evidence, perhaps the parents and professionals mistakingly thought these were important concerns for other children in the family.

Conclusions

Both in the literature and in respondents' families, there are definite gender and age differences about who assumes the obligation to care for the handicapper. Women usually do this kind of family labor -- most frequently it falls on the mother or eldest daughter/sister.[5] This phenomenon is also true for caring for the elderly or for a disabled spouse or parent. In the families of handicappers, this type of gender-specific expectations seem to be accentuated and become routinized. This chapter terms this kind of activity as a potential "trial and tribulation," but at least for some able sisters, it probably places them "at risk" for serious emotional problems.

In an article, "The Developmental Tasks of Siblingship Over the Life-Cycle," Ann Goetting (1986) reports that when parents do not, or cannot, carry out their responsibilities, siblings may provide needed resources for one another. Certainly, in this sample, this seems to be the case. I found that in mother-headed households, and/or where the mother worked outside the home, an older sister assumed the responsiblity for the handicapper. Goetting's findings support this notion; she writes:

> It is probably true that single-parent families, low-income families, and families where both parents participate in the labor-force are more likely to deligate caretaking responsiblities to siblings, as are families burdened with many children or with children who are in some way handicapped and therefore needful of close supervision (Goetting,1986:705).

For the most part in society, it is women who are involved in the caring relationships (Levande,1980; Graham, 1983; and Brittan and Maynard,1984). Graham writes:

> Although a universal need, only certain social relationships are seen to facilitate the giving and receiving of care. In general, caring relationships are those involving women: it is the presence of a woman -- as wife, mother, daughter, neighbor, friend -- which marks out a relationship as, potentially at least, a caring one... Male relationships, by contrast, are seen to be mediated in a different way, with the bonds -- ostensibly at least -- based not on compassion but on competition (Graham,1984: 15-16).

ENDNOTES

1
See Brittan and Maynard (1984) for a more complete discussion of the types of activities which women undertake within the family and the forms of female consciousness that are related to the sites of female activity in the home: 1) the notion that women see themselves primarily as caring, seeing for and catering for other family members' material and emotional needs; 2) women see themselves as coping, taking on the responsibilities and obligations of carer and accepting culpabilitly for faults and feelings of herself and family members; and 3) recognize that succoring, providing a sympathetic ear for any emotional problems they encounter, is another obligation.

2
Caring for frail and infirm elderly parents is a similar situation to caring for handicappers. Levande (1980) suggests that complex behaviors characterize a family in the process of either "self-selection" or "electing" a caretaker for elderly parents. According to her, "The child who ends up in the caretaker role may ironically be the one who has been least loved and is trying to reestablish a once-desired special relationship with the parent" (1980:306). Also see Walker (1983).

3
A complete discussion of courtesty stigma is beyond the scope of this chapter. For additional information on courtesy stigma, see Goffman (1963), Birenbaum (1970), Field (1976), Thomas (1980), Sensky (1982) or Livneh (1984).

4
Church was singled out as the place where some respondents were particularly embarrassed. Church is an institution with relatively rigid mores and expectations and perhaps the environment is perceived as less supporting than some other places. This is not true of all the respondents; some singled out church and church members as being particularly supportive.

While few of the people I talked to admitted to being embarrassed by their handicapper sibling, in the meager research on families of handicappers, embarrassment by able siblings is a dominant theme. For more about this topic, see Grossman (1972), Kew (1975), Featherstone (1980), and Milunsky (1981).

5
Feminists views on "caring" -- who does it and why -- are beyond the scope of this chapter, but for an interesting discussion of what caring means and what it entails, see Graham (1984). For a discussion as to whether parents/

Graham (1984). For a discussion as to whether parents/ mothers are the ideal people to care for ill children, see Oakley (1976). See Oliver (1983) for the social context of caring for wives and Ungerson (1983) for arguments about: 1) contradictions between the state's view of the family and roles within it and 2) how women and men actually view the family and how this may ultimately undermine the strength of gender stereotyping.

Chapter 8

> After Jacob [an older brother with muscular dystrophy] died, I dreamed about him. He'd sit up in the coffin and say, 'Susan, get me out of here.' [Interview #25]

"A POPULATION AT RISK?": POTENTIALLY SERIOUS EFFECTS OF HANDICAPPER SIBLINGS

Introduction

The quotation that introduces this chapter indicates that, for at least some able siblings, having a handicapper sister or brother is an important event in their lives. Even their dreams reflect the symbolic significance of this unique social relationship. But does a handicapper in the family put able siblings in jeopardy? Are they, as San Martino and Newman (1944) and Kew (1975) suggest, "a population at risk?" And if so, are all handicappers' siblings equally endangered? Are certain able siblings more likely than others to be harmed by the relationship? In this chapter, I discuss how family activities, composition, and life cycle influence the potential of risk.

As I have emphasized throughout, it is impossible to predict how any particular brother or sister will be affected by having a handicapper sibling, but common patterns and responses can be discerned. Some respondents report temper tantrums, disruptive behavior, psychosomatic pains and illnesses, and dreaming/fantacizing about the

handicapper. These can be seen as indicators of considerable stress. The meager literature on able siblings mentions the possibility that they over-identify with the handicapper, question their own worth, exhibit resentment, and may fantasize about the handicapper and his/her future.[1] The essential question is: do these indicate able siblings are truly "at risk?"

Behavioral Problems and Attention-Seeking Behavior

One of my original goals, prompted by a review of the literature, was to ascertain if able siblings really are potential victims. To that end, I asked the respondents if, when they were younger, they'd misbehaved, engaged in other attention-seeking activities, or experienced psychosomatic illnesses. Most of them replied, "No," to all of these. This may have been the case, but possibly they hid those feelings, even from themselves. Or perhaps they were aware of them, but didn't want to discuss it because, to them, this indicated some sort of character flaw.

In the interviews, only a few people mentioned having temper tantrums. When asked about it, one man said, "Oh, Jeeze, [I had] wild ones, until I was fourteen. I had all sorts of emotional misalignments [sic]." His family had an aloof father, abusive mother, a younger sister whom he saw as favored, and the handicapper brother. [Interview #29].

Another respondent, whose sister is retarded and has

tubulorous scorosis, answered the question, "Did you ever have temper tantrums as a child?," with, "Oh, yeah; I used to scream and scream, probably frustration was the main thing. I don't know what the cause of it was" [Interview #15]. Her family composition was that of a single parent household with just the two daughters -- able and handicapper. Later in the interview, she reported that she felt pressures to make up for her sister's inability to lead a "normal life."

Another facet of being "at risk" is having serious problems in school. When asked, "Did you ever have difficulties in school?" one young woman replied, "Yeah. I couldn't make friends in high school. I couldn't get along with anybody" [Interview #29]. When I probed to understand, she didn't seem to know if this was connected to her sister's situation -- it was just "the way it was." Another woman I spoke with has two adopted handicapper siblings. She answered the question with:

> Yeah. I was a problem child. I had no friends. I don't dress or act like everyone else. I would do stupid things, like lie under my desk, wouldn't do any of the work, just be a total pain in the butt. I had that reputation all through junior high and high school. I was not in the clique so I didn't have a lot of friends. I wasn't real happy. [Interview #18]

The respondent was also an adopted child. She indicated that she had a lot of difficulties prior to joining the family and it took quite some time to straighten things out

in her life. She calls herself "a hard to place child" and apparently most of her problems pre-dated entry of the handicappers into the family. Her comments are important because they indicate that an able sibling's problems or difficulties should not automatically be attributed to having a handicapper sister or brother. Other factors may be involved.

I stopped asking whether respondents had problems in school part way through the series of interviews since almost everyone denied that this was something they experienced. Whether this is true, or not, I have no way to ascertain. It could be that the people who volunteered to talk about their handicapper sibling may be more accepting and better adjusted than those studied by others.[2]

Health Problems

At the start of the interviewing process, I used the literature to generate topics of discussion. One of the dominant themes in the literature is how many able siblings experience psychosomatic pains and illnesses (Grossman,1972; Featherstone,1980; Beckman-Bell,1981; Milunsky,1981). These are seen as efforts by able siblings to gain attention from preoccupied or overworked parents. Because most of the respondents answered, "No," when I asked if they had ever experienced psychosomatic pains or illnesses, I asked this question of fewer than half of the people to whom I talked. Four women told me that they had experienced psychosomatic

pains or an able sibling had. One respondent replied, "Probably, I would imagine (I did). My mom used to think that my headaches were because of that [having a handicapper sister]" [Interview #15]. She is from a family consisting of a single-parent household where she is the only able child. When I asked, "Is there any way you are like Maxine?" [a sister who had been diagnosed as having muscular dystrophy], another respondent replied:

> When Max was younger she was very thin -- almost skeleton like. She was very, very thin. When I was a teenager [some years later], I became anorexic -- not to the point of being life-threatening, but very thin. My parents got very concerned, and I think I liked that concern. I think it [my problems] had a lot to do with her disease. I went to a psychologist for awhile. I dropped out of extra-curricular events. I dropped out of cheer leading, and I began to really withdraw. I eventually got over it. [Interview #2]

This was early in the interviewing process, and I failed to follow up with other inquiries to try and learn her own understanding of why this anorexia started and ended. Several years later, at the time of the interview with me, she showed no signs of being anorexic. But family composition may have played a part in her problems. Their are only four people in the family: she and her formerly handicapped sister and the parents -- both of whom are professionals with fast-paced careers. The mother continued to work throughout the therapy process and little outside help was provided. The respondent was required to look after her younger handicapper sister at a very early age,

and she expressed resentment at having to perform this work.

The young woman whose brother and sister had polio before she was born came from a different type of family. She described her health problems:

> I was on Lithium for a long time after high school. I didn't go to college, and they diagnosed me as 'manic depressive.' I sort of felt my mom going, 'Oh, my God, now my favorite child who is everything, now what does she have?' I felt my mom going right back into that role of super-mom to take care of me. I could see that recurring role in my parents eyes -- 'Oh, my God, we're going to have to go through this thing again.' And my brothers and sister looking at me and saying, 'You can't do this. You're the one who we're counting on.' I was real immobilized; I wouldn't move. But I didn't want anyone to feel that they had to take care of me. I wouldn't let my parents come to the hospital for a long time. I took myself off Lithium; I can't stand drugs. When I was in the manic stages, I drank a lot. I went into another form of therapy. I don't want it to be that I can't change it [her mental health.] My parents keep telling me I'm just like Rob and Karen. I can't believe I can't do something about it. I believe it's because I had to grow up so early. It's because my brother and sister had to have so much attention that my behavior problems have become so much of a problem, so late in life. [She's 23 now.] I never went through a rebellious stage. I never did anything they'd be ashamed of. And if I did, I made damn sure I didn't get caught. I started doing all those rebellious things when I was nineteen or twenty. When I was younger, there wasn't enough time in the day to punish me. [Her Mom was too busy to discipline her. Interview #3]

The respondent was the youngest of four children, born nearly a decade after the siblings with the polio. Her family was in a later stage of life cycle than most of the people to whom I spoke. Her family was not small, nor did her mother work outside the home. Her mother was very busy

working in polio and birth defect support groups and was also politically active, trying to get more benefits for handicappers. Her father was a professional, preoccupied with career and financially providing for the family. From an inappropriately early age, the respondent attempted to take care of the siblings with her assistance and emotional support. It's only recently that she realizes that she over-identified with her handicapper siblings and her mother's need for assistance.

When I asked another young woman about psychosomatic illnesses, she said they had never been a problem for her. However, at the end of the interview she brought up the subject. While she had not experienced psychosomatic illnesses, she thought her youngest brother did. He is 14 months younger than their handicapper brother, who has epilepsy, is severely retarded, and cannot speak. She volunteered:

> I recall something. When you were asking about the psychosomatic illnesses. I didn't, but I believe my [able] brother did. He went through a period when he couldn't walk because his leg was in so much pain. They did an operation and they removed some muscle [for a biopsy], and there was nothing [wrong]. After the hospital stay and the recuperation, he was fine. He was probably about seven. [Interview #14]

At that time, the handicapper was about eight years old and received a great deal of the parents' time and attention. Besides his other problems, he still is not completely toilet trained. In terms of family composition, the

handicapper brother was, and still is, "baby" of the family. The able brother, who is the youngest child, never had the opportunity to be indulged as the baby. That role was permanently filled. But when he was in the hospital he succeeded in getting a great deal of attention, and briefly, he was also "handicapped." Perhaps he found the role not that rewarding. After the biopsy established nothing physically wrong with him, he "recovered" and has apparently had no further problems. In this family, the mother works part-time, driving the handicapper school bus, and both parents devote a great deal of time and energy to political activities on behalf of handicappers.

In retrospect, I prematurely stopped asking questions about behavior and health problems. At the time, it seemed that almost everyone answered, "No." It was only later, as I began analyzing the data, that I realized that a significant minority were reporting these problems. If I had it to over again, I would continue to ask these questions.

Over-Identification, Jealousy and Guilt

Family dynamics are complex and multidimentional. One aspect of that interaction is how children develop a sense of self. All children use their families to define who they are, and certainly, siblings are a major source of personal identity. When one of the siblings is a handicapper, this

identification can create what Featherstone (1980) terms "a particular sort of vulnerability." The handicap may encourage them to question their own capabilities, potential, and health. An example of this over-identification is the respondent whose sister and brother had polio in their youth. They are ten and twelve years older than her. She volunteered the information that their handicaps have influenced her life a great deal. When she discussed her sister (now thirty-two), she said:

> I always saw my sister as more 'special' than any of us [the other three children]. I saw her as the smartest one. She's very thin, naturally curly hair -- everything I'm not. I was athletic. I was pudgy. I had straight hair. I told dirty jokes. People have told me I'm creative, but I tell them, 'No, Karen is the one who is.' And people tell me I'm funny, but I say, "You should see my sister.' [Interview #3]

This type of identification was unique among the respondents; I saw little demonstration of it among the other people to whom I talked. This respondent's identification allows her to empathize and understand the handicappers' lives. Most of the people I interviewed spoke with affection of their handicapper sister or brother, but empathy and understanding were rare.

Another response found among able siblings is jealousy; it is a common emotion among most siblings. According to evidence presented by Bank and Kahn (1982), jealousy and envy are "normal but transient emotional reactions" of siblings. As an illustration, of this transient quality,

the woman whose sister has recovered from a form of muscular dystrophy, said:

> When I was little, I was very jealous of the time and attention that Max got. She got to stay home on Wednesdays to rest, and I had to go to school. I couldn't understand why I couldn't stay home, too. [Interview #2]

When jealousy is directed toward a handicapper sibling, it may take the form of hostility toward the handicapper or someone else. If it is directed elsewhere, it's termed "disguised jealousy" (Darling and Darling,1982). Jealousy, disguised or otherwise, may contribute to an individual acting-out or turning to drugs or alcohol. An example of disguised jealousy may be the following -- certainly it is an example of hostility toward the mother. This is the same respondent who was just mentioned. When her sister was younger, she required a lot of therapy and attention. According to the respondent, her sister is no longer disabled; now she is "essentially normal." Repeatedly, the respondent mentioned how close they are and how much she loves her. When I asked her about family characteristics, the respondent discussed her mother and her relationship to both daughters:

> My mother is asking for a totally different relationship with my sister than she had with me. And I think a lot of that has to do with whether she feels guilty or if she wants Max to be the all-American girl. She takes great concern with her life -- her social life, her career life, where she's going to college, what she's going to

> wear the next day, who's going to ask her out, what club she's going to join. And with me, it was -- I always like to give this example: I was senior queen of my class and Max got sophomore princess. When I was queen, I got a hug and that was it. And with Maxine, it was the epitome of joy, and 'God, this is great!' It was always that way, and it gets more and more that way.
>
> Q: How do you feel about that?
>
> A: I resent it very, very much. [Interview #2]

The comment, "I always like to give this example," indicates that the respondent has thought about this before and has come up with a script on how to deal with it. Favoritism probably occurs in most families,[3] but left unchecked, it can create rivalries among the siblings. Whether or not the mother actually favors the younger daughter is not the issue; what is important is that the respondent perceives that she is the least-favorite child and this generates resentment. In this family, both parents are professionals and there are just the two children.

Another response I found among respondents was guilt. If a sister or brother has a prolonged or chronic illness in childhood, or a serious accident resulting in a permanent handicap, guilt feelings may emerge. According to Arstein (1979:187):

> Aside from genuine sympathy and fears for this loved and afflicted sister or brother, the siblings may feel envious and resentful of all the anxious attention given the sick child, particularly if for the time being their own needs are somewhat neglected. While they are worried about their siblings, the others may feel ashamed and guilty over their angry thoughts.

Some of the able sibling respondents experienced guilt because they can do things the handicapper cannot. As an example, when asked, "How do you feel toward Susan?" (the young woman permanently disabled by a beating), the respondent replied:

> I'm the one who feels guilty. She never shows it if she does. It's something we need to talk about. She was a freshman [in college] when the accident happened. She joined the track team as a walk-on, and she was doing real well. She was an honor student in psychology, and she's a writer. She's so creative and so imaginative. I was always jealous of her because I have no imagination whatsoever. It hurts me to see her not in school. [Interview #1]

Another able sibling, whose brother limps and has coordination problems with a relatively mild case of cerebral palsy, told me:

> I have real guilty feelings for leaving [home]...I think it's because I've always had health and stuff like that. Of all the family, I feel closest to him...I feel real sorry for him, and I'm making it up by sending him money. I don't have the time, and I guess I feel guilty for not spending the time with him that I should. [Interview #29].

His is the household with the abusive mother and passive father (his own terms for them). Despite the statement, "I've always had health," he later mentioned psychological problems and feelings for which he'd like to seek treatment.

Dreams/Daydreams/Fantasies

After interviewing nearly half of my sample, in the process of coding and reflecting upon the data, I noted that some respondents discussed their dreams about their handicapper sister or brother. This was such an intriguing topic that in each interview I began asking, "Have you ever dreamed about _____ (the handicapper sibling)?" The question never failed to startle and/or amuse. Many of the respondents immediately declared, "No," while others said they believed they had dreamed about him/her but they could not remember the specific content of the dream. About a third related dreams about their handicapper sibling; most of them did not attempt to interpret the dream -- they just reported what they remembered.

As illustrations of respondents' reactions to a handicapper sister or brother, I have included some of their dreams or daydreams. There are patterns to these individuals' dreams and fantasies that indicate these are related to their waking experiences. The fragment of a dream that opened this chapter is an example of how conceptually rich dreams -- awake or sleeping -- can be. Reported dreams may be useful in understanding the experiences, stresses, and conflicts of able siblings. Dreams are not just reflections of the dreamer's psychological state: they are also symbolic representations of actual, or fantasized, social relationships.

The late Calvin Hall, who was director of the Institute of Dream Research in Santa Cruz, wrote:

> The most important information provided by dreams is the way in which they illuminate the basic predicaments of a person as that person sees them. Dreams give one an inside view of the person's problems, a personal formulation that is not so likely to be as distorted or as superficial as are the resports in waking life... Our thesis is that dreams are one dependable source of information regarding subjective reality (Hall,1959:129-130).

Considering the many people who maintain they never dream, or say they cannot recall their dreams, the fact that one-third of the respondents who were asked to relate dreams about their handicapper sibling could do so, may be significant. Five respondents reported specific dreams of their handicapper sibling and five reported fantasies/day-dreams that they had about them. No one was specifically asked about daydreams or fantasies; that information was volunteered.

Historically, there has been a long tradition of dream analysis -- from Freud to Jung to Adler to Hall. During the last three decades, a great deal of research has been done on dreaming, particularly about the biological basis for it. Apparently dreaming is a universal human experience which serves some process necessary for healthy psychological functioning (Hall,1959). In another work, Hall wrote:

> A dream is a succession of images, predominantely visual in quality, which are experienced during sleep. A dream commonly has one or more scenes, several characters in addition to the dreamer, and a sequence of actions and interactions usually involving the dreamer. It resembles a motion picture or dramatic production in which the dreamer is both a participant and an observer (Hall,1966:3).

Information about dreams and daydreams can be found in a variety of places. For instance, in a Seixas and Youcha book about children of alcoholics, dreams are linked with the dreamer's waking reality. They write:

> Fantasies are not arbitrary; dreams (waking or sleeping) have meaning. They may lighten the burden by serving as an escape, they may have unconscious significance that is difficult to understand, or they may be used to explain the inexplicable. If they serve as an escape, they are usually full of sunshine and happy endings; if they originate in the unconscious, they appear strange or difficult to believe...and if they are explanations of the unknown, they help clarify the incomprehensible (Seixas and Youcha,1985:25).

This is equally applicable to able siblings of handicappers.

Some investigation of awake-fantasies of able siblings of handicappers has been done. Featherstone (1980) and Seligman (1983) have investigated conscious daydreams of able siblings. Their population was primarily siblings of mentally retarded individuals. In their fantasies about handicapper sisters and brothers, Featherstone observed themes of sorrow, frustration, and rage as well as thought about their future responsiblity for the handicapper. Some of the fantasies may also be positive or supportive in nature, too. Seligman writes:

> Fantasy often plays an important role in that it allows the child to express conflictive material, which helps to release pent up tensions. It may be that fantasy also allows for the acting out, through imagination, of solutions to dilemmas thought to be unsolveable (Seligman,1983:156).

In Calvin Hall's pioneer research, he and his staff classified thousands of recounted dreams into four basic components: settings, characters, actions, and emotions. According to Hall, a dream is like a play, in that it nearly always has a setting, which is usually conventional and familiar. A dream also has a cast of characters, which can be classified by age, sex, and relationship to the dreamer. Members of the dreamer's family make up a high percentage of dream characters; Hall speculates that we dream about family members because those are the ones with whom we are emotionally involved and about whom we have mixed feelings of affection, antagonism and unresolved tension. Hall wrote, "We dream about people who are associated in some way with our personal conflicts" (Hall, 1966:33).

An analysis of hundreds of dreams reveals that most of dream actions involve movement of some type, but passive activities like talking, watching, or seeing are also common. As for emotional content of dreams, unpleasant dreams are more numerous than pleasant ones. According to Hall's findings, "The unpleasant emotions of fear, anger and sadness are twice as frequent as the pleasant emotions of joy and happiness" (Hall,1966:40).

The respondents' dreams seem to be connected with their waking reality. In dreams and daydreams reported by my respondents, settings were usually the home or some other arena where the disabled sibling is/was commonly found. Characters included at least the dreamer and the handicapper, and the action varied, but frequently it involved

some "miraculous" activity or recovery on the part of the handicapper. Emotions ranged from calm acceptance to excitment and joy over the recovery of "normal" activity. However, as might be expected, many related dreams were sad.

In the dreams (both awake and sleeping) told to me by respondents, a number of themes seemed obviously connected to the reality of having a handicapper sibling: previews of anticipated experiences, a desire to be a savior and, linked with that, to be respected for saving the handicapper; a wish to have the sibling escape from the dilemma of disability, the notion that someone or something (a fairy godmother) will change things, sorrow about the disability or death, and guilt.

Some respondents had dreams that were previews or rehearsals of experiences that may have to face in the future, such as death of a loved-one. When I asked a man if he ever dreamed about his brother whose cancer of the spine is progressing rapidly, he replied:

> I don't know, just sleeping-type [sic] dreams. I find my thoughts sometimes going that way. Sometimes I ponder, the week or so after his last surgery, what it would be like if he weren't around, if death happened. That kind of haunted me for awhile. That kind of thing disturbed me. 'What would I do? How that would affect my life and stuff, [affect] my family in general?' It's kind of a morbid thought. After thinking about it, I have a calm feeling about possible acceptance of it. I don't know whether it's forethought that something may occur, but if something did happen, I think I'd be better able to handle it than I would have before. It wouldn't be the shock it would have [been] before. [Interview #32]

I got the impression this was a dream, but he may have meant daydream. In A Modern Dictionary of Sociology, daydreams are defined as:

> A type of mental fantasy that may be but is not necessarily wishful or purposeless thinking or a withdrawal from reality. For most people it is often an important way to preview or experience various possible roles they believe they desire or they expect to play in the future. Hence day-dreams may not only be creative but may also play an essential role in the preparation of realistic social behavior (Theodorson and Theodorson,1979: 102).

Certainly this served as a way to preview or experience the unthinkable -- "if death happened," the respondent believes he could now deal with it better. That is one function of fantasy, to help prepare you for roles you may have to play in the future.

Two examples of wishful thinking and the significance of sibling social relations that deviate from the norm are illustrated by a woman, talking about her only brother who has a relatively mild impairment due to cerebral palsy:

> There have been times, especially in my adolescence, you know when you have a brother that's a year and a half older, it's like, 'I wonder what it would be like to have a brother that played football or went to my high school?' and I could say, 'Hey, could I have a ride home?' or 'That's my brother.' Or you could have the guys over and stuff like that... It's nice to think about -- if my brother played football for Michigan State or U of M or something. [Interview #35]

Later in the interview I asked her, "Do you ever dream about Gary?" Her answer reflected another type of wishful thinking -- the desire to have a close, loving relationship with her brother. Unfortunately, while her brother's physical handicap is not profound, he acts resentful and is often difficult and surly to be around. (This was one of the few instances where the handicapper sibling was reported to be somewhat difficult or unpleasant.) When I asked her, "Do you ever dream about Gary?," she said:

> That's a strange question. In fact, I do, really weird dreams. I guess the general idea is that my brother and I are being really close, me hugging him, or things like that. I've hugged my brother before, but it's a very rare occasion. I dream I hug him and give him a warm kiss. Things like that. [Interview #35]

Even as young children, some of the respondents had fantasies of their handicapper sibling being "normal." One man talked about when he was very little and first became aware that his brother was never going to sit, walk, or talk. He thought:

> 'This really pisses me off. Why doesn't someone do something to help him walk and talk?' I'd think, 'Boy, when I get old enough, I'm going to figure out how to make him walk and talk.' [Interview #10]

Perhaps the fantasy served to solve the "problem;" it was a way of both verbalizing his frustration and offering hope to him when he was a small, powerless boy. In his fantasy, he

would be the hero and solve his brother's dilema. His comment is an illustration of the "Hansel and Gretel" phenomena that Banks and Kahn (1980) discuss -- he wanted to take care of his brother.

Another respondent also talked about the reality that her social relations with her sister were different than the norm. She discussed what life would be like if her sister weren't handicapped. (Her sister is retarded and has tubulorous scorosis.) When I asked her, "Has Vicky's handicap affected you?," She said:

> Yes, definitely. When I was younger I used to wonder if I would have turned out differently if my sister had been normal, or what she would have been like if she were normal. [Interview #15]

When I asked people if they'd ever dreamed about their handicapper sibling, I noticed that some talked about the person as if they were of sound body. They'd talk about the sibling walking or doing activities that they could not do if they were disabled. After that, I would specifically ask if the person was disabled in the dream. If the handicapper is "okay" in the night-dream, perhaps this is a way for the dreamer to escape current reality or the dreamer's expression of an unconscious wish -- a desire that the sibing be "normal." In dreams related to me, a common theme is this idea of normalcy -- a world where the handicapper is no longer disadvantaged but can function as they did before -- or as other people can. A woman whose half-brother was

beaten and became a quadriplegic four-and-a-half years ago, relates:

> I dreamt once that we were in the high school gym at a basketball game. At the beginning of the game, Jerry was in his wheelchair. After half-time, I don't know what happened to his wheel-chair, but he walked out of the lobby and came out onto the court and walked across [the floor] and sat down beside me. I remember that real well. In the dream, he started out using his hands. Unconsciously, I was excited; I could feel it in my dream being excited because he was doing this. But in the dream, I was just taking it for granted. And then I woke up. [Interview #40]

Her brother had been a high school basketball star, and the gymnasium was the one in their old home town. Her comment, "And then I woke up," is an understated way to indicate her sorrow that the dream wasn't reality. Later this same respondent told me, "I have these [day] dreams. I'd like to see someone find a way to fix his spinal cord, splice the nerves or something, electrically align them or something" [Interview #40]. Seixas and Youcha (1985) call this "magical thinking" -- the wish that someone, like a fairy godmother, will wave her wand and everything will miraculously be right.

As in their waking moments, guilt is a common theme in respondents' dreams. An example of guilt, combined with identification and a fantasy of "normalcy," was related by a woman talking about her foster-sibling. The respondent mentioned that at one time she was resentful of this girl, and sometimes, when she was younger, she would tease her and

call her names. The handicapper was a victim of child abuse (by her natural parent) and is partially paralyzed on her left side. The respondent said:

> I dreamed that she was 'normal.' I hate that word, but it's the only word I can come up with. There's this woman that has a broadway show, named Whoopi Goldberg. She has this one skit where she reminds me so much of Diane, because her arm is all tucked up and everything. She [Goldberg] says she has this dream where one day her arm will unfold, and she was crying. I have dreams like that about Diane. And then it's a disappointment to wake up and know it's not like that. One time I dreamt that she was normal, and I took on her handicap. [It] freaked me right out. [Laugh] And then, in my dream, she was doing all the mean things to me that I had done to her in the past. That really woke me up! I think that's one thing that made me realize that Diane is not to be treated as a geek [sic]. That really straightened me out. [Interview #22]

Hall reports that dreams, such as this one, can have a "profound effect upon waking consciousness" (1983:25) -- certainly the respondent indicated that this was so. After the dream, she treated her foster-sister differently, and they are now quite close, even though the respondent has married and left the community. This is the only reported dream where the able sibling took on the handicap/ disability.

I introduced this chapter with an example of the type of dream Seixas and Youcha discuss that has "unconscious significance that is difficult to understand" (Seixas and Youcha,1985:25) -- a statement by a woman about a dream of her brother sitting up in a coffin. Her older brother died

of muscular dystrophy and a younger brother also has the disease. During the interview, she mentioned that she and her brothers have been close, and she willingly did a lot for them. She gave no clues about the significance of this dream where her brother asked her to get him out of the coffin. Does it indicate that she feels an obligation to "rescue" him, a wish to be "savior?" Is it a reflection of her feelings of powerlessness, her inability to help her brothers? (I should have asked her how she felt during the dream or when she recalls it, but the imagery was so unexpected, that it didn't occur to me at the time.) The precise significance is unknown, but the content of the dream does indicate that his illness and death were significant events in her life. The phrase, "He [woul]'d sit up...," indicates that she had this dream more than once.

Another recurrent dream, combining the desire for "normalcy," wish fulfillment, and perhaps expressing guilt as well, was reported by a different respondent. This is also an example of an "anniversary dream" (one that reoccurs at particular times). It indicates the wish to be "savior" -- to be seen as important and be respected by others in the family. The respondent has a brother who has muscular dystrophy. For over a decade, he has been a wheelchair user.

> I remember a dream; I have it about Christmastime every year. In my dream, it would be Christmas morning, and all through the year since the last

> Christmas, Tim and I have been practicing [his] walking. And every day for a week or so, he's been getting better and better, but nobody else knows. We used to do stuff and nobody would know but he and I. So, we'd practice walking, and then on Christmas day, we'd get the whole family out in the hallway, and Tim would walk all the way to his bedroom. [Interview #30]

Characteristically, recurrent dreams do not deal with recent experiences; usually they deal with the past. According to research done at McGill University, recurrent dreams, such as the two I've mentioned, suggest a relationship between the dream and the dreamer's psychological conflict and distress (Bower,1986). In the latter case, the respondent was the younger sister. Because of her position in the family, she escaped most of the daily care of her brother. According to her, the older sister (whom I also interviewed) resented doing this care and the necessity of putting "her life on hold." Perhaps, unconsciously, the respondent feels uneasy and guilty that she has not been equally involved with her brother's care and therapy.

Conclusion

Able siblings' dreams, day-dreams, and fantasies about their handicappers sisters and brothers were interesting and revealing. In those reported, some dreams served as escape from a painful reality, others were rehearsals of events they may confront in the future, some revealed wishful thinking, and still others illustrate guilt. The dreams and

fantasies seem to be a way of coping with their reality. In the case of dreams and fantasies, family composition is not relevant; able siblings from all kinds of families reported their dreams and daydreams. An interesting finding is that both siblings of people handicapped from birth or early childhood and those disabled as adults, dream/fantasize about their handicapper sister or brother. Timing of disability is important in many respects, but in this area, it is less significant.

Are able siblings "a population at risk?" On the basis on this sample, we can conclude that at least some able sisters and brothers are. Those that are more likely to be in jeopardy are from certain types of families: single parent households, small families, families where the disability is denied or the handicapper rejected, and atypical families (in this case a family made up of hard-to-place adopted children and one where the mother was physically abusive to both her sons -- able and handicapper).

What is also apparent, is that severity of disability is <u>not</u> critical. The able siblings who reported psychological or physical problems had sisters and brothers who, by any objective standards, were not profoundly disabled or disadvantaged. By the same token, nearly all of those who had siblings seriously disabled, and handicapped to a near-total degree, reported few problems and seemed accepting of the situation. On the basis of my study, I believe that those who express a great deal of alarm over

families of handicappers, and predict a sad and troubled future for those famililes, are totally mistaken. Their concern is unwarranted. (Examples of this type of thinking, are the article by Fotheringham and Creals (1974) entitled, "Handicapped Children with Handicapped Families," another by Larcombe (1980), "A Handicapped Child Means a Handicapped Family," and a book by Shearer (1981) entitled Disabilty, Whose Handicap?.)

ENDNOTES

1
In the literature, most authors rely upon mothers, social workers, and other professionals for reports about problems of able siblings. In my opinion, this may present a distorted picture, but for this discussion see Voysey (1972), Kew (1975), Darling (1979), Thomas (1980), and Darling and Darling (1982).

2
For a complete description of able siblings of handicappers who agreed to particpate in various research studies see Grossman (1972), Featherstone (1980), and Milunsky (1981).

3
A complete discussion of sibling relationships in "normal" families is beyond this chapter. For additional information see Kirtpatrick (1963), Sutton-Smith (1970), Bank and Kahn (1975), Schvaneveldt and Ihinger (1979), and Pollak and Hundermark (1984).

Chapter 9

CONCLUSIONS

Introduction

I began this study because of a personal interest in how a physically disabled child affects the rest of the family -- most specifically -- the other children. From early on, it was apparent that to get a full and accurate picture, I could not rely on a standardized questionnaire. This conclusion had important consequences for both the study and my growth has a researcher. Open-ended interviews afforded insights and information that would have been impossible to attain in any other way. As for personal/ professional growth, all my professional life, I have assiduously avoided interviewing people. I convinced myself that I was not "good" at it, that it was an unwarranted invasion of respondents' privacy, that it was an inefficient and time-consuming use of time, and so on. I could come up with endless rationalizations about why I should not interview. But when I became interested in this topic, I realized there was no way around it -- interviews were essential. After talking to a few people it got easier, and I discovered that the respondents considered my questions legitimate and not invasions of their privacy. Most importantly, I was drawn further into the topic and increasingly convinced that it was a neglected but important

area. (At least two of the respondents expressed satisfaction that someone was finally looking at their experiences as siblings of a handicapper.)

Another of my original fears was that the grounded theory technique advocated by Glaser and Stauss (1979) would not work for me -- that nothing significant would emerge. As I coded the material, and made memos, I found interesting support for the findings in the literature (or contradictory evidence, in a few instances), but I found little that was new or innovative. It seemed the material was sterile -- or I was. Eventually, when I was totally emersed in the project, I began to speculate about what wasn't mentioned, brought up, dealt with. For me, that was a break through. It was like the psychology exercise where you're shown a black and white sketch and asked, "What do you see, an old woman or a young girl?" Most people see one or the other. In the case of my data, I clearly saw what the respondents reported, but it was not until I reversed my perceptions and sought out the ommissions that the grounded theory approach provided truly useful. All the material on family social relations, emerged from that approach.

Background

We can look at the problems associated with a physically handicapping condition as similiar to other social and psychological problems. A handicapper in the family is an example of the near-universal experience of

dealing with unexpected adversity. Very few families manage to completely avoid calamity and disappointment -- a serious accident, a retarded child, a chronically ill member, or some other extended setback. The central issue is how each family responds to severe and continued pressure.

This study focuses attention upon sibling relationships and recognizes their potential impact on handicapper and able children in varied types of families. We sorely need to better understand the effects of a disability on other children in the family. Many families struggle with the question of whether or not to institutionalize their handicapper child. Families need additional information to make intelligent decisions about whether home care is in the best interest of the handicapper child and/or the able siblings. Many people argue that all children should be reared by their parents, but there is definitely the possibility that for some children and families, keeping a handicapper child in the home may result in considerable stress on the parents and/or siblings and in outcomes such as abuse and neglect for the children themselves -- both able and handicapper.

The last twenty years has been a period of rapid changes for American families, including handicappers' families. Three demographic shifts have occurred that, together with deinstitutionalization and longer life-expectancies for the disabled, dramatically affect the quality of family life and the role(s) played by families

in society. These shifts include the increased number of women in the paid labor force, the higher divorce rate, and the declining birth rate. These five trends impinge on able siblings' lives, too.

Major Findings

In answer to the question, "How does a handicapper affect other children in the family?," the answer is -- it depends. That's not an evasion but a sincere statement of fact. No one seriously disputes that the presence of a handicapper influences family life, but from the evidence we now have, it appears that the effects are quite variable. The effects depend on a great number of factors.

Several findings that grew out of this study are particularly significant. A finding that I have never seen in the literature on handicappers and their families, is that timing of disability (adult-onset versus from-childhood) has major implications for how the handicapper is thought of, and treated, by his/her significant others, including able siblings. As a general rule, those who became disabled as adults retain more power and autonomy over their lives than those who have been handicappers since birth or early childhood. I believe the lack of options for from-childhood handicappers is the major sociological reason for their relative powerlessness. Most can't leave their family of orientation, and in fact, the

fear of being taken out of the home and placed into an institution is a real stress/worry for many of them. Adult-onset handicappers often have resources, including money from disability pensions, social security benefits, or salaries. Equally important, they weren't socialized to have low expectations or accept the ascribed status of "the handicapped."

Two other findings are interrelated: I found that extent of disability does not have a strong impact on the other children in the family, nor or all able siblings equally vulnerable for increased risk of physical or emotional problems.

In regard to the first observation, obviously extent of disability is important to the handicapper him/herself, and it may also be more crucial for the mother or primary care-taker. But on the basis of what I have learned in this study, I disagree with those that maintain degree of handicap is a significant factor in affecting able siblings. It undoubtedly has some effect on family life style, e.g., if the person cannot walk and must use a wheelchair, some accommodation must be made for that, but it does not automatically mean that all family members, including able siblings, are at risk because a sister or brother is seriously or profoundly disabled. In my sample many siblings, whose handicapper sister or brother was seriously disadvantaged, seemed healthy and accepting. Certainly they did not report a handicapper in the household was a traumatic event in their lives. Conversely, several

respondents did attribute their serious emotional or health problems to having a handicapper sister or brother, but by any objective standards, their siblings were not that disabled or disadvantaged.

The second observation is that not all able siblings are equally "at risk" for physical or emotional problems. On the basis of this study, I believe family composition is crucial in determining which able siblings are potentially vulnerable. Critical factors are: the size of the family, number of parents in the household, whether or not the mother works in the paid labor force, tolerance/intolerance for family members to express their feelings, the parents' attitudes toward the disability, and how they communicate those feelings to the other children.

In regard to family size, those from smaller households are more vulnerable -- especially if there are only two children, an able child and a handicapper. As Simmel (1959) points out, in small, close-knit relationships, the participants are more involved and there are more occasions for conflict. Small families are ripe for this kind of pressure. The decreasing birth rate and the longer life expectancies of the disabled means that potentially the population of those at risk will continue to grow.

Assuming the people is this study are in any way typical, children from single-parent household where the remaining parent is the primary wage earner are particularly vulnerable. (My sample included no one from a father-headed household, but presumably they would experience similiar

problems.) When mothers work outside the home, additional stresses may be put on able children, particularly the oldest daughter. Today a large percentage of mothers are in the paid labor force (Lein, 1986). So, too, are mothers of handicappers; over half of the respondents' mothers worked outside of the home at least part time, and several were the only support of the family. This trend is likely to continue. Divorce rates are even higher than the national average among handicappers' families, and even in two-parent households, economic necessity pushes some women, who might prefer to stay at home, into the paid labor force.

As for the vulnerability of eldest daughters, in the literature, this has received relatively more attention than effects on other family members (Grossman,1972; Kew,1975; Voysey,1975; Cleveland and Miller,1977; Featherstone,1980; Bank and Kahn,1982), but because of the potentially damaging effect on "big sisters," this special relationship warrants additional attention.

The tolerance of family members to express their feelings and grievances is another important factor. It isn't necessary for the family to always be harmonious; the central issue is being able to tolerate differences and successfully manage conflicts. Simmel (1959) maintains that in close relationships where hostile feelings are likely to be present, an absence of conflict may be an index of underlying, unresolved strains/tensions. Certainly that seemed to be true among the families in my sample where some family members disengaged and left their households. The

respondents recall no fighting or bickering -- just silence, increasing absences, and then the total departure.

There is ample evidence that the greater the importance attached to the maintenance of a particular group the more carefully its members protect its cohesiveness from conflict and tension. But frequently, the conflict and tension aren't removed but simply covered up or ignored until it reaches uncontollable dimensions. This happens, according to Simmel (1955), if participants in a close relationship view the relationship as tenuous and too delicate to withstand expressions of hostility. Under those circumstances, they may attempt to restrain acting out or expressing their hostile feelings. The closeness of the relationship and the strong affective mutual attachment of the participants may suppress the expression of conflict. Unfortunately, such suppression may lead to further intensification of the conflict once it breaks out. In households where strife is suppressed or unresolved, everyone -- including able siblings -- are more at risk. It isn't necessary to abolish differences. What is important is to effectively deal with differences and strive for the strategy Pruitt and Rubin (1986) term "problem-solving" -- reaching a mutually satisfactory solution to the conflict.

While tolerance to accept and deal with negative feelings or conflict is important, equally important is the parents' realistic acceptance of the disability and skill in communicating that acceptance to the other children. In my sample, no respondent reported emotional or physical

problems in families where the disability was realistically accepted and the handicapper not over-protected or rejected.

I believe, that if we took a survey of what Americans believe an ideal family/family relations should be, we would probably discover that we want and expect all the children in the family to be treated fairly and equitably by their parents, to have equal privileges and rights (except perhaps differing by age), that they be socialized to become autonomous, independent adults, that family members would be loyal and support one another through good times and bad and, perhaps, that boys and girls be socialized differently, with the girls taught to be more helpful and caring.

I believe that a strong case can be made for that scenario. That being the case, another potentially significant finding emerged from the grounded theory approach: social relations in handicappers family differ from stereotypical notions of what ideal family relations should be. In this sample I found a half-dozen variations from the myth of the "typical family": 1) as a group, able siblings accrued power they would not ordinarily attain if all the children were able; 2) a subordinate/superordinate status among the handicapper/able siblings tended to develop; 3) from-childhood handicappers tended to be socialized to become dependent, conforming, asexual beings; 4) some family members disaffiliated themselves physically or emotionally from the family; 5) gender-neutral or androgynous socialization more frequently occurred among these children -- with the possible exception of eldest

sisters; and paradoxically, 6) gender-expectations about who is responsible for caring were intensified for some women -- usually the mothers and/or eldest daughters.

Implications of the Findings

What is society's responsibility to the family and individuals in crisis? How can we alter social relations for more equity for everyone? It's past time for us to seriously consider the possibility of creating alternative social structures to replace or buttress the nuclear family. Family structures historically change; demographic evidence indicates that the traditional nuclear family with children raised by a mother who stays home, and a father who works outside the home, is no longer the predominant type of family (Lein,1986). The evidence is irrefutable, but our society continues to focus on the family -- and in particular the mother -- as the primary source of care for all children, including those that are handicappers. Mother as primary caretaker may work for some families, but the changing nature of the family in society means more single- and working-parent families. In addition, the evidence is overwhelming, and sometimes tragic, that mothering skills aren't instinctive and innate; they don't "come naturally" to all women. Several examples of this were brought up by the respondents. Even in this small sample, seven of the handicapper siblings (15.21 percent) were totally rejected

by their biological mothers or families. In fact, two of these children became disabled as a direct result of physical abuse by their mothers. (These children became the foster or adopted siblings of the people I interviewed.) But lack of mothering skills were apparent in at least three other instances, too. That means that in almost 25 percent of the families under study, mothering skills were inadequate or exceedingly weak.

We need to recognize the importance of individualizing care to meet various family types. There is nothing sacred about the so-called "traditional family" and its arrangements. Why is it that families are totally responsible for the care of a disabled member? De-institutionalization -- the notion of community care for special populations -- has shifted the responsibility to the family, and the increase in life expectancies of the disabled has dramatically increased the duration of that care.

"Experts" who maintain the family is at risk or handicapped contribute to the problem. They, too, place responsiblity for caring for a disabled family member totally on the individual family -- regardless of their emotional, psychological, or financial fitness. Placing this burden totally on individual families creates a "population at risk." Most families today are too small and too weak to undertake this type of care. The model of care is a hold-over from earlier gender divisions of labor. Years ago, most women didn't work outside the home and a more primitive medical establishment could not save many of

the disabled. Their shortened life limited the time and energy needed to care for a handicapper. Most died while they were still young and easy to carry or turn or bathe. Today, the life-expectancy of a disabled person is much, much longer, and this present problems -- but the problem has been assigned to the family; the state does not intervene unless the family refuses to accept responsibility, and for at least middle-class families, that refusal entails some stigma.

Note that the foregoing discussion is couched in terms of "family," however, in practice this usually means women -- usually mothers but sometimes it includes daughters or sisters or aunts. Women's close connection with family life has made them almost synomoymous with "family." It's as if we all learned, and accepted as valid, the equation, "Women = Family/Family = Women." For many people, including unfortunately many policy and opinion makers, women's natural sphere is the home. Brittan and Maynard write, in Sexism, Racism and Oppression:

> Common sense regards the family as a naturally given, inevitable, and immutable unit. It is regarded as socially and morally desirable, and as basic to society's well-being. Motherhood, particularly, is endowed with notions of the natural maternal instinct which impels women to self-sacrifice for the good of their children and/or the species in general. Since nature has ordained all this and present social relations allow for it, it would, so the argument goes, be going against nature to alter things in any way (Brittan and Maynard,1984:31).

I agree with them and with Renate Bridenthal (1982), who maintains that we must rethink the family and challenge dichotomies of private/public and family/society. Alternative family structures would not only make the care of handicappers more equitable, but they could also increase the options of everyone -- including handicappers.

Among the alternative structures are four specific types of services that should be priorities for development: 1) respite care on the British model where the state pays someone to come in a certain number of hours a day or week to assist with the care of the disabled, 2) financial incentives/cash subsidies to help families with the extraordinary costs that frequently occur, 3) counseling for parents and siblings to help them cope with their feelings, and 4) community-based services that are sufficiently comprehensive to allow parents the option to obtain in-home support services or opportunities for short- or long-term placement out of the home. Currently, when out-of-home placement is needed, families have a very difficult time securing a residential alternative. Community residences are not available in sufficient quantity to meet the need.

There is a widely believed myth that we are a child-centered society, but reality is quite different. There is a profound neglect of services for children who are disadvantaged and, particularly, for those who are mentally and/or physically disabled. We must provide more of these services, things like five-day-a-week residential placement, part-time, and/or temporary foster care and residential

schools. These are viable alternatives to full-time and long-term community residential placement. I am not suggesting that we return to the era of near-automatic institutionalization of the disabled. That approach is labeled, "The Toilet Assumption," by Phil Slater. It's the belief that unwanted matter and obstacles simply disappear if we can't see them. But for some individuals/families, out-of-home placement may be the lesser of evils. It's a difficult decision to make, I'm sure, but the option should be available. We also need to consider other alternatives such as communes or dehierarchized therapeutic communities.

Contributions of the Study

I believe an important contribution of this study is the methodology. I talked directly to able siblings, instead of asking parents or professionals what they think able sisters and brothers feel or experience. By listening empathically to the voices of able siblings and adding their voices to the dialogue, I've changed the terms of the discourse of "a population at risk." By talking to the people involved, I've tried to demystify this group and show that not all able siblings are at risk. As I have stressed throughout, being a sibling of a handicapper is not an experience that affects everyone the same way -- a fact that tends to be overlooked when we rely only on outside "experts" for information.

A second contribution is in the area of theory; the focus on social relations identifies and adds a new dimension to the literature on power and also to the area of minority relations. The previous research deals little with sibling power relationships or the effects of that unequal power on handicapper and able siblings. This finding about power and powerlessness raises some intriguing questions, especially how to account for the power of seemingly "powerless" individuals in families -- people like housewives in patriarchal families, children in most households, and from-childhood handicappers. This area needs to be investigated. Up to now it has seldom been addressed, and yet we know that under some circumstances, seemingly weak people <u>are</u> capable of exerting power, including within families. Do physical weakness and lack of resources limit, or neutralize, the usefulness of those commodities for those who have them? Another intriguing question -- could alternative family structures change the tendency toward intimate oppression?

In my view, another contribution is the use of non-ablest language. Before I started this research, I used ablest language, e.g., "confined to a wheelchair," "handicapped," "normal." In a conversation with Judy Gentile, head of Handicapper Affairs at Michigan State University and a wheelchair user, she gently took me to task and pointed out the implications of ablest language. I thought it over and made a resolve to use non-ablest language throughout the entire project. In the interviews, I raised the consciousness of able siblings, many of whom

admited they, too, had never considered the implications of the terms used to refer "handicapper." I believe this will be one of the first dissertations to do employ the term "handicapper" or to use the word in the title.

Suggestions for Further Research

I plan to continue investigating the effect of disability on family members -- particularly, the effect of an adult-onset disability. I would like to talk with not only able siblings, but also to the disabled individuals, and where applicable, the parents, spouse/partner, and children. The only work in this area, of which I'm aware, is in rehabilitation. I believe the social relations of such families needs to be investigated, too.

In addition, the present study needs to be expanded to include siblings of anyone who is a handicapper. When I was recruiting respondents, a number of people wanted to volunteer who had autistic brothers or sisters, learning-disabled siblings, and the like. These people should also be studied to look for similiarities or differences in their experiences. Ideally the research would also expand to include more minority members and people from other social classes. This could present additional problems of recruitment and gaining confidence of the respondents, but the problems are not insurmountable. An intriguing thought would be to somehow locate -- and persuade to be interviewed

-- the siblings and fathers who disengage and leave the household. Why did they leave? Did the handicapper have a major influence in that decision? What other factors were involved? Do they feel guilty about leaving and not helping? I've speculated about why they left, but until we actually talk with them, we really don't know. I'd also like to recruit other siblings who didn't leave home, but don't want to be interviewed. Their experiences might be quite different from those who volunteered to talk.

Another interesting area is the men who assume equal or primary caretaking responsiblities. In our culture, many, perhaps most, marriages tend to be role-segregated; the responsiblities and duties of the husband and wife are sharply separated. In this study, only seven of the fathers (17 percent) shared in any appreciable sense the responsibility for caring for the handicapper. The able children didn't know why their fathers helped or how they felt about it. Most expressed surprise when I mentioned that most fathers don't do this kind of work. It was something they grew up with and took for granted. Studying the characteristics and experiences of these men would be interesting and valuable. I would expect that these men were socialized differently than most American males and probably, what Komarovsky calls "the trained incapacity to share," was less stressed in their families.

There are a number of loose threads that I wish I had done differently. One of those is that I prematurely stopped asking about health issues. Only a minority of

respondents admitted to having psychological or psychosomatic problems, but this group is important. They are the ones who confirm that some able siblings are a population at risk. I also would have liked the opportunity to have asked all the respondents their dreams and fantasies about their handicapper sibling. I'd also ask if they remember dreaming about it as a child, what those dreams were, and if the sibling was disabled in the dream. A question that I wished I asked, but didn't: "Given the situation, you have a handicapper sibling, what would make all your lives easier, better?" It would be interesting to know if they'd given this any thought, and if so, what alternative solutions they may have considered.

Conclusions

The relevance of this study goes beyond able siblings' feelings about having a handicapper sister or brother, although I believe that is an important, relevant issue. But on a wider scale, this study brought up questions of how we, as a society, deal with individuals who are "different." Frequently, we separate them from the rest of the society -- the so-called "normal" people. In the past, this has been done to the retarded, the mentally disordered, and the physically handicapped. Investigating close contact of able and handicapper siblings provided insights into how we interact with people who are different than the norm and more general power relationships. Socialization, of both

the advantaged and disadvantaged persons, create and perpetuate much of the inequity. Now the question is, how can we change those relationships?

APPENDIX A

INFORMED CONSENT FORM

Michigan State University
Department of Sociology

1. I have freely consented to take part in a research project being conducted by Delores F. Wunder, a sociology graduate student, under the supervision of Dr. Barrie Thorne, her faculty advisor.

2. I understand that this research is designed to study the impact of orthopedically handicapped siblings on the other children of the family.

3. I understand that this interview will take one to two hours and will focus on my experiences growing up with a handicapped sibling.

4. I understand that I am not required to answer any questions against my will and that I am free to discontinue the interview at any time without penalty.

5. I understand that the interview will be recorded on tape but that these tapes will only be heard by the interviewer and her adviser.

6. I understand that portions of the interview will be included in the written results of the research project but that my identity and the name of my sibling will be kept in confidence and that I will remain anonymous.

7. I understand that further explanation of the research and/or the final results of the study will be made available to me at my request.

8. I understand that my participation in the research does not guarantee any beneficial results to me.

I have read and understand this consent form:

_____
(Signature)

_____
(Date)

APPENDIX B

ORIGINAL INTERVIEW SCHEDULE

INTERVIEW #
Date:_____

BIOGRAPHICAL DATA

1-a) Age:
1-b) Siblings: age & gender:

CHARACTERISTICS OF H (HANDICAPPER)

1-a) Describe H (physical appearance; nature of handicap).
1-b) How does H see self?
1-c) How does H feel toward you?
1-d) How do you feel toward H?

2-a) Is there any way H is like you? How?
2-b) Is there any way you are like him? How?

3) What services have been provided for H?

H'S IMPACT UPON YOU

1-a) How has H affected you?
1-b) What difference has H's handicap made a difference in your life?

2-a) How much time did you spend with H?
2-b) What activities did you do together when you were younger?
2-c) Did your parents like for you to spend time with H or did they leave it up to you?
2-d) Did your parents encourage or discourage you taking care of H?

3-a) Do you talk with your friends about H?
3-b) What do you tell them?
3-c) How many friends at MSU know about H's handicap?

4) When you were younger, did you ever wish that H were not around?

5-a) What do you think about the future of H?
5-b) What will H do? What will happen to H?
5-c) What is your role (if any) in H's future?
5-d) If there are other siblings, what will be their role in H's future?

6-a) Do you think that H has influenced your vocational choice in any way?
6-b) Can you think of anything good or beneficial that has come out of H's condition?

7-a) Think back; was there any time that being with H has proved embarrasing to you?
7-b) Do people ever stare at H? How does that make you feel?

FAMILY CHARACTERISTICS

1-a) How has having a handicapper affected the family as a whole?
1-b) Do you think H's handicap changed the family? If so, in what way?

2-a) What are your parents like?
2-b) What effect, if any, has it had on your father?
2-c) How does he feel about H's handicap?
2-d) Father's occupation:
2-e) Father's educational level:

3-a) What effect, if any, has it had on your mother?
3-b) How does she feel about H's handicap?
3-c) Mother's occupation:
3-d) Mother's educational level:

4-a) What effect (if any) has it had on your sisters and brothers?
4-b) How do you feel toward your sisters and brothers?

5) How do you feel toward your parents?

6-a) How do your siblings feel toward H?
6-b) Would you say that your family is a close one?
6-d) How much time do you spend with them?

7-a) How important is religion to your family?
7-b) Religious orientation:
7-c) How often did (or does) your family attend services or observe traditional holidays and customs?
7-d) Have they ever used religion to help explain or understand the fact of H's handicap? (examples?)
7-e) How important is this?

8-a) Has religion affected your view of H? How?
8-b) Has H's handicap affected your view of religion?

CURIOSITY

1-a) How old were you when you first realized H was a handicapper?
1-b) How did you learn about it?
1-c) Did you use to wonder about it very often?
1-d) If so, what did you do when you wondered?

2-a) Do you remember asking questions at any time about H? (examples?)
2-b) Who did you ask?
2-c) Were they answered to your satisfaction?

3) Are your family comfortable with questions about H?

4-a) Does your family often discuss H's handicap?
4-b) Who participates in these discussions?

5-a) Have you ever considered the possibility of having a handicapped child?
5-b) When did this first occur to you?

6-a) How do you think you'd react if you had a handicapper?
6-b) Would you do anything different than your parents did?

AGGRESSION

1) How do your parents feel about fighting among the children in the family? (Is this verbal or also physical?)

2-a) What did you do when you got mad at H?
2-b) What did you do when you got angry at your other siblings?

3-a) What would your parents say (or do) if you fought with H?
3-b) What would they say (or do) if you fought with your other sisters and brothers?
3-c) What did your siblings do when they got angry at H?
3-d) What did your siblings do when they got mad at you?

4-a) Did your parents ever say you shouldn't fight with H because of his/her handicap? (Did you accept this?)
4-b) Did your parents ever say you shouldn't fight with sisters?

5-a) What did your parents do when they got angry at H?
5-b) What did your parents do when they got angry at you?

6-a) Did they seem to resent the special privileges and expenditures spent on H?
6-b) Did you (or your siblings) ever resent the privileges or expenditures spent on H?

7-a) Some siblings say that they were jealous but did not really know or acknowledge it; it was "disguished jealousy." Did you ever experience this?

ADJUSTMENT

1) How do you feel you are doing at college? What is your grade point average?
2) Have you found it easy to make friends at college?

PROBLEMS

1-a) Did they ever have any difficulties in school?
1-b) Do you use drugs? (prescription or otherwise)

2-a) Did you ever have temper tantrums as a child?
2-b) Did you ever experience psychosomatic pains?
2-c) Have you ever had counseling or therapy?
2-d) Were you shy and cling to your parents a child?

LANGUAGE

1-a) Do you feel strongly about the use of language, e.g., "handicapper" as opposed to "handicap," "crippled," et cetera.
1-b) How does H feel about it?
1-c) How do your parents feel about it?

OTHER QUESTIONS:

1) What advice would you give someone if they'd just had a sibling who was born handicapped?

2) Is there anything you can think of that I haven't covered that you think is important or relevant?

3) Do you have any questions you'd like to ask about the research?

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