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SIBLINGS OF CHRONICALLY ILL AND DISABLED CHILDREN:
AN EXAMINATION OF PSYCHOLOGICAL FUNCTIONING AND SELF-ESTEEM

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A THESIS SUBMITTED IN PARTIAL FULFILLMENT
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Abstract

The presence of childhood chronic illness or disability is generally perceived as an emotionally costly and stressful experience for the child and family. While earlier descriptive studies consistently suggested that chronic illness or disability may predispose siblings to poorer adjustment and psychopathology, more recent controlled studies have failed to demonstrate marked differences between siblings and comparable controls. To provide further clarification, this study explored the general psychological functioning, social competency, and self-esteem of siblings. Twenty families of children with cystic fibrosis, for a total of 34 siblings and 12 families of children with autism, for a total of 19 siblings, and 26 normal control families participated. Standardized questionnaires from mothers and siblings, as well as interviews with siblings about their experiences were collected. Comparisons between siblings of autistic children and their matched control group reveal no significant differences on emotional and behavioral problems, social competency, or self-esteem. Comparisons between CF siblings and their matched control group reveal greater emotional and behavioral problems, no differences in social competency, and variable degrees of self-esteem. Findings suggest that there is no one-to-one correspondence

between chronic illness or disability and greater amounts of behavioral and emotional problems in siblings. To the extent that siblings are well-informed and involved in the care of the ill child in accord with age expectations, their sense of involvement in the family and mastery of illness related stresses may be enhanced. The results correspond well to previous findings that siblings depend largely upon their parents to help make sense of the illness, as well as to integrate it into every day life. Mastery on the part of the mothers in coping with the illness was associated with higher levels of self esteem in the siblings, particularly in the home environment. This suggests that siblings are positively influenced by their parents' efforts to cope with the illness.

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Many people, friends and colleagues alike, contributed to this project. I can only hope that they all understand how much I have appreciated their support and enthusiasm. Without exception, they believed that siblings had a special story to tell.

I am most grateful to the brothers and sisters, and their families, who patiently shared their stories with me. It was a privilege to hear about their experiences as siblings. They have grappled with the challenges put before them and woven them into their everyday lives. Through their eyes, I have learned about the sorrow and joy that childhood chronic illness and disability can bring to life. They have taught me more than they know. My hope is to do justice to their experiences and to teach others what they have so eloquently taught me.

Judith Williams deserves my heartfelt thanks. This project was developed as part of her larger project on family adaptation to childhood chronic illness. She has always been generous with her time, ideas and understanding. Throughout the long and often frustrating recruitment process, she was always there. I found great comfort in learning about siblings and families under Judith's guidance.

Al Berman, Joe Rossi, and Gene Knott, my committee

members, have instilled a quiet confidence in me. Throughout the project, they trusted in my abilities and judgment. Under their tutelage, I learned about the art of designing and implementing a clinical research project.

Many thanks go to Sarah Gossler of Rhode Island Hospital's Child Development Center, the staff of the Charles Bradley Program and Developmental Disabilities Unit of Bradley Hospital, Pauline Leonard and Dr. Jack Farley. Without them, the brothers and sisters would not have found their way to me. They helped explain the project to potential families in ways that underscored its meaningfulness and encouraged participation.

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Siblings of Chronically Ill and Disabled Children: An Examination of Psychological Functioning and Self-esteem

Introduction

Traditionally, chronically ill and disabled children have been viewed narrowly in terms of their physical and cognitive limitations, illness characteristics, and psychological functioning. Less frequently has the perspective been widened to include a more comprehensive view of the child within the context of the family, the meaning of the child's condition for the family, and the role of the larger social context in shaping the family's response to the child's condition (Williams, 1983). More recently, studies have addressed the broader picture of childhood chronic illness and disability. Among the broader topics of consideration is the experience of healthy siblings who grow up in families with chronically ill or disabled children.

Estimates of the number of chronically ill and disabled children vary depending upon how inclusively estimates are made and on the criteria used (Williams, 1983). The National Health Interview Survey indicates that in 1967 and 1981, respectively, 1.1% and 2.0% of children aged 0-16 years old had limitation of major activity due to illness or

disability. The increase in prevalence reflects the increased survivorship of patients due to improved treatment, changes in definitions, and improved case-finding and diagnosis (Gortmaker and Sappenfield, 1984). The Carnegie Council reports that 11.4% of American children are affected when the mentally retarded, emotionally disturbed and learning disabled are included (Gliedman and Roth, 1980). Dywab (1976) refers to an interdisciplinary discussion group where the numbers of handicapped children in the United States were estimated from less than 10% to more than 60%, the larger figure reflecting a broad ecological approach that included populations "at risk." Clearly, the discrepancy between available estimates illustrates the extent to which disability can be considered a social concept (Williams, 1983). Given the trend to include parents and siblings of chronically ill and disabled children among those who are affected, the numbers at risk become considerably larger.

Sibling relationships, while they vary greatly in intensity and variety, are viewed as lifelong processes which remain influential throughout the life cycle (Bank and Kahn, 1975, 1982; Dunn, 1985; Furman and Buhrmester, 1985). Unlike other relationships, the sibling relationship can endure over sixty to eighty years. It is estimated that approximately eighty percent (80%) of children in the United States are siblings (Brownmiller and Cantwell, 1976).

Minuchin et al. (1967) directly observed siblings from underprivileged families and concluded that brothers and sisters serve many important functions for each other. Siblings give reflected self-appraisal to each other; turn to each other when parents were disorganized; form cohesive, defensive groups; serve as socializers for each other; and reciprocally control behavior by bringing intense pressure to bear on one another. Lobato (1985) summarizes the functions of sibling relations according to three areas including socialization (e.g. sharing, companionship, negotiation); mediating parental power (e.g. joining and forming alliances, translating); and knowledge dissemination. There is widespread agreement that children contribute enormously not only to the lives of their siblings, but also to family life.

Dunn (1985) delves into the subject of sibling relationships with refreshing clarity and insight. The wide variability in the quality of sibling relationships cannot be explained merely in terms of birth order, age differences, or sex of the siblings. Dunn (1985) encourages that the pattern of influence between siblings be viewed complexly, taking into account factors such as the affectionate quality of the relationship, family style of interaction and communication, children's personalities, and children's relationships with their parents. Given the nature of sibling relationships, brothers and sisters

influence each other's development. Relationships between young siblings are described as emotional, intense, uninhibited, full of imitative behavior, and steeped in an understanding of how each behaves and what will affect him or her. In the context of the sibling relationship, children may demonstrate the ability to comfort and empathize. According to Dunn, the "emotional urgency" of the sibling relationship is critical to understanding why young children are able to grasp the feelings and intentions of their siblings. The degree of social understanding demonstrated between siblings suggests that learning to understand and interact with family members is of special adaptive significance.

Despite the growing literature on normal sibling relationships, comparatively little information is available concerning the relationships between chronically ill or disabled children and their healthy siblings. Clinical observations suggesting that siblings' adjustment may be adversely affected by the presence of illness or disability (Friedrich, 1977; Poznanski, 1969; Sourkes, 1977; Trevino, 1979), as well as parental concerns (McHale et al., 1984) have focused attention on the sibling population. Given the duration of typical sibling relationships, it is likely that siblings will live the longest with illness-related memories and concerns. Clinical and parental concerns, together with the nature of the sibling relationship, have fueled efforts

to understand the experience of siblings.

Generally, the presence of childhood chronic illness or disability within the family is perceived as an emotionally costly and stressful experience for the affected child and other family members (Comoroff and Maguire, 1981; Gallagher et al., 1983; Pless & Pinkerton, 1975; Poznanski, 1969). Many clinical case studies describe high stress, frequent emotional disturbance, and patterns of psychopathology in families of children diagnosed with serious illnesses (Ferrari, 1984). Similarly, some empirical literature supports the view that membership of a chronically ill or disabled child predisposes the family to negative psychological and social effects (Gath, 1973; Tew & Laurence, 1973). Considerably less literature has focused on the issues and needs of siblings, in favor of the chronically ill or disabled child and parents (McKeever, 1983; Sabbeth, 1984).

Efforts to explore the psychological functioning of siblings have been met with considerable conceptual and methodological challenges. The absence of an overall theory to guide predictions and to unify disparate findings has hindered research progress and discouraged bolder conclusions (Drotar & Crawford, 1985; McHale et al., 1984). Sibling adaptation research faces problems associated with determining relevant control and outcome variables, as well as the larger issues of measuring childhood psychopathology

and adaptive functioning. At the heart of the researcher's challenge are the unwieldy, multidimensional constructs of the sibling relationship, chronic illness and disability, and psychological functioning. On the other hand, the clinician's dilemma is that, despite the fact that all the "data" is not in, chronically ill and disabled children and their families need services. Given the complexity of factors that may mediate sibling adjustment, the formidable task remains to sort out what can be attributed to the illness or disability and what is more likely explained by the vast array of non-illness related influences.

Methodological problems involving investigator bias, sampling, and measurement contribute, in part, to discrepant results among various studies (Ferrari, 1984; Lobato, 1983; McKeever, 1983). While the area of sibling research has increased in methodological sophistication, and subsequently improved the overall confidence in the findings, clear-cut conclusions have not yet been established. The methodological inadequacies of earlier studies are relevant for understanding the original findings of greater pathology among siblings. Lobato (1985) describes an overall investigator bias that focuses on pathology. Sampling problems include absent or inadequate control groups and over-representation with repeated sampling of siblings from the same experimental families. The literature is fraught with studies of poorly defined and heterogeneous illness and

disability conditions. Ferrari (1984) explains that while some sibling adjustment problems have been reported among studies employing control groups, the rates are generally lower than studies without control groups. Lobato (1985) concludes that studies based strictly on maternal reports yield the most negative findings with respect to sibling adjustment. Additionally, concerns have been raised about retrospective data collection; variability in the quality of standardized instruments and, in some cases, data gathered with abbreviated projective assessments; and reliance on maternal and teacher reports rather than on self-reports.

Several underlying assumptions have guided research endeavours and interpretations in the sibling literature (Breslau et al., 1981; Lobato, 1983). It appears that many researchers and professionals began their work in the sibling area with the assumption that siblings are exposed to greater stress due to the illness or disability and, therefore, were at increased risk for psychological problems (Lobato, 1983). As a result, the majority of empirical studies have sought to establish whether indeed these children exhibit greater psychopathology than children who do not have chronically ill or disabled siblings. The assumption, in part, has contributed to an overall investigator bias that focuses almost exclusively on pathology (Drotar & Crawford, 1985; Lobato, 1983). In a recent review article, Drotar and Crawford (1985) conclude

that research on the psychological adjustment of chronically ill children has generally been guided by a disease or deficit-centered perspective which neglects the possibility that the illness may also provide opportunities for growth.

Several related assumptions contribute to the overall deficit-centered perspective. One assumption is that healthy children receive less parental attention due to the disproportionate amount of attention and care required of the ill or disabled child (Breslau et al., 1981; Gath, 1974; Vance et al., 1980). Consistent with this, siblings are generally described as vying for parental attention and at risk for manifesting a variety of psychological and social problems (e.g., aggression, anxiety, withdrawal, antisocial behavior) in an effort to refocus attention onto themselves (Pless and Pinkerton, 1975). Siblings are frequently described as having to assume domestic and child-care responsibilities beyond their developmental capacities (Hayden, 1974; Tew & Laurence, 1973). Farber and Ryckman (1965) postulated that these siblings may experience "role tension" when "regardless of his birth order in the family, the severely handicapped child essentially becomes the youngest child socially" and other siblings are expected to care for him and subordinate their needs to him (page 4). Related assumptions involve the notion that maternal physical and emotional impairment, as a result of caretaking demands of the ill or disabled child, may distort family

relationships and result in problems for other family members (Gath, 1974; Tew and Laurence, 1973). Breslau et al. (1981) postulate that the experience of having a chronically ill brother or sister may negatively impact upon siblings' body images or learned behaviors.

The supposition that brothers and sisters of chronically ill and disabled children, who are exposed to increased stress as a result of the illness, might not fare as well as other children seems to make sense. However, more recently, these views regarding the psychological sequelae in both children with chronic illness and their siblings have been challenged (Pless and Zvaglulis, 1981). While earlier descriptive studies consistently suggested that chronic illness and disability may predispose siblings to poorer adjustment and psychopathology (Cairns et al., 1979; Cleveland & Miller, 1977; Grossman, 1972; Poznanski, 1969; Spinetta & Deasy-Spinetta, 1981), more recent controlled studies have failed to demonstrate marked differences between siblings of chronically ill children and comparable controls (Breslau et al., 1981; Ferrari, 1984; Gayton et al., 1977). The notion that siblings of chronically ill children invariably demonstrate more overall psychopathology has been upstaged, and replaced with the idea that no one-to-one correspondence exists between the presence of childhood chronic illness and psychological disturbance in healthy siblings (Drotar & Crawford, 1985).

Breslau et al. (1981) completed one of the more frequently cited and carefully interpreted empirical studies in the field. They compared 239 healthy siblings (6-18 years) of children diagnosed with cystic fibrosis, cerebral palsy, myelodysplasia, or multiple handicapping conditions with a control group of 1,034 siblings of nonhandicapped children on the Langner Psychiatric Screening Inventory (Langner et al., 1976) completed by mothers. The siblings of chronically ill or disabled children did not manifest higher rates of severe psychological impairment or greater overall symptomatology than the control subjects. Scores on the seven subscales, revealed that there were no differences on the "regressive anxiety" and "conflict with parents" subscales; lower scores than the controls on "isolation"; and significantly higher scores than the controls on the "mentation problems", "fighting", and "delinquency" subscales. Findings suggested that type and severity of the illness or disability bore no relationship to the psychological functioning of the siblings. Sex and age of the healthy siblings were not related to psychological functioning, nor was birth order per se. However, birth order was found to have a statistically significant interactive effect with sex: among siblings younger than the ill or disabled child male siblings had greater impairment than females, whereas among siblings older than the ill or disabled child female siblings had greater impairment.

In a particularly well-designed study, Ferrari (1984) examined the psychosocial adjustment of siblings and parents of three groups of male children (pervasive developmental delay, juvenile onset diabetes, physically healthy) through the use of multiple measures obtained from the child, parents and school teacher. The results indicated that the course of any sibling's adjustment depends not only on variables related exclusively to his or her relationship with the ill child, but also on the adjustment of others in the sibling's environment, especially the mother. In general, results failed to support the view that siblings of chronically ill or disabled children are uniformly at greater risk for psychosocial impairment than siblings of normal children. The study failed to support the notion that siblings of children with highly visible conditions (e.g., pervasive developmental delay) manifest a greater degree of maladjustment. Interestingly, the siblings of pervasive developmentally delayed children had the lowest mean scores for externalizing problems and the highest mean scores for social competence. While the sample was restricted to boys, the findings provide tentative support for the hypothesis that siblings of same-sexed chronically ill or disabled children have higher rates of maladjustment than opposite-sexed pairs. While birth order is not specifically implicated, older siblings generally scored better on the

various measures of psychosocial adjustment. Both earlier age at diagnosis and longer periods of "sib-time post diagnosis" were associated with higher self-concept ratings and lower behavior problems. Results suggested that the impact of chronic illness on siblings may be less severe when illness onset is early, or after ample time has elapsed allowing for adjustment. Most often, the differences found were related exclusively to siblings of a particular illness group, rather than between normals and the larger illness group. This supports the idea that different chronic illnesses or disabilities may selectively predispose siblings to different sorts of psychosocial adjustment problems or differentially influence the parents' perception of their healthy children.

From interviews and projective assessments with five siblings of childhood cancer victims, Iles (1979) delivers a thoughtful paper which addresses the complexity of the sibling relationship. The author's intention was to illustrate the dynamics of the sibling relationship, and to move beyond the narrower question of whether siblings demonstrate greater degrees of maladjustment. The predominant theme endorsed by the siblings was one of change, most of which was unexpected and for which they were ill-prepared. Two areas that were affected consistently by the illness includes the sibling's interpersonal relationships and the external environment. Under the

stress of the illness, the sibling's usual means by which he or she relates to significant others in familiar surroundings is at severe risk. The stress of pediatric cancer may result in the following losses for siblings: disruption of interpersonal relationships (especially parents, ill sibling, peers); physical distortion of the ill sibling; disturbances in the routine of family life; and alterations in the environment. Siblings reported decreased availability of parents, especially mother, due to the time required at the hospital and care of the ill child. Siblings also reported increased demands placed upon them, particularly for their own care. Brothers and sisters described the need to have information about the illness and the need to be "special too." Regarding peer relationships, healthy siblings frequently found themselves in the position of explaining the illness to others and protecting the ill sibling. Changes in usual family routines were highlighted including the "empty house" and the presence of parental substitutes. The author emphasizes that, indeed, siblings are affected by the cancer and that care must be taken to anticipate and address these needs.

While the quality and intensity of sibling relationships between healthy children varies (Furman and Buhrmester, 1985), evidence suggests that relationships between healthy children and their handicapped siblings may vary to a considerably greater degree. McHale et al. (1984)

compared sibling relationships of mentally retarded, autistic, and healthy siblings between the ages of 6 to 15 years on both questionnaires and open-ended interviews. Comparisons of the groups revealed that mothers tended to rate relationships between children and their handicapped siblings more positively than relationships between children and their non-handicapped siblings. However, information provided by the siblings themselves provides a somewhat different picture. In contrast to the interview results of healthy siblings that revealed a relatively narrow range of responses, children with handicapped siblings showed a considerably wider range of responses to the interview questions. The authors estimate that about half of the children with handicapped siblings gave fairly negative reports about their sibling relationships, while the other half gave very positive reports. While a simple average of the responses yields results that, at first glance, look very similar to the comparison group, the greater degree of variability in the self-reported perceptions of their relationships with their brothers and sisters is critical to bear in mind.

To fully appreciate the literature devoted to sibling relationships between healthy and chronically ill or disabled brothers and sisters, it is important to consider several factors. These include the generally negative assumptions of investigators, thorny methodological

challenges, and especially wide variability in the perceptions of children regarding their relationships with their ill or disabled siblings. The initial research agenda of the field has been to identify the particular effects, if any, of the chronically ill or disabled child on the healthy siblings (Lobato, 1983). As elaborated previously, the expectation was that the healthy siblings would suffer negative effects. Research, to date, does not allow one to conclude that, of necessity, these siblings are negatively affected by the experience of having a chronically ill or disabled brother or sister. Rather, there has emerged a greater appreciation for the complexity and diversity of these relationships, as well as the potentially growth-promoting aspects of the experience. Toward this end, researchers have focused their efforts on elaborating the mediating factors that may explain why certain siblings are at greater risk for adverse experiences than others. Authors of review articles (Drotar & Crawford, 1985; Lobato, 1983; McHale et al., 1984; Simeonsson & McHale, 1981) have similarly categorized these mediating factors. Powell & Ogle (1985), in the first full-length book devoted to the subject, provide the most comprehensive view of mediating factors including: 1) family characteristics; 2) parental attitudes and expectations; 3) characteristics of the healthy sibling; 4) and characteristics of the chronically ill or disabled child.

Family characteristics relevant to the question of sibling adjustment include family size, socioeconomic status, and religion. In general, siblings from large families seem to adjust better to the presence of a chronically ill or disabled child provided their families have adequate financial resources (Lauterbach, 1974; McHale et al., 1984; Simeonsson & McHale, 1981; Taylor, 1974). The explanation offered is twofold. First, large families have more members among which the responsibility for care of the chronically ill or disabled child can be distributed. Second, the hopes and dreams of the family are carried on collectively rather than residing only in the ill or disabled child. There appears a qualitatively different challenge for families of low socioeconomic status compared with families from middle and upper SES levels. Farber (1960) found that low SES families experienced an "organizational crisis" focusing on the provision of daily care for the ill or disabled child and the associated drain on the families resources. On the other hand, middle and high SES families struggled with a "tragic crisis" focusing on the violation of their expectations and aspirations for the child member. In families with limited financial resources, where the burden of care must be partially absorbed by the healthy siblings, sisters are usually expected to carry greater caretaking responsibility and, consequently, are more adversely affected than brothers

(Gath, 1974; Taylor, 1974).

The role of family religion is less easily summarized. Stubblefield (1965) found that the birth of a mentally retarded child often precipitates a theological crisis for parents. Religious beliefs may figure prominently in one's understanding of the meaning of the illness or disability (Comoroff & Maguire, 1981). There is some evidence that Roman Catholic families may be more accepting of a mentally retarded child than Jewish or Protestant families, perhaps due to the explicit definitions supporting home and family life decreed by the Roman Catholic Church (Zuk et al., 1961). It appears that religious beliefs of the family, as well as parental values in general, influence sibling acceptance of a mentally retarded child, but the nature of that influence may be mediated by other variables (Simeonsson & McHale, 1981). The applicability of the above findings for families and siblings of non-retarded chronically ill or disabled children remains, as yet, unclear.

While predominantly anecdotal in nature, several authors describe the impact of parental attitudes and expectations on healthy siblings (Caldwell & Guze, 1960; Farber, 1960; Gralicker et al., 1962; Grossman, 1972; Poznanski, 1973). Before addressing the impact upon siblings, it is important to consider briefly the parental situation. McCollum & Gibson (1972), among others, suggest

a series of stages (e.g. prediagnostic, confrontational, and long-term adaptation) that parents experience upon learning about their child's illness or disability. Featherstone (1980) cautions that stage models, while serving a useful conceptual function, fail to capture the nonlinear nature of adaptation as well as the diversity of family experiences. With insight borne of her own experience as a mother of a multiply handicapped boy, she adds that rarely is the "promised land of acceptance" achieved on schedule, if at all. Poznanski (1973) highlights the stresses implicit in bearing and raising a chronically ill or disabled child including an initial insult to the parent's narcissism, prolonged caregiving demands, and compromises in the usual gratifications of watching a child achieve his full potential. Wikler et al. (1981) eloquently address the chronic nature of the sorrow that parents may experience, postulating that unachieved developmental milestones on the part of the child serve to rekindle parental grief.

Despite inconclusive information, there emerges a popular notion that the presence of a chronically ill or disabled child either brings a marriage closer together or destroys its very fabric. While most marriages survive, Featherstone (1980) describes four ways that a marriage may be stressed by a child's illness or disability: exciting powerful emotions in both parents; acting as a dispiriting symbol of shared failure; reshaping the organization of the

family; and creating fertile ground for conflict. In the end, parents are faced with difficult decisions about the distribution of the family's emotional and material resources. In starkest terms, there may ensue a continuing researchers and service providers (Lobato, 1983). Blackard & Barsh (1982) examined the extent to which professionals were able to predict accurately parents' responses to a questionnaire on the impact of having a handicapped child. Compared to parents' actual responses, professionals tended to overestimate the negative impact of the child on all aspects of the questionnaire including: changes in marital relationships; changes in family goals; restriction of family activities; effects on siblings; and financial costs. Results suggest that, from the parents' point of view, they are coping with the child's illness or disability. Featherstone (1980) reminds us that, with time, most parents make sense of the child's limitations and move in the direction of acceptance. Over time, the illness or disability becomes less prominent as a means of defining family life.

Most probably, it is the elusive concept of parental

acceptance that serves as a mediating factor in sibling adjustment. McHale et al. (1984) conclude that when parents are more accepting of a child's illness or disability, siblings are better adjusted. Similarly, the extent and openness of parental communication about the child's illness or disability is of major importance for sibling understanding and adjustment (Schreiber & Feeley, 1965; Simeonsson & McHale, 1981). To a large degree, brothers and sisters depend upon parents to help them make sense of the illness or disability, as well as to integrate it into everyday family life.

Characteristics of the chronically ill or disabled child that have been investigated with respect to sibling adjustment include the type of handicap, severity of handicap, age and gender of the child. Regarding the type of handicap, studies investigating a wide range of childhood chronic illnesses and handicapping conditions have yielded no significant one-to-one association between particular diagnoses and sibling adjustment patterns. Breslau et al. (1981) found that amongst brothers and sisters who had siblings with either cystic fibrosis, cerebral palsy, myelodysplasia, or multiple handicaps, the type and severity of the illness/disability bore no relationship to the psychological functioning of siblings. In general, studies examining the siblings of children with hearing impairments (Schwirian, 1976), autism (DeMyer, 1979; Sullivan, 1979),

cerebral palsy (Shere, 1956), and pediatric cancer (Binger et al., 1969; Gogan et al., 1977) describe relatively similar effects on siblings' psychological adjustment. Lobato (1983) concludes that factors other than the diagnosis may be more important in understanding how healthy siblings experience the physical and developmental problems of their brothers and sisters. Rather than diagnosis per se, the degree of ambiguity associated with the ill or disabled child's characteristics may be a more relevant mediating factor influencing sibling adjustment (McHale et al., 1984).

Early sibling researchers (Farber, 1959; Kirk and Bateman, 1964) postulated that greater severity of a child's handicapping condition would be associated with greater sibling maladjustment. However, subsequent research has demonstrated consistently that there is no simple linear relationship between the severity of a child's handicap and sibling psychological adjustment (Breslau et al., 1981; Grossman, 1972; Tew and Laurence, 1973). In particular, it seems that the degree of caretaking that the ill or disabled child requires, in combination with the family's financial and caretaking resources, impacts upon sibling adjustment.

The age of the chronically ill or disabled child appears relevant to sibling adjustment as well as overall degree of family disruption. Miller (1969) and Farber (1964) found that family life is increasingly disrupted as the

handicapped child grows older. Likewise, siblings experience more difficulties as their ill or disabled brother or sister gets older. Simeonsson and McHale (1981) conclude that assessment of the effects of an older, as opposed to younger, handicapped child on siblings may reveal more negative attitudes or poorer adjustment regardless of the sibling ordinal position.

With respect to healthy siblings, the characteristics that have received the most attention include gender and relative birth order. Studies with healthy sibling groupings have documented the significance of gender and birth order as determinants of siblings' family responsibilities and personality characteristics (Dunn and Kendrick, 1982; Lamb and Sutton-Smith, 1982). Oldest sisters, for example, generally assume greater responsibility for the care of younger siblings than either brothers or later-born sisters. Several studies have documented the particular vulnerability of older female siblings who grow up in families with chronically ill or disabled children, in part due to greater caretaking responsibilities characteristic of their sibling position (Cleveland and Miller, 1977; Grossman, 1972; McHale et al., 1984).

Breslau et al. (1981) found significant birth order-by-gender interaction effects on the overall psychological adjustment of siblings of children diagnosed with a variety

of conditions. Whereas, when birth order and gender were considered separately they were not predictive of sibling adjustment. Across the sample, younger brothers and older sisters demonstrated greater psychological impairment regardless of the actual age of the siblings. Grossman (1972) hypothesized that younger siblings, especially boys, may be relatively more deprived of their parents' attention throughout childhood and are probably less able to understand the circumstances and needs of the handicapped child. Older sisters, on the other hand, are at greater risk for difficulties due to the greater caretaking responsibilities implicit in their sibling position. Moreover, siblings of the same gender generally experience greater identification with the handicapped child and, consequently, greater psychological difficulties than opposite-sexed sibling pairs (McHale et al., 1984).

The relative age differential between the handicapped child and sibling impacts upon sibling adjustment (McHale et al., 1984). The greater the age difference between the children, particularly age spans of ten or more years, the better the sibling adjustment. Simeonsson and Bailey (1983) attribute this to less intense identification between the siblings as well as clearer distinctions between the children in terms of competencies.

The understanding of siblings with chronically ill or disabled brothers and sisters also requires the

investigation of resilience and protective factors in the face of adversity. Rutter (1981, 1985) addresses the broad issue of what constitutes stress in a child's life and what determines whether and how a child will cope with the situation. Some children demonstrate resiliency and manage to cope with stressful circumstances. Resiliency is complex and multidetermined. Rutter emphasizes that individual differences, including personal characteristics, vulnerability and protective factors, cognitive appraisal of the event and coping styles, determine whether stressors will have harmful or beneficial sequelae. In this same spirit, the sibling of a chronically ill or disabled child is met with what most people consider a more or less stressful experience.

While illness or disability of any kind are typically presumed to be stressful and negative, Parmalee (1986) considers the role of common childhood illnesses (e.g., colds, flu, minor gastrointestinal upsets) as normal events that have potentially beneficial effects. Common childhood illnesses represent important socializing events in children's lives. As such, illness may play a part in children's affective and cognitive development, as well as knowledge of self and other, prosocial behavior, and empathy. Illness provides opportunities not only to be taken care of, but also to empathize and care for others. Feshbach (1978) conceptualizes empathy as an integrated

concept including both emotional and cognitive components. Illness provides children with an opportunity to learn about and demonstrate empathic behavior including emotional capacity and responsiveness, the ability to discriminate and label affective states in others, and the ability to assume the perspective and role of another person. To the extent that chronic illness and disability share features with common childhood illnesses, they may play a part in the development of siblings' general social competence, their understanding of illness and wellness, and their empathic relatedness to others.

Several authors (Cairns et al. 1979; Carandang et al. 1979; Featherstone, 1980; Iles, 1979) discuss not only the stressful aspects, but also the potential opportunities for growth inherent in having a chronically ill or disabled brother or sister. Iles (1979), in her interviews of siblings of cancer patients, reported gains in empathy for parents' needs, cognitive understanding, respect for ill sibling and self-concept. She emphasized siblings' desire to contribute to the management of the illness, and implies that making a contribution is associated with positive outcome. Featherstone (1980), an educator and mother of a severely handicapped child, addresses the complexity of the sibling role with compassion and wisdom. She explains that as children puzzle over questions raised by disability, they struggle with embarrassment, conflicting loyalties,

identification, and confusion. Featherstone not only acknowledges the anger, guilt, frustration and fear that some children may be faced with, but also discusses opportunities for growth. These include increased tolerance for human differences, less casual acceptance of good health, and a sense of specialness concerning familial bonds. Similarly, retrospective accounts by siblings (Fromberg, 1984; Hayden, 1974) emphasize the complexity of the sibling relationship that includes both pain and joy.

Retrospective interviews conducted with college-aged and adult siblings of mentally retarded children provide further support that there are both positive and negative aspects of the experience (Cleveland and Miller, 1977; Grossman, 1972). Overall, Grossman (1972) estimated that approximately 45% of the college-aged siblings had benefitted from the experience of growing up with a retarded brother or sister. Siblings who had benefitted were judged to have "greater understanding of people in general and handicaps in particular, more compassion, more sensitivity of prejudice, and more appreciation of their own good health and intelligence than their peers" (page 92). Similarly, Cleveland and Miller (1977) found that the majority of their sample of adult siblings felt that they had adapted and coped successfully with the challenge of growing up with a mentally retarded sibling. Given that the subjects were interviewed retrospectively as adults, the sibling

experiences were most probably described with greater maturity, selectivity, and objectivity than would have been possible for them as children.

In an effort to educate clinicians and bring to life the challenge of living with diabetes, Strayhorn (1985) offers rare insight into the stressful "job" of diabetic management for children and their families. Strayhorn refrains from overpathologizing the diabetic child and family. He encourages those working with the family to avoid being overly critical and punitive towards patients and families who present less than total success at this onerous job. Strayhorn asserts that average levels of psychological skills probably do not insure good diabetic management. Rather, he believes that families who are coping well with childhood diabetes have superior psychosocial functioning. To be sure, this point of view has important implications for those clinicians who view symptoms as psychopathology. Strayhorn seems to expect some difficulty in managing childhood diabetes. Management difficulties do not necessarily indicate pathology but more likely reflect the nature of the task and less than superior psychosocial functioning.

Overall, the literature cautions against premature conclusion that siblings of chronically ill or disabled children are uniformly at greater risk for maladjustment (Ferrari, 1984). To the extent that siblings are well-

informed and involved in the care of the ill or disabled child in accord with age expectations, their sense of involvement in the family and mastery of illness or disability-related stresses may be enhanced (Drotar & Crawford, 1985). While most authors focus on the potential pathological consequences that may develop, there is considerable evidence that children are capable of coping and, in some instances, actually benefitting from growing up with a chronically ill or disabled brother or sister.

Statement of the Problem

To provide further clarification, the present study explored the general psychological functioning and self-esteem of siblings, as well as the experience of having a chronically ill or disabled brother or sister. The methodology combined both standardized instruments from multiple informants and semi-structured interviews of siblings. The siblings of autistic children were compared to their matched control group while the siblings of CF children were separately compared to their matched control group. Control variables included age and sex of the sibling and number of parents in the home. The interviews gathered information about aspects that may be associated with sibling adjustment: knowledge about the illness; the impact of the illness on the sibling relationship; changes in interpersonal relationships and family routines; information availability; and the ability of the sibling to help care for the ill or disabled child and to make a contribution to the family. The hypotheses that were tested included:

- I. Rates of overall behavioral and emotional problems in siblings of chronically ill or disabled children would not be different than rates in the matched control sample.
- II. Self-reported self-esteem of siblings of

chronically ill or disabled children would not be different from that of the matched control sample.

III. Social competency of siblings of chronically ill or disabled children would not be different from that of of the matched control sample.

IV. Mothers' lower estimation of the impact of the illness or disability on family functioning would be associated with higher self-reported self-esteem and lower behavioral and emotional problems in the siblings of chronically ill or disabled children.

Method

Participants:

Twenty families of children diagnosed with cystic fibrosis, twelve families of children diagnosed with autism or autistic-like presentations, and twenty-six normal control families participated in the study. Within the twenty families of cystic fibrosis children, 18 sisters and 16 brothers ranging in age from 3 to 23 years and their mothers participated. Within the twelve families of autistic or autistic-like children, 9 sisters and 10 brothers ranging in age from 5 to 19 years and their mothers participated. Within each of the twenty-six normal control families, one child who matched the age and sex of a sibling from either the cystic fibrosis or autistic group and his or her mother participated. The inclusion of two illness groups, cystic fibrosis and autism, was intended to illustrate the broader issues of siblings of chronically ill or disabled children and to improve the generalizability of the findings.

While only one sibling from each of the families of cystic fibrotic or autistic children was included in the analysis, the interview material from all of the siblings was included in the discussion. It was decided to restrict the analysis to only one sibling per family in order to avoid overrepresentation of any given family and to guard

against violation of the assumption of independence for the statistical analyses. Likewise, only one sibling from any normal control family was included in the analysis.

Procedure

The present study was part of a larger project on family adaptation to childhood chronic illness that was conducted at the Emma Pendleton Bradley Hospital and Rhode Island Hospital. Many of the families involved in the larger project participated in the sibling aspect of the study. In order to recruit families of children with cystic fibrosis, the researcher attended regularly scheduled Cystic Fibrosis parent meetings. In addition, the social worker assigned to the Cystic Fibrosis Clinic served as a liaison to inform and enroll families in the project. In order to recruit families of children with autism, the social workers who provided services for autistic children and their families served as liaisons to inform and enroll families in the project.

Interested families were then contacted by telephone and provided with details about project participation. A one time meeting to collect the data was scheduled with the mother and those siblings who wished to participate. Efforts were made to schedule the meetings at convenient times and locations. Families were offered the choice of home visits or combining the meetings with regularly scheduled clinic or hospital visits.

Following a brief description of the study, the mother and sibling(s) were asked to sign the Informed Consent Form (Appendix A1). During the remainder of the meeting, the mother completed the Child Behavior Checklist (CBCL) for each sibling that participated, the Impact-On-Family Scale (IOF) and a Family Information Form. While the mother completed the questionnaires, the researcher met with each sibling individually to administer the Coopersmith Self-Esteem Inventory (CSEI) and to conduct a semi-structured interview. The researcher audiotaped and took notes during the semi-structured interviews. While the interviews were not transcribed, the audiotapes were utilized to ensure accurate documentation of the siblings' responses. Following the meeting, a thank you letter was sent to the family.

The matched control children and their mothers were recruited from a local pediatric practice. The pediatric nurse served as liaison for the project. Families who had children who matched one of the previously interviewed siblings of cystic fibrosis or autistic children for sex, age, and number of parents in the household were eligible to participate. Upon arrival to the office for routine well-child visits, the nurse provided the mother with a brief description of the project and an introductory letter. If the family was interested in participating, the researcher telephoned them and arranged a convenient meeting time. The

Informed Consent Form (Appendix A2) was signed by both mother and child. While the researcher administered the Coopersmith Self-Esteem Inventory to the child, the mother completed the Child Behavior Checklist and Demographic Information Form. Following the meeting, a thank you letter was sent to the family.

Instruments

Child Behavior Checklist: (Appendix B1)

The Child Behavior Checklist (CBCL) is designed to record in a standardized format the social competencies and behavioral problems of children ages 4-16, as reported by their parents or others who know the child well (Achenbach & Edelbrock, 1978, 1981, 1983). Social competency is assessed by up to forty questions inquiring about the child's frequency and quality of participation in sports, nonsport activities, organized groups, jobs/chores, friendships, family, and school. The 118 behavior problem items, which include a wide range of potential problems, are scored on a 3-step response scale (0 = not true; 1 = somewhat or sometimes true; 2 = very true or often true). The CBCL is written at the fifth grade reading level and requires approximately 20 minutes for completion.

In the Child Behavior Checklist Manual, the authors summarize information regarding the reliability, interparent

agreement, and stability of the instrument. Concerning test-retest reliability of item scores, ratings of non-referred children were used since their scores would be less susceptible to regression toward the mean than referred children. The overall one-week reliability was .952 for the 118 behavior problem items and .996 for the social competency items ($N = 72$). Interparent reliability for children seen in a mental health setting is reported as .985 for the 118 behavior problems and .978 for the social competency items. Concerning the test-tetest reliability of the scale scores, the authors computed one-week test-retest reliabilities for raw scale scores of all age/sex groupings with the median correlation for all scales equal to .89. There were some exceptions to the high overall reliability including: the scale of Sex Problems for boys and girls ages 4-5 and girls ages 6-11 had low reliabilities (from .22 to 0.55); the Obsessive-Compulsive Scale for boys ages 12-16 had a reliability of -.12; and the Obese scale for girls 4-5 had a reliability of .42. This is not a major concern in the present study, however, as these particular subscales will not be used directly in the analyses.

A considerable number of validation studies have been completed with the CBCL. Achenbach and Edelbrock (1981) demonstrated that clinically-referred children received significantly higher scores than demographically similar non-referred children on 116 of the 118 behavior problem

items. Similarly, the clinically-referred children received significantly lower scores on all of the social competency items than the non-referred children. In an effort to establish construct validity, relations between scores derived from the CBCL and roughly analogous scores from other measures have been calculated (Achenbach & Edelbrock, 1978; Frame, Matson, Sonis, Fialkov and Kazdin, 1982; Hodges, McKnew, Cytryn, Stern and Klein, 1982; Michael, Klorman, Salzman, Borgstedt, and Dainer, 1981; Weissman, Orvaschel and Padian, 1980). For example, Pearson correlations between the Connors Parent Questionnaire and the CBCL for boys 6-11 years old are: Connors Anxiety with CBCL Schizoid, $r = .58$, and with CBCL Depressed, $r = .73$; Connors Psychosomatic with CBCL Somatic, $r = .85$; Connors Anti-social and CBCL Delinquent, $r = .77$; Connors Conduct Problem with CBCL Aggressive, $r = .84$; and Connors Impulsive-Hyperactive and CBCL Hyperactive, $r = .46$. In addition, the total behavior problem score has been found a useful discriminator of disturbed and nondisturbed children: using the 90% cutoff on the total score results in 90% of the non-referred sample being correctly classified in the normal range and 26% of the clinical sample being misclassified as from a non-referred sample.

Coopersmith Self-Esteem Inventory: (Appendix B2)

The Coopersmith Self-Esteem Inventory (CSEI) is a self-

report questionnaire designed to measure evaluative attitudes toward the self in social, academic, family, and personal areas of experience. The CSEI embraces a broad definition of self-esteem indicating the extent to which a person believes himself competent, successful, significant, and worthy (Coopersmith, 1981). The school form of the CSEI is designed for students 8-15 years old, though it has been utilized with children as young as 5 years old. The CSEI consists of 50 items measuring self-esteem and an 8-item Lie Scale. Each item is rated on a dichotomous scale as the child indicates whether the item is "Like Me" or "Unlike Me". When scored, the instrument yields a total score and four empirically-derived subscale scores including: General Self; Social Self-Peers; Home-Parents; and School-Academic. The CSEI may be self-administered by older children or administered by an interviewer. Completion time is approximately 10 to 15 minutes.

Internal consistency and reliability of the CSEI have been well documented. Spatz and Johnston (1973) administered the CSEI to over 600 students and obtained Kuder-Richardson reliability estimates of 0.81 for grade 5, 0.86 for grade 9, and .80 for grade 12. Kimball (1972) administered the instrument to 7600 children in grades 4-8 and reported internal consistencies ranging from .87 to .92. While some researchers question the appropriateness of stability estimates for affective tests, Rubin (1978) in a 3

year longitudinal study of children aged 9, 12, and 15 years found that children tested at the age of 12 and then again at age 15 showed greater test-retest consistency ($\bar{r} = .64$) than children tested at the earlier ages of 9 and 12 ($\bar{r} = 0.42$). Coopersmith (1967) reported five-week test-retest reliability of .88 for a sample of 50 children in grade five and three-year test-retest reliability of .70 for a sample of 56 children. Fullerton (1972) reported a one-year test-retest reliability of .64 for 104 children in fifth and sixth grades.

Kokenes (1974, 1978) in her studies of the comparative importance of home, peers, and school to the global self-esteem in preadolescents and adolescents confirmed the construct validity of the CSEI subscales as measuring sources of self-esteem. Cowan et al. (1978) included the CSEI in a multitrait, multimethod validation study ($N = 175$) with three self-report measures of self-esteem including the Bledsoe Self-Concept Scale, Piers-Harris Children's Self-Concept Scale, and the Purdue Self-Concept Scale and one behavior observational rating of self-esteem. While the requirement for convergent validity was met by the significant correlations among the self-report measures, the authors found no significant correlations between any of the self-report measures and the behavior observation rating.

Impact-on-Family Scale: (Appendix B3)

The Impact-On-Family Scale (IOF), a self-administered questionnaire completed by the parent(s), is designed to measure the impact of having a chronically ill child in the family (Stein and Reissman, 1980). The original pool of 190 items was generated from a review of the literature, interviews with a representative sample of mothers of chronically ill children, interviews with care providers, and clinical experience of the senior author. Efforts were made to write the items in both positive and negative directions in order to minimize response set phenomenon. Following two reviews by an expert panel, the item pool was reduced to 58 items. Items were scrutinized for clarity, redundancy, face validity, appropriateness for the construct being measured, and potential for differentiating the target population. The 58-item version was pretested (N = 52) with mothers of children with a variety of chronic illnesses. Informants were instructed to reply to each item on a four point scale: Strongly Disagree; Disagree; Agree; and Strongly Agree. Empirical analysis led to further refinement of the instrument and a reduction of the item pool to 32. Then, the 32-item version was administered to another sample of mothers with chronically ill children (N = 100), factor analysis and reliability work resulted in the retainment of 24 items.

The most recent IOF consists of 30 items which comprise five factor-analytically derived factors. Factor I,

Financial, contains four items relating to economic consequences for the family. Factor II, Familial-Social, contains nine items relating to the disruption in normal social interaction both within and outside the family system that is a direct consequence of the child's illness. Factor III, Personal Strain, relates to the personal disequilibrium experienced by the primary caretaker including fatigue, uncertainty, and difficulty planning for the future. Factor IV, Mastery, relates to the coping strategies employed by the family members to master the stress of the illness. Six items comprise the Sibling factor that focus on the impact on siblings. The internal consistency of the factor-derived subscales, computed by Cronbach's alpha, were .60 (Mastery), 0.72 (Sibling), .72 (Financial), .81 (Personal Strain), and 0.86 (Familial/Social). The internal consistency of the Total Score, which is a general measure of impact, was .88. Further reliability and validity work are currently underway.

Family Information Form: (Appendix B4)

Developed for this study, this form gathers family member information including: name; sex; age; educational/current school level; marital status; occupation; and ethnic origin. Socioeconomic status (SES) was calculated according to the Hollingshead (1975) four-factor index of social status. Mothers of chronically ill

or disabled children were asked some additional questions pertaining to the ill child's diagnosis, treatment course and need for hospitalization, daily care; to the relationship between the ill and able-bodied sibling; and to the sibling's possible concerns about the ill child and contribution within the household.

Semi-Structured Interviews: (Appendix B5)

Semi-structured interviews were conducted with the siblings to gather qualitative information about the experience of having a chronically ill brother or sister. The interviews required approximately 20-30 minutes. The researcher took as points of departure interview styles described by Iles (1979) and Pinyerd (1983) in their respective work with siblings of children with cancer and myelomeningocele. The interview inquired about those aspects alluded to in the literature which may be associated with sibling adjustment including: knowledge about the illness; changes in interpersonal relationships and family routines; and the ability to make a contribution to the family with respect to managing the child's chronic illness. In addition to the interview questions, participants were encouraged to speak generally about their experience of having a chronically ill or disabled brother or sister.

Results

Families and Siblings Included in the Analysis:

In order to avoid overrepresentation of any given family, statistical analyses of the questionnaires were restricted to one sibling per family. Efforts were made to include siblings from a wide age distribution in the statistical analyses, as well as from both sexes. The semi-structured interview material from all of the siblings is considered collectively in the discussion section.

Of the twenty families of children diagnosed with cystic fibrosis that participated in the study, one sibling from each of fourteen families was included in the analyses. Six families were excluded for the following reasons: three of the families had only two children both of whom were diagnosed with cystic fibrosis; one family had only two children one of whom was diagnosed with cystic fibrosis and the other with juvenile diabetes mellitus; one family had a healthy young adult sibling (21 years) who was interviewed only; and one family did not return the questionnaires. Of the larger group of twenty families, a total of 34 siblings (18 sisters and 16 brothers) ranging in age from 3 to 23 years were interviewed.

Of the twelve families with autistic or autistic-like children that participated, one sibling from each of the families was included in the questionnaire analyses. Within these twelve families, a total of 19 siblings (9 sisters and

10 brothers) ranging in age from 5 to 19 years were interviewed.

Twenty-six matched control children and their mothers completed the same questionnaires as the target families with the exception of the Impact-On-Family Scale. Similarly, to avoid overrepresentation of any given family only one matched control child was drawn from a family. The control children were not interviewed since they had not had the experience of growing up with a chronically ill or disabled brother or sister.

Siblings of Children with Autism:

One way repeated measures ANOVAs comparing the siblings of autistic children with their matched control group were performed utilizing the CBCL total social competence score (SCT), CBCL activities subscale (ACT), CBCL social subscale (SOC), CBCL school subscale (SCH), CBCL total behavior problem score (BPT), Coopersmith general self-esteem subscale (SEIGEN), Coopersmith social self-esteem scale (SEISOC), Coopersmith home self-esteem subscale, Coopersmith school self-esteem, Coopersmith total self-esteem scale, Coopersmith short self-esteem scale (SEISHT) and Coopersmith Lie Scale (SEILIE). A repeated measures ANOVA procedure was chosen due to its greater sensitivity as well as the matched control design of the study. Results are presented in Table 1.

Table 1

Repeated measures ANOVAs, Siblings of Autistic Children

Variable	<u>Control</u>		<u>Sibs of Autistic</u>		F(1,11)
	M	SD	M	SD	
CBCL SCT	44.4	9.1	46.2	11.3	0.12
CBCL ACT	46.3	8.2	46.6	7.2	0.00
CBCL SOC	44.8	9.2	45.4	10.0	0.02
CBCL SCH	49.3	6.6	50.2	6.8	0.11
CBCL BPT	51.2	8.8	52.3	11.2	0.06
SEIGEN	19.3	4.3	20.3	4.4	0.30
SEISOC	6.7	1.2	6.4	1.6	0.22
SEIHOME	5.8	2.1	5.9	1.6	0.04
SEISCH	5.5	2.2	5.9	2.1	0.30
SEITOT	74.0	17.1	77.2	16.0	0.20
SEISHT	17.4	5.0	18.3	4.1	0.22
SEILIE	1.9	1.3	2.4	2.1	0.70

Results with the siblings of autistic children support the major hypotheses. There were no significant differences between the siblings of autistic children and their matched control group on rates of overall behavioral and emotional problems, social competency, or self-reported self-esteem.

Siblings of Children with Cystic Fibrosis:

Repeated measures ANOVAs between the siblings of children with cystic fibrosis and their matched control group were performed on the same CBCL and Coopersmith Self-Esteem Inventory subscales explained in the above section. Results are reported below in Table 2.

Table 2

Repeated measures ANOVAs, Siblings of Children with Cystic Fibrosis

Variable	<u>Control</u>		<u>Sibs of CF Children</u>		F(1,13)	w ²
	M	SD	M	SD		
CBCL SCT	50.5	9.9	47.2	10.4	1.15	
CBCL ACT	50.9	5.9	46.4	8.1	3.60	
CBCL SOC	46.0	10.7	48.2	7.1	0.49	
CBCL SCH	52.4	3.7	49.4	5.4	1.86	
CBCL BPT	47.9	10.9	57.6	6.7	8.16*	.20
SEIGEN	20.8	3.3	19.2	3.8	1.62	
SEISOC	6.6	1.6	6.7	1.3	0.09	
SEIHOME	7.1	0.9	5.9	1.6	8.63*	.18
SEISCH	6.6	1.6	5.9	1.8	1.31	
SEITOT	82.1	10.7	75.4	12.0	3.65	
SEISHT	20.1	3.1	17.4	4.4	5.71*	.09
SEILIE	2.0	1.6	1.9	1.6	0.05	

*p < .05

Note: The degrees of freedom for CBCL SCT (1,12);
CBCL SCH (1,11)

Results with the CF siblings partially supported the hypotheses regarding level of behavioral/emotional problems and social competency. Mothers of CF siblings endorsed significantly more behavioral and emotional problems than mothers of the matched control children. Given that the CBCL Total Behavior Problem score provides an estimate of the mother's overall perception of problems, it is not possible to determine whether and/or which specific problems areas contributed to the higher endorsement. With respect to social competency, siblings of children with cystic fibrosis were not significantly different on any of the social competency parameters than their matched control group.

The hypothesis predicting no differences between the siblings of children with cystic fibrosis and their matched control group on self-reported self-esteem was only partially supported. On the Coopersmith general subscale, social subscale, school subscale, total self-esteem scale and the lie scale, there were no significant differences. However, the siblings of cystic fibrotic children demonstrated significantly lower self-reported levels of self-esteem in the home environment and as measured by the Coopersmith Self-Esteem Inventory short scale than did their matched control group.

While the Short Self-Esteem subscale indicates significant differences between the siblings of cystic

fibrotic children and their matched control group, neither the General subscale nor the overall Total Self-Esteem scale demonstrate significant differences. Generally, the larger Total Self-Esteem scale which consists of 50 items is considered more reliable and recommended than the 25-item Short Self-Esteem subscale. Closer examination of the Total Self-Esteem scale ANOVA results indicate that it approached significance ($F = 3.65$, $p = 0.08$). For the siblings of cystic fibrotic children, then, there is only partial support for the hypothesis that these children demonstrate no differences in levels of self-reported self-esteem than their matched control group.

Mother's Estimation of Impact on Family Functioning:

A Pearson correlation matrix was generated which computed intercorrelations between the subscales and total score of the Impact-On-Family (IOF) questionnaire completed by mothers and the CBCL and Coopersmith Self-Esteem Inventory subscales. Subscales of the IOF include: Financial (FIN); Social/Familial (SF); Personal Strain (PS); Mastery (MAS); Sibling (SIB). For the purposes of this analysis, data from both the CF and autistic siblings was collapsed. Details of the correlation matrix are presented below in Tables 3 and 4.

Table 3

Pearson Correlation Matrix, Mother's IOF and the CBCL

	FIN	SF	PS	MAS	SIB	TOT
CBCL SCT	-.05	.15	.02	-.05	-.07	.02
CBCL ACT	.05	.33*	.25	-.06	.14	.23
CBCL SOC	-.21	-.29	-.26	-.09	-.30	-.31
CBCL SCH	-.28	-.07	-.13	.05	-.21	-.21
CBCL BPT	.30	-.03	.04	.08	.02	.09
*p < .05 (N = 26)						

Table 4

Pearson Correlation Matrix, Mother's IOF and the Coopersmith Inventory

	FIN	SF	PS	MAS	SIB	TOT
SEIGEN	-.09	-.16	-.09	-.18	.07	-.12
SEISOC	.00	.00	.02	-.23	.21	.06
SEIHOME	-.14	-.21	-.20	-.50**	.17	-.23
SEISCH	-.32	-.14	-.02	-.40*	-.10	-.25
SEITOT	-.17	-.18	-.10	-.37*	.09	-.19
SEISHT	-.16	-.13	-.02	-.32	.13	-.13
*p < .05 **p < .01 (N = 26)						

The hypothesis that predicted mothers' lower estimation of the impact of illness on family functioning would be associated with lower behavioral and emotional problems and higher self-rated self-esteem was partially supported. The IOF Mastery subscale measuring parental and familial positive coping strategies was positively correlated with siblings total self-esteem, as well as self-esteem related to the home and school environments. The IOF Mastery subscale was better correlated with the siblings self-esteem ratings than those subscales devoted to specific stress areas (e.g., financial, social/familial, personal strain, siblings). None of the IOF subscales was significantly correlated with the overall level of behavioral and emotional problems, however the correlation between the IOF Financial subscale and the CBCL total behavior problem score approached significance ($r = .31$, $p = .06$).

Discussion

The presence of childhood chronic illness or disability continues to be perceived as an emotionally costly and stressful experience for the family. While there are similarities regarding families' responses and adaptation across many conditions, the nature of the illness or disability fleshes out the more specific demands placed upon the family and siblings (Poznanski, 1973). Parameters including chronicity, genetic predetermination, age of onset, daily treatment requirements, degree of visibility, functional limitations, and longevity contribute to the overall impact of the illness. Regardless of the particular illness or disability, however, an unmistakably negative valence characterizes most descriptions of family life including the experience of siblings.

Research efforts devoted to siblings began with the assumption that siblings were exposed to greater stress as a result of the illness or disability and, therefore, were at increased risk for psychological problems (Breslau et al., 1981, Lobato, 1983). Over time, a greater appreciation for the complexity and diversity among sibling outcomes has emerged. The notion that siblings invariably demonstrate more overall psychopathology has been replaced with the idea that no one-to-one correspondence exists between the presence of childhood chronic illness or disability and

psychological disturbance in healthy siblings. While this has been a liberalizing influence, the actual experience of siblings remains poorly understood because the majority of investigations have focused almost exclusively on psychopathology.

The results of this study support the view that there is no one-to-one correspondence between chronic illness or disability and greater amounts of behavioral and emotional problems in siblings. According to mothers' reports, siblings of children with autism do not demonstrate significantly more behavioral and emotional problems than normal control children. On the other hand, siblings of children with cystic fibrosis do. The results suggest that some, but not all, siblings of chronically ill or disabled children develop behavioral and emotional problems. These siblings do not invariably evidence greater problems. However, to claim that there is no difference between these siblings and matched control children in overall levels of emotional and behavioral problems oversimplifies the matter. Ultimately, such a conclusion would lead to an underestimation of the siblings who evidence behavioral and emotional problems.

This study offers no parsimonious explanation why the siblings of autistic children did not differ from their control group while the siblings of cystic fibrosis children did. The purpose of including the two groups was not to

compare them directly but to gain a broader perspective on the sibling experience. It may be that the mothers of autistic children are exposed to overall greater amounts of emotional and behavioral problems with their autistic children. Mothers of autistic children may have different internal standards for what constitutes behavioral and emotional problems. Compared to their autistic brothers and sisters, the siblings may seem relatively low on behavioral and emotional problems. Another possible explanation may be that mothers of autistic children provided socially desirable responses indicative of no pathology. Given the unfortunate history of "the refrigerator mother" etiology for autism, these mothers may be particularly intent on affirming the emotional health of their non-afflicted children. It is also likely that several mothers in the study have been sensitized to the concern for siblings' adjustment through books, other parents, and family-oriented treatment centers. This heightened sensitivity may have accounted, in part, for the higher ratings of the cystic fibrosis mothers.

Few studies have considered the positive aspects of siblings' functioning and how this might compare to normal control children. The results of this study indicate that the social competency of siblings of autistic and cystic fibrotic children is comparable to normal control children. With respect to the number and quality of activities,

friendships, and school performance, the siblings of chronically ill and disabled children do not differ from other children. Generally, childhood chronic illness and disability is thought to isolate families, attenuate family relationships, and compromise the degree of open communication within the family. However, the siblings' degree of social relatedness and participation in activities and friendships is discrepant with such a bleak description of their families. Given the central role that families play in the socialization of their children, the results cast some doubt on the accuracy of the family's image as socially isolated and constricted.

Often, siblings serve as an interface between the family and larger society. In particular, these siblings may be responsible for explaining the illness or disability to other children, looking after the special needs of their brother or sister at school, and, if necessary, protecting them from the insensitivities of other children (Iles, 1979; Featherstone, 1980). The results of the study suggest that the social development of these siblings is not necessarily compromised as a result of these additional responsibilities. In fact, a case could be made that good social skills may be essential for the siblings to carry out these responsibilities on behalf of the family.

Self-reported self-esteem serves as another useful indicator of children's psychological well-being. The

results of this study indicate that siblings of autistic children do not differ from normal control children on indices of general self-esteem, as well as self-esteem particular to home, school, and social spheres. Siblings of children with cystic fibrosis present a more mixed picture of self-esteem. In the school and social arenas, they have comparable self-esteem to other children. However, on self-esteem related to the home environment, these siblings are significantly lower than normal control children. There were inconsistencies on the indices of general self-esteem with the short Coopersmith SEI revealing a significantly lower self-esteem and the full-length SEI revealing no significant differences. For the purposes of this study, the most salient finding is that CF siblings have lower self-esteem related to the home environment than other children. The lower self-esteem within the home environment contributes to the overall lower estimation of self-esteem.

Again, there is no parsimonious explanation for why CF siblings suffer from lower estimates of self-esteem within the home while autistic siblings do not. The temptation might be to conclude that the home environments of families with cystic fibrotic children are more stressful and less supportive of siblings. However, such a generalization does not seem warranted or appropriate. It would be far more useful to speculate about the role of cystic fibrosis as it relates to family life and how this might impact upon

the siblings.

Children with cystic fibrosis vary widely in the severity of their illness and caretaking demands. Typical home management includes medication and daily chest physical therapy. It is likely that the caretaking demands may, at certain times, disrupt or preempt family routines. Siblings may view the time that parents devote to CF management as special time for the ill child from which they are excluded. Generally, the home management of cystic fibrosis is carried out by the parents. It may be that siblings see their parents as competent with respect to understanding and managing the illness, while they by comparison feel ill-equipped. Siblings of autistic children, on the other hand, may at times see their parents as equally confused and frustrated as they are. The management of autism may involve a more family-centered approach which not only overcomes the dichotomy of "expert parent" and "ill-equipped sibling" that may contribute to lowered self-esteem, but also grants siblings more clearcut participation.

Another possible explanation for the lowered self-esteem of the CF siblings lies in the nature of the illness. Siblings of CF children may identify more closely with their brothers and sisters than siblings of autistic children. Cystic fibrosis is a physical disorder, more severe though not entirely unlike physical illnesses that siblings may have experienced. Children with CF are capable of

participating in the majority of regular childhood endeavours, including forming emotional attachments with their brothers and sisters. CF siblings may experience lower self-esteem as a result of growing up with a chronically ill brother or sister, who is basically like them, but who also requires constant medical management and whose life span will undoubtedly be shorter than their own. This is in contrast to siblings of autistic children who may view their brothers and sisters as essentially different than themselves, thus serving the protective function of decreasing the degree of identification.

Mothers' estimation of the impact of the illness on the family has some relevancy to understanding siblings' general level of self-esteem, particularly within the home. Mothers' degree of mastery over the illness was highly correlated with siblings' total self-esteem, as well as self-esteem related specifically to the school and home settings. It is important to note that siblings' self-reported self-esteem was more sensitive to the mothers' own feelings of mastery than to the amount of financial, social-familial, or personal stress attributed to the illness. In the context of the IOF scale, mastery is broadly conceptualized as being able to utilize available resources, openly discussing the illness with partner and family members, and learning to manage the child's illness. These results correspond well to previous findings that siblings

depend largely upon their parents to make sense of the illness, as well as to integrate it into everyday family life (Featherstone, 1980; McHale et al., 1984). Siblings who perceive mastery on the part of their parents in dealing with the illness have higher levels of self-esteem, particularly within the home environment. This suggests that siblings are positively influenced by their parents' attempts to cope with the illness. In addition, this parental sense of mastery provides siblings with a model for how to deal efficaciously with the illness.

While efforts were made to address some of the methodological limitations of earlier studies, limitations remain. To reduce the problem of overrepresentation of families, only one sibling per family was included in the analysis. The study employed a matched control group design. It was decided to match the siblings on age, sex, and number of parents in the home. While the availability of control families did not permit, it may have been superior to match the children for relative birth order and sibling constellation. Unlike earlier studies that focused almost exclusively on parent report, questionnaire data was collected from both mother and sibling. In addition to information indicative of behavioral and emotional problems, data was collected about positive aspects of sibling functioning including social competency and self-esteem. Due in part to the small sample size and the choice of

assessment instrument, it was not possible to make finer discriminations as to what particular behavioral and emotional problems the cystic fibrosis children differed on. Also, the severity of CF illness was not taken into account, nor was the severity/level of functioning of the autistic children. While the semi-structured interviews with the siblings provided rich information about the experience of growing up with a chronically ill or disabled child, the data does not lend itself easily to statistical analysis.

Despite these limitations, the study lends additional support to more recent conclusions that siblings of chronically ill or disabled children do not invariably manifest psychological maladaptation (Breslau et al., 1981; Ferrari, 1984). The study moves beyond the narrower consideration of psychopathology in siblings, to find that siblings are comparable to other children in social competency and some areas of self-esteem. Similarly, the importance of parental mastery as it relates to sibling self-esteem was highlighted. This represents a shift from focusing almost exclusively on pathology to looking at possible strengths of the siblings. The sibling interview data provides a wonderful opportunity to consider the challenges of siblings and how they attempt to meet them.

Siblings need information in order to make sense of the illness or disability. To assess how well informed siblings were, they were asked to explain what they understood about

their brother or sister's illness. With respect to the CF siblings, most children provided accurate, age-appropriate information. Most siblings provided responses about the medical complications of cystic fibrosis. Most frequently, they discussed the "lung problems" and "digestive problems" in concrete terms. Respiratory complications including coughing, "gross lungs," "clogged up lungs," and "trouble with breathing" were most prominent in their descriptions. Two children answered "it's one of the badest diseases that a person can have" and "It's a bad disease and you feel bad for him." Some siblings provided information about the treatment of the illness including chest physical therapy, medication, "enzymes for digestion", and hospitalization. One 7 year old girl focused in on the "short fingers" (finger clubbing) that is due to longstanding compromised peripheral circulation. Some older siblings commented about the genetic basis of the illness and life expectancy ("most people don't live beyond 20 years old"). One child commented about the national research efforts that are "finding more and more cures." Of the entire group of CF siblings, two of them said that they did not know anything. When asked if they would like to learn about the illness, they said yes.

There was considerable variability among the descriptions of autism provided by the siblings. Given the ambiguous nature of autism and wide range of functioning

among autistic children, it is understandable that siblings had some difficulty. Most often, siblings provided descriptions of their brother or sister's presentation rather than general information about autism. Some siblings compared autism to mental retardation, "it's almost like being retarded but it's different..there are lots of different kinds of autism...some talk a lot and others don't talk at all." Siblings highlighted that their autistic brother or sister was different, not like other children. When asked to explain what made them different, siblings offered: "he's a little slow, it takes him longer to learn"; temper tantrums, "hyper behavior and banging on things"; "he rocks so we have special places that are safe for him to rock"; "likes to be alone"; and "he can't do some things like use the phone or tie his shoes." Siblings frequently referred to communication and speech problems. Some of the older siblings focused on the strengths of their brothers and sisters including drawing, musical skills and mathematical abilities.

Across both the autistic and CF groups, siblings made distinctions between what they had told the interviewer about the illness and what they would tell a friend at school. In most cases, siblings censor and scale down the information that they tell classmates. Many siblings confide in one or two close friends about the illness, but are reluctant to divulge details to other children. Reasons

mentioned for their restraint include embarrassment, privacy, and protection of their brother or sister. An 8 year old boy explained, "you watch it...you don't tell everyone because you don't want them to know.. I just tell my best friends because they care, the others don't."

Siblings were asked whether the illness had caused any differences in the relationships with their brothers or sisters or within their families. With respect to the CF siblings, most described their relationships as similar to other brothers and sisters. Some siblings worry that their brother or sister might deteriorate and need to be hospitalized. Younger siblings describe "feeling bad" and older siblings describe "being more sympathetic" towards their brothers and sisters. Several siblings explained that the ill children receive more parental attention because they are sick. A 9 year old girl explained, "He needs a little more attention so then I try to understand and it doesn't bother me...I'm the oldest so I try to be responsible." To the same issue a 13 year old girl said, "I don't say anything about it for a long time and then it builds up and I'll bring it up to my parents... it's aggravation...it works about 1 out of 5 times to remind them." Another 8 year old boy explains, "They used to play with me more, but now that M. is born they have to give her medicine and chest therapy...it's not that bad for me because I have my friends and my cousins." Different

siblings commented that the illness had brought the family closer together, had caused many arguments between the parents, made the family more thankful and religious, or made the parents worry more.

Siblings of autistic children ascribe many differences to their families due to the autistic child. Several siblings explained that there is a greater "alertness" within the household to ensure the care of the autistic child. Siblings are enlisted by parents to share in the responsibility of supervising or entertaining their brothers and sisters. Some siblings commented about restrictions on family life due to the autistic child: "we can't go some places like restaurants", "he doesn't like new people coming over so my friends can't come over", "I have to really watch my stuff because she gets into everything (especially homework)", "we have to keep the doors locked because he wanders away...I'm always afraid that he'll wander onto the highway", and "it's really hard to find someone to take care of him so we really can't go too many places because he could act up." On the other hand, some brothers and sisters speak about the family's commitment to care for the child and how that engenders a special closeness within the family. A 12 year old girl said, "It doesn't have to be difficult. It brings a different closeness to the family...we all get involved with M. in a way we usually wouldn't."

Siblings were asked whether they had any special worries or concerns about their brothers or sisters. The majority of worries for CF siblings focused around progression of the illness and the need for hospitalization. Specifically, they worried about coughing, vomiting, choking, and stopping breathing. A 13 year old brother of an infant with CF said, "I worry that he'll choke...every night I always go in and check his breathing before I go to sleep...for peace of mind." Siblings make the distinction between times when the CF is well controlled and when their brothers and sisters are "really sick." During times when the illness is under control, the siblings do not seem to focus a great deal on the CF. However, during times when the children are "really sick", the siblings are apt to worry. Some children focused in on how long their brothers and sisters would live: "I worry about how much time she has left...and whether she'll be able to earn her degree in social work", "I hope that she lives to be at least 12 years old", and "I'm scared that one morning she won't be breathing anymore."

Siblings of autistic children expressed concerns about safety and the future quality of their brothers' and sisters' lives. Specifically, several children worried about wandering behavior and possible harm by traffic. There were concerns that their brothers and sisters would be misunderstood or ridiculed by others. An 8 year old brother

explained, "he gets picked on...it's hard to protect him." A 12 year old twin of an autistic girl said, "Some people make fun of her...I get nervous that she'll do something wrong and they won't understand." These siblings appear to think a good deal about the future, particularly how their brothers and sisters will fare and be provided for. A 15 year old brother put it this way, "I hope that he'll be able to talk and that in the future he'll be a regular human being." Many of the siblings were unsure of what to expect in the future, thus contributing to their concerns. One 12 year old sister anticipates "when he gets older it may be more difficult...I worry about his progress...will he be able to take care of himself?" Similarly, another 12 year old sister says "When she grows up where will she go...I imagine that I'll take care of her."

Siblings of both autistic and CF children were asked who they would turn to if they had questions about their brother or sister. Almost invariably, siblings said that they would turn to their parents first. Some siblings mentioned that books and pamphlets had been helpful. Some siblings of older CF children turned to their brothers and sisters directly. One child participated in a structured group experience designed for siblings. Older siblings may confide in their close friends. One 12 year old sibling of an autistic child described a friendship that was very helpful to her, "I would turn to my best friend S...we talk

a lot about my brother...we try to concentrate on his progress not his failures."

In an effort to learn about the contributions that siblings might make to their brothers and sisters' care, siblings were asked whether and how they participated in the care. While the parents are primarily responsible for the CF child's care, most CF siblings indicated that they were involved in the care in some capacity. The specific contributions of siblings were age dependent. Younger children said that they played with their brothers and sisters when they were sick, kept them company during their treatments, entertained them, and visited them in the hospital. Several siblings mentioned that they remind their siblings to take their medication with meals, help crush up pills if they are too big to swallow, or count out the pills. Several older siblings had learned how to do the chest physical therapy treatments. In most cases, siblings said that they "help out their parents" or "take turns doing the treatments." An 18 year old sister said that she adhered to the dietary restrictions of her CF sibling in order "to make it easier" for her. Also, some siblings mentioned that they were involved in local fund-raising efforts and class science projects about CF.

Likewise, siblings of autistic children are involved in their brothers and sisters' care. Most often, siblings said that they babysit or "keep an eye on" their brothers

and sisters. One 18 year old brother offered that "when babysitting M. you have to be very vigilant...you can't do anything else...you are very tied up with him." Many siblings commented that they participate in favorite activities together including watching television, sorting out baseball cards, reading, listening to music and playing. Some siblings get involved with teaching their autistic brothers and sisters. An 8 year old brother proudly reported that he had "learned all my brother's signs for communicating...I helped teach my parents." Another 12 year old brother said, "I try to keep her away from sugar, play with her...teach her about bikes and skating, especially about safety." A 19 year old sister considered herself "a second mother" to her younger autistic brother.

Towards the end of the interview, siblings were asked what advice they would offer to other brothers and sisters who grow up in families with ill or disabled children. The siblings had a considerable amount to say. CF siblings stressed the importance of learning about the illness and treatment procedures. They advised siblings to talk about the illness with family members and to share their feelings. An 18 year old sister offered that "it helps to have a family that stays together, to keep your head on right, and to accept the realities." They suggested that it is important for siblings to help take care of their brothers and sisters. A 17 year old brother suggested that siblings

"not put everything off to the future, don't wait...be tolerant and imagine what it is like." Several siblings stressed the importance of treating the ill child as a regular person: "they're no differenter than anybody else", "the person is basically normal, you don't need to shy away" and "it's a terrible disease but the kids who have it want to be treated like normal kids because they are normal kids."

Siblings of autistic children also had some advice to offer. They emphasized the importance of learning the autistic child's routines, particularly ways that effectively "calm them down." The ability to praise the autistic child "for even the littlest thing" and "taking pride in his accomplishments" were suggested. Several siblings stressed the importance of patience and realistic expectations. In contrast to the CF siblings who emphasized the normalcy of CF children, siblings of autistic children emphasized that autistic children were basically different. A 7 year old brother put it this way, "Don't laugh or make fun, remember that he can't help it...he was just born that way." Similarly, a 15 year old brother said, "Remember he's not exactly normal...relax and don't push it too far...be forgiving." Siblings advocate hopefulness as a strategy: "try to be strong and never give up hope" and "don't give up on them...try to befriend them and spend time with them." An 18 year old brother offered, "the autistic person is

different, but once you get past that it's the same...you still have all the love of a brotherly bond."

Taken together, the questionnaires and sibling interviews provide a rich source of information about the sibling experience. The questionnaires enabled comparison between the siblings of children with cystic fibrosis and autism with normal control children. The data collected in this study supports current conclusions that childhood chronic illness represents a stressor to the family and siblings. Some, but not all, siblings of chronically ill or disabled children may develop emotional or behavioral problems. Similarly, some siblings may be at risk for lower self-esteem, particularly within the home environment. It is important to remember that psychopathology and self-esteem are multi-determined constructs. It is oversimplistic to attribute differences in sibling characteristics solely to the presence of childhood chronic illness in the family. The presence of the illness does not, of necessity, translate into psychopathology for siblings.

As gleaned from the interviews, these siblings are faced with certain challenges due to the illness or disability. Given that siblings are positively influenced by the parental sense of mastery in handling the illness, it is important that parental mastery be fully supported. In order to make sense of the illness, siblings need honest and

understandable information about their brothers and sisters. Given that most siblings turn to their parents for information, parents need to be equipped to handle questions. It is important to provide ongoing, integrated information that is commensurate with the sibling's age and developmental level.

An atmosphere of open communication and shared responsibility for the ill or disabled child is viewed positively by siblings. Siblings seem to benefit from making a contribution to their brother or sister's care. Upon interview, siblings report that they may help the parents with treatments, remind siblings to take medications, babysit, entertain, visit or teach their brothers and sisters. Making contributions to the care of an ill or disabled child can serve an empowering function for siblings. It is important to find ways for siblings to make contributions that are developmentally appropriate and reasonable.

With respect to future research implications, this study illustrates the utility of moving beyond questions regarding the likelihood of psychopathology in sibling populations. The more fruitful research questions may be to consider the particular challenges that siblings are met with and how they do or do not cope with them. The study suggests that the siblings themselves are an excellent source of information. Further exploration of the day-to-

day strategies that siblings use to cope with the stressful aspects of having an ill or disabled brother or sister is needed. Further investigation of the strengths and resiliency of the families and siblings who are coping well would enhance our understanding of effective family functioning. It would be worthwhile to further investigate how age differences between the siblings and gender pairings impact on sibling adjustment. Longitudinal studies that investigate the sibling relationship over time would enhance our knowledge base and help to design better educational and supportive services for siblings.

Bibliography

- Achenbach, T.M. and Edelbrock, C.S. (1978). The classification of child psychopathology: A review of empirical efforts. Psychological Bulletin, 85, 1275-1301.
- Achenbach, T.M. and Edelbrock, C.S. (1981). Behavioral problems and competencies reported by parents of normal and disturbed children aged four through sixteen. Monographs of the Society for Research on Child Development, 46(1).
- Achenbach, T.M. and Edelbrock, C.S. (1983). Manual for the Child Behavior Checklist and Revised Child Behavior Profile. Burlington, VT: Queen City Printers, Inc.
- Bank, S. and Kahn, M. (1975). Sisterhood-brotherhood is powerful: Sibling-subsystems in family therapy. Family Process, 14(3), 311-339.
- Bank, S. and Kahn, M. (1982). The Sibling Bond. New York: Basic Books, Inc., Publishers.
- Binger, C.M., Ablin, A.R., Feuerstein, R.C., Kushner, J.H., Zoger, S. and Mikkelsen, C. (1969). Childhood leukemia: Emotional impact on patient and family. New England Journal of Medicine, 280, 414-418.
- Blackard, M.K. and Barsh, E.T. (1982). Parents' and professionals' perceptions of the handicapped child's impact on the family. TASH Journal, 7, 62-70.
- Breslau, N., Weitzman, M. and Messenger, K. (1981). Psychologic functioning of siblings of disabled children. Pediatrics, 67(3), 344-353.
- Brownmiller, N. and Cantwell, D. (1976). Siblings as therapists: A behavioral approach. American Journal of Psychiatry, 133(4), 447-450.
- Cairns, N. U., Clark, G. M., Smith, S. D. and Lansky, S. B. (1979). Adaptation of siblings to childhood malignancy. Pediatrics, 95(3), 484-487.
- Caldwell, B.M. and Guze, S.B. (1960). A study of the adjustment of parents and siblings of institutionalized and noninstitutionalized retarded children. American Journal of Mental Deficiency, 64, 845-861.
- Carandang, M. L. A., Folkins, C. H., Hines, P. A. and Steward, M. S. (1979). The role of cognitive level and

- sibling illness in children's conceptualizations of illness. American Journal of Orthopsychiatry, 49(3), 474-481.
- Cleveland, D.W. and Miller, N.B. (1977). Attitudes and life commitments of older siblings of mentally retarded adults: An exploratory study. Mental Retardation, 15, 38-41.
- Comoroff, J. and Maguire, P. (1981). Ambiguity and the search for meaning: Childhood leukaemia in the modern clinical context. Social Science Medicine, 15B, 115-123.
- Coopersmith, S. (1967). The Antecedents of Self-Esteem. San Francisco: W.H. Freeman.
- Coopersmith, S. (1981). SEI: Self-Esteem Inventories, Palo Alto, CA: Consulting Psychologists Press, Inc.
- Cowan, R., Altmann, H. and Pysh, F. A. (1978). A validity study of selected self-concept instruments. Measurement and Evaluation in Guidance, 10, 211-221.
- DeMyer, M.K. (1979). Comments on "Siblings of Autistic Children." Journal of Autism and Developmental Disabilities, 9, 296-298.
- Drotar, D. and Crawford, P. (1985). Psychological adaptation of siblings of chronically ill children: Research and practice implications. Developmental and Behavioral Pediatrics, 6(6), 355-362.
- Dunn, J. (1985). Sisters and Brothers. In: Bruner, J., Cole, M. and Lloyd, B. (Series Eds.) The Developing Child Series. Cambridge, Massachusetts: Harvard University Press.
- Dunn, J. and Kendrick, C. (1982). Siblings: Love, Envy, and Understanding. Cambridge Massachusetts: Harvard University Press.
- Dywab, G. (1976). What should be our national policy toward handicapped children? In: N.B. Talbott (Ed.) Raising Children in Modern America, Boston: Little Brown Company.
- Farber, B. (1959). Effects of a severely mentally retarded child on family integration. Monographs of the Society for Research in Child Development, 24, (2, Serial No. 71).
- Farber, B. (1960). Effects of a severely mentally retarded child on family integration. Monographs of the Society for Research in Child Development, 21, (1, Serial No. 75).
- Farber, B. (1964). Family: Organization and Interaction. San Francisco: Chandler.

- Farber, B. and Ryckman, D.B (1965). Effects of severely retarded mentally retarded children on family relationships. Mental Retardation Abstracts, 2, 1-17.
- Featherstone, H. (1980). A Difference in the Family, New York: Basic Books.
- Ferrari, M. (1984). Chronic illness: Psychosocial effects on siblings-I. Chronically ill boys. Journal of Child Psychology and Psychiatry, 25(3), 459-476.
- Feshbach, N.D. (1978). Studies of empathic behavior in children. In B.A. Mahler (Ed.), Progress in Experimental Personality Research (Vol. 8, pp. 1-47). New York: Academy Press.
- Frame, C., Matson, J. L., Sonis, W. A., Fialkov, M. J. and Kazdin, A.E. (1982). Behavioral treatment of depression in a prepubertal child. Journal of Behavior Therapy and Experimental Psychiatry, 13, 239-243.
- Friedrich, W.N. (1977). Ameliorating the psuchological impact of chronic physical disease on the child and family. Journal of Pediatric Psychology, 2, 26-31.
- Fromberg, R. (1984). The sibling's changing roles. In: Schopler, E. and Mesibov, G.B. (Eds.) The Effects of Autism on the Family, New York: Plenum Press.
- Fullerton, W. S. (1972). Self-disclosure, self-esteem and risk-taking: A study of their convergent and discriminate validity in elementary school children. Doctoral dissertation, University of California, Berkeley.
- Furman, W. and Buhrmester, D. (1985). Children's perceptions of the qualities of sibling relationships. Child Development, 56, 448-461.
- Gallagher, J. J., Beckman, P. and Cross, A. H. (1983). Families of handicapped children: Sources of stress and its amelioration. Exceptional Children, 50(1), 10-19.
- Gath, A. (1972). The mental health of siblings of congenitally abnormal children. Journal of Child Psychology and Psychiatry, 13, 211-218.
- Gath, A. (1973). The school aged siblings of mongol children. British Journal of Psychiatry, 132, 161-167.
- Gath, A. (1974). Sibling reactions to mental handicap: A comparison of the brothers and sisters of mongol children.

- Journal of Child Psychology and Psychiatry, 15, 187-198.
- Gayton, W. F., Friedman, S. B., Tavormina, J. F. and Tucker, F. (1977). Children with cystic fibrosis: I. Psychological test findings of patients, siblings, and parents. Pediatrics, 59(6), 888-894.
- Gliedman, J. and Roth, W. (1980). The Unexpected Minority: Handicapped Children in America. New York: Harcourt, Brace, Javanovich.
- Gogan, J.C., O'Malley, T.E. and Foster, D.J. (1977). Treating the pediatric cancer patient: A review. Journal of Pediatric Psychology, 2, 42-48.
- Gogan, J.C. and Slavin, L.A. (1981). Interviews with brothers and sisters. In: Koocher and J.E. O'Malley (Ed). The Damocles : Psychosocial Consequences of Surviving Childhood Cancer New York: McGraw-Hill.
- Gortmaker, S.L. and Sappenfield, W. (1984). Chronic childhood disorders: Prevalence and impact. Pediatric Clinics of North America, 31, 3-18.
- Gralicker, B.V., Fishler, K. and Koch, R. (1962). Teenage reaction to a mentally retarded sibling. American Journal of Mental Deficiency, 66, 838-843.
- Grossman, F.K. (1972). Brothers and Sisters of Retarded Children. New York: Syracuse University Press.
- Hayden, V. (1974). The other children. Exceptional Children, 4, 26-29.
- Hodges, K., McKnew, D., Cytryn, L., Stern, L. and Kline, D. (1982). The Child Assessment Schedule (CAS) diagnostic interview: A report on the reliability and validity. Journal of the American Academy of Child Psychiatry, 21, 468-473.
- Hollingshead, A. B. (1975). Four factor index of social status. Unpublished manuscript, Yale University Department of Sociology, New Haven, Connecticut.
- Iles, J. P. (1979). Children with cancer: Healthy siblings' perceptions during the illness experience. Cancer Nursing, October, 371-377.
- Kimball, O. M. (1973). Development of norms for the Coopersmith Self-Esteem Inventory: Grades four through eight. Doctoral dissertation, Northern Illinois University, 1972. Dissertation Abstracts International, 34, 1131-1132.

- Kirk, S.A. and Bateman, B.D. (1964). Ten years of research at the Institute for Research on Exceptional Children, Urbana: University of Illinois.
- Kokenes, B. (1974). Grade level differences in factors of self-esteem. Developmental Psychology, 10, 954-958.
- Kokenes, B. (1978). A factor analytic study of the Coopersmith Self-Esteem Inventory. Adolescence, 13, 149-155.
- Lamb, M.E. and Sutton-Smith, B. (Eds.) (1982). Sibling relationships: Their nature and significance across the life span. Hillsdale, New Jersey: Erlbaum.
- Langner, T.S., Gersten, J.C. and McCarthy, E.D. (1976). A screening inventory for assessing psychiatric impairment in children 6 to 18. Journal of Consulting and Clinical Psychology, 44, 286.
- Lauterbach, C.G. (1974). Socio-behavioural adaptation of siblings of the mentally handicapped child. Scranton, Pennsylvania: Printshop.
- Lavigne, J. V. and Ryan, M. (1979). Psychologic adjustment of siblings of children with chronic illness. Pediatrics, 63, 616-627.
- Lobato, D. (1983). Siblings of handicapped children: A review. Journal of Autism and Developmental Disorders, 13(4), 347-364.
- Lobato, D. (1985, October). Brothers and sisters of handicapped children. Invited workshop presented at the annual conference of the Berkshire Association for Behavior Analysis and Therapy, Amherst, Massachusetts.
- McCollum, A.T. and Gibson, L.E. (1970). Family adaptation to the child with cystic fibrosis. Pediatrics, 77, 571-578.
- McHale, S.M., Simeonsson, R.J. and Sloan, J.L. (1984). Children with Handicapped Brothers and Sisters. In: Schopler, E. and Mesibov, G.B. (Eds.) The Effects of Autism on the Family, New York: Plenum Press.
- McKeever, P. (1983). Siblings of chronically ill children: A literature review with implications for research and practice. American Journal of Orthopsychiatry, 53, 209-218.
- Michael, R. L., Klorman, R., Salzman, L. F., Borgstedt, A. D. and Dainer, K.B. (1981). Normalizing effects of

- methylphenidate on hyperactive children's vigilance performance and evoked potentials. Psychophysiology, 18, 665-677.
- Miller, L.G. (1969). The seven stages in the life cycle of a family with a mentally retarded child. Washington Institution Department Proceedings of the 9th Annual Research Meeting, 2, 78-81.
- Minuchin, S., Montalvo, B., Guerney, B.G., Rosman, B. and Schumer, F. (1967). Families of the Slums: An Exploration of Their Structure and Treatment. New York: Basic Books.
- Parmalee, A.H. (1986). Children's illnesses: Their beneficial effects on behavioral development. Child Development, 57, 1-10.
- Pinyerd, B.J. (1983). Siblings of children with myelomeningocele: Examining their perceptions. Maternal-Child Nursing, 12, 61-70.
- Pless, I.B. and Pinkerton, P. (1975). Chronic Childhood Disorder: Promoting Patterns of Adjustment, Chicago: Year Book Medical Publishers, Incorporated.
- Pless, I.B. and Zvagulis, I. (1981). The health of children with special needs. In: Research Priorities in Maternal and Child Health, Report of a Conference. Washington, D.C.: USDHHS, Office for Maternal and Child Health, (PHS) 3M/2-82:185.
- Powell, T.H. and Ogle, P.A. (1985). Brothers and Sisters: A Special Part of Exceptional Families, Baltimore Maryland: Paul H. Brookes Publishing Co., Inc.
- Poznanski, E.O. (1969). Psychiatric difficulties in siblings of handicapped children. Clinical Pediatrics, 8, 232-234.
- Poznanski, E.O. (1973). Emotional issues in raising handicapped children. Rehabilitation Literature, 34, 322-326.
- Rubin, R.A. (1978). Stability of self-esteem ratings and their relation to academic achievement: A longitudinal study. Psychology in the Schools, 15, 430-433.
- Rutter, M. (1981). Stress, coping and development: Some issues and some questions. Journal of Child Psychology, 22, 323-356.
- Rutter, M. (1985, August). Resilience in the face of adversity: Protective factors and resistance to psychiatric

- disorder. Paper presented at the annual Maurice Laufer lecture, Emma Pendleton Bradley Hospital, East Providence, Rhode Island.
- Sabbeth, B. (1984). Understanding the impact of childhood chronic illness on families. Pediatric Clinics of North America, 31, 47-57.
- Schreiber, M. and Feeley, M. (1965). Siblings of the retarded: A guided group experience. Children, 12(6), 221-225.
- Schwirian, P.M. (1976). Effects of the presence of a hearing-impaired preschool child in the family on behavior patterns of older "normal" siblings. American Annals of the Deaf, 121, 373-380.
- Shere, M.O. (1956, February). Socio-emotional factors in families of the twin with cerebral palsy. Exceptional Children, 197-199 and 206-210.
- Siemon, M. (1981). Siblings of the chronically ill or disabled child. Nursing Clinics of North America: Symposium on Pediatric Care: Psychosocial Aspects, 19(2), 295-306.
- Simeonsson, R.J. and McHale, S.M. (1981). Review: Research on handicapped children: Sibling relationships. Child: Care, Health, and Development, 7, 153-171.
- Simeonsson, R.J. and Bailey, D.B. (1983). Siblings of handicapped children. Paper presented at NICHD Conference on Research on Families with Retarded Children.
- Sourkes, B. (1977). Facilitating family coping with childhood cancer. Journal of Pediatric Cancer, 2, 65-68.
- Spatz, K. and Johnston (1973). Internal consistency of the Coopersmith Self-Esteem Inventory. Educational and Psychological Measurement, 33, 875-876.
- Spinetta, J.J. and Deasey-Spinetta, P. (1981). Living with Childhood Cancer. St Louis, Missouri: C.V. Mosby.
- Stein, R.E.K. and Reissman, C.K. (1980). The development of an Impact-On-Family Scale: Preliminary findings. Medical Care, 18, 465-472.
- Strayhorn, J. M. (1985). Psychoeducational strategies with diabetic children and their families. In: A.N. O'Quinn (Ed.), Management of Chronic Disorders of Childhood. Boston: G.K. Hall Medical Publishers.

- Stubblefield, H.W. (1965). Religion, parents, and mental retardation. Mental Retardation, 3, 8-11.
- Sullivan, R.C. (1979). Siblings of autistic children. Journal of Autism and Developmental Disorders, 9, 287-296.
- Taylor, L.S. (1974). Communication between mothers and normal siblings of retarded children: Nature and modification. Dissertation, University of North of Carolina.
- Tew, B.J. and Laurence, K.M. (1973). Mothers, brothers, and sisters of patients with spina bifida. Developmental Medicine and Child Neurology, 15, 69-76.
- Trevino, F. (1979). Siblings of handicapped children: Identifying those at risk. Social Casework, 60, 488-493.
- Vance, J.C., Fazan, L.E., Satterwhite, B. and Pless, I.B. (1980). Effects of nephrotic syndrome on the family: A controlled study. Pediatrics, 65, 948-955.
- Weissman, M.M., Orvaschel, H. and Padian, N. (1980). Children's symptom and social functioning self-report scales: Comparison's of mothers' and children's reports. The Journal of Nervous and Mental Disease, 168, 736-740.
- Wikler, L., Wasow, M. and Hatfield, E. (1981). Chronic sorrow revisited: Attitude of parents and professionals about adjustment to mental retardation. American Journal of Orthopsychiatry, 51, 63-70.
- Winer, B.J. (1971). Statistical Principles in Experimental Design. New York: McGraw-Hill Book Company.
- Williams, J.R. (1983). Family Adaptation to Childhood Chronic Illness. Grant proposal submitted the the Maternal Child Health Service, United States Government.
- Zuk, G.H., Miller, R.L., Bartram, J.B. and Kling, F. (1961). Maternal acceptance of retarded children: A questionnaire study of attitudes and religious background. Child Development, 32, 525-540.

RHODE ISLAND HOSPITAL
PROVIDENCE, RI 02902

RIH Project #

Name of Patient

AGREEMENT TO PARTICIPATE IN CLINICAL INVESTIGATION

Family Adaptation to Childhood Chronic Illness

Your child is being asked to participate in a research project as described in this form below. All such research projects carried out in this Hospital are covered by the rules of both the Federal Government and the Rhode Island Hospital. These rules require that you give your signed agreement for your child to participate in this project.

The researcher (or your doctor) will explain to you in detail the purpose of the project, the procedures to be used, and the potential benefits and possible risks of participation. You may ask him/her any questions you may have to help you understand the project. A basic explanation of the project is written below. Please read this explanation and discuss with the researcher (or your doctor) any questions you might have.

Federal and Hospital regulations require that the "assent" of your child be requested and obtained by the researcher before your child may participate in this project. These requirements and the procedures for meeting them will be fully explained to you by the researcher (or your doctor).

If you then decide that your child may participate in the project, please sign this form on the line below in the presence of a witness and the person who explained the project to you. You should be given a copy of this form to keep.

1. NATURE AND PURPOSE OF THE PROJECT

Your family is asked to participate in a study of the challenges and stresses of rearing a chronically ill child. By talking to the child's sibling, we hope to learn more about the experience of growing up as the brother/sister of a chronically ill child.

2. EXPLANATION OF PROCEDURES

If your family decides to participate in this one aspect of the study exploring the sibling experience, we will do the following:

- a) interview your child regarding knowledge of the illness, adjustment to the illness at home and school, and perceptions about having a chronically ill brother/sister.
- b) ask him/her to complete some information forms about your family and rating scales that specifically deal with his/her sibling's illness.
- c) ask the parent(s) to complete some questionnaires that inquire about general family information and more specific information about your child.
- d) at some future time, we may ask him/her to participate in a series of group meetings with other families of chronically ill children (the meetings will be arranged at times that are convenient for him/her).

3. DISCOMFORTS AND RISKS

These procedures will cause him/her no physical discomfort and entail no physical risk.

4. BENEFITS

He/she may find it helpful to talk about some of these issues with us. Other families to whom we have talked in the past have found it so. We cannot and do not guarantee or promise that he/she will derive any personal benefit from participating in this study.

5. CONFIDENTIALITY

All records relating to this project will be handled and safeguarded according to standard Hospital policy for all medical records. His/her record will always be handled in conformity with the Rhode Island Act relating to the confidentiality of health care information.

6. REFUSAL/WITHDRAWAL

His/her decision to participate or not will in no way prejudice the care his/her sibling receives at the hospital. If he/she decides to participate, he/she is free to withdraw his/her consent at any time without prejudice.

- 7. We do not expect any unusual risks as a direct result of this project. However, should an unforeseen physical injury occur, appropriate medical care, as determined by the Hospital, will be provided but no financial compensation will be given. Further information in regard to this provision can be obtained from the Research and Sponsored Projects Administration Office.

I ACKNOWLEDGE THAT I HAVE READ AND FULLY UNDERSTAND THE ABOVE EXPLANATION OF THIS PROJECT, THAT ALL OF MY QUESTIONS HAVE BEEN SATISFACTORILY ANSWERED, AND I GIVE/DECLINE PERMISSION FOR MY CHILD TO PARTICIPATE IN THIS RESEARCH PROJECT.

Signature of Parent

Date

Signature of Parent

Date

I AGREE TO PARTICIPATE IN THIS PROJECT

Signature of child

Date

IF SUBJECT IS UNABLE TO SIGN OR EXCEPTION TO ASSENT IS SOUGHT, PLEASE EXPLAIN:

I ACKNOWLEDGE THE PROCESS AND/OR SIGNATURE OF STATEMENT SET FORTH ABOVE

Qualified Witness

Date

I CERTIFY THAT I HAVE EXPLAINED FULLY TO THE ABOVE PARENTS AND PATIENTS THE NATURE AND PURPOSE, PROCEDURES, AND THE POSSIBLE RISKS AND POTENTIAL BENEFITS OF THIS RESEARCH PROJECT.

Signature of Researcher

Date

IF SIGNED BY AGENT OTHER THAN PARENT AND SUBJECT, PLEASE EXPLAIN BELOW:

RHODE ISLAND HOSPITAL
PROVIDENCE, RI 02902

RIH Project #C

Name of Patient

AGREEMENT TO PARTICIPATE IN CLINICAL INVESTIGATION

Family Adaptation to Childhood Chronic Illness

Your child is being asked to participate in a research project as described in this form below. All such research projects carried out in this Hospital are covered by the rules of both the Federal Government and the Rhode Island Hospital. These rules require that you give your signed agreement for your child to participate in this project.

The researcher (or your doctor) will explain to you in detail the purpose of the project, the procedures to be used, and the potential benefits and possible risks of participation. You may ask him/her any questions you may have to help you understand the project. A basic explanation of the project is written below. Please read this explanation and discuss with the researcher (or your doctor) any questions you might have.

Federal and Hospital regulations require that the "assent" of your child be requested and obtained by the researcher before your child may participate in this project. These requirements and the procedures for meeting them will be fully explained to you by the researcher (or your doctor).

If you then decide that your child may participate in the project, please sign this form on the line below in the presence of a witness and the person who explained the project to you. You should be given a copy of this form to keep.

1. NATURE AND PURPOSE OF THE PROJECT

Your family is asked to participate in a study of the challenges and stresses of rearing a chronically ill child. In order to better understand the impact of having a chronically ill brother or sister, we also need to talk to children who have not had chronic illness in the family.

2. EXPLANATION OF PROCEDURES

If your family decides to participate in this one aspect of the study exploring the sibling experience, we will do the following:

- a) ask him/her to complete an information form about himself/herself in social, academic and family settings.
- b) ask the parent(s) to complete some questionnaires that inquire about general family information and more specific information about your child.

3. **DISCOMFORTS AND RISKS**

These procedures will cause him/her no physical discomfort and entail no physical risk.

4. **BENEFITS**

He/she may find it helpful to talk about some of these issues with us. Other families to whom we have talked in the past have found it so. We cannot and do not guarantee or promise that he/she will derive any personal benefit from participating in this study.

5. **CONFIDENTIALITY**

All records relating to this project will be handled and safeguarded according to standard Hospital policy for all medical records. His/her record will always be handled in conformity with the Rhode Island Act relating to the confidentiality of health care information.

6. **REFUSAL/WITHDRAWAL**

His/her decision to participate or not will in no way prejudice the care the family receives at the hospital. If he/she decides to participate, he/she is free to withdraw his/her consent at any time without prejudice.

7. We do not expect any unusual risks as a direct result of this project. However, should an unforeseen physical injury occur, appropriate medical care, as determined by the Hospital, will be provided but no financial compensation will be given. Further information in regard to this provision can be obtained from the Research and Sponsored Projects Administration Office.

I ACKNOWLEDGE THAT I HAVE READ AND FULLY UNDERSTAND THE ABOVE EXPLANATION OF THIS PROJECT, THAT ALL OF MY QUESTIONS HAVE BEEN SATISFACTORILY ANSWERED, AND I GIVE/DECLINE PERMISSION FOR MY CHILD TO PARTICIPATE IN THIS RESEARCH PROJECT.

Signature of Parent

Date

Signature of Parent

Date

I AGREE TO PARTICIPATE IN THIS PROJECT

Signature of child

Date

IF SUBJECT IS UNABLE TO SIGN OR EXCEPTION TO ASSENT IS SOUGHT,
PLEASE EXPLAIN:

I ACKNOWLEDGE THE PROCESS AND/OR SIGNATURE OF STATEMENT SET
FORTH ABOVE

Qualified Witness

Date

I CERTIFY THAT I HAVE EXPLAINED FULLY TO THE ABOVE PARENTS
AND PATIENTS THE NATURE AND PURPOSE, PROCEDURES, AND THE POSSIBLE
RISKS AND POTENTIAL BENEFITS OF THIS RESEARCH PROJECT.

Signature of Researcher

Date

IF SIGNED BY AGENT OTHER THAN PARENT AND SUBJECT, PLEASE EXPLAIN
BELOW:

CHILD BEHAVIOR CHECKLIST FOR AGES 4-16

For Office Use Only
DS

CHILD'S NAME _____			PARENT'S TYPE OF WORK Please indicate how the parent's work affects the child's behavior. (For example, the parent's work may be a source of stress or a source of pride.)	
SEX ☐ Boy ☐ Girl	AGE _____	RACE _____	FATHER'S TYPE OF WORK _____	MOTHER'S TYPE OF WORK _____
TODAY'S DATE _____		CHILD'S BIRTH-DATE _____	THIS FORM FILLED OUT BY _____	
Mo _____ Day _____ Yr _____		Mo _____ Day _____ Yr _____	☐ Mother ☐ Father ☐ Other (Specify) _____	
GRADE IN SCHOOL _____				

I. Please list the sports your child most likes to take part in. For example: swimming, baseball, skating, skate boarding, bike riding, fishing, etc.	Compared to other children of the same age, about how much time does he/she spend in each?	Compared to other children of the same age, how well does he/she do each one?
☐ None	Don't Know Less Than Average Average More Than Average	Don't Know Below Average Average Above Average
a. _____	— — — —	— — — —
b. _____	— — — —	— — — —
c. _____	— — — —	— — — —

II. Please list your child's favorite hobbies, activities, and games, other than sports. For example: stamps, dolls, books, piano, crafts, singing, etc. (Do not include T.V.)	Compared to other children of the same age, about how much time does he/she spend in each?	Compared to other children of the same age, how well does he/she do each one?
☐ None	Don't Know Less Than Average Average More Than Average	Don't Know Below Average Average Above Average
a. _____	— — — —	— — — —
b. _____	— — — —	— — — —
c. _____	— — — —	— — — —

III. Please list any organizations, clubs, teams, or groups your child belongs to.	Compared to other children of the same age, how active is he/she in each?
☐ None	Don't Know Less Active Average More Active
a. _____	— — — —
b. _____	— — — —
c. _____	— — — —

IV. Please list any jobs or chores your child has. For example: paper route, babysitting, making bed, etc.	Compared to other children of the same age, how well does he/she carry them out?
☐ None	Don't Know Below Average Average Above Average
a. _____	— — — —
b. _____	— — — —
c. _____	— — — —

- V. 1. About how many close friends does your child have? ☐ None ☐ 1 ☐ 2 or 3 ☐ 4 or more
2. About how many times a week does your child do things with them? ☐ Less than 1 ☐ 1 or 2 ☐ 3 or more

VI. Compared to other children of his/her age, how well does your child:

	Worse	About the same	Better
a. Get along with his/her brothers & sisters?	☐	☐	☐
b. Get along with other children?	☐	☐	☐
c. Behave with his/her parents?	☐	☐	☐
d. Play and work by himself/herself?	☐	☐	☐

VII. 1. Current school performance—for children aged 8 and older:

	Failing	Below average	Average	Above average
☐ Does not go to school:				
a. Reading or English	☐	☐	☐	☐
b. Writing	☐	☐	☐	☐
c. Arithmetic or Math	☐	☐	☐	☐
d. Spelling	☐	☐	☐	☐
Other academic subjects—for example: history, science, foreign language, geography.				
e. _____	☐	☐	☐	☐
f. _____	☐	☐	☐	☐
g. _____	☐	☐	☐	☐

2. Is your child in a special class?

☐ No ☐ Yes—what kind?

3. Has your child ever repeated a grade?

☐ No ☐ Yes—grade and reason

4. Has your child had any academic or other problems in school?

☐ No ☐ Yes—please describe

When did these problems start?

Have these problems ended?

☐ No ☐ Yes—when?

VIII. Below is a list of items that describe children. For each item that describes your child now or within the past 6 months, please circle the 2 if the item is very true or often true of your child. Circle the 1 if the item is somewhat or sometimes true of your child. If the item is not true of your child, circle the 0. Please answer all items as well as you can, even if some do not seem to apply to your child.

0 = Not True (as far as you know) 1 = Somewhat or Sometimes True 2 = Very True or Often True

0	1	2	1	Acts too young for his/her age	16	0	1	2	31	Fears he/she might think or do something bad	
0	1	2	2	Allergy (describe): _____							
				_____		0	1	2	32	Feels he/she has to be perfect	
						0	1	2	33	Feels or complains that no one loves him/her	
0	1	2	3	Argues a lot		0	1	2	34	Feels others are out to get him/her	
0	1	2	4	Asthma		0	1	2	35	Feels worthless or inferior	50
0	1	2	5	Behaves like opposite sex	20	0	1	2	36	Gets hurt a lot, accident-prone	
0	1	2	6	Bowel movements outside toilet		0	1	2	37	Gets in many fights	
0	1	2	7	Bragging, boasting		0	1	2	38	Gets teased a lot	
0	1	2	8	Can't concentrate, can't pay attention for long		0	1	2	39	Hangs around with children who get in trouble	
0	1	2	9	Can't get his/her mind off certain thoughts; obsessions (describe): _____		0	1	2	40	Hears things that aren't there (describe): _____	
				_____							55
0	1	2	10	Can't sit still, restless, or hyperactive	25	0	1	2	41	Impulsive or acts without thinking	
0	1	2	11	Clings to adults or too dependent		0	1	2	42	Likes to be alone	
0	1	2	12	Complains of loneliness		0	1	2	43	Lying or cheating	
0	1	2	13	Confused or seems to be in a fog		0	1	2	44	Bites fingernails	
0	1	2	14	Cries a lot		0	1	2	45	Nervous, highstrung, or tense	60
0	1	2	15	Cruel to animals	30	0	1	2	46	Nervous movements or twitching (describe): _____	
0	1	2	16	Cruelty, bullying, or meanness to others							
0	1	2	17	Day-dreams or gets lost in his/her thoughts		0	1	2	47	Nightmares	
0	1	2	18	Deliberately harms self or attempts suicide		0	1	2	48	Not liked by other children	
0	1	2	19	Demands a lot of attention		0	1	2	49	Constipated, doesn't move bowels	
0	1	2	20	Destroys his/her own things	35	0	1	2	50	Too fearful or anxious	65
0	1	2	21	Destroys things belonging to his/her family or other children		0	1	2	51	Feels dizzy	
0	1	2	22	Disobedient at home		0	1	2	52	Feels too guilty	
0	1	2	23	Disobedient at school		0	1	2	53	Overeating	
0	1	2	24	Doesn't eat well		0	1	2	54	Overtired	
0	1	2	25	Doesn't get along with other children	40	0	1	2	55	Overweight	70
0	1	2	26	Doesn't seem to feel guilty after misbehaving					56	Physical problems without known medical cause:	
0	1	2	27	Easily jealous		0	1	2	a.	Aches or pains	
0	1	2	28	Eats or drinks things that are not food (describe): _____		0	1	2	b.	Headaches	
				_____		0	1	2	c.	Nausea, feels sick	
						0	1	2	d.	Problems with eyes (describe): _____	
0	1	2	29	Fears certain animals, situations, or places; other than school (describe): _____		0	1	2	e.	Rashes or other skin problems	75
				_____		0	1	2	f.	Stomachaches or cramps	
0	1	2	30	Fears going to school	45	0	1	2	g.	Vomiting, throwing up	
						0	1	2	h.	Other (describe): _____	

0 = Not True (as far as you know)

1 = Somewhat or Sometimes True

2 = Very True or Often True

0	1	2	57.	Ph	daily attacks people		0	1	2	34.	Strange behavior (describe):	
0	1	2	58.	Picks nose, skin, or other parts of body	(describe):							
						30	0	1	2	35.	Strange ideas (describe):	
0	1	2	59.	Plays with own sex parts in public		16						
0	1	2	60.	Plays with own sex parts too much			0	1	2	36.	Stubborn, sullen, or irritable	
0	1	2	61.	Poor school work			0	1	2	37.	Sudden changes in mood or feelings	
0	1	2	62.	Poorly coordinated or clumsy			0	1	2	38.	Suiks a lot	45
0	1	2	63.	Prefers playing with older children		20	0	1	2	39.	Suspicious	
0	1	2	64.	Prefers playing with younger children			0	1	2	90.	Swearing or obscene language	
0	1	2	65.	Refuses to talk			0	1	2	91.	Talks about killing self	
0	1	2	66.	Repeats certain acts over and over; compulsions (describe):			0	1	2	92.	Talks or walks in sleep (describe):	
0	1	2	67.	Runs away from home			0	1	2	93.	Talks too much	50
0	1	2	68.	Screams a lot		25	0	1	2	94.	Teases a lot	
0	1	2	69.	Secretive, keeps things to self			0	1	2	95.	Temper tantrums or hot temper	
0	1	2	70.	Sees things that aren't there (describe):			0	1	2	96.	Thinks about sex too much	
							0	1	2	97.	Threatens people	
							0	1	2	98.	Thumb-sucking	55
							0	1	2	99.	Too concerned with neatness or cleanliness	
0	1	2	71.	Self-conscious or easily embarrassed			0	1	2	100.	Trouble sleeping (describe):	
0	1	2	72.	Sets fires								
0	1	2	73.	Sexual problems (describe):			0	1	2	101.	Truancy, skips school	
							0	1	2	102.	Underactive, slow moving, or lacks energy	
						30	0	1	2	103.	Unhappy, sad, or depressed	60
0	1	2	74.	Showing off or clowning			0	1	2	104.	Unusually loud	
0	1	2	75.	Shy or timid			0	1	2	105.	Uses alcohol or drugs (describe):	
0	1	2	76.	Sleeps less than most children			0	1	2	106.	Vandalism	
0	1	2	77.	Sleeps more than most children during day and/or night (describe):			0	1	2	107.	Wets self during the day	
							0	1	2	108.	Wets the bed	65
0	1	2	78.	Smears or plays with bowel movements		35	0	1	2	109.	Whining	
0	1	2	79.	Speech problem (describe):			0	1	2	110.	Wishes to be of opposite sex	
							0	1	2	111.	Withdrawn, doesn't get involved with others	
0	1	2	80.	Stares blankly			0	1	2	112.	Worrying	
0	1	2	81.	Steals at home						113.	Please write in any problems your child has that were not listed above:	
0	1	2	82.	Steals outside the home			0	1	2			70
0	1	2	83.	Stores up things he/she doesn't need (describe):		40	0	1	2			

PLEASE BE SURE YOU HAVE ANSWERED ALL ITEMS.

PAGE 4

UNDERLINE ANY YOU ARE CONCERNED ABOUT

In: Achenbach, T.M. and Edelbrock, C.S. (1983).
Manual for the Child Behavior Checklist and
Revised Child Behavior Profile. Burlington,
 VT: Queen City Printers, Inc.

INSTRUCTIONS FOR HAND SCORING THE CHILD BEHAVIOR PROFILE

Social Competence Scales

There are some small differences between the entry formats for hand scoring and computer scoring the social competence scales. When using our computer programs, the data should therefore be entered according to the computer scoring instructions (see Appendix B). If a parent checks more than 1 box where only 1 should be checked, score the average of the 2 boxes checked. Be certain to use a scoring Profile appropriate for the child's sex and age.

Activities Scale

Do not score this scale if data are missing for more than 1 of the 6 scores indicated below beside Roman numerals I, II, and IV. The Roman numerals correspond to those on Page 1 of the CBCL and on the Activities scale of the Profile scoring form.

I-A. # of Sports. If parent reports 0 to 1 sport - enter 0 on Profile
 2 sports - enter 1 on Profile
 3 sports - enter 2 on Profile

I. Please list the sports your child most likes to take part in. For example: swimming, baseball, skating, skate boarding, bike riding, fishing, etc.

I-A - 0 1 None
 0 a. _____
 1 b. _____
 2 c. _____

I-B. Mean Score for Participation & Skill in Sports. If parent reports no sports, enter 0.

For each response of *Less Than Average* or *Below Average* - score 0
Average - score 1
More Than Average or *Above Average* - score 2

Excluding blanks and *I don't know* responses, compute the mean of these scores by summing them and dividing by the number of scores you have summed. Enter this mean on the Profile.

HAND SCORING INSTRUCTIONS

Compared to other children of the same age, about how much time does he/she spend in each?

Less Than Average	More Than Average	Don't Know	Below Average	Above Average
0	1	2	0	1
()	()	()	()	()
()	()	()	()	()
()	()	()	()	()

Compared to other children of the same age, how well does he/she do each one?

Don't Know	Below Average	Above Average
0	1	2
()	()	()
()	()	()
()	()	()

I-B = $\frac{\text{sum of scores}}{\text{number of scores}}$

II-A. # of Non-sports Activities. Do not count listening to radio or TV, goofing off, or the like as activities.

II. Please list your child's favorite hobbies, activities, and games, other than sports. For example: stamps, dolls, books, piano, crafts, singing, etc. (Do not include T.V.)

II-A = 0 1 None
 0 a. _____
 1 b. _____
 2 c. _____

II-B. Mean of Participation & Skill in Activities. Compute mean as specified for sports in I-B above. Enter this mean on the Profile.

Compared to other children of the same age, about how much time does he/she spend in each?

Less Than Average	More Than Average	Don't Know	Below Average	Above Average
0	1	2	0	1
()	()	()	()	()
()	()	()	()	()
()	()	()	()	()

II-B = $\frac{\text{sum of scores}}{\text{number of scores}}$

IV-A. # of Jobs or Chores. Include paying and nonpaying jobs and chores.

- IV. Please list any jobs or chores your child has. For example: paper route, babysitting, making bed, etc.

IV-A = 0 1 1 None

0 a. _____

1 b. _____

2 c. _____

IV-B. Mean Job Quality. Compute mean as specified in I-B above. Enter this mean on the Profile.

Compared to other children of the same age, how well does he/she carry them out?

IV-B = $\frac{\text{sum of scores}}{\text{number of scores}}$

Don't know	Less Active	Average	More Active
0	1	2	
()	()	()	()
()	()	()	()
()	()	()	()

Total Score for Activities Scale. Sum the 6 scores just entered on the Activities scale of the Profile. If missing data prevent computation of 1 score, substitute the mean of the other 5 for the missing score in computing the total. After computing the total, round off to the nearest .5 and mark the corresponding number in the column of scores appropriate for the child's age.

Social Scale

Do not score this scale if data are missing for more than 1 of the 6 scores indicated below beside Roman numerals III, V, and VI. The Roman numerals correspond to those on Pages 1 and 2 of the CBCL and on the Social scale of the Profile scoring form.

III-A. # of Organizations. If 0 or 1 organization - enter 0 on Profile
 III. Please list any organizations, clubs, teams, or groups your child belongs to.
 2 - enter 1 on Profile
 3 or more - enter 2 on Profile

III-A = 0 1 None

0 a. _____

1 b. _____

2 c. _____

III-B. Mean of Participation in Organizations. Compute mean as specified in I-B above. Enter this mean on the Profile.

III-B = $\frac{\text{sum of scores}}{\text{number of scores}}$

Compared to other children of the same age, how active is he/she in each?

Don't know	Less Active	Average	More Active
0	1	2	
()	()	()	()
()	()	()	()
()	()	()	()

V-1. # of Friends.

If 0 or 1 friends - enter 0 on Profile
 2 or 3 friends - enter 1 on Profile
 4 or more friends - enter 2 on Profile

1. About how many close friends does your child have?

() None () 1 () 2 or 3 () 4 or more
 V-1 = 0 1 2

V-2. Contacts with Friends. If parent checks *None* in V-1 - enter 0 on Profile
 Less than 1 - enter 0 on Profile
 1 or 2 - enter 1 on Profile
 3 or more - enter 2 on Profile

2. About how many times a week does your child do things with them?

() less than 1 () 1 or 2 () 3 or more
 V-2 = 0 1 2

VI-A. Behavior with Others. For items a, b, and c:

If parent checks *worse* - score 0
about the same - score 1
better - score 2

Excluding any item for which the parent did not check a box, compute the mean of these scores and enter it on the Profile.

VI. Compared to other children of his/her age, how well does your child:

Worse About the same Better

- a. Get along with his/her brothers and sisters? 0 1 2
 () () ()
 b. Get along with other children? () () ()
 c. Behave with his/her parents? () () ()

VI-A $\frac{\text{sum of a b c}}{\text{number of scores}}$

VI-B. Play/work by self. For item d:

If parent checks *worse*—enter 0 on Profile
about the same—enter 1 on Profile
better—enter 2 on Profile

d. Play and work by himself/
 herself?

() () ()
 VI-B = 0 1 2

Total Score for Social Scale. Sum the 6 scores just entered on the *Social* scale of the Profile. If missing data prevent computation of 1 score, substitute the *mean* of the other 5 for the missing score in computing the total. After computing the total, round off to the nearest .5 and mark the corresponding number in the column of scores appropriate for the child's age.

School Scale

Do *not* score if the child is below age 6, not in school, or if data are missing for any of the 4 scores indicated below for Items VII-1 through VII-4, which appear on Page 2 of the CBCL, and on the *School* scale of the Profile scoring form.

VII-1. Mean performance. For each academic subject checked

failing—score 0
 below average—score 1
 average—score 2
 above average—score 3

Enter the *mean* of these scores on the Profile. (Academic subjects include reading, writing, arithmetic, spelling, science, English, foreign language, history, social studies, and similar subjects. Do *not* count physical education, art, music, home economics, driver education, industrial arts, typing, or the like.)

VII. 1. Current school performance—for children aged 6 and older:

	Failing	Average	Above Average	Above
	Below	Below	Average	Average
() Does not go to school	0	1	2	3
a. Reading or English	()	()	()	()
b. Writing	()	()	()	()
c. Arithmetic or Math	()	()	()	()
d. Spelling	()	()	()	()
Other academic subjects— for example: history, science, foreign language, geography.	()	()	()	()
e.	()	()	()	()
f.	()	()	()	()
g.	()	()	()	()
h.	()	()	()	()

VII-1—sum of scores/number of scores

VII-2. Special Class. For any type of remedial special class (for retarded, emotionally disturbed, learning disabled, perceptual-motor handicapped, reading readiness, resource room, etc.)—enter 0 on Profile
not in remedial class—enter 1 on Profile

2. Is your child in a special class?
 () No () Yes—what kind?
 VII-2 = 1 0

VII-3. Repeated Grade. If any grades were repeated—enter 0 on Profile
no grades repeated—enter 1 on Profile

3. Has your child ever repeated a grade?
 () No () Yes—grade and reason
 VII-3 = 1 0

VII-4. School Problems. If any school problem is stated that was present in the last 6 months and was not already scored above—enter 0 on Profile
no problem beside those scored above—enter 1 on Profile

4. Has your child had any academic or other problems in school?
 () No () Yes—please describe
 VII-4 = 1 0 (for problems present in the past 6 months and not already scored above)

Total Score for School Scale. Sum the 4 scores just entered on the *School* scale of the Profile, unless 1 or more score is missing. After computing the total, round off to the nearest .5 and mark the corresponding number in the column of scores appropriate for the child's age. The numbers you have marked for the three social competence scales can now be connected to form a profile.

Total Social Competence Score (Optional)

A total social competence score can be obtained by summing the totals of the 3 scales. T scores for total social competence scores are listed on the following pages.

Behavior Problem Scales

Do *not* score if data are missing for more than 8 items, not counting #56h and #113, unless it is clear that the parent intended blanks to be 0s. If a parent circles two numbers for an item, score the item 1.

Item Scores

Place the Page 3 template for a child of this age and sex over Page 3 of the CBCL. The Roman numerals and letters beside each item number indicate the scales on which the item is scored. If the parent circled 1 or 2 beside an item,

enter the 1 or 2 on the appropriate scales of the Profile. Repeat using the Page 4 template on Page 4. Comments written by the parent should be used in judging whether items deserve to be scored, with the following guidelines:

- a. For each behavior reported by the parent, only the CBCL item that most specifically describes the behavior should be scored. If the parent's comments show that more than one item has been scored for a particular behavior, or if the parent writes in a behavior for #56h or 113 that is specifically covered elsewhere, count only the most specific item.
- b. For extreme behaviors (e.g., sets fires, attempts suicide)—if parent notes that it happened once but circles 0 or leaves it blank, score 1 unless it clearly happened earlier than the interval specified in the rating instructions (e.g., 6 months).
- c. For items on which parent notes "used to do this," score as the parent scored it, unless it clearly occurred earlier than the interval specified in the instructions.
- d. When in doubt, score item the way the parent scored it, unless it is clear that the parent has scored it inappropriately, especially on the following items:
 9. Obsessions—exclude anything that is clearly not obsessional; e.g., do not score "won't take no for an answer."
 28. Eats or drinks things that are not food—do not count sweets and junk food.
 40. Hears things and 70. Sees things—do not score anxiousness about sounds and sights that others also notice; e.g., afraid noises at night might be burglars; do not score experiences while under the influence of drugs or alcohol.
 46. Nervous movements—if "can't sit still" or anything entirely covered by Item 10 is entered here, score only Item 10.
 - 56d. Problems with eyes—do not score "wears glasses," "near-sighted," and other ordinary visual problems having an organic basis.
 66. Compulsions—do not score noncompulsive behavior; e.g., "keeps hitting brother."
 72. Sets fires—score playing with matches or lighter if parent reports it.
 77. Sleeps more than most—do not score "wants to stay in bed," but score difficulties in waking child.
 83. Stores up things—do not score hobby collections, such as stamps, dolls, or miniatures.
 84. Strange behavior and 85. Strange ideas—if what the parent describes is specifically covered by another item, score the more specific item instead.
 105. Alcohol or drugs—do not score tobacco or medication.

113. Additional problems—score only if not specifically covered by another item; if parent lists more than 1 "other" item, count only highest toward total behavior problem score.

Scale Scores

To obtain the total raw score for the behavior problem scales, sum the 1s and 2s you have entered for each scale. Then mark the corresponding number in the graphic display above the scale and connect the marked numbers to form a profile. Percentiles based on normal children can be read from the left side of the graphic display. T scores can be read from the right side.

Internalizing and Externalizing

Using the box to the right of the Behavior Problems Profile, enter the score (0, 1, or 2) for each behavior problem next to the item's number under the heading *Item*. Sum the scores to get the Total Internalizing score and likewise for the Total Externalizing score. Under the heading *Total*, locate the total you have obtained. The score to the right of that number is the T score. (The Internalizing and Externalizing scores can not be computed by adding scale totals, because some items appear on more than one scale.)

Total Behavior Problem Score

To compute the total behavior problem score, sum the 1s and 2s on the CBCL and enter the sum to the right of the Profile. If the parent has entered a problem for Item 56h or 113 that is not covered by another item, include the score for 56h or 113. If more than one problem has been entered for item 113, count only the one having the highest score. The total behavior problem score can be cross-checked by subtracting the number of items scored as present from the sum of 1s and 2s. The difference should equal the number of 2s. (The number and sum of items can not be computed by adding scale totals, because some items appear on more than one scale.) T scores for the total social competence score and total behavior problem score are listed in the tables that follow.

SCHOOL FORM

SEI

Coopersmith Inventory

Stanley Coopersmith, Ph.D.
University of California at Davis

Please Print

Name _____ Age _____

School _____ Sex: M ___ F___

Grade _____ Date _____

Directions

On the next pages, you will find a list of statements about feelings. If a statement describes how you usually feel, put an X in the column "Like Me." If the statement does not describe how you usually feel, put an X in the column "Unlike Me." There are no right or wrong answers.

Consulting Psychologists Press, Inc.
577 College Ave., Palo Alto, CA 94306

Like Me

- ☐ 1. Things usually don't bother me.
- ☐ 2. I find it very hard to talk in front of the class.
- ☐ 3. There are lots of things about myself I'd change if I could.
- ☐ 4. I can make up my mind without too much trouble.
- ☐ 5. I'm a lot of fun to be with.
- ☐ 6. I get upset easily at home.
- ☐ 7. It takes me a long time to get used to anything new.
- ☐ 8. I'm popular with kids my own age.
- ☐ 9. My parents usually consider my feelings.
- ☐ 10. I give in very easily.
- ☐ 11. My parents expect too much of me.
- ☐ 12. It's pretty tough to be me.
- ☐ 13. Things are all mixed up in my life.
- ☐ 14. Kids usually follow my ideas.
- ☐ 15. I have a low opinion of myself.
- ☐ 16. There are many times when I'd like to leave home.
- ☐ 17. I often feel upset in school.
- ☐ 18. I'm not as nice looking as most people.
- ☐ 19. If I have something to say, I usually say it.
- ☐ 20. My parents understand me.
- ☐ 21. Most people are better liked than I am.
- ☐ 22. I usually feel as if my parents are pushing me.
- ☐ 23. I often get discouraged at school.
- ☐ 24. I often wish I were someone else.
- ☐ 25. I can't be depended on.
- ☐ 26. I never worry about anything.
- ☐ 27. I'm pretty sure of myself.
- ☐ 28. I'm easy to like.
- ☐ 29. My parents and I have a lot of fun together.

Short

Like Me

- ☐ 30. I spend a lot of time daydreaming.
- ☐ 31. I wish I were younger.
- ☐ 32. I always do the right thing.
- ☐ 33. I'm proud of my school work.
- ☐ 34. Someone always has to tell me what to do.
- ☐ 35. I'm often sorry for the things I do.
- ☐ 36. I'm never happy.
- ☐ 37. I'm doing the best work that I can.
- ☐ 38. I can usually take care of myself.
- ☐ 39. I'm pretty happy.
- ☐ 40. I would rather play with children younger than I am.
- ☐ 41. I like everyone I know.
- ☐ 42. I like to be called on in class.
- ☐ 43. I understand myself.
- ☐ 44. No one pays much attention to me at home.
- ☐ 45. I never get scolded.
- ☐ 46. I'm not doing as well in school as I'd like to.
- ☐ 47. I can make up my mind and stick to it.
- ☐ 48. I really don't like being a boy.
- ☐ 49. I don't like to be with other people.
- ☐ 50. I'm never shy.
- ☐ 51. I often feel ashamed of myself.
- ☐ 52. Kids pick on me very often.
- ☐ 53. I always tell the truth.
- ☐ 54. My teachers make me feel I'm not good enough.
- ☐ 55. I don't care what happens to me.
- ☐ 56. I'm a failure.
- ☐ 57. I get upset easily when I'm scolded.
- ☐ 58. I always know what to say to people.

Gen

Soc

H

Sch

Total

 x2 =

L

Administration, Scoring, and Interpretation

Administration

The SEI may be administered to groups or individuals. The School Form is used with children and adolescents aged eight through fifteen; the Adult Form, with persons aged sixteen and above. Administration time rarely exceeds ten minutes.

During administration, introductory or explanatory remarks should be kept to a minimum. An example of an appropriate introduction is, "Today you will be filling out a questionnaire. Your answers will help me know you and your likes and dislikes better." The words *self-esteem*, *self-concept*, and *self-evaluation* should not be used. This will help prevent biased responses, which may invalidate the test. (Note that the inventory is labeled "Coopersmith Inventory" and that the term *self-esteem* does not appear on any of the three forms.)

Once the inventories have been distributed, have the examinees complete the identifying information (name, age, etc.). If the examinees will have difficulty entering the information themselves or if time is limited, it may be necessary for the person administering the inventory to complete this task beforehand.

For the School Form, read the directions aloud and have the students follow along on their inventory booklets. Then have them complete the practice item. (If the School Short Form is being administered, the examinees will also need to be instructed to stop after completing Item 25.)

Once it is certain that all students understand the task, they may be instructed to open their booklets and begin. For groups or individuals who may have difficulty reading the items, it is appropriate for the administrator to read them aloud.

The Adult Form is usually self-administered. However, if there is any question as to a person's ability to complete the inventory on his or her own, follow the procedures described for the School Form.

Questions should be discouraged once the examinees have begun working. Clarification of word meanings may be necessary, but caution should be taken not to influence an examinee's responses. If the items are being read aloud, be sure to avoid making any statement seem inherently positive or negative.

Once the inventories have been completed and they are being collected, check to make sure the identifying information has been completed.

Scoring

The SEI can be scored in a few minutes by using the scoring keys for the form that has been administered. It is strongly recommended that the scoring keys be used since they greatly reduce scoring time and the possibility of errors. If a scoring key is not available, the general rules listed below should be followed when scoring the self-esteem items.

- 1 Score negative items *correct* (for example, "I get upset easily at home") if they have been answered "unlike me."
- 2 Score positive items *correct* (for example, "I'm pretty sure of myself") if they have been answered "like me."

The School Form includes eight items that constitute the Lie Scale. The Lie Scale items (26, 32, 36, 41, 45, 50, 53, and 58) are always scored separately; that is, responses to these items should never be included in the self-esteem score. To score the Lie Scale, award one point for each Lie Scale item answered "like me."

The four subscales of the School Form may be scored separately. The items corresponding to each subscale are shown on the following page.

Subscales	Items	Total Possible Raw Score
General Self	1, 3, 4, 7, 10, 12, 13, 15, 18, 19, 24, 25, 27, 30, 31, 34, 35, 38, 39, 43, 47, 48, 51, 55, 56, 57	26
Social Self-Peers	5, 8, 14, 21, 28, 40, 49, 52	8
Home-Parents	6, 9, 11, 16, 20, 22, 29, 44	8
School-Academic	2, 17, 23, 33, 37, 42, 46, 54	8

To arrive at a Total Self Score, sum the number of self-esteem items answered correctly. For the School Form, multiply the total raw score by two. This results in a maximum possible Total Self Score of 100. For the School Short Form and the Adult Form, multiply the total raw score by four. This also results in a maximum possible Total Self Score of 100 so that results of the different forms are readily comparable.

The total score for the Lie Scale (School Form only) is obtained by summing the points awarded on the eight items (maximum possible score is 8). A high Lie Scale score suggests defensiveness in a student's responses. (Note that the opposite method of scoring the Lie Scale items was used for earlier editions of the SEI. A low Lie Scale score previously indicated defensiveness. Since that approach is not widely accepted, the scoring was changed.)

Scores are entered in the boxes provided inside the School Form booklet. Each box is labeled with an abbreviation of the score to be entered. These abbreviations were used so as not to influence examinees' responses. Each abbreviation is defined below.

- Gen = General Self Subscale Score
- Soc = Social Self-Peers Subscale Score
- H = Home-Parents Subscale Score
- Sch = School-Academic Subscale Score
- Total = Total Self Score (all items *except* Lie Scale)
- L = Lie Scale Score
- Short = Student Short Form Total Self Score

NOTE: A service to score and report SEI results by computer is available. For more information, contact the publisher.

Interpretation

There are no exact criteria for high, medium, and low levels of self-esteem. They should and will vary with the characteristics of the sample, the distribution of scores, and theoretical and clinical considerations. Therefore, the guidelines given here are meant to be general guidelines and should be used with caution.

Two procedures are recommended when the SEI is being used in the school setting: the supplemental use of a behavior observational rating and the development of local norms. It is assumed that in clinical or treatment settings supplemental measures or observations will always be used.

For the SEI, high scores correspond to high self-esteem. In most studies the distributions of SEI scores have been skewed in the direction of high self-esteem (negatively skewed). The means have generally been in the range of from 70 to 80 with a standard deviation of from 11 to 13. Scores on the SEI have been shown to increase slightly and monotonically with grade level. For comparison purposes, several normative samples are discussed in Chapter 6.

Employing position in the group as an index of relative self-appraisal, the upper quartile generally can be considered indicative of high self-esteem, the lower quartile generally as indicative of low self-esteem, and the interquartile range generally as indicative of medium self-esteem.

A high score on the Lie Scale may indicate that the examinee responded defensively or thought he or she understood the "intention" of the inventory and was attempting to respond positively to all items. In such instances, the inventory may be invalid if a supplemental observational rating or teacher report indicates low or medium self-esteem for the examinee. Further evaluation is warranted.

Appendix B.

I.O.I. QUESTIONNAIRE

These are some statements that people have made about living with an ill child. For each statement, please circle whether for your child's illness you do strongly agree, agree, disagree or strongly disagree with the statement.

	<u>Strongly Disagree</u>	<u>Disagree</u>	<u>Agree</u>	<u>Strongly Agree</u>
1. The illness caused financial problems for the family.....	1	2	3	4
2. Time was lost from work because of hospital appointments.....	1	2	3	4
3. I cut down the hours I worked to care for my child.....	1	2	3	4
4. Additional income was needed in order to cover medical expenses..	1	2	3	4
5. Because of the illness, we were not able to travel out of the city...	1	2	3	4
6. People in the neighborhood treated us specially because of my child's illness.....	1	2	3	4
7. We had little desire to go out because of my child's illness....	1	2	3	4
8. It was hard to find a reliable person to take care of my child..	1	2	3	4
9. Sometimes we had to change plans about going out at the last minute because of my child's state.....	1	2	3	4
10. We saw family and friends less because of the illness.....	1	2	3	4

	Strongly Disagree	Disagree	Agree	Strongly Agree
11. Because of what we shared we were a closer family.....	1	2	3	4
12. Sometimes I wondered whether my child should have been treated "specially" or the same as a normal child.....	1	2	3	4
13. My relatives were understanding and helpful with my child.....	1	2	3	4
14. I thought about not having more children because of the illness..	1	2	3	4
15. My partner and I discussed my child's problems together.....	1	2	3	4
16. We tried to treat my child as if he/she were a normal child.....	1	2	3	4
17. I didn't have much time left over for other family members after caring for my child.....	1	2	3	4
18. Our family gave up things because of my child's illness.....	1	2	3	4
19. Fatigue was a problem for me because of my child's illness....	1	2	3	4
20. I lived from day to day and didn't plan for the future.....	1	2	3	4
21. Nobody understood the burden I carried.....	1	2	3	4
22. Traveling to the hospital was a strain on me.....	1	2	3	4
23. Learning to manage my child's illness made me feel better about myself.....	1	2	3	4
24. Sometimes I felt like we were living on a roller coaster: in crisis when my child was acutely ill, OK when things were stable..	1	2	3	4

Please rate the following 2 statements (25-26) ONLY if there were other children (siblings) in the household:

	Strongly Disagree	Disagree	Agree	Strongly Agree
25. It was hard to give attention to the other children because of the needs of my child.....	1	2	3	4
26. Having a child with an illness made me worry about my other children's health.....	1	2	3	4

Please rate the remaining statements (27-30) ONLY if there were other children in the household AND they were at least 4 years old:

	Strongly Disagree	Disagree	Agree	Strongly Agree
27. There was fighting between the children because of my child's special needs.....	1	2	3	4
28. My other children were frightened by his/her illness.....	1	2	3	4
29. My other children seemed to have more illnesses, aches and pains than most children their age.....	1	2	3	4
30. The school grades of my other children suffered because of my child's illness.....	1	2	3	4

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Ruth E.K. Stein, M.D.
Catherine K. Riessman, Ph.D.

Today's Date: _____

Family Name: _____

Your Name: _____

Address: _____

Please list the names of all members living in the household and provide the following information for each member:

[illegible]

(use back of page if your household has more people)

FAMILY INFORMATION FORM (continued)

-2-

Do you have relatives living near you? _____ If yes, who are they? _____

What language is spoken at home? _____ Is there a second language spoken? _____ If yes, what? _____

What, if any, is the religious affiliation of your family? _____

Would you briefly describe the place and neighborhood you live in? _____

How long have you lived in your present place? _____ How often have you moved? _____

When was your child's illness diagnosed? _____

How long did it take for your child to be properly diagnosed? _____

Compared to other children with the illness, would you say that your child's course has been mild, moderate or severe? _____

Has the child been hospitalized for the illness? If yes, please give approximate dates. _____

Does your child require daily medication and/or treatment for the illness? If yes, please describe briefly: _____

Do you think that the illness has made any difference in the relationship between the ill child and his/her brother/sister (the one being interviewed)? If yes, please describe briefly: _____

Does brother/sister have any special worries or concerns about the ill child? If yes, please describe briefly: _____

Is brother/sister involved in the ill child's care in any way? (e.g., help with treatments, teaching, babysitting, entertaining, visiting)? If yes, please describe briefly: _____

THANK YOU VERY MUCH FOR YOUR PARTICIPATION

SEMI-STRUCTURED INTERVIEW:
SIBLINGS OF CHRONICALLY-ILL CHILDREN

1. Who lives at home with you?

<u>Name</u>	<u>Age</u>	<u>Relationship</u>
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

2. How do you get along with your brother/sister? Do you get along like friends who really like each other, sort of like each other, or don't like each other very much?
3. Is anything different between you and your brother/sister because he/she has _____?
4. Can you tell me what you know/ what you have been told about your brother/sister's illness?
5. If one of the kids' at school asked you about your brother/sister's illness, what would you say?
6. Do you think that it has made a difference in your family to have a child with an illness like your brother/sister? What difference has it made?

7. Has it made a difference for you? At home? At school? With your friends?
8. Do you have any special worries or concerns about your brother/sister?
9. Are you involved in your brother/sister's care in any way? Do you help out your brother/sister or your family in any other ways?
10. If you had a question about your brother/sister's illness or just wanted to talk about it with someone, who would you turn to?
11. If you could teach people about what it's like to grow up with a brother/sister with an illness, what would be the most important things that you would say?
12. I've asked you many questions. Is there anything important that I did not ask about that you want to share with me? Are there any questions that you have for me?