DOCUMENT RESUME

ED 385 097	EC 304 131
AUTHOR	McDonald, Thomas P.; And Others
TITLE	Family Caregiving for Children with a Serious Emotional Disability. Phase One Technical Report.
INSTITUTION	Portland State Univ., OR. Research and Training Center on Family Support and Children's Mental Health.
SPONS AGENCY	National Inst. on Disability and Rehabilitation Research (ED/OSERS), Washington, DC.; Substance Abuse and Mental Health Services Administration (DHHS/PHS), Rockville, MD.
PUB DATE	Sep 93
CONTRACT	133B90007-92
NOTE	148p.
AVAILABLE FROM	Research and Training Center on Family Support and Children's Mental Health, Regional Research Inst. for Human Services, Portland State Univ., P.O. Box 751, Portland, OR 97207-0751 ($8).
PUB TYPE	Reports - Research/Technical (143) -- Statistical Data (110) -- Tests/Evaluation Instruments (160)
EDRS PRICE	MF01/PC06 Plus Postage.
DESCRIPTORS	*Child Rearing; Children; Coping; Demography; Elementary Education; Elementary School Students; *Emotional Disturbances; *Family Environment; Family Involvement; Family Problems; Family Relationship; *Models; *Parent Attitudes; Preschool Children; Preschool Education; Severe Disabilities; Severity (of Disability); Social Support Groups; Stress Variables
IDENTIFIERS	North Carolina

ABSTRACT

A survey of 258 North Carolina families with children (ages 3 to 12) having emotional disturbances focused on: (1) the wide range of characteristics of the child, family, and community; (2) characteristics that families bring to their situation as well as characteristics that can be changed by experience and the use of resources and services; and (3) a model permitting the testing of specific, causal links between variables. Following an overview, discussion of conceptual and methodological issues involved in defining the study population, and a brief literature review leading to the formation of the family caregiving model which served as the study's basis are described. The model identifies three major stages in the family caregiving process: antecedents, mediators, and outcomes. Study findings are reported in the following categories: demographic characteristics, severity of the child's disability, perception of the child's positive contribution to the family, coping patterns, relative and social supports, use of formal supports, and caregiver stress. Appended are the descriptive statistics for item and scale scores and the data collection questionnaire that was used. (Contains 55 references.) (DB)

FAMILY CAREGIVING FOR CHILDREN WITH A SERIOUS EMOTIONAL DISABILITY

PHASE ONE
TECHNICAL REPORT

Thomas P. McDonald, Ph.D.
Richard Donner, M.S.W.
Tom Gregoire, M.S.W.
John Poertner, D.S.W.
Theresa Early, M.S.W.

University of Kansas
School of Social Welfare
Twente Hall
Lawrence, Kansas 66045-2510

Produced and Distributed by:
Research and Training Center on Family Support
and Children's Mental Health
Regional Research Institute for Human Services
Portland State University
P.O. Box 751
Portland, Oregon 97207-0751
(503) 725-4040

September 1993

McDonald, T. P., Donner, R., Gregoire, T., Poertner, J. & Early, T. (1993). Family caregiving for children with a serious emotional disability: Phase one technical report. Portland, OR: Portland State University, Research and Training Center on Family Support and Children's Mental Health.

This publication was developed with funding from the National Institute on Disability and Rehabilitation Research, United States Department of Education, and the Substance Abuse & Mental Health Services Administration, United States Department of Health and Human Services (NIDRR grant number 133B90007-92). The content of this publication does not necessarily reflect the views or policies of the funding agencies.

ACKNOWLEDGEMENTS

The authors wish to acknowledge the cooperation and assistance provided by staff and administrators of the Children's Mental Health Services in the Division of Mental Health, Mental Retardation and Substance Abuse, North Carolina Department of Human Services. Lenore Behar, Chief of Children's Mental Health Services in North Carolina, was our first point of contact in the state. Her guidance in designing and operating a quality program in North Carolina made it an ideal site for our study. Her openness to research was refreshing and deeply appreciated. Susan Robinson, in central office, acted as our liaison and helped the study through several difficult periods. Tim Wildfire and Deborah Dickerson assisted in identifying cases and accessing MIS information. Numerous people in regional and area offices in North Carolina were involved in generating sample lists and assisting in mailings. Special thanks to Marian Hartman, Betsy Owen, Judy Nebrig, Ken Schoonhagen, Ed Lueth, Peter Horner, Tom Bainbridge, Julia Gagliardi, Joan Holland, Art Costantini, Carl Edge, Ellen Burnett, Randy Horton, Ted Lane, and Betty Evans.

Finally, we wish to thank the families who responded to our questionnaire for their time and willingness to assist all people in this field who are attempting to better understand and support family caregiving of children with emotional disabilities. We hope this study will contribute to that effort.

TABLE OF CONTENTS

OVERVIEW

The usual difficulties that families face in meeting the needs of their children become even more pronounced when the child has a severe emotional disability. Research in this field has done little to contribute to the basic understanding of the complex inter-relationships between child, family and community resources. To date, most work has been descriptive. While this research has provided useful information about the strengths of families, the importance of life cycles, the types of coping strategies used, responses to stress, and the interactions of family members, it has contributed little to an understanding of how these forces interact. In addition, previous research has been influenced by prevailing views of families whose children have emotional or behavioral disabilities that tend to take a blaming posture in holding parents responsible for the development or maintenance of their child's disability and focus narrowly and negatively on the child and parents in designing interventions. Partially as a result of this stance, the conceptual approach taken toward studying children with emotional disabilities has tended to emphasize the child as the major focus rather than the family or larger systemic context of the problem. This limited view has had a constraining influence on research designs, and thus variables that may have considerable influence in the overall process have been excluded from study.

More recent practice and research discards the assumption of homogeneity among families and the assumption that a "pathological response" is inevitable. Rather, attempts are made to look more comprehensively at factors influencing family functioning, to describe which families are most vulnerable, to identify unmet service needs, and to develop responsive strategies. In its most radical departure, this approach stresses the normality and inherent strengths of families and seeks to describe the potential psychological, material and social resources such families use as they cope with their circumstances (Byrne and Cunningham, 1985). This line of research is still in the early stages of development. While its conceptual underpinnings are beginning to be established, no comprehensive models of family caregiver systems have yet been articulated and tested. This project builds upon previous research by: (1) measuring a wide range of characteristics of the child, family, and community; (2) examining characteristics that families bring to their situation as well as characteristics that can logically change on the basis of both experience and the use of resources and services; and (3) specifying a model that permits the testing of specific, causal links between variables. The purpose of this report is to provide detailed information about the procedures followed in conducting the survey of families with children with emotional disabilities. In Part II we provide a description of the conceptual and methodological issues involved in defining the study population. Part III provides a brief literature review leading to the formulation of a family caregiving model which serves as the basis for subsequent instrument development and hypotheses testing. A more detailed literature review is available as a separate report from the Research and Training Center on Family Support and Children's Mental Health (McDonald, Donner, & Poertner, 1992). The questionnaire development process is described in Part IV and a complete copy of the final questionnaire is provided in Appendix B. The data collection process and data analysis plan is described in Part V. Findings in this report are limited to descriptive statistics broken down for the two sample strata. When possible, scores for our sample are compared with normative or other available research data. These findings are highlighted in the narrative in Part VI. Descriptive statistics for all item and scale scores are presented in their entirety in Appendix A. Additional reports and papers that focus on specific components of the caregiver model and ultimately more comprehensive tests of the overall model will be forthcoming.

STUDY POPULATION

The term "severe emotional disorder" when applied to children and adolescents is not derived from a consistent framework that defines the signs or symptoms of emotional disorders, nor does it provide clear or adequate guidelines for policies relative to this group. Identifying children and youth with serious emotional disorders in need of mental health services is made difficult by this lack of a common frame of reference and terminology for defining these children. Education categorizes this group as behavior disordered, mental health categorizes them as emotionally disturbed or mentally ill, child welfare categorizes them as children in need of care, and juvenile justice categorizes them as delinquent.

In the following sections we will look at the scope of the problem of severe emotional disorders among children and adolescents, the evolution of the National Institute of Mental Health definition of children with emotional problems, and the specification of the population used for our sample.

SCOPE OF THE PROBLEM

Lacking a consensus on definition, no one knows how many children are in need of mental health services, nor even how many are actually receiving services. Estimates vary but there appears to be general agreement that a "large" number of children are in need of services and many do not receive the needed services (Looney, 1988).

The President's Commission on Mental Health of 1978 estimated that 5 to 15 percent of all children had emotional disorders according to the criteria they set forth. They further suggested that 3 to 9 million children, 16 percent of the total population under age 18, require some type of mental health services at some time, but only 2 percent, or just under 1 million children, receive mental health services. Other estimates suggest that 3 million children -- or 5 percent of all children -- have serious emotional disorders, and that as many as two thirds of this group are not getting services with the most troubled least likely to get help (Knitzer, 1982; Silver, 1988).

EVOLVING DEFINITIONS

In its report in 1970, the Joint Commission on the Mental Health of Children delineated a broad category of signs and symptoms that define the "emotionally disturbed child." Such a child is:

> ". . one whose progressive personality development is interfered with or arrested by a variety of factors so that he shows an impairment in the capacity expected of him for his age and endowment: (1) for reasonably accurate perception of the world around him; (2) for impulse control; (3) for satisfying and satisfactory relations with others; (4) for learning; and (5) for any combination of these" (Joint Commission, 1970).

This report by the Joint Commission on Mental Health of Children was significant in that it provided an authoritative definition of children with emotional problems for the first time. These concepts were reiterated in Hobbs's Future of Children (1975), in the report of the President's Commission on Mental Health (1978) and the subsequent National Plan for the Chronically Mentally Ill (NIMH, 1980). However, the definition had yet to be operationalized.

Efforts to arrive at an operational definition proceeded on two somewhat separate fronts. Epidemiologists based their definition on DSM-III criteria, and service providers focused on a broader definition based on age of the child and service needs. Each of these approaches is examined in detail in the following sections.

DELINEATING THE POPULATION BY DIAGNOSTIC CATEGORIES

The epidemiological approach was initiated by the National Institute of Mental Health's Division of Biometry and Epidemiology. The Institute initiated a five site study using a specially developed Diagnostic Interview Schedule (DIS) that utilized DSM-III criteria to define the adult population.

Studies that used the Diagnostic and Statistical Manual of Mental Disorders III- Revised Edition (DSM III R) demonstrated some diagnostic consistency and indicated that children could be assessed reliably (Strober, Green, and Carlson, 1981). Those groups of diagnoses according to DSM III classification revealed the following disorders and their occurrences:

- *Intellectual*: (mental retardation): prevalence was 1 to 2 percent of the population (Administration for Developmental Disabilities, 1981);
- *Behavioral*: This included attention deficit disorder (prevalence was 3 percent of prepubertal children) and conduct disorders (prevalence was estimated to be at 3.5 percent, Silver, 1988);
- *Emotional:* This included disorders where anxiety was a predominant feature (believed to occur frequently, but prevalence data were not collected) and "other disorders of infancy, childhood and adolescence." Using a systematic psychiatric evaluation and specific diagnostic criteria for affective disorder developed for DSM III (DICA), more than 25 percent of a randomly selected group of children referred to a major psychiatric center met the criteria for some type of affective disorder, of which 82 percent qualified for a diagnosis of major depressive disorder (Cantwell, 1983);
- *Physical Disorders*: This included Anorexia Nervosa (1 in 250 females between ages twelve and eighteen were determined to be at risk of developing this disorder), stereotyped movement disorders (reported in school surveys in 12 percent to 24 percent of the children), and stuttering (1 percent of all children); and,

- *Developmental*: This included pervasive and specific disorders. In terms of developmental language disorders, it was estimated that 1 in every 1,000 children had expressive language disorder, 1 in every 2,000 had a receptive language disorder and 6 percent male and 3 percent female children had an articulation disorder (Gould, 1981).

A Diagnostic Interview Schedule specifically for children (DISC) was being field tested in 1989 (Silver, 1988). Once the instrument is finalized, a national study of children and adolescents was to be undertaken but as of this writing the study has not been done. Although diagnostic labels do not specify the severity or chronicity of the disability and do not imply treatment, they do offer one way to begin to describe the target population. It is evident that greater efforts are needed toward obtaining nosological quality with regard to the problems of adolescents and children.

Delineating the Population by Age Group and Service Needs

The service providers' approach to characterizing children with emotional problems was based on the child's age and service needs. In 1984 the National Institute of Mental Health initiated a federally funded program aimed at improving the services for children with emotional disorders and their families. This new Children and Adolescent Service System Program (CASSP) focused on Knitzer's (1982) finding that 21 states did not have a special mental health focus for children and adolescents. As the basis for the specification of children with severe emotional disorders, CASSP used the views of the those attending a workshop of State Mental Health Program Directors and the previous definitions to establish the criteria to define these children and adolescents. Five criteria, written broadly enough to allow each state to redefine the service population and parameters, were developed: age, disability, multi-agency need, mental illness, and duration.

Age was the first CASSP criterion. Customarily the age of majority is when the child reaches the age of eighteen or twenty-one, depending on the individual state's policy. The final determination as to the age parameters is usually political in nature, based on the state's views on when a child achieves majority status.

Disability was the second and, perhaps the most important, criterion. The definition required a primary focus on the child's degree of disability. CASSP specified this criterion to involve assessment of impairment in the child's ability to perform in the family, in the school and in the community.

Multi-agency need was the third criterion. By definition, the child or adolescent should have a degree of disturbance that would require services from at least two community agencies, such as mental health, special education, juvenile justice, or social welfare.

Mental illness was the fourth CASSP parameter. Although there was no consensus that the DSM III served a role in clarifying service needs, it was decided that being mentally ill or having an emotional disorder required the presence of a mental illness as defined by the DSM III classification system.

Duration was the final CASSP criterion. At least one year duration of the disability was the suggested limit, with the exception for those conditions in which there was a substantial risk of duration for more than one year.

Based on these CASSP criteria each state was allowed to develop its own definition of children and youth with severe emotional problems. Depending upon how narrowly or widely the population is defined, it appears that the number of those affected ranges from 1 million children to as high as 16 million. Wamis and Weinstein (1982) point out that the available data vary so much, not only because of variations in definition, but also because: (1) it is not clear if figures relate to incidence (number of new cases occurring within a given time period) or prevalence (total number of cases at any given time); (2) diagnostic categories are defined inconsistently; and (3) data are compiled without systematic attention to the definition of age groups.

SPECIFYING THE POPULATION FOR THIS STUDY

While the above classifications shed some degree of light upon diagnoses, age of child and patterns of service usage, they fail to illuminate those factors that contribute to an operational definition of "severe emotional disorder" among children and adolescents. This limitation impedes professional consensus about diagnostic classification and potentially clouds research efforts.

For the pusposes of this study, we believed it was impractical to arrive at our own operational definition for this population that would enjoy widespread acceptance. Even if we did derive our own definition, we lacked the resources to then use the definition to identify suitable subjects. Instead, we selected a site that used the broad CASSP parameters and had made significant progress in operationalizing this definition and identifying children and youth with emotional problems throughout their state. The site selection of North Carolina met this criteria and is further discussed in later sections.

A MODEL OF FAMILY CAREGIVING

The purpose of this section is to describe a conceptual model of family caregiving that will help us understand the reality of families caring for a child with an emotional disorder. The amount of literature on families is huge. The literature on families of children with emotional disorders is much smaller and is dominated by a philosophy of "guilt by association." The dominant model is to measure a set of characteristics of the child, a set of characteristics of other family members, correlate the findings and imply a causal relationship. The literature on families' perceptions, use of resources, and coping with a child with an emotional disorder is nonexistent. Consequently this review uses the literature on how families respond to a child's chronic illness or disability. This literature is extensive and cuts across numerous professional domains and academic disciplines (Knafl & Deatrick, 1987). Although caring for a child with an emotional disability may be very different subcategory of concern, it is our judgment that this literature is the most useful as a starting point.

The intent is for this model to be comprehensive, taking into account the multitude of variables and factors that contribute to families' perceptions, coping, and use of resources, and the consequences to the family of caring for a child with a disability or chronic illness. Our interest in gaining an understanding of these processes and outcomes for families and their children is to identify aspects of the caregiving process and environment that may be points of intervention to positively influence the outcomes. This model serves as a guide for the subsequent construction of a data collection instrument and the planned analyses. A more detailed literature review and description of the Family Caregiving Model is provided in a separate report (McDonald, Donner & Poertner, 1992).

The effort to articulate a conceptual model for understanding the experience of families with children with chronic illness or disability is intended to support recent trends in research by: (1) identifying the central underlying constructs that current research and theory suggest are crucial to understanding family caregiving systems; (2) comparing and contrasting nominal and operational definitions for these constructs; and (3) relating these constructs in a comprehensive model of family caregiving based on a synthesis of major theories and empirical research.

In this effort to articulate a causal model, we draw upon research on how families respond to a child's chronic illness or disability. The research represented in this literature is based upon a body of sociological and psychological theory dealing with concepts such as control, self-esteem, causal attribution, stress and coping, anxiety, and cognitive adaptation. Despite the volume of research and prominent theoretical underpinnings, this work has done little to contribute to the basic understanding of the complex interrelationships between child, family and community resources and services and how these relationships can be fostered to support the family in performance of its traditional roles. Regarding the utility of this research, Knafl and Deatrick (1987) observe:

> Ideally, this body of research should provide a rich data base for practitioners working with families in which there is an ill or disabled child member. In reality, it presents an overwhelming and confusing body of information characterized by competing hypotheses, conflicting findings, and tentative conclusions. (p.300)

Numerous factors have contributed to this situation. Studies are predicated on different underlying assumptions regarding the nature of the illness experience and the family's response to it (Knafl & Deatrick, 1987). Research that has attempted to study the impact of the child's illness or disability on the family has been found to be biased toward dysfunctionality. Turnbull, Behr, and Tollefson (1986) have noted that the assumption by researchers that the impact of mental retardation is pervasively negative has led to designs in which the possibility of positive effects is virtually unexplored and that when a result suggestive of a positive outcome is observed, it either is attributed to a methodological flaw or to socially desirable responding.

Diversity in theoretical perspectives has been a further contributor to the confusion described by Knafl and Deatrick (1987). Two bodies of work in different disciplines but concerning the same field have developed apparently independently of each other, without attempt at integration by the primary authors. Lazarus' work in psychology resulting in the book, *Stress, Appraisal and Coping* (1984), contains no mention of the work done from a more sociological perspective on family stress (Hill, 1949; McCubbin, Sussman, & Patterson, 1983). Behr (1989) only recently has provided an integration of work on cognitive adaptation in the study of adjustment to threatening events with the early work of Hill (1949) and more recent models by McCubbin and Patterson (1983). A third source of the disarray is the lack of well-articulated, comprehensive models. Most studies have been descriptive, focusing narrowly on one or two components in what is generally regarded as a complex multidimensional process (Byrne & Cunningham, 1985; Crinic, Friedrick, & Greenberg, 1983). Concerning the statistical bias that is known to result from model specification error (see for example: Pedhazur, 1982, pp. 225-230), Turnbull and her colleagues provide the following characterization of the state of research on families with children with mental retardation:

> The typical design, utilizing a small sample and perhaps one or two independent or control variables, is inadequate to account for this complexity and may yield results that are conflicting or nonsignificant (Turnbull, Behr, et al., 1986).

Conceptual ambiguities mirror and contribute to the confusion that exists. "Stress" is variously conceptualized as a cause and as an effect (McCubbin, 1979; McCubbin & Patterson, 1981). It also is defined as a process (Lazarus & Folkman, 1984). "Cognitive coping," "appraisal" and "perception" are used interchangeably by some authors, while others perceive distinctions. In one model, adaptation appears to be an outcome influenced by coping, but upon closer examination seems to be defined as successful coping (McCubbin, H.I. & Thompson, 1987). The lack of conceptual clarity and diversity in theoretical perspectives and assumptions virtually guarantees a lack of consensus in measurement and methodological approaches. Various reviewers in the field have confirmed this notion (McDonald-Wikler, 1986; Lazarus & Folkman, 1987; Behr, 1989).

Our task in this paper is to impose a degree of order on a disorganized body of work. Some might argue that such an attempt is doomed from the start; that the confusion in the literature reflects the complex interactions of dynamic forces inherent in the operation of an ongoing process like a family system; that tight definitions and causal ordering cannot be imposed on such a system. While acknowledging the complexity of family caregiving systems and the limitations of research methodologies, the authors believe that current knowledge in this field can be processed in such a way that existing ambiguities and conflicting views at least can be identified and framed in a way that will permit systematic ongoing exploration and improved understanding. The authors believe that much of the existing confusion results from a failure to integrate theories and studies in a systematic and disciplined manner guided by an explicit conceptual model.

Several assumptions ground this effort. First, the authors believe in the ability to articulate a causal model that "explains" the operation of family caregiving systems and that can guide research and practice interventions. In building such a causal model, the importance of particular family and child descriptors and identified processes, such as appraisal or coping, are to be judged on the basis of their role in determining identified outcomes. Descriptors or processes that have theoretical interest but are not linked to outcomes for families and children are of no concern within an applied caregiving model. The search is to identify factors that might be manipulated or supported in ways which could lead to better outcomes for families and children. A final assumption we make is that the model will explain outcomes that are both positive and negative. This assumption is consistent with a growing body of literature indicating that some families appear to be destroyed by caring for a child with chronic illness or disability while others appear to be enhanced. Byrne and Cunningham (1985) found that stress was not an unavoidable outcome for families with children with mental retardation, but the degree of stress experienced by the family was influenced by a combination of factors. Resolution and growth was one of four themes identified in Mullins' (1987) content analysis of books written by parents of children with disabilities. The majority of these authors felt their lives were enriched and made more meaningful through caring for their child with a disability.

The development of a model of family caregiving can be of use to families, to professionals and to researchers. The need to understand how something works in a causal sense is central to each of these groups. All are vitally interested in "making things better" and must therefore be interested in cause and effect relationships. The research reported here is an attempt to obtain and promote a better understanding of such relationships in the family caregiving system, thereby contributing to "making things better" for the families and children involved.

The remainder of this section will briefly describe two dominant models for understanding family stress and coping, articulate a new, more comprehensive model for understanding the family caregiving process, and discuss measurement issues in testing and using such a model.

EXISTING MODELS

Two models that attempt to identify and relate the various factors that influence individuals and families dealing with "crisis" or "stress" dominate the current literature. These models attempt to be rather inclusive in their conceptualization of the "stress and coping" process and both have strongly influenced theory and research in the field. Neither model in its original form focuses on family caregiving or on families with children with chronic illness or disability; however, both have been applied by researchers in this field.

The first model developed as a research framework in the field of sociology. Hill (1949, 1958) is credited with the original formulation of this family crisis model known as the ABCX Model. This model has undergone significant reformulations with the most notable recent versions being the Double ABCX (McCubbin & Patterson, 1982) and the T-Double ABCX (McCubbin & McCubbin, 1987).

In Hill's (1958) formulation, Factor A, the stressor event, interacting with Factor B, the family's crisis-meeting resources, interacting with Factor C, the definition the family makes of the event, produces Factor X, the family crisis. This model is diagramed in Figure 1. This formulation highlighted two areas that previously had been overlooked -- the way families define events and their resources for coping with these defined events. Also, by attempting to explicate the process by which families respond to stress, Hill drew attention to the variance that exists in crises, with some being more severe than others.

McCubbin and Patterson (1982) expanded on Hill's theoretical foundations, proposing a conceptual formulation that recognized the interaction of stress, coping and adaptation. Like Hill's original work which grew out of the study of families' reaction to the stress generated by separations and reunions associated with World War II, the McCubbin and Patterson refinements resulted from a longitudinal study of families with a spouse or father who was held prisoner or was unaccounted for as a result of the Vietnam War. This "crisis" context has influenced the conceptualizations of both the stimulus and response in these models, in that the stimulus is considered to be an event to which a response will be made within a limited amount of time. In other words, stress for families is seen as event-focused and the response is confined to the period of time in which a family decides how to respond and takes beginning responsive actions.

In McCubbin's and Patterson's work, the original model is extended by tracking family process both before and after the stressor event (McCubbin, et al., 1980; McCubbin & Patterson, 1981, 1982, 1983). In Hill's framework, a family, when confronted with a particular stressor, reacts to reduce the stressor based upon their resources and their perception of the event. While Hill conceptualized stressors as both normative (expected over the course of life) and nonnormative (sudden and unexpected) both were expected to produce crisis.

McCubbin and Patterson (1982) extended this analysis beyond the point of crisis, recapitulating the ABCX Model in response to both the original stressor and the crisis itself. In this model the family experiences not only the original stressor but also an accumulation of demands. Three types of stressors can accumulate during a crisis: (1) the initial event; (2) those that result from changes in the family's life and experiences; and (3) those that result

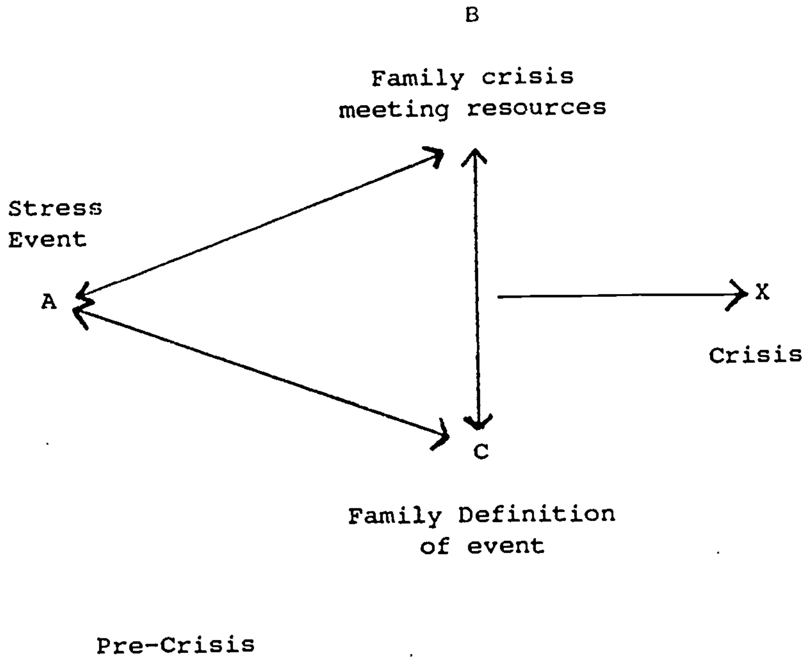

Figure 1. ABCX Model
(Hill, 1949)

from the family's attempts to deal with their problems. In this way, stress and the changes resulting from it are seen more as an ongoing process for the family which could possibly lead to positive outcomes. A schematic diagram of the Double ABCX Model of Family Adjustment and Adaptation (McCubbin & Patterson, 1983) is shown in Figure 2. The major contribution of this reformulation is the labeling of the interaction of factors ABC as "coping" and the introduction of the concept "adaptation" to describe the family adjustment over time. Adaptation, in this model, appears to provide an outcome criterion denoting a certain level of functioning achieved over time through the adjustment process (Behr, 1989). However, adaptation is not clearly defined and is not conceptually distinct from coping.

The original model of Hill and the extended models formulated by McCubbin, et al., provide a framework for tracking the family process in response to a stressor life event. They are useful in their attempts to identify the major factors at work in this process, and the more recent work of McCubbin begins to recognize and identify outcomes of this process. Similarly, the models have evolved to realistically view the periodic eruption of family problems as a "normal" phenomenon, and implicitly define the family as an active agent of its destiny.

The major shortcomings of these models derive from ambiguous or tautological definitions for the central constructs and unclear causal linkages between these constructs. In particular, there is a failure to separate cognitive processes from behavior and behaviors that are a response to stress from outcomes that are produced. Conceptual ambiguities such as these contribute to difficulties in separating causal linkages but are not the only source of confusion. Nor does it appear to be the case that these ambiguities are simply a reflection of a complex, human process. For example, in the adaptation model, factor AA is described as <u>interacting</u> with R and T, with R "<u>determined</u> in part by the concurrent pile-up of demands" (AA) (McCubbin & McCubbin, 1987). Following normal conventions, the relationships shown in the diagram would lead to the following simplified causal statement: X and AA cause R which in turn causes T. However, it is not possible to know if this is what the authors intended.

The second model has grown out of the stress literature in psychology and social psychology. It is perhaps best exemplified, particularly when searching for more comprehensive versions, in the work of Lazarus and his colleagues. Not surprisingly, these authors have focused more on the cognitive aspects of stress and coping and only more recently have expanded to include other theories and to identify other factors and their roles in this process. On the other hand, while Hill's early work and the subsequent versions of his model recognize the cognitive process as the "C" factor, labeled "perception," research based on these sociological models has paid limited attention to the importance of perception and has not clearly distinguished perception and coping.

Unlike the Hill model, Lazarus' stress model does not specifically apply to families but primarily is concerned with the individual and with explaining individual differences in response to stress. Stress is defined as arising from "the relationship between the person and the environment, which takes into account characteristics of the person on the one hand, and the nature of the environmental event on the other" (Lazarus & Folkman, 1984, p. 21). In this conceptualization, stress is not a variable but a "rubric consisting of many variables and processes" and central is the specification of "antecedents, processes, and outcomes that are relevant to stress phenomena" (Lazarus & Folkman, 1984, p. 12).

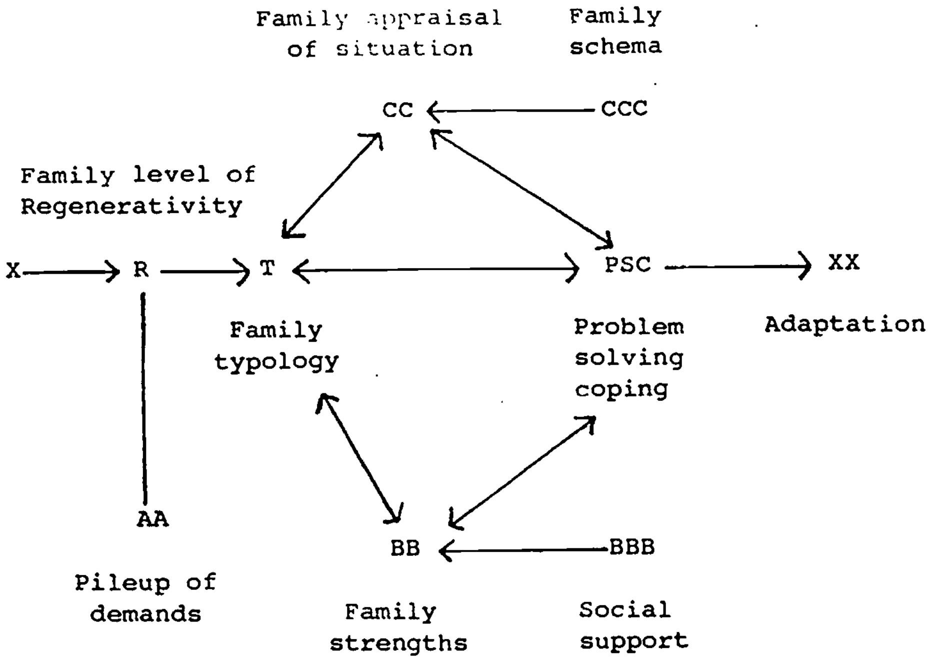

Figure 2. Adaptation Phase of T-Double ABCX Model (McCubbin & McCubbin, 1987)

Cognitive appraisal, the critical concept explaining the judgment that a particular person-environment relationship is stressful, is viewed as the central mediator or process variable in a "cognitive theory of stress." Three kinds of cognitive appraisal are identified: (1) primary appraisal -- judgment that an encounter is irrelevant, benign-positive or stressful; (2) secondary appraisal -- judgment concerning what might and can be done; and (3) reappraisal -- based on new information from the environment and/or the person.

The other major process or mediator variable identified by Lazarus and Folkman (1984) is "coping." Coping is defined as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p. 141).

Lazarus and Folkman also discuss the role of emotion as a mediator in the stress process. The cognitive approach to emotion leads them to "say that those values, commitments, and goals that are engaged in a transaction influence how the person construes a situation, and hence the emotions he or she will experience" (Lazarus & Folkman, 1984, p. 284). The interaction of appraisal, coping and emotion is perhaps best articulated in a 1988 article in which emotion is described as arising initially from appraisal to influence coping efforts that lead to reappraisal and a new emotion. Emotion is thus conceptualized as an immediate effect arising from the mediating functions of appraisal and coping.

Having identified the central mediators of stress as emotion, appraisal and coping, Lazarus and Folkman (1984) turn to the identification of antecedents and adaptational outcomes. Antecedent variables are divided into two categories: person factors, and environment factors. Commitments and beliefs are identified as the most important person factors affecting cognitive appraisal (p. 80). Identified properties of encounters (environment) that create the potential for (appraised) threat, harm, or challenge are identified as: (1) novelty; (2) predictability; (3) event uncertainty; (4) temporal factors (imminence, duration, and temporal uncertainty); (5) ambiguity; and (6) timing of the events in relation to the life cycle.

Three basic kinds of outcomes are identified: (1) functioning in work and social living; (2) morale or life satisfaction; and (3) somatic health (Lazarus & Folkman, 1984). These long-term adaptational outcomes are not viewed as direct products of coping and appraisal, but rather as arising from the effects of these processes on the short-term outcomes of stressful encounters including: (1) positive or negative feelings; (2) quality of outcome of stressful encounters; and (3) somatic changes and acute illness. Health and morale appear to be the most clearly articulated and discrete adaptational outcomes conceptualized. All these components and perspectives are represented in the diagram shown in Figure 3.

A particular strength of the work of Lazarus and his colleagues, from the perspective of this study, is the examination of appraisal and coping processes in terms of their effects on adaptational outcomes. Much theory and research in this field, including the work of Hill, has lost sight of this linkage by focusing solely on the coping process. The linkage to outcomes provides a criterion that can be used to judge which aspects of a process are important. While not all research must be subjected to this criterion, when we strive to help families and to help practitioners in their work, it is a central concern.

	Causal Antecedents	Mediating Processes	Immediate Effects	Long-term Effects
SOCIAL	SES Cultural templates Institutional systems Group structures (e.g., role patterns) Social networks	Social supports as proffered Available social/institutional means of ameliorating problems	Social disturbances Government responses Sociopolitical pressures Group alienation	Social failure Revolution Social change Structural changes
PSYCHOLOGICAL	Person variables: values-commitments beliefs-assumptions, e.g., personal control cognitive-coping styles Environmental (Situational) variables: situational demands imminence timing ambiguity social and material resources	Vulnerabilities Appraisal-Reappraisal Coping: problem-focused emotion-focused cultivating, seeking & using social support Perceived social support: emotional tangible informational	Positive or negative feelings Quality of outcome of stressful encounters	Morale Functioning in the world
PHYSIOLOGICAL	Genetic or constitutional factors Physiological conditioning-individual response stereotypy (e.g., Lacey) Illness risk factors-e.g., smoking	Immune resources Species vulnerability Temporary vulnerability Acquired defects	Somatic changes (precursors of illness) Acute illness	Chronic illness Impaired physiological functioning Recovery from illness Longevity

Figure 3. Cognitive Appraisal Model of Stress and Coping
(Lazarus & Folkman, 1984)

Other strengths of this model include the explicit focus on person and environment, consistent with ecological approaches to research and practice with families and children. The definition of coping which includes both cognitive and behavioral components seems to reflect the experience of families of children with chronic illness or disability. Families caring for children with chronic illness or disability "cope" with this task through various cognitive means, such as comparing their situation with that of others, as well as through specific behaviors designed to access resources and relieve stress.

As is true in any developing area, problems remain with the theory. Cognitive coping and cognitive appraisal do not seem to be well distinguished. Recognition of the role of emotion in the process is a significant contribution, yet distinguishing emotion which contributes to coping and that which results from coping is problematic, in part because of the subjective and retrospective nature of measurement. Finally, the systems perspective reflected in Figure 3 recognizes the complexity of the multiple factors and dimensions while considering antecedents, processes and effects.

A NEW MODEL FOR FAMILY CAREGIVING

Building on the theoretical work described briefly in the preceding section and in detail in a prior monograph (McDonald, Donner and Poertner, 1991), the study reported here was guided by a new model for family caregiving which is diagramed in Figure 4. This model is consistent with both the Lazarus and McCubbin models in that it identifies three major stages in the family caregiving process: antecedents, mediators and outcomes. Causality is expected to flow from left to right, that is antecedents to mediators to outcomes, with mediators interacting as diagramed.

The literature and research found to be the most relevant in building a model of family caregiving for children with a chronic illness or disability relates to the study of stress, coping and appraisal. If one follows the suggestion of Lazarus that stress be regarded as a rubric rather than a simple variable (Lazarus, 1966; Lazarus & Folkman, 1984; Lazarus, Delongis, Folkman & Gruen, 1985; Lazarus, 1990), the model of Figure 4 can also be thought of as a model of the "stress process." Indeed, family caregiving of children with a chronic illness or disability can be thought of as a special instance of stress and coping. While some of the unique characteristics of the family caregiving model result from simply applying more general stress models within this specific context, the model expands upon and differs in significant ways from previous conceptualizations. These differences are described in the following sections which focus on the three major construct categories: antecedents, mediators and outcomes.

THE MEDIATING PROCESS

We focus first on the mediating process since this appears to be the area where there has been the most attention but the greatest difficulty in specifying unique components and the relationships between these components. Perceptions, coping and emotion are three critical constructs identified as part of the mediating process which determines how a family will deal with its child's disability or illness and the outcomes they will achieve. The mediating

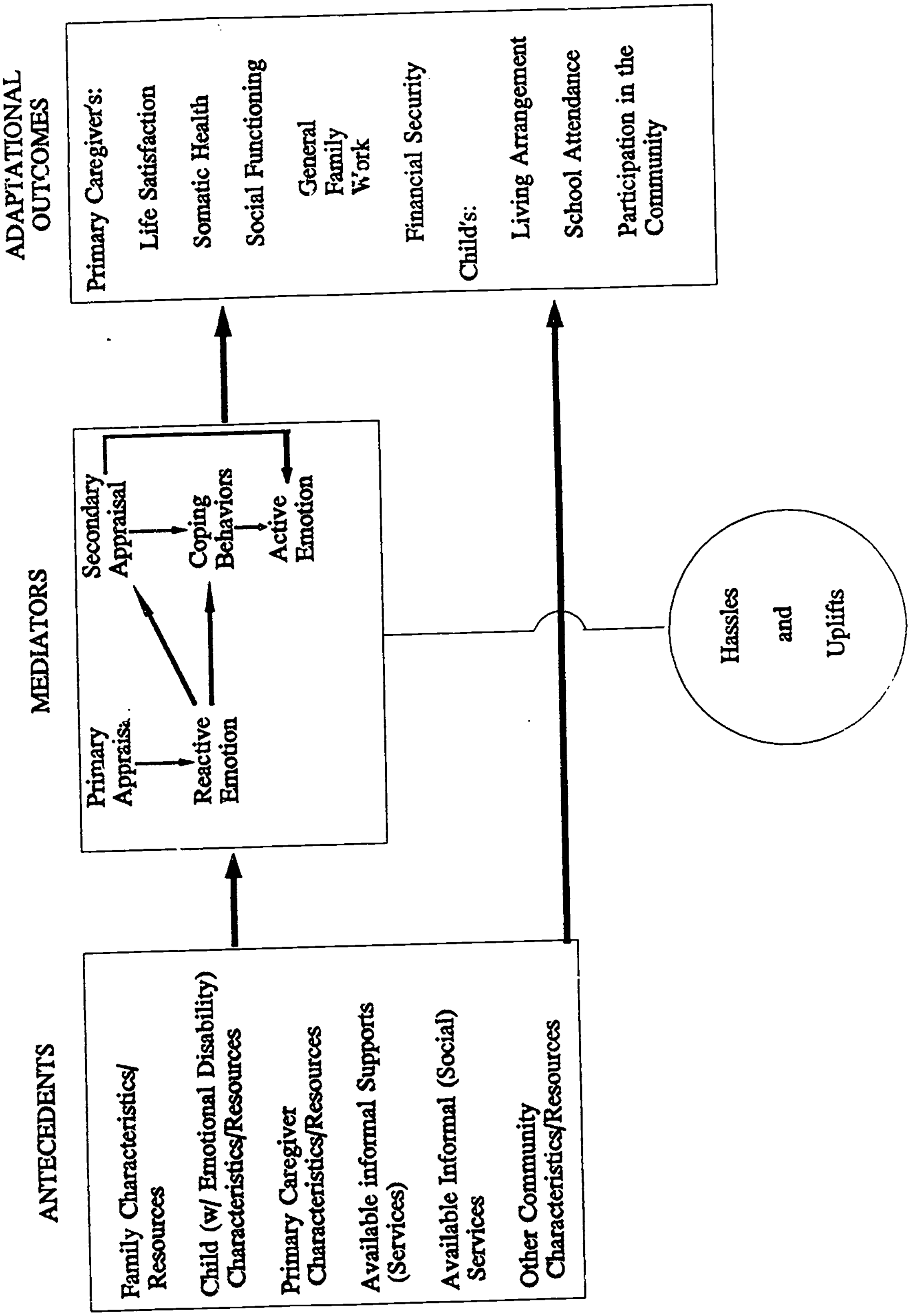

Figure 4. Family Caregiver Conceptual Model

process is seen as beginning with *primary appraisal*, which is defined as *the judgment that an encounter or event is irrelevant, benign-positive, or stressful* (Lazarus and Folkman, 1984). The event could be, for example, the diagnosis or labeling of the child as having an "emotional disorder." If the involved professional was seen by the parents as incompetent, they might find this event to be irrelevant. If the professional explained that the label was simply necessary to access needed services and held no other meaning, the parent might view it as benign or even supportive. If, however, the label meant that the child would be removed from his or her school and placed in a residential center far removed from the home, the event could be perceived as extremely important and threatening. Emotion is seen as arising directly from this primary appraisal. We refer to this as *reactive emotion*, defined as *positive or negative feelings resulting from the perception of the stressor event.*

Also arising from the primary appraisal and influenced by the reactive emotion is the *secondary appraisal*, defined as *a judgment concerning what might and can be done and how the event or encounter should continue to be perceived.* The (primary and secondary) appraisal process and accompanying (reactive) emotion may then lead to a behavioral coping response. In some situations no behaviors will ensue. For example, the event may be judged to be irrelevant, giving rise only to feelings of indifference with no further thoughts or actions; or the situation may be judged to be threatening but that nothing can be done to change it, giving rise to feelings of anxiety and vulnerability but no action; or such an event could be reappraised with a decision to "try to ignore it."

The last example points to a major distinction of this model from that of Lazarus and Folkman, in that reappraisal is not identified as a separate construct here. Conceptually, we find "reappraisal," as used by Lazarus and Folkman, troublesome as a distinct construct. In part the term is subsumed under "cognitive coping" strategies. We find it clearer to view coping as behaviors and cognitions as appraisals and thus include "cognitive coping" under secondary appraisal. We also find it difficult to distinguish "reappraisal," as the final step of one encounter from primary appraisal in a second encounter. We would argue that the interaction of the person/environment modifies the environment thereby initiating a new encounter.

As indicated in the above examples, secondary appraisal and the coping response give rise to a new set of emotions. In the caregiving model this is designated as *active emotion* which *relates to positive and negative feelings about the results of the appraisal and coping response.*

CAUSAL ANTECEDENTS

A number of researchers have identified variables that contribute to or influence the family's response to caring for a child with a disability. Most of the studies do not differentiate between those variables associated with perception, coping, emotion, or adaptation separately, but rather identify those variables that influence the mediating process and outcomes as a whole. The four major categories identified in the literature include: (1) internal family characteristics/resources; (2) child characteristics/resources; (3) family supports; and (4) community characteristics/resources.

Internal family characteristics identified in the literature that affect the adaptational process include: (1) the life experience of the family (McCubbin, 1979); (2) the life cycle of the family (Byrne & Cunningham, 1985); (3) the socioeconomic status of the family (Dunlap & Hollinsworth, 1977; Farber, 1959; Flynt & Wood, 1989; Gallagher, et al., 1983); and (4) the family's world view (Dunlap & Hollinsworth, 1977; Farber, 1959; Levinson, 1975). Other research studies have identified the quality of the marital relationship (Abbott & Meredith, 1986; Beckman, 1983; Flynt & Wood, 1989; Freidrich, et al., 1985) and spouse support (Abbott & Meredith, 1986; Freidrich, et al., 1985; McKinney & Patterson, 1987) as variables that influence the mediating process of dealing with a child with a disability. The family's religious beliefs (Abbott & Meredith, 1986) also have been found to influence how a family handles having a child with a disability.

The research literature identifies four major child variables that influence the mediating process: (1) the diagnosis or severity of the child's disability (Freidrich, et al., 1985; Pollner & Wikler, 1985; Wikler, 1986); (2) the age of the child (Anderson, 1981; Farber, 1959; Gallagher, et al., 1983); (3) the sex of the child (Chigier, 1972; Farber, 1959); and (4) the child's limitations (Barsch, 1964; Farber, 1959).

Primary caregiver characteristics influencing the adaptational process include the level of education of the parents (Dunlap & Hollinsworth, 1977; Farber, 1959; Levinson, 1975) and whether they use social comparisons (Vonkrs, 1981). The supports available to families seem to influence their capacity to deal with their child with a disability. Some studies have found that the availability of formal supports (services) influences the adaptational process (Abbott & Meredith, 1986; Donovan, 1988). Other studies have shown that the availability of informal (social) supports, including availability of extended family (Friedrich, et al. 1985; McCubbin, 1988), influences the family's capacity to deal with their child.

The mediating process is influenced by other community characteristics or resources, including variables such as the size and racial mix of the community, the per capita income, and the community view of the child (Fairfield, 1983).

ADAPTATIONAL OUTCOMES

In assessing adaptational outcomes for families with children with chronic illness or disability, the conceptual framework provided by Lazarus and Folkman (1984) appears to be useful in that it more fully separates adaptational outcomes from the antecedents and mediating process that determine these outcomes. It will be remembered, however, that the Lazarus model focuses on stress, appraisal, and coping for individuals rather than for families. This is less problematic if the caregiving model explicitly focuses on individual family members, their personal situations and experiences, and their experience of family functioning. Since conceptualizing and operationalizing "family variables" is inherently problematic and measures of family functioning are not widely agreed upon, this is probably the best strategy to pursue at this time in any case.

While all family members should be considered as data sources in constructing an accurate picture of family impact, two members are of primary concern and should be viewed conceptually as the source for constructing outcome measures. In families with children with a disability or chronic illness, it is unusual to find equally divided responsibility for caregiving. In most instances a primary caregiver, usually the mother, can be readily identified (Friesen, 1989). Also of central concern is the well-being of the child experiencing the disability or illness. By focusing on the adaptational outcomes of these two family members, we have a better chance of building a consistent and valid model of family caregiving. Other family members are not to be ignored, but their activities and experiences are to be viewed from the perspective of their contribution to the functioning of the primary caregiver and the child living with a chronic illness or disability.

Lazarus and Folkman (1984) provide three conceptual categories for outcomes (social functioning, life satisfaction and somatic health) that can be readily operationalized and applied to the primary caregiver. To these we would add a construct reflecting the family's financial status. Unlike Stein and Reissman (1980), we would operationalize this construct as a distinct measure of financial stress and not attribute the burden to the child's illness or disability in the variable itself.

Specifying desired outcomes for the child is more problematic. In the model being built, behaviors and certain aspects of the child's health are viewed as exogenous variables that influence both mediators and outcomes. One could expect the child's behaviors or health at an earlier point in time to influence the family's appraisals, emotions and coping behaviors and, ultimately, current and future behavior and health of the child. With adequate prospective longitudinal studies, such models could be estimated. Cross-sectional or retrospective studies will find it harder to disentangle these effects.

Another important set of adaptational outcomes for the child lend themselves more readily to study. These outcomes reflect the recent emphasis of federal law (P.L. 101-476 and P.L. 96-272) on normalizing living arrangements. Positive adaptational outcomes here would be reflected in the ability of the family to keep the child in their home or minimize placement days when placement was necessary, the child's ability to attend and participate meaningfully in school, and participation in other community activities appropriate to the child's age.

DEVELOPMENT OF THE FAMILY CAREGIVER SURVEY

OVERVIEW

One of the major tasks of the project was to identify existing instruments that measure the family caregiver model in all of its stages. In that process we determined three specific limitations with current instrumentation: (1) while several instruments have been developed to assess various components of the model, none have attempted to look at the unique constructs of caring for a child with severe emotional problems; (2) most instruments look at individual measures of stress at a single point in time (Friedrich, Greenberg et al., 1983; Holroyd, 1974; Lazarus & Folkman, 1987; Matheny et al., 1986), rather than measuring stress over time; and (3) finally, most instruments fail to obtain a general measure of stress at the family level, but instead measure stress for individual family members (McCubbin & Thompson, 1987).

In the formulation of our Family Caregiver Model three major stages have been identified pertaining to the process of family response to the demands of caring for a child with a disability: (1) antecedents; (2) mediators; and (3) outcomes. These are consistent with both the Lazarus and McCubbin models which attempt to identify and relate the various factors which influence individuals and families dealing with "crisis" or "stress." These two theories were selected because they dominate the current family research literature and appear most relevant.

The following sections will describe the rationale for selection of measures to test the constructs of the Family Caregiver Model and the process of the review and field testing of the survey instrument. The instrument itself can be found in Appendix B.

SELECTION OF MEASURES

Antecedent Variables. The antecedent variables are most readily operationalized because they are the most concrete. These variables included: (1) the sex of the child; (2) the age of the child; (3) the relationship to the child; (4) the parents' employment status, (5) the income of the family; (6) the marital status of the parents; (7) the parents' education; (8) the race of the family; and (9) the religious beliefs of the family.

Other antecedent variables that were less readily operationalized included: (1) characteristics of the child's disability; (2) the availability and use of formal and informal supports; and (3) information about the community in which the family resides (e.g., racial composition, size, and services available). The severity of the child's disability was measured with the Child Behavior Checklist (Achenbach, 1981). We relied on the Family Coping Coherence Scale and the Social Support Index developed by McCubbin et al.(1981) to operationalize the availability and use of formal and informal supports. Both of these scales have been widely used and accepted.

Two additional measures were included as antecedent variables to test for the influence of formal supports. These measures were developed by the Portland Research and Training Center on Family Support and Children's Mental Health (1991) and have not been previously tested. The two measures are: (1) the Professional Relationship Scale-- measuring the caregiver's experience with professionals; and (2) the Service Utilization Scale-- measuring the services used by the child and/or family.

Mediating Variables. The mediating variables are much more difficult to operationalize. This is because most available instruments have not differentiated mediators from outcomes nor have they recognized the discrete constructs inherent in the mediating process. As discussed in the previous section, we have defined the mediating process to include three primary constructs: (1) perception; (2) coping; and (3) emotion. The need, in the current study, to rely on previously developed and tested scales and the constraints of a cross-sectional design, presented major limitations in the measurement of mediating constructs. Future work utilizing longitudinal designs and more intense contact with informants will be required to better disentangle this mediating process for families caring for children with serious disabilities or chronic illness.

The current study measured perception by utilizing the Positive Contribution Scale (Behr, 1989) and the six items identified as measuring perception within the Coping Health Inventory for Parents (McCubbin & McCubbin, 1983). The Positive Contribution Scale is noteworthy in that it operationalizes new thinking in this field that moves away from a focus on negative aspects of caregiving.

Another operationalization of perception that attempts to capture the person's cognitive appraisal of an event was developed by Folkman and Lazarus (1985), in their Stress Questionnaire, which we did not use for two reasons. First, the Stress Questionnaire was designed to test a single stressful event over a short time period, and is more suited to use in a longitudinal design. Secondly the Stress Questionnaire is over ten pages long, and including this scale would have increased the survey time to over an hour.

The second construct in the mediating process, coping, has been operationalized in many ways. The checklists developed by both McCubbin and Lazarus are quite similar. We have relied on the Coping Health Inventory for Parents developed by McCubbin & McCubbin (1983) because it has been used extensively to measure coping patterns of families caring for a chronically ill member and was more manageable in length.

We were unable to operationalize the construct of emotion. There has been only one attempt at identifying emotion as a part of the mediating process. Folkman and Lazarus operationalized it in part of their Stress Questionnaire. As previously noted, however, we chose not to utilize the instrument because of its design and length. Therefore, emotion as a component of the mediating process is not operationalized in this study.

Outcome Variables. Difficulties in operationalizing the adaptational outcomes arose primarily from two sources. As noted in the previous section, many researchers have not differentiated outcomes from the mediating process. Ideally, our model would like to focus on family outcomes. Unfortunately, these are ill-defined and operationalized in the field with some debate continuing as to whether the family can be a unit of analysis apart from simply a sum of its individual members. In the end, the constraints of our cross-sectional survey dictated that we focus on the perceptions and functioning of the primary caregiver (usually the mother) and the affected child.

We defined the outcomes to include those related to the caregiver (life satisfaction, somatic health, and social functioning); and those related to the normalization of the child's life (the child's living arrangement, school attendance, and participation in the community). We have relied on the self-report measures developed by Press (1989) to assess the caregiver outcomes.

The situation of the child is assessed through the use of objective measures of the child's status as reported by the primary caregiver (where they reside, where they attend school and participation in activities).

Review and Testing. The field test of the Family Caregiver Survey involved a three step process following the guidelines of Dillman (1978) and Moser and Kalton (1972). The first step of the process was a peer review. The survey was reviewed by colleagues at the University of Kansas, School of Social Welfare and staff of the Portland Research and Training Center. Their input consisted of concerns regarding the length of the survey, formatting suggestions, and being sure that the instructions for each section were clear. Staff of the Portland Research and Training Center suggested the inclusion of the Professional Relationship Scale and the Service Utilization Scale. Allen Press, of the University of Kansas, made modifications in the Preventative Measures of Stress and Satisfaction to incorporate more recent versions of his scales. Once these suggestions were incorporated, the survey was printed for a field test.

Variables and instruments included in the draft of the Family Caregiver Survey that was used for the field test are listed in Figure 5.

The field test survey was administered to nine caregivers of children with emotional problems. Five of the caregivers had a child between the ages of six and twelve, and four caregivers had a child between the ages of three and five. All of the children met the definitional criteria of the population to be sampled and were from the Topeka, Kansas area. Each of the participants in the field test was paid $20 for their participation.

Parents of children involved in the field test were contacted by the researchers to see if they would be willing to assist us in the field test. Once the caregivers agreed to be a part of the field test, a packet was sent to them including the survey, a letter explaining our project, a consent form, and a reimbursement form. The parent who was the child's primary caregiver was asked to complete the survey and make comments throughout the survey when questions or problems arose. Once they returned the questionnaire, a copy was made of the completed survey and returned to them to be used in a telephone debriefing with the researchers. An appointment time was set to contact the caregiver to review their completed survey. Each participant in the field study was asked the following questions:

1. How long did it take to complete the questionnaire? Did you have any interruptions?
2. When you first saw it did you think it would take you longer to complete?

CONSTRUCT	INSTRUMENT	AUTHOR
ANTECEDENT VARIABLES		
Sex of Child		
Age of Child		
Parents' Employment		
Marital Status		
Parent Education		
Race		
Income		
Religious		
Severity of Disability	Child Behavior Checklist	Achenbach (1981)
Family Supports	Family Coping Coherence Scale	McCubbin & Patterson (1981)
Social Supports	Social Support Index Stress Questionnaire	Folkman & Lazarus (1985)
MEDIATORS		
Perception	Positive Contribution Scale Coping Health Inventory for Parents	Behr (1989) McCubbin et al. (1983)
Coping	Coping Health Inventory for Parents Stress Questionnaire	McCubbin et al. (1983) Folkman & Lazarus (1985)
Emotion	Stress Questionnaire	Folkman & Lazarus (1985)
ADAPTATIONAL OUTCOMES		
Life Satisfaction Somatic Health Social Functioning	Preventive Measures	Press (1986-1989)
Child's Living Arrangement School Attendance Participation in Community	Child Behavior Checklist	Achenbach (1981)

Figure 5. Model Constructs and Data Sources

3. Was there anything in the letter that was unclear?

4. Were the instructions clear?

5. Were the questions clear?

6. Were there any questions that were offensive/upsetting?

7. Were there any questions that you thought were nobody else's business?

8. Do you think other parents who do not know us would do this survey? Would people be motivated to answer the survey for $10?

9. Is there anything we could do to make it more family friendly?

10. We are interested in family's thoughts, feelings and experiences regarding having a child with emotional problems -- does this survey seem relevant to this goal?

11. Other comments?

Once the debriefings were completed, all of the parents' feedback was compiled and reviewed by the researchers. The following is a summary of the feedback from the participants in the field test of the Family Caregiver Survey.

Field test feedback. It took the participants an average of one hour to complete the survey even though most of them thought it would take longer when they first saw it. All of the parents in the field test thought the directions in the cover letter were clear. There were two places where instructions within the survey were unclear, and the participants made suggestions as to how to reword the instructions. A few parents gave some editing suggestions on some questions. The parents did not feel that any of the questions were offensive or upsetting, and the majority felt that the questions were appropriate to the goals of the project. Parents indicated that they felt other parents would be willing to fill out the questionnaire and that paying caregivers $10 for participating would help in getting parents to participate. A few suggestions were made to make the survey more understandable to families, but overall the participants in the field test thought the questionnaire was comprehensive and easy to fill out.

The third step in the field test process was to finalize the Family Caregiver Survey. The feedback from the field test was reviewed by the researchers and incorporated into the final draft of the survey. The entire survey was reviewed by the researchers and their colleagues at the University of Kansas for final edits and formatted to make the questionnaire as user friendly as possible.

Summary of Instrument Development. The Family Caregiver Survey was developed to test the variables defined in the Family Caregiver Model, which examines the process of a family's response to the demands of caring for a child with an emotional disability. Instruments were selected that had been tested with other populations and had a high degree of reliability. A peer review and field test of the survey was completed prior to the final questionnaire being printed for distribution in North Carolina. The final survey can be found in Appendix B.

ADMINISTERING THE SURVEY

OVERVIEW

The Family Caregiver Study was designed to collect data from and about two sources. The study conducted mail surveys with the primary caregiver to obtain data on the child, family and caregiver. A separate data collection effort obtained data on demographic and service characteristics of the communities in which the families resided. Linkage of these data created a data base which permitted the testing of the conceptual model presented in Section III.

Pragmatic considerations required that the study be conducted in a single state. The study used purposive sampling to assure adequate variance in the variables of interest as dictated by the model described in previous sections of this report. With the availability of previously tested measures of the variables in the model, the researchers elected to utilize a mail questionnaire following "The Total Design Method" described by Dillman (1978).

The following sections will describe in detail the site selection process, the procedures utilized to recruit family caregivers to participate in the study, the data collection procedures and the analytic procedures used.

SITE SELECTION

The selection of a state was a critical task of the project. Two criteria were of primary consideration in this selection process: (1) the ability to identify a racially diverse population from which to select a sample; and (2) assured variation in critical independent variables in the model.

The site chosen for the study had to have a clear definition of "children and youth with a severe emotional disability" that was uniformly used at local levels. In addition to having a clear definition, the state also needed to be actively engaged in the identification of children with serious emotional disorders, particularly children under the age of 6. This criterion meant that the state must be fairly far along in the development of a statewide system for identification of infant, toddler, and preschool children under P.L. 99-457 and its subsequent amendments (P.L. 99-457 is the Education of the Handicapped Act Amendments of 1986, which includes provisions for handicapped children of all ages, most specifically for children with handicaps and "at risk" children between the ages of birth and six and their families). In addition to the site having uniform definitions to identify the sample, it was necessary that the state have a diverse enough population to test the caregiver model.

The second criterion was that the state have substantial variation in available community resources and services to children with severe emotional disabilities and their families. Given the general lack of services to this population, the state selected had to be one that was progressive and innovative. Even in such a state, we expected innovations and more comprehensive services to be focused upon specific locales and not be uniformly available statewide.

Other considerations in selecting the site included the quality and availability of data on services and families, the attitudes of state, area and local offices toward the involvement of families in research, and protocols for obtaining human subject research approval. Finally, of course, the critical state agencies all had to agree to participate.

Once the criteria were set to select a state to be involved in the study, the investigators followed a two step process in deciding which state best met the criteria. The first step was to contact individuals who had knowledge from a national perspective regarding which states might be appropriate study sites. In an effort to elicit nominations from people with a national perspective, contact was made with representatives from the Children and Adolescent Service System Program (CASSP) at the National Institute of Mental Health, the Portland Research and Training Center, the South Florida Research and Training Center, the Georgetown CASSP Technical Assistance Center, and the Beach Center on Families With Disabled Members. Each of the persons contacted was told about the research and asked to suggest states that they felt met all or most of the criteria. Six state CASSP directors were also surveyed, as was the President of the Federation of Families for Children's Mental Health. A total of twelve persons were contacted to nominate states to be considered. Of the states suggested, six were mentioned as meeting all or most of the criteria. Those six states were Florida, Kentucky, Maine, Maryland, North Carolina, and Ohio.

Once this list was compiled, the second step involved the collection of more specific data related to the selection criteria. A matrix was set up to look at each state along the parameters defined earlier. The primary consideration of having sufficient variation in available community resources and services was examined relative to four criteria:

1. *How long the state had been a CASSP project and the focus of the project* -- This was critical because state CASSP grants were focused on a variety of initiatives and the states receiving the grants were at various stages of developing definitions of target populations, services, and resources for families of children with severe emotional problems.

2. *Whether the state had been a recipient of a Robert Wood Johnson community-based service grant* -- This was an important consideration because the recipients of these grants had to demonstrate state and local service collaboration and propose the development of an array of community services to children with emotional disorders and their families.

3. *Whether education and mental health divisions were working cooperatively* -- This was important because the development of services and resources in local communities is enhanced by education and mental health services working cooperatively.

4. *Which state agency was responsible for the implementation of Part H of PL 99-457* -- States that were implementing Part H of PL 99-457 (0-3 year old) out of the same agency were more likely to include infants, toddlers, and preschool children with severe emotional problems to be eligible for services under PL 99-457.

Information on these criteria was obtained by contacting the CASSP directors in the states, and by reviewing reports published by the National CASSP office, the Portland and Florida Research and Training Centers, and the Georgetown CASSP Technical Assistance Center.

As the process of soliciting the above information progressed, it became clear that two conditions were of primary importance in determining which states met most or all of the criteria set forth. The first of these was whether the state had included children with emotional problems in their implementation plan under P.L. 99-457 and Part H of the same law. This was important to our study because the sample design called for one-fourth of the sample to come from families of children under the age of 6. Many states did not include children with emotional disabilities in their target under the implementation of this mandate. Only two states of those nominated to be considered for our study, North Carolina and Maryland, had developed systems for the implementation of P.L. 99-457 that included children with emotional disabilities as a part of their plan.

The second important condition was the degree of variance in mental health services and population characteristics across the state. Almost all of the states indicated having a wide range of available services within their state but only North Carolina, Ohio and Florida, of those initially identified, also included a significant minority population.

As the investigation proceeded, it became clear that North Carolina met nearly all of the criteria set forth. North Carolina has long been a leader in many areas of service development and research for children with severe emotional disorders and their families. North Carolina was in its third year of CASSP funding and had targeted infants, toddlers, and preschool children with emotional problems in the implementation of P.L. 99-457 and Part H, having developed specific criteria for inclusion of children with emotional disabilities in their 99-457 plan. The project also had a clear definition of children with severe emotional disorders following the national guidelines cited earlier. Because of the CASSP grant, being a recipient of a Robert Wood Johnson grant for community-based services and the development of eight other projects, the state had a wide range of services available to families. Not all services were available in all parts of the state, however, and this geographical diversity of the state, together with its racially diverse population, made North Carolina conducive to this study.

Once the decision was made to select North Carolina as the site for the study, contact was made with the Chief of the Children's Mental Health Services in the Division of Mental Health, Mental Retardation and Substance Abuse in the North Carolina Department of Human Services. Agreements to participate were secured and a liaison with the research project was assigned. This finalized the process of selecting a site for the study.

Site Description - North Carolina. In 1970, the State of North Carolina established an Office of Child Mental Health, initiating one of the earliest efforts in the country to focus on the needs of children with severe emotional problems. As a result the State has developed a strong infrastructure for planning, organizing and implementing children's mental health services through a well organized mental health delivery system.

The Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (MH/DD/SAS) is located in the Department of Human Resources (DHR), an umbrella agency responsible for the State's human service programs. The Child and Family Services Branch is located within the Mental Health Section of the Division and is responsible for statewide oversight of child mental health services.

MH/DD/SAS administers a budget of $525,000,000 (FY89) for programs to serve three disability groups: those with mental illness, people with developmental delays, and substances abusers. Mental health services in North Carolina are provided by a well-developed network of state and local programs. State operated programs include four regional psychiatric hospitals, five regional mental retardation centers, three alcohol rehabilitation centers, and three special care facilities, two of which are re-education centers for children. During FY88 approximately 169,000 clients were served; of these, 102,000 were served for mental health problems. The FY88 budget for child mental health was $74,000,000; in FY88 25,000 children were served.

The state is divided into four regions, with state staff located in regional offices to provide technical assistance and to monitor both fiscal and programmatic functions of local programs. Each regional office has a child specialist who provides staff support to the regional management team and technical assistance to area programs.

The local community-based services are provided by 41 area programs which serve the state's 100 counties. Each area program is governed by an area board, whose membership is broadly representative of the community.

In 1987, the North Carolina Legislature adopted a ten year plan for the expansion of services for children with emotional disorders. This commitment was a result of the Child Mental Health Plan which described the continuum of care, gaps in services, the cost in completing the continuum statewide, and the management supports to sustain it.

North Carolina has frequently been recognized for its exemplary child mental health services, based primarily on achievements in implementing a full continuum of care statewide for a segment of the child mental health population. In 1981, in response to a class action suit (*Willie M. et al. vs. Hunt et al.*, (1980)), mental health and education services expanded significantly to meet the needs of approximately 1200 children who were members of the legal class composed of children with serious emotional, mental and/or neurological disabilities, with assaultive behavior. The successful development of services for this difficult population required significant changes in service delivery and in attitudes about how and where these children could best be served. Building the continuum for the *Willie M.* class resulted in an infrastructure for a system which could include all children with emotional disorders.

As a part of these efforts, North Carolina, in accordance with CASSP guidelines, adopted definitions of children with emotional disorders for children older than the age of five. For children under the age of six they used the definition of "Atypical Developmental Delay," which encompasses children with emotional problems. These definitions were used in our study to define the sample population eligible for participation in the research. The North Carolina definition for a child with serious emotional disturbance, age six to 18 is:

> The child has a DSM-III-R diagnosis of emotional disturbance or neurological impairment and at least one of the following:
>
> (i) serious emotional disturbance with a duration of more than one year or projected to continue for more than one year;
>
> (ii) has a developmental delay of more than two years documented by standardized tests;
>
> (iii) needs the services of more than two agencies;
>
> (iv) needs more than two services from mental health agencies; OR
>
> (v) has been served in psychiatric hospital or intensive residential program or needs such services.

For children under age six, the state definition of atypical development includes children who:

> demonstrate significantly atypical behavioral, socioemotional, motor, or sensory development as manifested by:
>
> (a) diagnosed hyperactivity, attention deficit disorder, or other behavioral disorders; or
>
> (b) identified emotional/behavioral disorders such as:
>
> 1. delay or abnormality in achieving emotional milestones, such as: pleasurable interest in adults and peers, ability to communicate emotional needs, and ability to tolerate frustration;
> 2. persistent failure to initiate or respond to most social interactions;
> 3. fearfulness or other distress that does not respond to comforting of caregivers;
> 4. indiscriminate sociability, for example, excessive familiarity with relative strangers;
> 5. self-injurious or other aggressive behavior; or
> 6. substantiated physical abuse, sexual abuse, or other environmental situation that raise significant concern regarding the child's emotional well-being.

Summary of Site Selection Process. While the choice of one site to test the Family Caregiver Model was partly a function of pragmatics it was also based on the fact that few states systematically identified children with emotional disorders between the ages of three to five. While only one state was initially selected for this study, the effort may be expanded to additional states if results warrant. However, there is no reason to expect that children with severe emotional disabilities are different in one state than they are in another. The Family Caregiver Model suggests a complex process whereby community factors may influence coping strategies, perceptions of the problem, and both the availability and use of services. North Carolina has adequate variation in these community factors, providing us a fertile site in which to test the model. North Carolina best optimizes the availability of the population needed to test the model and assures us a variation of the other critical independent variables to test the model. Since other state definitions of children with emotional problems may vary, the generalizability of our results may be limited.

SAMPLE SELECTION

The identification and recruitment of families for this project required a two stage process. To ensure confidentiality families eligible for inclusion in the study had to be identified and initially contacted by state agencies. Once families agreed to be a part of the study the university-based research team established direct contact for the completion of the questionnaire.

Purposive sampling was used rather than representative sampling for this study. This was because the goal of the study was to examine relationships between critical constructs identified in the Family Caregiver Model. Our interest in sampling then was to obtain adequate variation in the variables of interest. We were not interested in obtaining a representative sample of the population of North Carolina that could be used to describe the characteristics of this population. The procedures used to select the sample are similar to those used by the Research and Training Center of South Florida in a longitudinal study of services to children with emotional disabilities (1989) and by the Beach Center on Families and Disability at the University of Kansas in a national mail survey of families who have a child with a developmental disability (1990). The following sections will describe the sampling frame used for this study and the process used to secure the sample for the Family Caregiver Study.

Sampling Strata. For this study, families recruited were stratified into two groups by age of child having an emotional disability. The groups consisted of families with a child 3-5 years of age and those with a child 6-12. The six and older group were defined as children with emotional disturbances utilizing the North Carolina CASSP definition as cited earlier. Contact with these families was obtained through the cooperation of the local programs.

Since many children are formally identified as having an emotional disorder only after enrollment in school, identification of families in the three to five age group was more difficult. With the recent passage of P.L. 99-457, Amendments to the Education of Handicapped Act of 1986, each state had to develop a policy to provide appropriate early intervention services to all preschoolers with disabilities. This includes a definition of "developmentally delayed" that is to be used in targeting services and a comprehensive system for locating children. By using a state where such a definition was operative, the study was able to construct a sample of families with a child three to five years of age. In North Carolina the definition of Atypical Developmental Delay included children with emotional problems. Contact with these families was also obtained through the cooperation of community mental health centers that were providing early intervention services.

Phase I- Regional Solicitation The first phase of the recruitment of families began with the identification of area mental health programs in North Carolina that would give us the diversity in service and population characteristics needed to adequately test the Family Caregiver Model. The criteria used to determine which area programs would be invited to participate were : (1) population diversity (primarily race and urban/rural); (2) community service diversity; (3) identification of children in the 3-5 age group; and (4) a willingness to participate. In consultation with the Chief of Children's Mental Health Services in the Division of Mental Health, Mental Retardation and Substance Abuse in North Carolina, the project staff initially selected 7 area mental health programs in three regions of the state to be asked to participate. These seven programs covered 17 counties.

Mental health services in North Carolina are provided by state and local programs. The state is divided into four regions, with state staff located in regional offices to provide technical assistance and to monitor fiscal and programmatic functions of local programs. Each regional office initially had a child and adolescent specialist who provided staff support to the local area programs. The mental health service system is further divided into 41 catchment areas. These local community-based service centers serve the state's 100 counties. Each area program has staff designated as children and youth specialists who provide services to the families of children with emotional problems.

The second step of this phase of selection of the sample was to establish contact and support from the regional child specialist in the four regions of the state. This was accomplished by sending each of them a packet of information describing the project and a request for them to compose a letter of support to the area programs in their region. Follow up phone calls were made to the regional specialists by project staff to answer any questions they had and to secure their support. Because the regional specialists had direct contact with the local agency children and youth specialists, they were asked to apprise them of the study and tell them they had been selected to participate. The regional specialists were also asked to nominate other area programs in their region that met the criteria to be included in the sample.

Phase II - Agency Solicitation. Once letters of support were received from the regional specialists, the project staff sent out packets of information to the area mental health programs. The packets included the letter of support from the regional coordinator, a letter describing the project, an overview of the project and definition of the population criteria to be included in the sample, a list of the procedures the agency would follow and a model letter of support for the area specialist to use in writing a letter that would be sent to families inviting them to participate in the study.

A follow up phone call to the agency's children and youth specialist was made to answer any questions they had and secure their agreement to participate. In addition to the initial 7 area programs identified in Phase I, 6 other area programs were recommended to be included in the project and 10 agreed to participate.

The decision as to who should be included in the sample was simplified by the fact that the State Department of MH/DD/SAS had implemented a management information system that defined severity of disability for three categories. This system, referred to as the "Pioneer Project", was established in 1987 and was implemented in 17 od the 41 catchment areas at the time of this study. For those programs involved in the study that were a part of the Pioneer Project, all of the children identified as Level I or Level II were to be included in the sample. Level I and Level II categorizes clients who are the most severe. The Pioneer criteria were based on the state CASSP definition of severe emotional disturbance and the definition of Atypical Developmental Delay. Of the 10 area centers who agreed to participate in the study 7 were on the Pioneer System. For the other 3 centers the Division of Data Processing in the central office agreed to produce a list of those children served from that area that would meet the Pioneer criteria utilizing a computer mapping including the primary diagnosis. These list of clients were sent to the area specialists to be used in pulling the population to be included in the sample.

To ensure confidentiality the agency was asked to send the family solicitation packets directly to the identified families. The specialist was asked to write a letter of support on agency letterhead that would be included in the packet sent to families. The project staff assembled the family solicitation packet and returned them to the agency for mail labeling. The family solicitation packet included: (1) a letter of support from the agency; (2) letter describing the project; and (3) a return card if they were willing to participate. Following the suggestions of Dillman (1978) on conducting mail surveys, the agency was asked to send out a reminder letter to all potential participants one week later. To ensure that the agency would not know which families agreed to participate, the caregiver was asked to return the agreement to participate card directly to the project staff at the University of Kansas.

Approximately 1800 family solicitation packets were sent to families in 18 counties covered by the 10 mental health area programs that agreed to participate. About one-fourth returned the agreement cards indicating a willingness to participate in the study. Of these, 108 were screened out due to age of the child. Fourteen families returned two cards for different children in the family; a decision was made to complete only one questionnaire for each family. Ultimately, questionnaires were mailed to 335 families.

Phase III - Family Participation. By completing the card agreeing to participate in the study, the caregiver released their name to the project and allowed us to establish direct contact with them. After receiving the post card, project staff assigned an I.D. number to the family and mailed them a survey packet. The survey packet included: (1) a letter thanking them for responding; (2) the survey; (3) informed consent form, approved by the University of Kansas Human Subjects Review Committee; (4) an information statement to sign to receive $10 for participating; and (5) separate return envelopes for the survey and the consent forms. A total of 335 survey packets were sent to families who had volunteered to participate in the study. Seventy-seven percent of the surveys (N=258) were completed and processed. The majority of these (N=218) are for the older 6 to 12 age cohort.

Sample Size. The size of the sample was dictated by the research questions. In order to complete the planned analysis which called for structural equation modeling with the older cohort, a target sample size of 400 respondents was desired - 100 in the 3-5 age group and 300 in the 6-12 age group. Following the suggestions of Dillman (1978) for mail surveys, decisions were made regarding the number of solicitation letters necessary to yield the expected number of respondents. According to Dillman, 19-27% of those receiving the initial solicitation letter would request a copy of the survey, another 15-25% would respond after a reminder mailing. A minimum of 60% of those who agree to participate could be estimated to respond to the mailed survey. This return rate can be enhanced to 70-75% if other incentives and follow-up strategies are used. In this study caregivers were paid $10 as an incentive to fill out the survey. Followup phone calls were made to persons who had agreed to participate but had not returned the survey after a second reminder mailing.

As noted above, in this study only 26 percent of those who received the two mailings of the solicitation letter requested a survey. This response rate was considerably below the 30 to 50 percent rate that one could normally expect. Concerns with minimizing on-site work to help gain agency cooperation and the desire to assure that respondents would not be known to the agency dictated the decision to have families respond directly to the University research offices in Kansas. In retrospect we may have done better if the return had gone to an address in North Carolina. On the other hand, our survey return rate of 77 percent of those who agreed to participate is quite good.

Summary of Sample Selection. Purposive sampling was utilized in this study to maximize the diversity needed to test the Family Caregiver model. Participants were stratified into two groups by age of the child with emotional problems, using uniform definitions established by the North Carolina CASSP project. Agencies that agreed to participate in the study used uniform identification procedures to ensure that all caregivers whose children met the definitional criteria would receive an invitation to participate in the study. Procedures were employed that ensured confidentiality of the families by having the agencies send out the solicitation packets. The project established a relationship with the caregiver only after the family member sent the project the request to be sent a survey. Follow up efforts were made to guarantee that participants completed the survey, even though families were permitted to withdraw from the study at any time.

DATA COLLECTION

The project obtained data from two primary sources. The primary data collection activity involved a mail survey with primary caregivers of children with emotional disabilities. In an effort to reduce the amount of data on the child requested in the survey, additional data was collected from the North Carolina management information system (MIS) on all children in the study. A separate data collection effort was made to obtain community and service characteristics from the communities in which the families resided. The following sections will describe these data collection efforts.

Caregivers. Once the caregiver released their name to the project by sending in the card indicating their willingness to participate, the researchers sent the caregiver a survey packet. Included in the packet was the North Carolina Family Caregiver questionnaire (See Appendix B). The caregiver was asked to take time to fill out the questionnaire entirely and return it to the project in a postage paid return envelope. They were instructed to contact the researchers if they had any questions.

To increase the response rate of participants the project followed the guidelines of the "Total Design Method" outlined by Dillman (1978). If the completed survey was not received by the project in two weeks a reminder post card was sent to the caregiver. If we still did not receive the survey, a phone call was made to the family and an offer to fill out the survey over the phone was made. A total of 335 surveys were mailed. 272 questionnaires (81 percent) were ultimately completed and returned. While followup phone calls were made to complete parts of several questionnaires or to clarify answers, no subjects asked to complete the questionnaire by phone. Fourteen questionnaires were not processed because the subjects' age was older than 12 at the time of the survey.

The North Carolina Family Caregiver questionnaire addressed a number of variables in the Family Caregiver Model. The survey was made up of a number of scales previously tested, plus demographic information on the child and caregiver. Scales were used to gather information on the caregivers perception of and coping with their child's disability, and family and social supports available to and used by the caregiver. The survey also included questions regarding the services utilized by their child, the caregiver's relationship with professionals, the caregiver's level of stress, the child's behavior, and demographics on the child and the family.

The questionnaire was formatted in such a way as to make it easy for the caregiver to fill out, with clear instructions on each section. The survey was 22 pages long and took about one hour to complete. There was a section at the end of the survey for the caregiver to write any general comments about raising a child with emotional problems.

To ensure anonymity, the caregiver was asked to return the completed survey in a separate envelope from the consent form and the reimbursement form. The survey was assigned an identification number by the researchers before it was sent out. This number corresponded to the family ID number assigned when the agreement card was initially returned to the project.

Once the survey was returned the project staff sent the caregiver a thank you letter, a copy of the consent form and $10 for participating. If the caregiver asked questions in the survey regarding resources or services, a handwritten note was sent, directing the caregiver to contact the children and youth specialist in their area. Completed questionnaires were keyed for computer processing by project staff.

MIS Data. To reduce the amount of information on the child in the survey, the project secured data on each child from the management information system (MIS) in the state Department of Mental Health, Developmental Disabilities and Substance Abuse Services (MH/DD/SAS). These data are standard information submitted on all clients served in the North Carolina mental health system. The researchers compiled a list of identification numbers for each child with a completed survey and submitted the list on disk to the Division of Data Processing in North Carolina. This file was matched against the MIS file and an extract file of survey subjects was created.

The information in the North Carolina management information system included the following data on each child:

- Diagnosis
- Program tracking data
- Level of severity of the disability
- North Carolina Functional Assessment Scale
- Services utilized

These data were merged with survey data for analyses.

Community data. A major set of variables in the Family Caregiver Model includes information regarding the community and services available to children with emotional problems and their families. To secure these community data the researchers obtained information about each region, mental health catchment area and county in the study. The data came from a number of different sources and covered a number of variables. Figure 6 lists the data obtained and their sources. Using the county of residence for each survey participant, regional, area and county data were attached to each case record.

Summary of Data Collection Process. To fully test the Family Caregiver Model the project obtained data from two primary sources. Through the use of a mail questionnaire, the Family Caregiver Survey, data were obtained on a number of variables related to the child and the family. These data were augmented by data from the North Carolina MIS, which included other descriptors of the child. The second major data collection effort involved obtaining information on demographics and service characteristics from communities in which the families reside. This effort utilized existing data bases including census data, state reports and studies conducted by other researchers. Once the data were obtained from all three of these sources, it was merged into a single data file to support analyses related to the Family Caregiver Model.

DATA ANALYSIS

The analysis presented here in the technical report is limited to descriptive statistics. Appendix A presents descriptive statistics for all questionnaire items and scale scores. Frequency distributions are presented for categorical variables and means and standard deviations are presented for continuous variables. All results are presented for both sample strata (3-5 year olds and 6-12 year olds) separately. These findings are presented in the same order as the items appear in the questionnaire (see Appendix B) to facilitate interpretation.

The use of standardized tests within the survey instrument allows some comparisons of this sample with other normative samples and samples of families of children with other disabilities. These comparisons are provided in the following section. The major focus for future planned analyses will be the relationships between various constructs, leading ultimately to a test of the full Family Caregiving Model. Planned statistical procedures include confirmatory factor analysis and covariance structure analysis as well as more traditional mean comparison and regression procedures.

Figure 6. Community Variables and Sources

REGIONAL DATA	**SOURCE**
▸ number of children with SED ages 6-12 (receive diagnostic and treatment services)	Statewide Assessment of Unmet Service Needs for Seriously Emotionally Disturbed Youth, Ages 6-12, 1988-1989
▸ children presenting as emergencies	Statewide Assessment of Unmet Service Needs for Seriously Emotionally Disturbed Youth, Ages 6-12, 1988-1989
▸ Children in need of specific services: family preservation day treatment therapeutic home/foster care group home hospitalization	Statewide Assessment of Unmet Service Needs for Seriously Emotionally Disturbed Youth, Ages 6-12, 1988-1989

MENTAL HEALTH CATCHMENT AREA DATA	**SOURCE**
▸ services available: family preservation youthful sex offender demonstration site homeless youth demonstration site UNC training development site day treatment case management CASSP site Robert Wood Johnson site Ft. Bragg demonstration outpatient mental health	Child Mental Health Services in NC
▸ number of children served	North Carolina Area Programs Annual Statistical Report, 1990

COUNTY DATA	**SOURCE**
▸ childhood population 1990	NC Child Advocacy Institute Fact Sheet
▸ children in single-parent families 1980	NC Child Advocacy Institute Fact Sheet
▸ working mothers with children under 6	NC Child Advocacy Institute Fact Sheet
▸ adult illiteracy	NC Child Advocacy Institute Fact Sheet
▸ median family income 1986	NC Child Advocacy Institute Fact Sheet

▶ children living in poverty 1986	NC Child Advocacy Institute Fact Sheet
▶ children receiving food stamps 1987	NC Child Advocacy Institute Fact Sheet
▶ children receiving AFDC 1987	NC Child Advocacy Institute Fact Sheet
▶ children on child care waiting list 1990	NC Child Advocacy Institute Fact Sheet
▶ teenage births 1989	NC Child Advocacy Institute Fact Sheet
▶ infant mortality 1989	NC Child Advocacy Institute Fact Sheet
▶ inadequate prenatal care 1986	NC Child Advocacy Institute Fact Sheet
▶ children receiving Medicaid 1986	NC Child Advocacy Institute Fact Sheet
▶ at-risk population receiving WIC 1987	NC Child Advocacy Institute Fact Sheet
▶ low-birth weight 1989	NC Child Advocacy Institute Fact Sheet
▶ children reported abused/neglected 1990	NC Child Advocacy Institute Fact Sheet
▶ children confirmed abused/neglected 1990	NC Child Advocacy Institute Fact Sheet
▶ children in out-of-home placement 1990	NC Child Advocacy Institute Fact Sheet
▶ per-pupil spending 1986	NC Child Advocacy Institute Fact Sheet
▶ high school dropouts 1986	NC Child Advocacy Institute Fact Sheet
▶ arrests of children age 15 and under 1989	NC Child Advocacy Institute Fact Sheet
▶ youth in training schools 1990	NC Child Advocacy Institute Fact Sheet
▶ youth in detention centers 1990	NC Child Advocacy Institute Fact Sheet
▶ population	NC Population Projections: 1988-2010
▶ population by race and sex	NC Population Projections: 1988-2010
▶ age distribution	NC Population Projections: 1988-2010

North Carolina Projections: 1988-2010 prepared by the North Carolina Office of State Budget and Management, Management and Information Services

Child Mental Health Services in North Carolina prepared by the North Carolina Department of Human Resources, Division of Mental Health, Developmental Disabilities, and Substance Abuse Services, Mental Health Section, Child and Family Services Branch

Statewide Assessment of Unmet Service Needs for Seriously Emotionally Disturbed Youth, ages 6-12, 1988-1989 prepared by the North Carolina Department of Human Resources, Division of MH/MR/SAS, Office of Child and Family Services, September 1989

North Carolina Area Programs Annual Statistical Report prepared by Brenda Dillard, North Carolina Division of Mental Health, Developmental Disabilities and Substance Abuse Services

FINDINGS

DEMOGRAPHIC CHARACTERISTICS

The sample consists of 40 children, age 3 to 5, and 218 children, age 6 to 12. The younger group splits evenly between males and females while two-thirds of the older group consists of males. Almost all of the children (94 percent) were living at home at the time of the survey.

In almost all cases (90 percent of the younger group and 81 percent of the older group), the respondent to the survey was the mother of the designated child. Only 12 fathers completed surveys. The majority of the families had other children in addition to the study child (78 percent for the younger group and 86 percent of the older group). Approximately half of the families were headed by a married couple while one-third were divorced or separated single parents. Approximately half of the families reported that they lived in a small or large city (population of 25,000 or more), while one- quarter lived in small towns (population of 2,500 or less) or rural areas. While the majority of respondents reported their racial or ethnic identification as "White," almost one-third of respondents for the older group identified themselves as "Black."

More than 20 percent of the respondents had not graduated from high school. While 23 percent of the respondents for the younger group had graduated from college, only 8 percent of the older group had a college degree. Over 40 percent of the respondents were employed full-time while slightly more than half of the respondents' partners were employed full-time. One-third of the respondents reported gross household annual income below $10,000.

These findings suggest that this sample of parents may be considerably different than those responding to many past surveys in that they are more representative of lower income and minority families than is usually the case. We attribute these differences to the methodologies used in this and other studies. Other studies have relied heavily on parent support groups for identifying possible participants. White, middle-class families tend to be over-represented in these groups. The methodology employed here identified families receiving services through public agencies which are likely to serve all types of families and particularly low income families.

SEVERITY OF THE CHILD'S DISABILITY

The nature and severity of the child's emotional disability was measured using the Achenbach Child Behavior Checklist (CBCL) (Achenbach, 1991). The CBCL provides normative data by age and gender. Table 1 shows scale scores for our sample of children with emotional disabilities and scores for comparable age normative samples provided by Achenbach (1991). Table 2 provides a comparison of our sample with two criterion groups used by Achenbach to test the validity of the CBCL. The two criterion groups consist of children referred for mental health services and demographically matched nonreferred children. The referred sample includes children referred for mental health services or participating in special education classes for behavioral/emotional problems. Age ranges for the different samples

TABLE 1. CHILD BEHAVIOR CHECKLIST MEAN SCORES STUDY VS. NORMATIVE SAMPLES

		Normative Sample		Study Sample	
Competence Scales		Boys 6-11	Girls 6-11	Boys 6-12	Girls 6-12
	N=	458	488	146	71
Activities		6.4	6.4	5.8	5.9
SD		1.7	1.8	1.8	2.0
Social		6.9	6.9	5.0	5.7
SD		2.0	2.0	2.2	2.1
School		5.1	5.3	3.0	3.8
SD		.9	.8	1.3	1.3
Total Competence		18.6	18.7	13.8	15.8
SD		3.3	3.6	3.6	3.8
Problem Scales		Boys 4-11	Girls 4-11	Boys 6-12	Girls 6-12
	N=	581	619	146	71
Withdrawn		1.8	2.0	5.3	5.0
SD		1.8	2.0	3.4	3.6
Somatic Complaints		.8	1.0	3.4	3.9
SD		1.3	1.6	3.3	3.5
Anxious/Depressed		3.1	3.4	9.7	9.3
SD		3.1	3.3	5.1	6.3
Social Problems		2.0	1.9	6.4	5.3
SD		1.9	1.7	3.0	3.3
Thought Problems		.5	.5	3.0	2.1
SD		.9	1.0	2.6	2.0
Attention Problems		3.3	2.5	10.3	8.1
SD		2.8	2.5	4.4	5.2
Delinquent Behavior		1.6	1.2	6.5	4.2
SD		1.7	1.4	4.6	2.9
Agressive Behavior		8.2	7.0	21.1	16.3
SD		5.8	5.2	7.6	9.0
Sex Problems		.1	.2		
SD		.5	.5		
Internalizing		5.6	6.3	17.6	17.4
SD		4.7	5.5	9.6	10.9
Externalizing		9.8	8.2	27.6	20.5
SD		7.1	6.1	11.0	11.2
Total Problems		24.3	23.1	76.3	64.7
SD		15.6	15.5	29.9	33.3

TABLE 2. CHILD BEHAVIOR CHECKLIST MEAN SCORES STUDY VS. REFERRED AND NONREFERRED SAMPLES

	A		B		C	
	Referred Sample		Nonreferred Sample		Study Sample	
	Boys 4-11	Girls 4-11	Boys 4-11	Girls 4-11	Boys 4-11	Girls 4-11
N=	582	619	582	619	136	82
Competence Scales						
Activities	5.9	5.6	6.4	6.4	5.6	5.8
SD	1.8	1.8	1.7	1.8	2.0	2.1
Social	5.0	5.1	6.9	6.9	5.0	5.5
SD	2.1	2.1	2.0	2.1	2.1	2.2
School	3.4	3.8	5.1	5.3	3.2	3.9
SD	1.3	1.3	.9	.8	1.2	1.3
Total Competence	14.5	14.6	18.5	18.7	13.8	15.9
SD	3.6	3.8	3.3	3.6	3.5	3.8
Problem Scales						
Withdrawn	4.1	4.6	1.8	2.0	5.1	4.4
SD	3.3	3.4	1.9	2.0	3.4	3.2
Somatic	1.7	2.3	.8	1.0	3.0	2.9
SD	2.2	2.8	1.3	1.6	3.2	3.0
Anxious/Depressed	7.9	8.5	3.1	3.4	9.2	8.4
SD	5.8	5.6	3.1	3.3	5.6	6.1
Social Problems	4.7	4.9	2.0	1.9	6.3	5.0
SD	3.0	3.2	1.9	1.7	2.8	3.1
Thought Problems	1.9	1.8	.5	.5	3.1	2.2
SD	2.0	2.1	.9	1.0	2.7	2.2
Attention Problems	8.2	7.3	3.3	2.5	10.1	7.8
SD	4.4	4.6	2.8	2.5	4.6	5.0
Delinquent Behavior	4.3	3.3	1.6	1.2	6.2	4.2
SD	3.3	3.1	1.7	1.4	4.3	3.2
Aggressive Behavior	16.6	14.2	8.2	7.0	21.7	16.9
SD	8.8	8.7	5.8	5.2	8.0	8.6
Sex Problems	.5	.6	.1	.2		
SD	1.1	1.2	.5	.5		
Internalizing	13.1	14.6	5.5	6.3	27.9	15.4
SD	8.7	9.2	4.7	5.5	10.1	10.1
Externalizing	20.9	17.5	9.8	8.2	27.9	21.1
SD	11.3	11.1	7.0	6.1	11.2	11.2
Total Problems	54.5	52.1	24.2	23.1	76.1	63.3
SD	26.6	27.3	15.6	15.5	30.4	31.0

described in Table 1 differ because of inconsistencies and changes in Achenbach's reports. In the text of the most recent CBCL manual, normative competency scores are reported for 6 to 11 year olds. The author reports that competence scales are not scored for 4-5-year olds because children of these ages are seldom in school situations, where academic competence is evaluated and that other competence scales were not found to discriminate well between referred and nonreferred 4 and 5 year-old children (Achenbach, 1991, p. 30). Nevertheless, these scales are reported in an appendix for 4 to 11 year old children both referred and nonreferred. Problem scales are reported by Achenbach for referred and nonreferred children ages 4 to 11. In designing our stratified sample, our study anticipated age group differences between preschoolers and grade school children. Thus strata were defined as 3-5 year-olds and 6-12 year-olds. In Table 2, we have reconstructed our samples to more closely conform with the comparison samples provided by Achenbach.

A comparison of referred and nonreferred samples shown in Table 2, columns A and B, reveals large differences with the nonreferred group having higher competence scores and lower problem scores for all scales. These results, as described by Achenbach, provide support for the validity of the CBCL. Similarly, Table 1 shows our sample of children known to the public mental health system as having significantly lower competencies and higher problem scores. All comparisons of the study sample to the normative samples in Tables 1 and 2 (boys to boys and girls to girls) are statistically significant. In addition, a comparison of our sample with the referred sample (Table 2, columns A and C) reveals our sample of boys to have lower total competency scores and higher problem scores on each subscale and summative scale (Internalizing, Externalizing and Total Problems). Our sample of girls are more nearly identical to Achenbach's sample of referred girls. The study sample of girls, however, scores significantly higher on delinquent and aggressive problem behaviors resulting in significantly higher summative scale scores for Externalizing and Total Problems.

PERCEPTION OF POSITIVE CONTRIBUTION

The very idea that children with disabilities might have a positive rather than just a negative impact on their families is relatively new in the field and little research has been done in this area. Fortunately, researchers at the University of Kansas, Beach Center on Families and Disability, have done considerable work in developing measurement tools which incorporate this strengths perspective. The current study utilized the Positive Contribution test (Behr, Murphy and Summers, 1992) to measure the parents perception regarding the positive contribution of their child to the parent's life and development.

Earlier work by Summers, Behr and Murphy (1990) permitted comparisons of our sample with a sample of parents with children with various different disabilities (primarily developmental disabilities) and a non-disability sample. Results from this comparison on the nine Positive Contribution Subscales are shown in Table 3. Higher mean scores indicate greater agreement with the positive statement.

In general the scores for our sample of parents of children with an emotional disability fall between the scores for the general disability and non-disability groups. Compared to children with some disability, children without a disability are more likely to be perceived as a source of: happiness and fulfillment, expanded social network and awareness of future issues. On

TABLE 3. CROSS SAMPLE COMPARISONS ON THE POSITIVE CONTRIBUTIONS SCALES

	Group[1]			
	A	B	C	
Scale	Disability	Non-Dis	Emotional	Sig. Dif.
Source of Pride and Cooperation	3.333	2.642	2.573	A-B, A-C
	.587	.529	.562	
	n=58	n=57	n=259	
Source of Strength and Family Closeness	3.073	3.103	3.117	
	.497	.428	.462	
	n=57	n=58	n=259	
Source of Happiness and Fulfillment	3.144	3.552	3.110	A-B, C-B
	.516	.428	.527	
	n=58	n=58	n=258	
Source of Personal Growth and Maturity	2.572	2.778	2.835	A-B, A-C
	.600	.462	.537	
	n=59	n=58	n=259	
Source of Learning through Experience with Special Problems in Life	3.324	2.612	3.004	A-B, A-C
	.389	.461	.475	
	n=54	n=47	n=259	
Source of Career/Job Growth	2.390	2.677	2.534	A-B
	.596	.498	.581	
	n=57	n=58	n=252	
Source of Expanded Social Network	2.421	2.954	2.570	A-B, C-B
	.678	.517	.557	
	n=58	n=57	n=259	
Source of Awareness about Future Issues	2.898	3.216	2.974	A-B, C-B
	.555	.494	.528	
	n=59	n=57	n=254	
Source of Understanding of Life's Purpose	2.918	2.825	3.159	C-B
	.474	.594	.513	
		n=57	n=259	

[1] Data for the general disability and non-disability samples are from Summers, J.A., Behr, S.K. & Murphy, D.L. (1990). *The family perceptions research project -- Final report.* Lawrence, KS: Institute for Lifespan Studies, Beach Center on Families and Disability, University of Kansas.

the other hand, parents of children with some type of disability are more likely to perceive their children as a source of "learning through experience with special problems in life" and parents of children with an emotional disability are more likely than parents with a child with no disability to perceive their child as a source of "understanding life's purpose." Parents of children with an emotional disability were more likely to agree that their child was a source of "pride and cooperation," "personal growth and maturity," and "learning through experience," than were parents of children with other types of disabilities.

COPING PATTERNS

Table 4 provides a comparison of the coping patterns of caregivers of children with severe emotional disabilities (study sample) with the coping patterns of mothers who have a chronically ill child (normative sample) and those of mothers of children with cerebral palsy. The comparison data are provided by McCubbin and Thompson (1987) who view the data on families with children who have a chronically ill child as normative data. The data on low and high conflict families with children with cerebral palsy was provided as a validity check in the testing of the instrument by McCubbin.

Higher scores on the coping scales are indicative of greater use of the coping pattern. It can be seen that, in high conflict families, mothers use of all three coping patterns was significantly higher than in low conflict families ($p \leq .05$ for all three scales). McCubbin and Thompson maintain that this is consistent with their theoretical understanding of coping in that "coping behaviors are developed in response to stressful situations and high conflict in a family is one index of family stress" (p.178- 179). Following this logic, it would appear that caregivers in families with children with severe emotional disabilities are experiencing even greater stress than are high conflict families of children with cerebral palsy. They are significantly more likely to use all three patterns of coping than are any of the three comparison groups, including the "high conflict" group. The study sample is particularly more likely to attempt to gain an understanding of their child's problem by talking with professionals and other parents.

TABLE 4. COMPARISONS OF COPING PATTERNS

Coping Scales	Low Conflict Families N≈105[1]	High Conflict Families N≈105[1]	Normative Sample N=308	Study Families N=258
Integration, Cooperation, Optimism	36.3	42.8	40	47.3***
SD	19.4	10.4	15	7.4
Support, Esteem, Stability	24.0	30.9	28	38.7***
SD				
Medical Communication and Consultation	13.7	15.8	15	24.2***
SD	8.0	5.1	7	6.0

[1] McCubbin and Thompson (1987) do not provide sample sizes for the low and high conflict families with children with cerebral palsy. The N's provided here are estimates based on the assumption of equal numbers in each group.

***$P \leq .001$ for comparisons of study sample with all other samples.

RELATIVE AND SOCIAL SUPPORTS

The use of informal supports is critical to understanding the family caregiving process. Two subscales of the Family Index of Regenerativity and Adaptation - General (FIRA-G) (McCubbin, 1987) were included in the survey instrument. The dimensions measured are "Relative and Friend Support" and "Social Support." Scale scores for these two scales for the study subjects and for a normative sample of families with preschool and schoolage children are presented in Table 5. Scores on the "Relative and Friend Support" scale are nearly identical for the two samples, however, the sample of caregivers of children with serious emotional disabilities has significantly lower reported social supports.

TABLE 5. COMPARISONS OF RELATIVE AND SOCIAL SUPPORTS

Scale	Normative Sample	Study Sample
Relative and Friend Support	25.0	25.9
SD	6.0	5.7
N=	1000	258
Social Support	45.3	39.1 ***
SD	7.5	6.7
N=	1036	258

*** $p \leq .001$

Use of Formal Supports

Scales for measuring the parent's experience with the formal support system were adapted from an instrument developed by the Portland Research and Training Center. These instruments do not provide normative data and have not been widely used elsewhere and will be most useful in exploring the impact of formal support experiences on the mediating process and adaptational outcomes of family caregiving.

On the surface, the Professional Collaboration Items (p. A-43,44) suggest moderate levels of collaboration with professionals. The major exception to this is the area of cultural and ethnic awareness and competency which appears to receive little attention by professionals in the judgment of the respondents.

Caregiver Stress

The primary outcome measure for this study is caregiver stress as reported by the primary caregiver for the child. This measure was operationalized using a version of the Preventive Measures' Quick Stress Inventory (Press, 1990). The inventory uses a set of 13 items addressing different areas of a person's life (e.g., job, home and family, social life). The respondent is asked to rate their stress, ability to handle responsibilities, and amount of pleasure experienced in each area. Item scores are summed to produce three scale scores for each respondent (i.e. stress, responsibility, and pleasure). Item and scale scores can be found in Appendix A (pp. A-48 to A-56).

Average response scores indicate that respondents experience some to moderate stress in all areas. The highest stress areas are "home and family" and "children," while the lowest reported stress areas are "social life," "pleasurable activities (music, movies, hobbies, etc.)," "your physical appearance," and "your physical health." Parents of preschool children consistently reported higher stress levels, however, these differences are not statistically significant.

With regard to handling their responsibilities in each of these life areas, caregivers generally reported doing "well." Areas caregivers felt they were handling more poorly included "the way you feel about yourself," "keeping weight at appropriate level," "managing time," and "taking care of your physical health." Interestingly, caregivers felt that they were doing a better job at handling responsibilities for their children and for their home and family. Those who had jobs also tended to report that they were doing "very well" at handling those responsibilities.

Caregivers reported that they derived the most pleasure from their children and considerably less from their jobs, physical appearance, weight, and ability to manage time.

Normative data was provided by Press on some common scale items for a sample of 1761 women between the ages of 20 and 54. Caregivers of children with severe emotional disabilities reported significantly higher stress levels than this normative sample with respect to job, marriage or primary relationship, and other family relationships. No differences were found with respect to physical health, social life, physical appearance and time management. Caregivers were less dissatisfied about their weight.

Compared with a group of 325 women employed primarily at white-collar jobs with several different small companies, the caregivers were less stressed about their jobs, but more stressed about their marriage or primary relationship, other family relationships, social life, feelings about themselves, physical health, and life in general. No differences were found with respect to fun from pleasurable activities or time management.

Finally, we were able to compare our predominantly female caregivers with a sample of 115 female college students, a group generally considered to be under high stress. The caregivers reported higher stress levels in five areas: marriage or primary relationship, other family relationships, fun from pleasurable activities, physical health, and life in general. The students reported higher levels in only two areas, job (or lack thereof) and time management. There were no differences with regard to social life and how they felt about themselves.

SUMMARY AND CONCLUSIONS

The primary purpose of this technical report is to provide detailed documentation and description of the process and procedures used in conducting a large and intensive survey of families of children with severe emotional disabilities. Findings are limited to descriptive statistics for the sample which is compared to normative data and other samples when these comparative data are available.

The sample consists of 258 caregivers of children ages 3 to 12 who were known to the public mental health system in North Carolina. The respondents are primarily the mothers of the children who were living in their homes at the time of the survey. The sample appears somewhat unique in that low income, rural, and minority families are well represented. The children involved in the survey appear to suffer from very serious emotional and behavioral problems. This is particularly true for the boys, however, the girls appear to have problem behaviors which are as severe as other clinical samples in most areas and more severe with respect to delinquent and aggressive behaviors. The families appear to be socially isolated and under a great deal of stress, even more than other comparative high stress groups.

The data collection process used in this study was guided by a comprehensive model of family caregiving. Future planned analyses will focus on this model in an attempt to gain a better understanding of how families can be supported in carrying out their caregiver roles. The findings reported here suggest that this sample will provide fertile ground for exploration of this model.

REFERENCES

Abbott, D. & Meredith, W. (1986). Strengths of parents with retarded children. *Family Relations, 35*, 371-375.

Administration for Developmental Disabilities (1981). *Special report on the impact of the change in the definition of developmental disabilities*. Washington, DC: Department of Health and Human Services.

Anderson, J. (1981). The social construction of illness experience: Families with a chronically-ill child. *Journal of Advanced Nursing, 6*, 427-434.

Barsch, R. (1964). The handicapped ranking scale among parents of handicapped children. *American Journal of Public Health, 54*, 1560-1567.

Beckman, P. (1983). Characteristics of handicapped infants: A study of the relationship between characteristics and stresses as reported by mothers. *American Journal of Mental Deficiency, 88*, 150-156.

Behr, S. (1989). *Underlying dimensions of the construct of positive contributions that individuals with developmental disabilities make to their families: A factor analytic study*. Unpublished doctoral dissertation. Lawrence, KS: The University of Kansas.

Byrne, E. & Cunningham, C. (1985). The effects of mentally handicapped children on families: A conceptual review. *Child Psychology and Psychiatry, 26*(6), 847-864.

Cantwel, D. (1983). Childhood depression: What do we know, where do we go? In Guze, et al (Eds.), *Childhood psychopathology and development.* New York: American Psychopathological Association Series.

Chigier, E. (1972). *Down's Syndrome*. Lexington, MA: D.C. Heath.

Crinic, K., Friedrich, W. & Greenberg, M. (1983). Adaptations of families with mentally retarded children: A model of stress, coping and family ecology. *American Journal of Mental Deficiency, 88*(2), 125-138.

Donavan, A. (1988). Family stress and ways of coping with adolescents who have handicaps: Maternal perceptions. *American Journal on Mental Retardation, 92*(6), 502-509.

Dunlap, W. & Hollinsworth, J. (1977). How does a handicapped child affect the family? Implications for practitioners. *The Family Coordinator, 26*(3), 286-293.

Fairfield, B. (1983). Parents coping with genetically handicapped children: Use of early recollections. *Exceptional Children, 49*(5), 411-415.

Farber, B. (1959). Effects of severely mentally retarded child on family integration. *Monographs of the Society for Research in Child Development.* (Serial No. 71).

Flynt, S. & Wood, T. (1989). Stress and coping of mothers of children with moderate mental retardation. *American Journal on Mental Retardation, 94*,(3), 278-283.

Folkman, S. & Lazarus, R. (1985). If it changes it must be a process: Study of emotion and coping during three stages of college examination. *Journal of Personality and Social Psychology, 48*(1), 150-170

Friedrich, W. (1979). Predictors of the coping behaviors of mothers of handicapped children. *Journal of Consulting and Clinical Psychology, 47.*

Friedrich, W., Greenberg, M. & Crinic, K. (1983). A short-form of the questionnaire on resources and stress. *American Journal of Mental Deficiency, 88*(1), 41-48.

Friedrich, W., Wilturner, L. & Cohen, D. (1985). Coping resources and parenting mentally retarded children. *American Journal of Mental Deficiency, 90*, 130-139.

Friesen, B. (1989). National study of parents whose children have serious emotional disorders. In A. Algain, R. Friedman, A. Dochnowski, K. Kutash, S. Silver & M. Johnson (Eds.), *Children's mental health services and policy: Building a research base.* Tampa, FL: University of South Florida Research and Training Center for Children's Mental Health, Florida Mental Health Institute.

Gallagher, J., Beckman, P. & Cross, A. (1983). Families of handicapped children: Sources of stress and its amelioration. *Exceptional Children, 50*(1), 10-17.

Gould, M., Wunsch-Hitgzig, R. & Dohrenwend, B. (1981). Estimating the prevalence of childhood psychopathology. *American Academic of Child Psychiatry, 20*, 462-476.

Hill, R. (1949). *Families under stress.* New York: Harper and Row.

Hill, R. (1958). Generic features of families under stress. *Social Casework, 49*, 139-150.

Hobbs, N. (1975). *The futures of children.* San Francisco: Jossey-Bass Publishers.

Joint Commission on the Mental Health of Children (1970). *Crisis in child mental health: Challenge for the 1970's.* New York: Harper and Row.

Knafl, K. & Deatrick, J. (1987). Conceptualizing family response to a child's chronic illness or disability. *Family Relations, 36*, 300-304.

Knitzer, J. (1982). *Unclaimed children.* Washington, DC: Children's Defense Fund.

Lazarus, R. (1966). *Psychological stress and the coping process.* New York: McGraw-Hill.

Lazarus, R., Delongis, A., Folkman, S. & Gruen, R. (1985). Stress and adaptational outcomes: The problem of confounded measures. *American Psychologist, 40*(7), 770-779.

Lazarus, R. & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer Publishers Co.

Lazarus, R. & Folkman, S. (1987). Transactional theory and research on emotion & coping. *European Journal Of Personality, 1*, 141-169.

Levinson, R. (1975). *Family crisis and adaptation coping with a mentally retarded child*. Unpublished doctoral dissertation, University of Wisconsin, Madison, WI.

Looney, J. (1988). *Chronic mental illness in children and adolescents*. Washington, DC: American Psychiatric Press.

McCubbin, H. (1979). Integrating coping behavior in family stress theory. *Journal of Marriage and the Family, 41*, 237- 244.

McCubbin, H. et. al. (1980). Family stress, coping and social support: A decade review. *Journal of Marriage and the Family, 42*, 855-871.

McCubbin, H. & McCubbin, M. (1987). Family stress theory and assessment: The T-Double ABCX model of family adjustment and adaptation. In H. McCubbin & A. Thompson (Eds.), *Family assessment inventories for research and practice*. Madison, WI: University of Wisconsin-Madison.

McCubbin, H. & Patterson, H. (1981). *Systematic assessment of family stress, resources and coping: Tools for research, education and clinical intervention.* St. Paul, MN: University of Minnesota.

McCubbin, H. & Patterson, J. (1982). Family adaptation to crisis. In H. McCubbin, A. Cauble & J. Patterson (Eds.), *Family stress, coping, and social support* (pp. 26- 47). Springfield, IL: Charles C. Thor as.

McCubbin, H. & Patterson, J. (1983). Family transitions: Adaptation to stress. In H. McCubbin & C. Figley (Eds.), *Stress and the family: Coping with normative transitions, 1*, (pp. 5-25). New York: Brunner/Mazel.

McCubbin, H., Sussman, M. & Patterson, J. (1983). Introduction. In H. McCubbin, M. Sussman & J. Patterson (Eds.), *Social stress and the family: Advances and development in family stress theory and research*, (pp. 1-6). New York: Haworth Press.

McCubbin, H. & Thompson, A. (1987). *Family assessment inventories for research and practice*. Madison, WI: University of Wisconsin-Madison.

McCubbin, M. (1988). Family stress, resources and family types: Chronic illness in children. *Family Relations, 37,* 203-210.

McDonald, T., Donner, R. & Poertner, J. (1992). *Building a conceptual model of family response to a child's chronic illness or disability.* Portland, OR: Portland State University, Research and Training Center on Family Support and Children's Mental Health.

McDonald-Wikler, L. (1986). Family stress theory and research on families of children with mental retardation. In J. Gallagher & P. Vietze (Eds.), *Families of handicapped persons,* (pp. 167-196). Baltimore: Paul H. Bookes.

McKinney, B. & Peterson, R. (1987). Predictors of stress in parents of develop mentally disabled children, *Journal of Pediatric Psychology, 12,* 133-150.

Pedhazur, E. (1982). *Multiple regression in behavioral research.* New York: Holt, Rinehart and Winston.

Pollner, N. & Wikler, L. (1985). The social construction of unreality: A case study of a family's attribution of competence to a severely retarded child. *Family Process, 24,* 241-257.

President's Commission on Mental Health (1978). *Report of the sub-task panel on infants, children and adolescents: Vol. 3.* Washington, DC: U.S. Government Printing Office.

Silver, H. (1988). Scope of the problem in children and adolescents. In Looney, J. (Ed.), *Chronic mental illness in children and adolescents.* Washington, DC: American Psychiatric Press.

Stein, R. & Riessman, C. (1980). The development of an impact-on-family scale: Preliminary findings. *Medical Care, 18*(4), 465-472.

Strober, M., Green, J. & Carlson, G. (1981). Reliability of psychiatric diagnosis in hospitalized adolescents. *Archives of General Psychiatry, 38.*

Turnbull, A., Behr, S. & Tollefson, N. (1986, May). *Positive contributions that persons with mental retardation make to their families.* Paper presented at American Association on Mental Deficiency, Denver, CO.

Vonkrs, M. (1981). Familial coping with chronic and severe childhood illness: The case of coptic fibrosis. *Social Science Medicine, 15*(A), 289-297.

Wikler, L. (1986). Family stress theory and research on families of children with mental retardation. In J. Gallagher & P. Vietze (Eds.), *Families of handicapped persons: Research programs and policy issues,* (pp. 167-197). Baltimore: Brookes.

APPENDIX A

POSITIVE CONTRIBUTION ITEMS

	Mean	Std Dev	# Cases
1. MY CHILD IS WHY I MET SOME OF MY BEST FRIENDS			
3-5 YEARS OLD	1.97	.69	40
6-12 YEARS OLD	2.35	.76	216
2. MY CHILD IS WHY I AM A MORE RESPONSIBLE PERSON			
3-5 YEARS OLD	3.20	.82	40
6-12 YEARS OLD	3.10	.80	218
3. MY CHILD IS THE REASON I'VE LEARNED TO CONTROL MY TEMPER			
3-5 YEARS OLD	2.80	.99	40
6-12 YEARS OLD	2.92	.81	218
4. MY CHILD IS RESPONSIBLE FOR MY LEARNING TO BE PATIENT			
3-5 YEARS OLD	2.76	.87	39
6-12 YEARS OLD	2.90	.79	218
5. MY CHILD IS RESPONSIBLE FOR MY INCREASED AWARENESS OF PEOPLE WITH DISABILITIES			
3-5 YEARS OLD	2.92	.99	40
6-12 YEARS OLD	3.01	.87	216
6. MY CHILD IS FUN TO BE AROUND			
3-5 YEARS OLD	3.23	.77	39
6-12 YEARS OLD	3.12	.68	216
7. MY CHILD IS RESPONSIBLE FOR MY BEING MORE AWARE AND CONCERNED FOR THE FUTURE OF HUMANITY			
3-5 YEARS OLD	3.20	.79	40
6-12 YEARS OLD	3.03	.71	218
8. MY CHILD IS KIND AND LOVING			
3-5 YEARS OLD	3.27	.75	40
6-12 YEARS OLD	3.21	.72	214
9. MY CHILD IS HELPFUL TO OTHER FAMILY MEMBERS, WHICH SAVES TIME AND ENERGY FOR ME			
3-5 YEARS OLD	2.40	.90	40
6-12 YEARS OLD	2.57	.82	214

	Mean	Std Dev	# Cases
10. MY CHILD IS THE REASON I ATTEND RELIGIOUS SERVICES MORE FREQUENTLY			
3-5 YEARS OLD	2.45	.93	40
6-12 YEARS OLD	2.46	.86	215
11. MY CHILD IS THE REASON MY LIFE HAS BETTER STRUCTURE			
3-5 YEARS OLD	2.70	.88	40
6-12 YEARS OLD	2.81	.80	217
12. MY CHILD IS THE REASON I AM MORE REALISTIC ABOUT MY JOB			
3-5 YEARS OLD	2.76	.90	39
6-12 YEARS OLD	2.67	.79	209
13. MY CHILD IS A SOURCE OF PRIDE BECAUSE OF HIS/HER ARTISTIC ACCOMPLISHMENTS			
3-5 YEARS OLD	2.77	.89	40
6-12 YEARS OLD	2.94	.74	217
14. I CONSIDER MY CHILD TO BE HELPFUL WITHOUT HAVING TO BE ASKED			
3-5 YEARS OLD	2.60	.92	40
6-12 YEARS OLD	2.33	.83	218
15. I CONSIDER MY CHILD TO BE WHAT GIVES OUR FAMILY A SENSE OF CONTINUITY -- A SENSE OF HISTORY			
3-5 YEARS OLD	2.47	.81	40
6-12 YEARS OLD	2.63	.71	214
16. I CONSIDER MY CHILD TO BE AN ADVANTAGE TO MY CAREER			
3-5 YEARS OLD	2.15	.83	40
6-12 YEARS OLD	2.30	.72	213
17. I CONSIDER MY CHILD TO BE VERY AFFECTIONATE			
3-5 YEARS OLD	3.15	.62	39
6-12 YEARS OLD	3.14	.76	214
18. I CONSIDER MY CHILD TO BE WHAT MAKES ME REALIZE THE IMPORTANCE OF PLANNING FOR MY FAMILY'S FUTURE			
3-5 YEARS OLD	3.22	.80	40
6-12 YEARS OLD	3.25	.66	217
19. I CONSIDER MY CHILD TO BE A GREAT HELP AROUND THE HOUSE			
3-5 YEARS OLD	2.42	.95	40
6-12 YEARS OLD	2.52	.83	215

	Mean	Std Dev	# Cases
20. I CONSIDER MY CHILD TO BE WHAT GIVES ME COMMON GROUND WITH OTHER PARENTS			
3-5 YEARS OLD	2.70	.85	40
6-12 YEARS OLD	2.82	.74	216
21. I CONSIDER MY CHILD TO BE RESPONSIBLE FOR MY TAKING BETTER CARE OF MYSELF			
3-5 YEARS OLD	2.65	.92	40
6-12 YEARS OLD	2.70	.81	218
22. I CONSIDER MY CHILD TO BE RESPONSIBLE FOR MY INCREASED SENSITIVITY TO PEOPLE			
3-5 YEARS OLD	2.72	.81	40
6-12 YEARS OLD	2.78	.72	217
23. I CONSIDER MY CHILD TO BE THE REASON I AM MORE PRODUCTIVE			
3-5 YEARS OLD	2.66	.80	39
6-12 YEARS OLD	2.66	.75	216
24. I CONSIDER MY CHILD TO BE THE REASON I BUDGET MY TIME BETTER			
3-5 YEARS OLD	2.95	.67	40
6-12 YEARS OLD	2.89	.67	216
25. I CONSIDER MY CHILD TO BE THE REASON I AM ABLE TO COPE BETTER WITH STRESS AND PROBLEMS			
3-5 YEARS OLD	2.42	1.08	40
6-12 YEARS OLD	2.60	.88	215
26. I CONSIDER MY CHILD TO BE ABLE TO USE GOOD JUDGMENT			
3-5 YEARS OLD	2.32	.94	40
6-12 YEARS OLD	2.50	.83	217
27. THE PRESENCE OF MY CHILD IS AN INSPIRATION TO IMPROVE MY JOB SKILLS			
3-5 YEARS OLD	2.42	.93	40
6-12 YEARS OLD	2.55	.78	211
28. THE PRESENCE OF MY CHILD HELPS ME UNDERSTAND PEOPLE WHO ARE DIFFERENT			
3-5 YEARS OLD	3.07	.79	40
6-12 YEARS OLD	3.06	.73	218

	Mean	Std Dev	# Cases
29. THE PRESENCE OF MY CHILD CONFIRMS MY FAITH IN GOD			
3-5 YEARS OLD	2.92	.76	40
6-12 YEARS OLD	2.98	.85	218
30. THE PRESENCE OF MY CHILD GIVES A NEW PERSPECTIVE TO MY JOB			
3-5 YEARS OLD	2.62	.80	40
6-12 YEARS OLD	2.62	.76	211
31. THE PRESENCE OF MY CHILD IS A REMINDER THAT ALL CHILDREN, INCLUDING THOSE WITH DISABILITIES, NEED TO BE LOVED			
3-5 YEARS OLD	3.67	.61	40
6-12 YEARS OLD	3.71	.48	218
32. THE PRESENCE OF MY CHILD IS A REMINDER THAT EVERYONE HAS A PURPOSE IN LIFE			
3-5 YEARS OLD	3.52	.71	40
6-12 YEARS OLD	3.47	.63	218
33. THE PRESENCE OF MY CHILD HELPS ME TAKE THINGS AS THEY COME			
3-5 YEARS OLD	3.17	.63	40
6-12 YEARS OLD	3.24	.66	216
34. THE PRESENCE OF MY CHILD TEACHES OTHERS ABOUT UNCONDITIONAL LOVE			
3-5 YEARS OLD	2.87	.79	40
6-12 YEARS OLD	2.95	.75	215
35. THE PRESENCE OF MY CHILD IS A SOURCE OF PRIDE BECAUSE OF HIS/HER ATHLETIC ACHIEVEMENTS			
3-5 YEARS OLD	2.58	.88	39
6-12 YEARS OLD	2.72	.77	217
36. THE PRESENCE OF MY CHILD CHEERS ME UP			
3-5 YEARS OLD	3.17	.64	39
6-12 YEARS OLD	3.16	.66	215
37. THE PRESENCE OF MY CHILD RENEWS MY INTEREST IN PARTICIPATING IN DIFFERENT ACTIVITIES			
3-5 YEARS OLD	2.87	.68	40
6-12 YEARS OLD	2.88	.68	217

	Mean	Std Dev	# Cases
38. THE PRESENCE OF MY CHILD IS VERY UPLIFTING			
3-5 YEARS OLD	3.02	.66	39
6-12 YEARS OLD	2.99	.68	215
39. THE PRESENCE OF MY CHILD MAKES US MORE IN CHARGE OF OURSELVES AS A FAMILY			
3-5 YEARS OLD	3.02	.61	40
6-12 YEARS OLD	3.02	.69	216
40. BECAUSE OF MY CHILD MY CIRCLE OF FRIENDS HAS GROWN LARGER			
3-5 YEARS OLD	2.45	.90	40
6-12 YEARS OLD	2.38	.77	217
41. BECAUSE OF MY CHILD MY SOCIAL LIFE HAS EXPANDED BY BRINGING ME INTO CONTACT WITH OTHER PEOPLE			
3-5 YEARS OLD	2.62	.83	40
6-12 YEARS OLD	2.42	.80	218
42. BECAUSE OF MY CHILD I LEARNED ABOUT PROBLEMS CHILDREN MAY HAVE			
3-5 YEARS OLD	3.37	.62	40
6-12 YEARS OLD	3.38	.59	218
43. BECAUSE OF MY CHILD I HAVE LEARNED TO ADJUST TO THINGS I CANNOT CHANGE			
3-5 YEARS OLD	3.22	.69	40
6-12 YEARS OLD	3.28	.62	217
44. BECAUSE OF MY CHILD I AM MORE ACCEPTING OF THINGS			
3-5 YEARS OLD	3.00	.68	39
6-12 YEARS OLD	3.20	.61	217
45. BECAUSE OF MY CHILD I HAVE SOMEONE WHO SHARES RESPONSIBILITY FOR DOING SEVERAL TASKS AROUND THE HOUSE			
3-5 YEARS OLD	2.32	.76	40
6-12 YEARS OLD	2.50	.76	217
46. BECAUSE OF MY CHILD I AM MORE COMPASSIONATE			
3-5 YEARS OLD	3.02	.61	40
6-12 YEARS OLD	3.06	.63	215
47. BECAUSE OF MY CHILD I LEARNED MORE ABOUT EMOTIONAL PROBLEMS			
3-5 YEARS OLD	3.32	.69	40
6-12 YEARS OLD	3.39	.55	218

	Mean	Std Dev	# Cases
48. BECAUSE OF MY CHILD MY FAMILY IS MORE UNDERSTANDING ABOUT SPECIAL PROBLEMS			
3-5 YEARS OLD	3.10	.67	40
6-12 YEARS OLD	2.94	.67	218
49. BECAUSE OF MY CHILD I AM GRATEFUL FOR EACH DAY			
3-5 YEARS OLD	3.17	.71	40
6-12 YEARS OLD	3.18	.68	217
50. BECAUSE OF MY CHILD OUR FAMILY HAS BECOME CLOSER			
3-5 YEARS OLD	2.62	.83	40
6-12 YEARS OLD	2.76	.83	214
51. BECAUSE OF MY CHILD I AM MORE SENSITIVE TO FAMILY ISSUES			
3-5 YEARS OLD	3.02	.73	40
6-12 YEARS OLD	3.21	.61	216
52. BECAUSE OF MY CHILD MY OTHER CHILDREN HAVE LEARNED TO BE AWARE OF PEOPLE'S NEEDS AND THEIR FEELINGS			
3-5 YEARS OLD	2.70	.83	34
6-12 YEARS OLD	2.75	.82	206
53. BECAUSE OF MY CHILD I HAVE MANY UNEXPECTED PLEASURES			
3-5 YEARS OLD	3.02	.86	40
6-12 YEARS OLD	2.98	.76	218

POSITIVE CONTRIBUTION SCALES

	Mean	Std Dev	# Cases
POSITIVE CONTRIBUTION: LEARNING THROUGH EXPERIENCE WITH SPECIAL PROBLEMS			
3-5 YEARS OLD	20.95	3.77	40
6-12 YEARS OLD	21.042	3.25	218
POSITIVE CONTRIBUTION: HAPPINESS & FULFILLMENT			
3-5 YEARS OLD	18.93	3.54	39
6-12 YEARS OLD	18.61	3.10	218
POSITIVE CONTRIBUTION: PERSONAL STRENGTH & FAMILY CLOSENESS			
3-5 YEARS OLD	21.25	3.27	40
6-12 YEARS OLD	21.90	3.21	218
POSITIVE CONTRIBUTION: UNDERSTANDING LIFE'S PURPOSES			
3-5 YEARS OLD	12.57	2.33	40
6-12 YEARS OLD	12.64	2.00	218
POSITIVE CONTRIBUTION: AWARENESS OF FUTURE ISSUES			
3-5 YEARS OLD	8.90	1.90	40
6-12 YEARS OLD	8.92	1.52	213
POSITIVE CONTRIBUTION: PERSONAL GROWTH & MATURITY			
3-5 YEARS OLD	19.52	4.33	40
6-12 YEARS OLD	19.90	3.66	218
POSITIVE CONTRIBUTION: EXPANDED SOCIAL NETWORK			
3-5 YEARS OLD	12.62	2.92	40
6-12 YEARS OLD	12.88	2.76	218
POSITIVE CONTRIBUTION: CAREER OR JOB GROWTH			
3-5 YEARS OLD	9.96	2.54	40
6-12 YEARS OLD	10.16	2.29	211
POSITIVE CONTRIBUTION: PRIDE & COOPERATION			
3-5 YEARS OLD	17.45	4.30	40
6-12 YEARS OLD	18.10	3.87	218

CHILD BEHAVIOR CHECKLIST ACTIVITY ITEMS

	3-5 YEARS OLD		6-12 YEARS OLD	
	n	%	n	%
SPORTS PARTICIPATION				
Does Do Sports..........	35	87.5%	212	97.2%
Does No Sports..........	5	12.5%	6	2.8%
TIME SPENT IN 1st SPORT				
Less Than Average.......	6	18.2%	44	21.3%
Average.................	17	51.5%	124	59.9%
More Than Average.......	10	30.3%	39	18.8%
TIME SPENT IN 2nd SPORT				
Less Than Average.......	7	26.9%	40	21.1%
Average.................	14	53.8%	120	63.2%
More Than Average.......	5	19.2%	30	15.8%
TIME SPENT IN 3rd SPORT				
Less Than Average.......	5	23.8%	41	26.5%
Average.................	12	57.1%	82	52.9%
More Than Average.......	4	19.0%	32	20.6%
HOW WELL DOES 1st SPORT				
Less Than Average.......	3	10.0%	24	11.9%
Average.................	13	43.3%	119	59.2%
More Than Average.......	14	46.7%	58	28.9%
HOW WELL DOES 2nd SPORT				
Less Than Average.......	3	12.5%	31	16.8%
Average.................	14	58.3%	112	60.9%
More Than Average.......	7	29.2%	41	22.3%
HOW WELL DOES 3rd SPORT				
Less Than Average.......	2	10.0%	24	15.8%
Average.................	15	75.0%	93	61.2%
More Than Average.......	3	15.0%	35	23.0%
HOBBY PARTICIPATION				
Does Do Hobbies.........	37	92.5%	203	93.1%
Does No Hobbies.........	3	7.5%	15	6.9%
TIME SPENT IN 1st HOBBY				
Less Than Average.......			15	7.5%
Average.................	18	50.0%	106	53.0%
More Than Average.......	18	50.0%	79	39.5%

	3-5 YEARS OLD		6-12 YEARS OLD	
	n	%	n	%
TIME SPENT IN 2nd HOBBY				
Less Than Average.......	1	3.2%	13	7.7%
Average.................	22	71.0%	96	56.8%
More Than Average.......	8	25.8%	60	35.5%
TIME SPENT IN 3rd HOBBY				
Less Than Average.......	2	7.7%	15	12.1%
Average.................	17	65.4%	73	58.9%
More Than Average.......	7	26.9%	36	29.0%
HOW WELL DOES 1st HOBBY				
Less Than Average.......	1	2.8%	14	7.6%
Average.................	16	44.4%	96	52.2%
More Than Average.......	19	52.8%	74	40.2%
HOW WELL DOES 2nd HOBBY				
Less Than Average.......	3	10.3%	13	8.2%
Average.................	17	58.6%	89	56.0%
More Than Average.......	9	31.0%	57	35.8%
HOW WELL DOES 3rd HOBBY				
Less Than Average.......	3	11.5%	14	12.0%
Average.................	13	50.0%	54	46.2%
More Than Average.......	10	38.5%	49	41.9%
A. IS CHILD IN A CLUB				
IS IN CLUB..............	9	22.5%	114	52.3%
NO CLUB.................	31	77.5%	104	47.7%
A.TIME SPENT AT 1ST CLUB				
NOT IN CLUB.............	31	77.5%	106	48.6%
LESS THAN AVERAGE.......			13	6.0%
AVERAGE.................	7	17.5%	68	31.2%
MORE THAN AVERAGE.......	2	5.0%	31	14.2%
B.TIME SPENT AT 2ND CLUB				
NOT IN CLUB.............	40	100.0%	170	78.0%
LESS THAN AVERAGE.......			6	2.8%
AVERAGE.................			33	15.1%
MORE THAN AVERAGE.......			9	4.1%

	3-5 YEARS OLD		6-12 YEARS OLD	
	n	%	n	%
C.TIME SPENT AT 3RD CLUB				
NOT IN CLUB.............	40	100.0%	205	94.0%
LESS THAN AVERAGE.......			1	.5%
AVERAGE.................			7	3.2%
MORE THAN AVERAGE.......			5	2.3%
DOES CHILD HAVE JOB OR CHORES?				
HAS JOB.................	30	75.0%	190	87.2%
NO JOB..................	10	25.0%	28	12.8%
HOW WELL DOES 1st JOB OR CHORE				
Less Than Average.......	3	10.7%	54	29.0%
Average.................	20	71.4%	108	58.1%
More Than Average.......	5	17.9%	24	12.9%
HOW WELL DOES 2nd JOB OR CHORE				
Less Than Average.......	7	31.8%	53	32.3%
Average.................	13	59.1%	88	53.7%
More Than Average.......	2	9.1%	23	14.0%
HOW WELL DOES 3rd JOB OR CHORE				
Less Than Average.......	1	7.7%	29	26.4%
Average.................	10	76.9%	65	59.1%
More Than Average.......	2	15.4%	16	14.5%
# OF CLOSE FRIENDS				
NONE....................	8	20.0%	33	15.2%
ONE.....................	4	10.0%	29	13.4%
TWO OR THREE............	17	42.5%	99	45.6%
FOUR OR MORE............	11	27.5%	56	25.8%
TIMES/WEEK CHILD W/ THEM				
LESS THAN ONE...........	6	17.6%	51	24.4%
ONE OR TWO..............	10	29.4%	74	35.4%
THREE OR MORE...........	18	52.9%	84	40.2%

	3-5 YEARS OLD		6-12 YEARS OLD	
	n	%	n	%
HOW WELL DOES CHILD GET ALONG WITH BROTHERS AND SISTERS?				
NOT APPLICABLE	6	15.8%	25	11.7%
WORSE	5	13.2%	50	23.4%
ABOUT THE SAME	18	47.4%	113	52.8%
BETTER	9	23.7%	26	12.1%
HOW WELL DOES CHILD GET ALONG WITH OTHER KIDS?				
WORSE	11	27.5%	65	30.1%
ABOUT THE SAME	21	52.5%	123	56.9%
BETTER	8	20.0%	28	13.0%
HOW WELL DOES CHILD BEHAVE WITH PARENTS?				
WORSE	19	47.5%	79	36.7%
ABOUT THE SAME	13	32.5%	100	46.5%
BETTER	8	20.0%	36	16.7%
HOW WELL DOES CHILD PLAY & WORK BY SELF?				
NOT APPLICABLE			1	.5%
WORSE	5	12.5%	40	18.4%
ABOUT THE SAME	14	35.0%	103	47.5%
BETTER	21	52.5%	73	33.6%
FOR THOSE IN SCHOOL:				
SCHOOL WORK: READING				
FAILING	1	11.1%	17	8.5%
BELOW AVERAGE			48	24.1%
AVERAGE	4	44.4%	102	51.3%
ABOVE AVERAGE	4	44.4%	32	16.1%
SCHOOL WORK: WRITING				
FAILING	1	9.1%	16	8.1%
BELOW AVERAGE			51	25.8%
AVERAGE	8	72.7%	100	50.5%
ABOVE AVERAGE	2	18.2%	31	15.7%
SCHOOL WORK: MATH				
FAILING			14	7.1%
BELOW AVERAGE	2	22.2%	36	18.4%
AVERAGE	4	44.4%	99	50.5%
ABOVE AVERAGE	3	33.3%	47	24.0%

	3-5 YEARS OLD		6-12 YEARS OLD	
	n	%	n	%
CHILD IN SPECIAL CLASS?				
NO......................	6	25.0%	113	54.9%
YES.....................	7	29.2%	91	44.2%
CHILD NOT IN SCHOOL.....	11	45.8%	2	1.0%
CHILD REPEATED GRADE?				
NO......................	12	52.2%	131	63.3%
YES.....................			74	35.7%
NOT IN SCHOOL...........	11	47.8%	2	1.0%
GRADE REPEATED BY CHILD				
KINDERGARTEN............			24	11.8%
1.......................			26	12.7%
2.......................			8	3.9%
3.......................			5	2.5%
4.......................			3	1.5%
5.......................			2	1.0%
6.......................			2	1.0%
7.......................	11	47.8%	2	1.0%
8.......................			1	.5%
NOT IN SCHOOL	12	52.2%	131	64.2%
HAD ANY SCHOOL PROBLEMS?				
NO......................	7	30.4%	51	24.8%
YES.....................	5	21.7%	153	74.3%
CHILD NOT IN SCHOOL.....	11	47.8%	2	1.0%
PROBLEMS ENDED?				
NO......................	4	25.0%	137	79.7%
YES.....................	1	6.3%	33	19.2%
NOT IN SCHOOL...........	11	68.8%	2	1.2%

CHILD BEHAVIOR CHECKLIST ACTIVITY SCALES

	Mean	Std Dev	# Cases
CBCL ACTIVITY COMPETENCE SCALE			
3-5 YEARS OLD	5.09	2.13	40
6-12 YEARS OLD	5.83	1.89	218
CBCL SOCIAL COMPETENCE SCALE			
3-5 YEARS OLD	5.13	1.89	34
6-12 YEARS OLD	5.23	2.14	207
CBCL SCHOOL COMPETENCE SCALE			
3-5 YEARS OLD	4.27	.62	11
6-12 YEARS OLD	3.26	1.30	197
CBCL TOTAL COMPETENCE SCALE			
3-5 YEARS OLD	15.76	3.03	10
6-12 YEARS OLD	14.43	3.75	188

CHILD BEHAVIOR CHECKLIST PROBLEM ITEMS

	3-5 YEARS OLD		6-12 YEARS OLD	
	n	%	n	%
1. ACTS TOO YOUNG FOR HIS/HER AGE				
Not True	11	27.5%	59	27.4%
Sometimes True	20	50.0%	95	44.2%
Often True	9	22.5%	61	28.4%
2. ALLERGY				
Not True	25	67.6%	127	66.8%
Sometimes True	6	16.2%	38	20.0%
Often True	6	16.2%	25	13.2%
3. ARGUES A LOT				
Not True	4	10.0%	9	4.2%
Sometimes True	9	22.5%	77	35.8%
Often True	27	67.5%	129	60.0%
4. ASTHMA				
Not True	36	92.3%	170	84.2%
Sometimes True	1	2.6%	15	7.4%
Often True	2	5.1%	17	8.4%
5. BEHAVES LIKE OPPOSITE SEX				
Not True	30	75.0%	190	89.2%
Sometimes True	10	25.0%	20	9.4%
Often True			3	1.4%
6. BOWEL MOVEMENTS OUTSIDE TOILET				
Not True	33	82.5%	186	87.7%
Sometimes True	5	12.5%	15	7.1%
Often True	2	5.0%	11	5.2%
7. BRAGGING, BOASTING				
Not True	19	47.5%	72	34.0%
Sometimes True	17	42.5%	95	44.8%
Often True	4	10.0%	45	21.2%

	3-5 YEARS OLD		6-12 YEARS OLD	
	n	%	n	%
8. CAN'T CONCENTRATE, CAN'T PAY ATTENTION FOR LONG				
Not True................	8	21.1%	28	13.3%
Sometimes True..........	19	50.0%	73	34.8%
Often True..............	11	28.9%	109	51.9%
9. CAN'T GET HIS/HER MIND OFF CERTAIN THOUGHTS; OBSESSIONS				
Not True................	18	45.0%	79	36.6%
Sometimes True..........	11	27.5%	66	30.6%
Often True..............	11	27.5%	71	32.9%
10. CAN'T SIT STILL, RESTLESS, OR HYPERACTIVE				
Not True................	6	15.0%	31	14.4%
Sometimes True..........	17	42.5%	64	29.6%
Often True..............	17	42.5%	121	56.0%
11. CLINGS TO ADULTS OR TOO DEPENDENT				
Not True................	11	27.5%	77	36.0%
Sometimes True..........	19	47.5%	86	40.2%
Often True..............	10	25.0%	51	23.8%
12. COMPLAINS OF LONELINESS				
Not True................	31	77.5%	85	39.7%
Sometimes True..........	6	15.0%	95	44.4%
Often True..............	3	7.5%	34	15.9%
13. CONFUSED OR SEEMS TO BE IN A FOG				
Not True................	27	69.2%	120	55.8%
Sometimes True..........	8	20.5%	73	34.0%
Often True..............	4	10.3%	22	10.2%
14. CRIES A LOT				
Not True................	22	55.0%	109	50.0%
Sometimes True..........	10	25.0%	84	38.5%
Often True..............	8	20.0%	25	11.5%
15. CRUEL TO ANIMALS				
Not True................	22	55.0%	163	75.1%
Sometimes True..........	17	42.5%	46	21.2%
Often True..............	1	2.5%	8	3.7%

	3-5 YEARS OLD		6-12 YEARS OLD	
	n	%	n	%
16. CRUELTY, BULLYING, OR MEANNESS TO OTHERS				
Not True................	13	32.5%	70	32.4%
Sometimes True..........	15	37.5%	109	50.5%
Often True..............	12	30.0%	37	17.1%
17. DAY-DREAMS OR GETS LOST IN HIS/HER THOUGHTS				
Not True................	20	50.0%	84	38.9%
Sometimes True..........	16	40.0%	94	43.5%
Often True..............	4	10.0%	38	17.6%
18. DELIBERATELY HARMS SELF OR ATTEMPTS SUICIDE				
Not True................	33	82.5%	184	84.8%
Sometimes True..........	6	15.0%	28	12.9%
Often True..............	1	2.5%	5	2.3%
19. DEMANDS A LOT OF ATTENTION				
Not True................	2	5.0%	26	11.9%
Sometimes True..........	13	32.5%	86	39.4%
Often True..............	25	62.5%	106	48.6%
20. DESTROYS HIS/HER OWN THINGS				
Not True................	13	33.3%	83	38.4%
Sometimes True..........	17	43.6%	78	36.1%
Often True..............	9	23.1%	55	25.5%
21. DESTROYS THINGS BELONGING TO HIS/HER FAMILY OR OTHER CHILDREN				
Not True................	17	42.5%	85	39.0%
Sometimes True..........	15	37.5%	92	42.2%
Often True..............	8	20.0%	41	18.8%
22. DISOBEDIENT AT HOME				
Not True................	4	10.0%	32	14.7%
Sometimes True..........	17	42.5%	113	51.8%
Often True..............	19	47.5%	73	33.5%
23. DISOBEDIENT AT SCHOOL				
Not True................	13	33.3%	51	23.5%
Sometimes True..........	16	41.0%	110	50.7%
Often True..............	10	25.6%	56	25.8%

	3-5 YEARS OLD		6-12 YEARS OLD	
	n	%	n	%
24. DOESN'T EAT WELL				
Not True	20	50.0%	127	58.3%
Sometimes True	16	40.0%	66	30.3%
Often True	4	10.0%	25	11.5%
25. DOESN'T GET ALONG WITH OTHER CHILDREN				
Not True	11	27.5%	42	19.3%
Sometimes True	22	55.0%	132	60.6%
Often True	7	17.5%	44	20.2%
26. DOESN'T SEEM TO FEEL GUILTY AFTER MISBEHAVING				
Not True	9	23.1%	51	23.5%
Sometimes True	15	38.5%	90	41.5%
Often True	15	38.5%	76	35.0%
27. EASILY JEALOUS				
Not True	10	25.0%	41	19.0%
Sometimes True	18	45.0%	94	43.5%
Often True	12	30.0%	81	37.5%
28. EATS OR DRINKS THINGS THAT ARE NOT FOOD				
Not True	33	82.5%	194	90.2%
Sometimes True	5	12.5%	14	6.5%
Often True	2	5.0%	7	3.3%
29. FEARS CERTAIN ANIMALS, SITUATIONS, OR PLACES, OTHER THAN SCHOOL				
Not True	22	56.4%	132	60.8%
Sometimes True	9	23.1%	57	26.3%
Often True	8	20.5%	28	12.9%
30. FEARS GOING TO SCHOOL				
Not True	35	87.5%	175	80.6%
Sometimes True	5	12.5%	33	15.2%
Often True			9	4.1%
31. FEARS HE/SHE MIGHT THINK OR DO SOMETHING BAD				
Not True	28	70.0%	126	58.9%
Sometimes True	8	20.0%	78	36.4%
Often True	4	10.0%	10	4.7%

	3-5 YEARS OLD		6-12 YEARS OLD	
	n	%	n	%
32. FEELS HE/SHE HAS TO BE PERFECT				
Not True................	33	82.5%	114	53.0%
Sometimes True..........	6	15.0%	65	30.2%
Often True..............	1	2.5%	36	16.7%
33. FEELS OR COMPLAINS THAT NO ONE LOVES HIM/HER				
Not True................	24	60.0%	69	32.2%
Sometimes True..........	13	32.5%	104	48.6%
Often True..............	3	7.5%	41	19.2%
34. FEELS OTHERS ARE OUT TO GET HIM/HER				
Not True................	24	60.0%	107	49.8%
Sometimes True..........	12	30.0%	77	35.8%
Often True..............	4	10.0%	31	14.4%
35. FEELS WORTHLESS OR INFERIOR				
Not True................	30	75.0%	82	38.7%
Sometimes True..........	7	17.5%	104	49.1%
Often True..............	3	7.5%	26	12.3%
36. GETS HURT A LOT, ACCIDENT-PRONE				
Not True................	19	48.7%	129	59.2%
Sometimes True..........	14	35.9%	65	29.8%
Often True..............	6	15.4%	24	11.0%
37. GETS IN MANY FIGHTS				
Not True................	18	45.0%	91	42.1%
Sometimes True..........	15	37.5%	91	42.1%
Often True..............	7	17.5%	34	15.7%
38. GETS TEASED A LOT				
Not True................	25	62.5%	65	30.1%
Sometimes True..........	10	25.0%	97	44.9%
Often True..............	5	12.5%	54	25.0%
39. HANGS AROUND WITH CHILDREN WHO GET IN TROUBLE				
Not True................	35	87.5%	122	56.5%
Sometimes True..........	2	5.0%	69	31.9%
Often True..............	3	7.5%	25	11.6%

	3-5 YEARS OLD		6-12 YEARS OLD	
	n	%	n	%

40. HEARS THINGS THAT AREN'T THERE

Not True................	36	90.0%	189	88.3%
Sometimes True..........	4	10.0%	17	7.9%
Often True..............			8	3.7%

41. IMPULSIVE OR ACTS WITHOUT THINKING

Not True................	5	12.5%	35	16.2%
Sometimes True..........	20	50.0%	93	43.1%
Often True..............	15	37.5%	88	40.7%

42. LIKES TO BE ALONE

Not True................	20	50.0%	106	49.1%
Sometimes True..........	18	45.0%	90	41.7%
Often True..............	2	5.0%	20	9.3%

43. LYING OR CHEATING

Not True................	13	32.5%	54	24.8%
Sometimes True..........	19	47.5%	111	50.9%
Often True..............	8	20.0%	53	24.3%

44. BITES FINGERNAILS

Not True................	23	57.5%	95	44.2%
Sometimes True..........	9	22.5%	69	32.1%
Often True..............	8	20.0%	51	23.7%

45. NERVOUS, HIGHSTRUNG, OR TENSE

Not True................	16	40.0%	63	29.3%
Sometimes True..........	13	32.5%	89	41.4%
Often True..............	11	27.5%	63	29.3%

46. NERVOUS MOVEMENTS OR TWITCHING

Not True................	26	65.0%	133	61.9%
Sometimes True..........	10	25.0%	44	20.5%
Often True..............	4	10.0%	38	17.7%

47. NIGHTMARES

Not True................	17	42.5%	110	50.9%
Sometimes True..........	19	47.5%	91	42.1%
Often True..............	4	10.0%	15	6.9%

	3-5 YEARS OLD		6-12 YEARS OLD	
	n	%	n	%
48. NOT LIKED BY OTHER CHILDREN				
Not True................	28	70.0%	89	41.4%
Sometimes True..........	9	22.5%	102	47.4%
Often True..............	3	7.5%	24	11.2%
49. CONSTIPATED, DOESN'T MOVE BOWELS				
Not True................	32	80.0%	164	76.3%
Sometimes True..........	6	15.0%	39	18.1%
Often True..............	2	5.0%	12	5.6%
50. TOO FEARFUL OR ANXIOUS				
Not True................	25	62.5%	107	49.5%
Sometimes True..........	10	25.0%	80	37.0%
Often True..............	5	12.5%	29	13.4%
51. FEELS DIZZY				
Not True................	39	100.0%	178	82.8%
Sometimes True..........			32	14.9%
Often True..............			5	2.3%
52. FEELS TOO GUILTY				
Not True................	35	87.5%	160	74.8%
Sometimes True..........	5	12.5%	44	20.6%
Often True..............			10	4.7%
53. OVEREATING				
Not True................	32	80.0%	138	64.2%
Sometimes True..........	4	10.0%	41	19.1%
Often True..............	4	10.0%	36	16.7%
54. OVERTIRED				
Not True................	28	71.8%	131	60.1%
Sometimes True..........	8	20.5%	73	33.5%
Often True..............	3	7.7%	14	6.4%
55. OVERWEIGHT				
Not True................	37	92.5%	178	81.7%
Sometimes True..........	1	2.5%	19	8.7%
Often True..............	2	5.0%	21	9.6%

	3-5 YEARS OLD		6-12 YEARS OLD	
	n	%	n	%

56. PHYSICALLY ATTACKS PEOPLE

Not True................	20	50.0%	127	59.6%
Sometimes True..........	14	35.0%	74	34.7%
Often True..............	6	15.0%	12	5.6%

57. POOR SCHOOL WORK

Not True................	31	77.5%	81	38.4%
Sometimes True..........	7	17.5%	79	37.4%
Often True..............	2	5.0%	51	24.2%

58. PICKS NOSE, SKIN, OR OTHER PARTS OF BODY.

Not True................	19	47.5%	121	56.3%
Sometimes True..........	14	35.0%	56	26.0%
Often True..............	7	17.5%	38	17.7%

59. PHYSICAL PROBLEMS WITHOUT KNOWN MEDICAL CAUSE:

a. ACHES AND PAINS

Not True................	34	85.0%	141	65.9%
Sometimes True..........	5	12.5%	58	27.1%
Often True..............	1	2.5%	15	7.0%

b. HEADACHES

Not True................	30	75.0%	100	46.9%
Sometimes True..........	9	22.5%	91	42.7%
Often True..............	1	2.5%	22	10.3%

c. NAUSEA, FEELS SICK

Not True................	30	75.0%	142	66.7%
Sometimes True..........	10	25.0%	58	27.2%
Often True..............			13	6.1%

d. PROBLEMS WITH EYES

Not True................	36	90.0%	158	73.1%
Sometimes True..........	1	2.5%	43	19.9%
Often True..............	3	7.5%	15	6.9%

	3-5 YEARS OLD		6-12 YEARS OLD	
	n	%	n	%

e. RASHES OR OTHER SKIN PROBLEMS

Not True...............	28	70.0%	147	67.7%
Sometimes True..........	7	17.5%	54	24.9%
Often True..............	5	12.5%	16	7.4%

f. STOMACH ACHES OR CRAMPS

Not True................	27	67.5%	118	54.6%
Sometimes True..........	10	25.0%	77	35.6%
Often True..............	3	7.5%	21	9.7%

g. VOMITING, THROWING UP

Not True................	36	90.0%	183	84.7%
Sometimes True..........	4	10.0%	29	13.4%
Often True..............			4	1.9%

h. OTHER

Not True................	25	92.6%	100	88.5%
Sometimes True..........	1	3.7%	4	3.5%
Often True..............	1	3.7%	9	8.0%

60. PLAYS WITH OWN SEX PARTS IN PUBLIC

Not True................	32	80.0%	193	88.5%
Sometimes True..........	6	15.0%	19	8.7%
Often True..............	2	5.0%	6	2.8%

61. PLAYS WITH OWN SEX PARTS IN PUBLIC

Not True................	33	84.6%	179	82.1%
Sometimes True..........	3	7.7%	31	14.2%
Often True..............	3	7.7%	8	3.7%

62. POORLY COORDINATED OR CLUMSY

Not True................	26	65.0%	139	64.4%
Sometimes True..........	12	30.0%	61	28.2%
Often True..............	2	5.0%	16	7.4%

63. PREFERS PLAYING WITH OLDER CHILDREN

Not True................	15	38.5%	91	41.9%
Sometimes True..........	17	43.6%	82	37.8%
Often True..............	7	17.9%	44	20.3%

	3-5 YEARS OLD		6-12 YEARS OLD	
	n	%	n	%

64. PREFERS PLAYING WITH YOUNGER CHILDREN

Not True................	23	59.0%	84	38.7%
Sometimes True..........	16	41.0%	97	44.7%
Often True..............			36	16.6%

65. REFUSES TO TALK

Not True................	21	53.8%	121	55.5%
Sometimes True..........	12	30.8%	76	34.9%
Often True..............	6	15.4%	21	9.6%

66. REPEATS CERTAIN ACTS OVER AND OVER, COMPULSIONS

Not True................	27	69.2%	122	58.4%
Sometimes True..........	4	10.3%	57	27.3%
Often True..............	8	20.5%	30	14.4%

67. RUNS AWAY FROM HOME

Not True................	38	95.0%	188	86.2%
Sometimes True..........	2	5.0%	22	10.1%
Often True..............			8	3.7%

68. SCREAMS A LOT

Not True................	13	32.5%	114	53.3%
Sometimes True..........	15	37.5%	67	31.3%
Often True..............	12	30.0%	33	15.4%

69. SECRETIVE, KEEPS THINGS TO SELF

Not True................	25	62.5%	90	41.9%
Sometimes True..........	11	27.5%	86	40.0%
Often True..............	4	10.0%	39	18.1%

70. SEES THINGS THAT AREN'T THERE

Not True................	36	92.3%	195	91.1%
Sometimes True..........	3	7.7%	17	7.9%
Often True..............			2	.9%

	3-5 YEARS OLD		6-12 YEARS OLD	
	n	%	n	%

71. SELF-CONSCIOUS OR EASILY EMBARRASSED

EASILY EMBARRASSED				
Not True................	28	70.0%	80	37.0%
Sometimes True..........	10	25.0%	91	42.1%
Often True..............	2	5.0%	45	20.8%

72. SETS FIRES

Not True................	39	97.5%	185	86.0%
Sometimes True..........	1	2.5%	23	10.7%
Often True..............			7	3.3%

73. SEXUAL PROBLEMS

Not True................	35	89.7%	176	84.6%
Sometimes True..........	4	10.3%	20	9.6%
Often True..............			12	5.8%

74. SHOWING OFF OR CLOWNING

Not True................	9	22.5%	41	18.9%
Sometimes True..........	18	45.0%	104	47.9%
Often True..............	13	32.5%	72	33.2%

75. SHY OR TIMID

Not True................	21	52.5%	115	53.0%
Sometimes True..........	17	42.5%	82	37.8%
Often True..............	2	5.0%	20	9.2%

76. SLEEPS LESS THAN MOST CHILDREN

Not True................	23	59.0%	128	60.4%
Sometimes True..........	10	25.6%	55	25.9%
Often True..............	6	15.4%	29	13.7%

77. SLEEPS MORE THAN MOST CHILDREN DURING DAY AND/OR NIGHT

Not True................	34	85.0%	165	77.1%
Sometimes True..........	2	5.0%	40	18.7%
Often True..............	4	10.0%	9	4.2%

	3-5 YEARS OLD		6-12 YEARS OLD	
	n	%	n	%

78. SMEARS OR PLAYS WITH BOWEL MOVEMENTS

Not True................	33	82.5%	202	92.7%
Sometimes True..........	5	12.5%	13	6.0%
Often True..............	2	5.0%	3	1.4%

79. SPEECH PROBLEM

Not True................	26	65.0%	159	74.6%
Sometimes True..........	6	15.0%	33	15.5%
Often True..............	8	20.0%	21	9.9%

80. STARES BLANKLY

Not True................	24	61.5%	141	65.3%
Sometimes True..........	15	38.5%	66	30.6%
Often True..............			9	4.2%

81. STEALS AT HOME

Not True................	34	85.0%	144	66.7%
Sometimes True..........	4	10.0%	56	25.9%
Often True..............	2	5.0%	16	7.4%

82. STEALS OUTSIDE THE HOME

Not True................	33	82.5%	158	74.9%
Sometimes True..........	5	12.5%	43	20.4%
Often True..............	2	5.0%	10	4.7%

83. STORES UP THINGS HE/SHE DOESN'T NEED

Not True................	33	82.5%	138	64.5%
Sometimes True..........	4	10.0%	41	19.2%
Often True..............	3	7.5%	35	16.4%

84. STRANGE BEHAVIOR

Not True................	29	74.4%	149	70.6%
Sometimes True..........	6	15.4%	44	20.9%
Often True..............	4	10.3%	18	8.5%

85. STRANGE IDEAS

Not True................	33	86.8%	166	79.8%
Sometimes True..........	4	10.5%	37	17.8%
Often True..............	1	2.6%	5	2.4%

	3-5 YEARS OLD		6-12 YEARS OLD	
	n	%	n	%

86. STUBBORN, SULLEN, OR IRRITABLE

STUBBORN				
Not True	7	17.5%	33	15.3%
Sometimes True	17	42.5%	110	51.2%
Often True	16	40.0%	72	33.5%

87. SUDDEN CHANGES IN MOOD OR FEELING

Not True	11	27.5%	47	21.9%
Sometimes True	20	50.0%	110	51.2%
Often True	9	22.5%	58	27.0%

88. SULKS A LOT

Not True	23	57.5%	89	42.2%
Sometimes True	9	22.5%	85	40.3%
Often True	8	20.0%	37	17.5%

89. SUSPICIOUS

Not True	27	67.5%	128	59.8%
Sometimes True	9	22.5%	60	28.0%
Often True	4	10.0%	26	12.1%

90. SWEARING OR OBSCENE LANGUAGE

Not True	22	55.0%	111	51.9%
Sometimes True	14	35.0%	75	35.0%
Often True	4	10.0%	28	13.1%

91. TALKS ABOUT KILLING SELF

Not True	35	87.5%	167	77.0%
Sometimes True	3	7.5%	46	21.2%
Often True	2	5.0%	4	1.8%

92. TALKS OR WALKS IN SLEEP

Not True	28	70.0%	156	71.9%
Sometimes True	11	27.5%	47	21.7%
Often True	1	2.5%	14	6.5%

	3-5 YEARS OLD		6-12 YEARS OLD	
	n	%	n	%

93. TALKS TOO MUCH

Not True	11	27.5%	56	25.8%
Sometimes True	19	47.5%	86	39.6%
Often True	10	25.0%	75	34.6%

94. TEASES A LOT

Not True	18	45.0%	90	41.5%
Sometimes True	13	32.5%	97	44.7%
Often True	9	22.5%	30	13.8%

95. TEMPER TANTRUMS OR HOT TEMPER

Not True	4	10.0%	46	21.2%
Sometimes True	18	45.0%	81	37.3%
Often True	18	45.0%	90	41.5%

96. THINKS ABOUT SEX TOO MUCH

Not True	33	82.5%	172	80.0%
Sometimes True	5	12.5%	35	16.3%
Often True	2	5.0%	8	3.7%

97. THREATENS PEOPLE

Not True	23	57.5%	129	59.7%
Sometimes True	10	25.0%	69	31.9%
Often True	7	17.5%	18	8.3%

98. THUMB-SUCKING

Not True	29	72.5%	188	87.4%
Sometimes True	2	5.0%	10	4.7%
Often True	9	22.5%	17	7.9%

99. TOO CONCERNED WITH NEATNESS OR CLEANLINESS

Not True	33	82.5%	177	81.2%
Sometimes True	6	15.0%	31	14.2%
Often True	1	2.5%	10	4.6%

100. TROUBLE SLEEPING

Not True	22	56.4%	133	61.6%
Sometimes True	14	35.9%	59	27.3%
Often True	3	7.7%	24	11.1%

	3-5 YEARS OLD		6-12 YEARS OLD	
	n	%	n	%

101. TRUANCY, SKIPS SCHOOL

Not True................	39	100.0%	198	92.5%
Sometimes True..........			12	5.6%
Often True..............			4	1.9%

102. UNDERACTIVE, SLOW MOVING, OR LACKS ENERGY

Not True................	36	90.0%	158	72.8%
Sometimes True..........	4	10.0%	45	20.7%
Often True..............			14	6.5%

103. UNHAPPY, SAD, OR DEPRESSED

Not True................	25	62.5%	78	35.9%
Sometimes True..........	14	35.0%	109	50.2%
Often True..............	1	2.5%	30	13.8%

104. UNUSUALLY LOUD

Not True................	8	20.0%	47	21.6%
Sometimes True..........	13	32.5%	100	45.9%
Often True..............	19	47.5%	71	32.6%

105. VANDALISM

Not True................	28	71.8%	166	77.9%
Sometimes True..........	10	25.6%	38	17.8%
Often True..............	1	2.6%	9	4.2%

106. USES ALCOHOL OR DRUGS

Not True................	40	100.0%	208	95.9%
Sometimes True..........			8	3.7%
Often True..............			1	.5%

107. WETS SELF DURING THE DAY

Not True................	32	80.0%	201	92.6%
Sometimes True..........	7	17.5%	14	6.5%
Often True..............	1	2.5%	2	.9%

108. WETS THE BED

Not True................	24	60.0%	165	76.0%
Sometimes True..........	9	22.5%	36	16.6%
Often True..............	7	17.5%	16	7.4%

	3-5 YEARS OLD		6-12 YEARS OLD	
	n	%	n	%

109. WHINING

Not True................	6	15.0%	98	45.4%
Sometimes True..........	23	57.5%	81	37.5%
Often True..............	11	27.5%	37	17.1%

110. WISHES TO BE OF OPPOSITE SEX

Not True................	38	95.0%	203	94.9%
Sometimes True..........	2	5.0%	8	3.7%
Often True..............			3	1.4%

111. WORRYING

Not True................	23	57.5%	82	38.0%
Sometimes True..........	11	27.5%	105	48.6%
Often True..............	6	15.0%	29	13.4%

112. WITHDRAWN

Not True................	29	74.4%	130	59.9%
Sometimes True..........	10	25.6%	73	33.6%
Often True..............			14	6.5%

113. PLEASE WRITE IN ANY PROBLEMS YOUR CHILD HAS THAT WERE NOT LISTED

OTHER PROBLEMS 1

Not True................	1	10.0%	8	15.7%
Sometimes True..........	3	30.0%	12	23.5%
Often True..............	6	60.0%	31	60.8%

OTHER PROBLEMS 2

Not True................			3	15.8%
Sometimes True..........	1	25.0%	6	31.6%
Often True..............	3	75.0%	10	52.6%

OTHER PROBLEMS 3

Not True................			2	20.0%
Sometimes True..........			1	10.0%
Often True..............	1	100.0%	7	70.0%

CHILD BEHAVIOR CHECKLIST PROBLEM SCALES

	Mean	Std Dev	# Cases
CBCL ANXIOUS SCALE			
3-5 YEARS OLD	3.94	2.81	40
6-12 YEARS OLD	5.18	3.43	218
CBCL DEPRESSION SCALE			
3-5 YEARS OLD	2.18	2.28	40
6-12 YEARS OLD	3.51	3.39	216
CBCL UNCOMMUNICATIVE SCALE			
3-5 YEARS OLD	6.10	5.63	40
6-12 YEARS OLD	9.55	5.52	218
CBCL OBSESSIVE/COMPULSIVE SCALE			
3-5 YEARS OLD	4.63	2.61	40
6-12 YEARS OLD	6.03	3.11	218
CBCL SOMATIC SCALE			
3-5 YEARS OLD	2.47	2.25	40
6-12 YEARS OLD	2.74	2.49	213
CBCL SOCIAL WITHDRAWAL SCALE			
3-5 YEARS OLD	7.94	4.47	40
6-12 YEARS OLD	9.60	4.79	217
CBCL HYPERACTIVE SCALE			
3-5 YEARS OLD	4.57	3.68	40
6-12 YEARS OLD	5.76	4.25	217
CBCL AGGRESSIVE SCALE			
3-5 YEARS OLD	20.39	9.24	40
6-12 YEARS OLD	19.52	8.37	218
CBCL DELINQUENT SCALE			
3-5 YEARS OLD	12.94	5.56	40
6-12 YEARS OLD	11.40	7.12	218

	Mean	Std Dev	# Cases
CBCL INTERNALIZED PROBLEMS			
3-5 YEARS OLD	11.81	8.70	40
6-12 YEARS OLD	17.52	10.02	216
CBCL EXTERNALIZED PROBLEMS			
3-5 YEARS OLD	24.96	12.38	40
6-12 YEARS OLD	25.29	11.51	217
CBCL TOTAL PROBLEMS SCALE			
3-5 YEARS OLD	64.50	28.03	40
6-12 YEARS OLD	72.61	31.40	218

FIRA-G RELATIVE AND FRIEND SUPPORT ITEMS

	Mean	Std Dev	# Cases
WE COPE WITH FAMILY PROBLEMS BY:			
1. SHARING OUR DIFFICULTIES WITH RELATIVES			
3-5 YEARS OLD	2.89	1.16	39
6-12 YEARS OLD	3.11	1.09	216
2. SEEKING ADVICE FROM RELATIVES			
3-5 YEARS OLD	2.80	1.22	40
6-12 YEARS OLD	2.95	1.10	215
3. DOING THINGS WITH RELATIVES (GET TOGETHERS)			
3-5 YEARS OLD	3.37	1.23	40
6-12 YEARS OLD	3.29	1.09	217
4. SEEKING ENCOURAGEMENT AND SUPPORT FROM FRIENDS			
3-5 YEARS OLD	3.65	1.16	40
6-12 YEARS OLD	3.74	.99	216
5. SEEKING INFORMATION AND ADVICE FROM PEOPLE FACED WITH THE SAME OR SIMILAR PROBLEM			
3-5 YEARS OLD	3.62	1.10	40
6-12 YEARS OLD	3.73	.95	218
6. SHARING CONCERNS WITH CLOSE FRIENDS			
3-5 YEARS OLD	3.77	.99	40
6-12 YEARS OLD	3.84	.95	217
7. SHARING PROBLEMS WITH NEIGHBORS			
3-5 YEARS OLD	2.37	1.05	40
6-12 YEARS OLD	2.48	1.00	217
8. ASKING RELATIVES HOW THEY FEEL ABOUT THE PROBLEMS WE FACE			
3-5 YEARS OLD	2.62	.97	40
6-12 YEARS OLD	2.97	1.16	217

FIRA-G RELATIVE AND FRIEND SUPPORT SCALE

	Mean	Std Dev	# Cases
FIRA-G RELATIVE & FRIEND SUPPORT SCALE			
3-5 YEARS OLD	25.12	6.34	40
6-12 YEARS OLD	26.13	5.52	217

FIRA-G SOCIAL SUPPORT ITEMS

	Mean	Std Dev	# Cases
1. IF I HAD AN EMERGENCY, EVEN PEOPLE I DO NOT KNOW IN THIS COMMUNITY WOULD BE WILLING TO HELP			
3-5 YEARS OLD	3.87	.88	40
6-12 YEARS OLD	3.50	1.01	217
2. I FEEL GOOD ABOUT MYSELF WHEN I SACRIFICE AND GIVE TIME AND ENERGY TO MEMBERS OF MY FAMILY			
3-5 YEARS OLD	3.97	1.02	40
6-12 YEARS OLD	4.09	.67	218
3. THE THINGS I DO FOR MEMBERS OF MY FAMILY MAKE ME FEEL PART OF THIS VERY IMPORTANT GROUP			
3-5 YEARS OLD	4.22	.69	40
6-12 YEARS OLD	3.94	.90	217
4. PEOPLE HERE KNOW THEY CAN GET HELP FROM THE COMMUNITY IF THEY ARE IN TROUBLE			
3-5 YEARS OLD	3.53	.99	39
6-12 YEARS OLD	3.35	.98	217
5. I HAVE FRIENDS WHO LET ME KNOW THEY VALUE WHO I AM AND WHAT I CAN DO			
3-5 YEARS OLD	3.70	1.09	40
6-12 YEARS OLD	4.00	.91	217
6. PEOPLE CAN DEPEND ON EACH OTHER IN THIS COMMUNITY			
3-5 YEARS OLD	3.45	.98	40
6-12 YEARS OLD	3.27	.97	215
7. MEMBERS OF MY FAMILY SELDOM LISTEN TO MY PROBLEMS OR CONCERNS; I USUALLY FEEL CRITICIZED			
3-5 YEARS OLD	2.52	1.41	40
6-12 YEARS OLD	2.84	1.35	215
8. MY FRIENDS IN THIS COMMUNITY ARE A PART OF MY EVERYDAY ACTIVITIES			
3-5 YEARS OLD	2.60	1.12	40
6-12 YEARS OLD	2.76	1.10	217

	Mean	Std Dev	# Cases
9. THERE ARE TIMES WHEN FAMILY MEMBERS DO THINGS THAT MAKE OTHER MEMBERS UNHAPPY			
3-5 YEARS OLD	3.87	.99	40
6-12 YEARS OLD	3.95	.91	215
10. I NEED TO BE VERY CAREFUL HOW MUCH I DO FOR MY FRIENDS BECAUSE THEY TAKE ADVANTAGE OF ME			
3-5 YEARS OLD	2.70	1.22	40
6-12 YEARS OLD	3.00	1.26	217
11. LIVING IN THIS COMMUNITY GIVES ME A SECURE FEELING			
3-5 YEARS OLD	3.40	.98	40
6-12 YEARS OLD	3.31	1.05	218
12. THE MEMBERS OF MY FAMILY MAKE AN EFFORT TO SHOW THEIR LOVE AND AFFECTION FOR ME			
3-5 YEARS OLD	3.37	1.10	40
6-12 YEARS OLD	3.57	1.17	214
13. THERE IS A FEELING IN THIS COMMUNITY THAT PEOPLE SHOULD NOT GET TOO FRIENDLY WITH EACH OTHER			
3-5 YEARS OLD	2.60	1.19	40
6-12 YEARS OLD	2.91	1.07	218
14. THIS IS NOT A VERY GOOD COMMUNITY TO BRING CHILDREN UP IN			
3-5 YEARS OLD	2.41	1.09	39
6-12 YEARS OLD	2.45	1.11	216
15. I FEEL SECURE THAT I AM AS IMPORTANT TO MY FRIENDS AS THEY ARE TO ME			
3-5 YEARS OLD	3.70	.91	40
6-12 YEARS OLD	3.70	.98	216
16. I HAVE SOME VERY CLOSE FRIENDS OUTSIDE THE FAMILY WHO I KNOW REALLY CARE FOR ME AND LOVE ME			
3-5 YEARS OLD	3.82	1.10	40
6-12 YEARS OLD	4.05	.93	217
17. MEMBER(S) OF MY FAMILY DO NOT SEEM TO UNDERSTAND ME; I FEEL TAKEN FOR GRANTED			
3-5 YEARS OLD	2.70	1.32	40
6-12 YEARS OLD	3.07	1.28	217

FIRA-G SOCIAL SUPPORT SCALE

	Mean	Std Dev	# Cases
FIRA-G SOCIAL SUPPORT INDEX			
3-5 YEARS OLD	56.30	6.73	40
6-12 YEARS OLD	56.10	6.72	218

CHIP ITEMS

	Mean	Std Dev	# Cases
1. TRYING TO MAINTAIN FAMILY STABILITY			
3-5 YEARS OLD	3.05	.79	39
6-12 YEARS OLD	3.13	.82	214
2. ENGAGING IN RELATIONSHIPS AND FRIENDSHIPS WHICH HELP ME TO FEEL IMPORTANT AND APPRECIATED			
3-5 YEARS OLD	2.48	.75	39
6-12 YEARS OLD	2.39	.93	216
3. TRUSTING MY SPOUSE (OR FORMER SPOUSE) TO HELP SUPPORT ME AND MY CHILD(REN)			
3-5 YEARS OLD	2.76	1.30	39
6-12 YEARS OLD	2.22	1.23	216
4. SLEEPING			
3-5 YEARS OLD	1.97	.93	39
6-12 YEARS OLD	1.81	.84	212
5. TALKING WITH THE STAFF (NURSES, SOCIAL WORKER, ETC.) WHEN WE VISIT THE MENTAL HEALTH AGENCY/HOSPITAL			
3-5 YEARS OLD	2.52	1.03	38
6-12 YEARS OLD	2.66	.97	216
6. BELIEVING THAT MY CHILD(REN) WILL GET BETTER			
3-5 YEARS OLD	3.00	.93	40
6-12 YEARS OLD	3.20	.76	217
7. WORKING, OUTSIDE EMPLOYMENT			
3-5 YEARS OLD	1.92	.89	39
6-12 YEARS OLD	2.07	1.13	211
8. SHOWING THAT I AM STRONG			
3-5 YEARS OLD	2.87	.86	39
6-12 YEARS OLD	2.92	.85	214
9. PURCHASING GIFTS FOR MYSELF AND/OR OTHER FAMILY MEMBERS			
3-5 YEARS OLD	2.10	.85	39
6-12 YEARS OLD	2.14	.87	213

	Mean	Std Dev	# Cases
10. TALKING WITH OTHER INDIVIDUALS/PARENTS IN MY SAME SITUATION			
3-5 YEARS OLD	1.97	.83	40
6-12 YEARS OLD	2.17	.91	217
11. EATING			
3-5 YEARS OLD	2.05	1.10	40
6-12 YEARS OLD	2.08	.98	215
12. GETTING OTHER MEMBERS OF THE FAMILY TO HELP WITH CHORES AND TASKS AT HOME			
3-5 YEARS OLD	2.20	.95	39
6-12 YEARS OLD	2.27	.89	217
13. GETTING AWAY BY MYSELF			
3-5 YEARS OLD	1.64	.62	39
6-12 YEARS OLD	1.84	.82	217
14. TALKING WITH THE DOCTOR ABOUT MY CONCERNS ABOUT MY CHILD(REN)			
3-5 YEARS OLD	2.30	1.10	39
6-12 YEARS OLD	2.60	.96	218
15. BELIEVING THAT THE MENTAL HEALTH AGENCY/HOSPITAL HAS MY FAMILY'S BEST INTEREST IN MIND			
3-5 YEARS OLD	2.89	.96	39
6-12 YEARS OLD	2.81	.92	216
16. BUILDING CLOSE RELATIONSHIPS WITH PEOPLE			
3-5 YEARS OLD	2.07	.82	40
6-12 YEARS OLD	2.21	.90	217
17. BELIEVING IN GOD			
3-5 YEARS OLD	3.46	.91	39
6-12 YEARS OLD	3.42	.82	217
18. DEVELOP MYSELF AS A PERSON			
3-5 YEARS OLD	2.82	.79	39
6-12 YEARS OLD	2.90	.93	216
19. TALKING WITH OTHER PARENTS IN THE SAME TYPE OF SITUATION AND LEARNING ABOUT THEIR EXPERIENCE			
3-5 YEARS OLD	2.05	.99	39
6-12 YEARS OLD	2.25	.99	217

	Mean	Std Dev	# Cases
20. DOING THINGS TOGETHER AS A FAMILY (INVOLVING ALL MEMBERS OF THE FAMILY)			
3-5 YEARS OLD	2.82	.82	39
6-12 YEARS OLD	2.68	.93	216
21. INVESTING TIME AND ENERGY IN MY JOB			
3-5 YEARS OLD	2.17	.88	39
6-12 YEARS OLD	2.22	1.02	215
22. BELIEVING THAT MY CHILD IS GETTING THE BEST CARE POSSIBLE			
3-5 YEARS OLD	3.30	.73	39
6-12 YEARS OLD	2.92	.86	218
23. ENTERTAINING FRIENDS IN OUR HOME			
3-5 YEARS OLD	1.71	.79	39
6-12 YEARS OLD	1.72	.76	218
24. READING ABOUT HOW OTHER PERSONS IN MY SITUATION HANDLE THINGS			
3-5 YEARS OLD	2.00	.80	38
6-12 YEARS OLD	2.34	.92	217
25. DOING THINGS WITH FAMILY RELATIVES			
3-5 YEARS OLD	2.05	.85	39
6-12 YEARS OLD	2.20	.91	214
26. BECOMING MORE SELF RELIANT AND INDEPENDENT			
3-5 YEARS	2.78	.77	38
6-12 YEARS	2.92	.86	215
27. TELLING MYSELF THAT I HAVE MANY THINGS I SHOULD BE THANKFUL FOR			
3-5 YEARS OLD	3.00	.85	39
6-12 YEARS OLD	3.24	.79	216
28. CONCENTRATING ON HOBBIES (ART, MUSIC, JOGGING, ETC.)			
3-5 YEARS OLD	1.84	.84	39
6-12 YEARS OLD	2.04	.88	217
29. EXPLAINING OUR FAMILY SITUATION TO FRIENDS AND NEIGHBORS SO THEY WILL UNDERSTAND US			
3-5 YEARS OLD	2.07	.91	38
6-12 YEARS OLD	2.01	.79	214

	Mean	Std Dev	# Cases
30. ENCOURAGING CHILD(REN) WITH EMOTIONAL PROBLEMS TO BE MORE INDEPENDENT			
3-5 YEARS OLD	2.20	.86	39
6-12 YEARS OLD	2.51	.90	216
31. KEEPING MYSELF IN SHAPE AND WELL GROOMED			
3-5 YEARS OLD	2.65	1.00	40
6-12 YEARS OLD	2.58	.94	217
32. INVOLVEMENT IN SOCIAL ACTIVITIES (PARTIES, ETC.) WITH FRIENDS			
3-5 YEARS OLD	1.71	.82	39
6-12 YEARS OLD	1.68	.71	218
33. GOING OUT WITH MY SPOUSE ON A REGULAR BASIS			
3-5 YEARS OLD	1.48	.75	39
6-12 YEARS OLD	1.57	.87	214
34. BEING SURE PRESCRIBED MEDICAL TREATMENTS FOR CHILD(REN) ARE CARRIED OUT AT HOME ON A DAILY BASIS			
3-5 YEARS OLD	2.82	1.14	39
6-12 YEARS OLD	3.12	.96	215
35. BUILDING A CLOSER RELATIONSHIP WITH MY SPOUSE			
3-5 YEARS OLD	2.07	.96	38
6-12 YEARS OLD	2.15	1.14	211
36. ALLOWING MYSELF TO GET ANGRY			
3-5 YEARS OLD	2.37	.89	40
6-12 YEARS OLD	2.19	.86	218
37. INVESTING MYSELF IN MY CHILD(REN)			
3-5 YEARS OLD	3.00	.79	39
6-12 YEARS OLD	3.04	.81	216
38. TALKING TO SOMEONE (NOT PROFESSIONAL COUNSELOR/DOCTOR) ABOUT HOW I FEEL			
3-5 YEARS OLD	2.17	.96	39
6-12 YEARS OLD	2.54	.92	215
39. READING MORE ABOUT THE EMOTIONAL PROBLEM WHICH CONCERNS ME			
3-5 YEARS OLD	2.30	.92	39
6-12 YEARS OLD	2.49	.94	218

	Mean	Std Dev	# Cases
40. TALKING OVER PERSONAL FEELINGS AND CONCERNS WITH SPOUSE			
3-5 YEARS OLD	1.97	.91	38
6-12 YEARS OLD	2.18	1.14	214
41. BEING ABLE TO GET AWAY FROM THE HOME CARE TASKS AND RESPONSIBILITIES FOR SOME RELIEF			
3-5 YEARS OLD	1.84	.62	39
6-12 YEARS OLD	1.92	.77	218
42. HAVING MY CHILD WITH THE EMOTIONAL PROBLEMS SEEN AT THE CLINIC/HOSPITAL ON A REGULAR BASIS			
3-5 YEARS OLD	2.95	1.17	40
6-12 YEARS OLD	2.94	.94	217
43. BELIEVING THAT THINGS WILL ALWAYS WORK OUT			
3-5 YEARS OLD	2.95	.78	40
6-12 YEARS OLD	2.97	.86	218
44. DOING THINGS WITH MY CHILDREN			
3-5 YEARS OLD	3.30	.68	40
6-12 YEARS OLD	3.19	.76	218

CHIP SCALES

	Mean	Std Dev	# Cases
CHIP: OPTIMISTIC PERCEPTION			
3-5 YEARS OLD	18.54	3.22	39
6-12 YEARS OLD	18.58	3.38	218
CHIP: MAINTAIN FAMILY			
3-5 YEARS OLD	31.44	4.78	39
6-12 YEARS OLD	32.05	5.52	218
CHIP: ORIGINAL MAINTAIN FAMILY			
3-5 YEARS OLD	47.00	6.56	39
6-12 YEARS OLD	47.41	7.47	218
CHIP: SUPPORT AND ESTEEM			
3-5 YEARS OLD	37.84	6.88	39
6-12 YEARS OLD	38.91	7.02	218
CHIP: UNDERSTANDING			
3-5 YEARS OLD	22.41	6.45	39
6-12 YEARS OLD	24.46	5.76	218

PROFESSIONAL COLLABORATION ITEMS

HAS THIS PROFESSIONAL:

	Mean	Std Dev	# Cases
1. SPECIFICALLY ASKED YOU FOR YOUR OPINIONS ABOUT WHAT TREATMENT AND SERVICES YOUR CHILD OR FAMILY SHOULD RECEIVE?			
3-5 YEARS OLD	2.64	1.34	39
6-12 YEARS OLD	2.56	1.35	214
2. FELT THAT YOUR VIEW OF YOUR CHILD'S DISABILITY HAS BEEN USEFUL IN MAKING DECISIONS ABOUT TREATMENT AND SERVICES?			
3-5 YEARS OLD	2.02	1.15	39
6-12 YEARS OLD	2.27	1.25	215
3. INCLUDED YOU AND YOUR FAMILY IN DEFINING GOALS FOR TREATMENT AND SERVICES FOR YOUR CHILD?			
3-5 YEARS OLD	2.02	1.14	40
6-12 YEARS OLD	2.22	1.25	213
4. DISCOUNTED OR IGNORED THINGS THAT YOU OR YOUR FAMILY MEMBERS HAVE SAID?			
3-5 YEARS OLD	4.52	.71	40
6-12 YEARS OLD	4.22	1.07	214
5. ASKED FOR YOUR PERCEPTIONS OR OPINIONS ABOUT THE SERVICES THAT YOUR CHILD AND FAMILY HAVE BEEN GETTING?			
3-5 YEARS OLD	2.87	1.41	40
6-12 YEARS OLD	2.86	1.29	214
6. MADE CHANGES IN HIS OR HER ASSESSMENT OF YOUR CHILD AS A RESULT OF DISCUSSION AND FEEDBACK FROM YOUR FAMILY?			
3-5 YEARS OLD	3.00	1.21	39
6-12 YEARS OLD	3.10	1.31	210
7. REGARDED YOU AND YOUR FAMILY MEMBERS' VIEWS OF YOUR CHILD'S DISABILITY OR ILLNESS AS IMPORTANT TO ASSESSING WHAT PROBLEMS NEED TO BE ADDRESSED?			
3-5 YEARS OLD	2.07	1.11	40
6-12 YEARS OLD	2.20	1.23	210
8. HAVE YOU OR YOUR FAMILY MEMBERS BEEN INVOLVED IN THE DEVELOPMENT OF THE TREATMENT OR SERVICE PLAN FOR YOUR CHILD?			
3-5 YEARS OLD	2.35	1.25	40
6-12 YEARS OLD	2.26	1.29	214

	Mean	Std Dev	# Cases
HAS THIS PROFESSIONAL:			
9. SPECIFICALLY ASKED YOU FOR FEEDBACK ABOUT THE WAY HE OR SHE IS WORKING WITH YOU AND YOUR FAMILY?			
3-5 YEARS OLD	2.76	1.47	39
6-12 YEARS OLD	2.97	1.43	214
10. TREATED YOU AS A VALUABLE ASSET IN YOUR CHILD'S TREATMENT?			
3-5 YEARS OLD	1.75	1.17	40
6-12 YEARS OLD	2.07	1.26	213
11. MADE CHANGES IN TREATMENT OR SERVICES ON THE BASIS OF FEEDBACK FROM YOU OR YOUR FAMILY MEMBERS?			
3-5 YEARS OLD	2.69	1.39	39
6-12 YEARS OLD	3.02	1.38	209
12. TALKED WITH YOU AND YOUR FAMILY ABOUT HOW MUCH YOUR ETHNICITY OR CULTURAL BACKGROUND SHOULD BE CONSIDERED IN DEVELOPING SERVICES OR TREATMENT PLANS?			
3-5 YEARS OLD	4.25	1.25	40
6-12 YEARS OLD	3.90	1.38	210
13. IN ACTUALITY, HAS THE SERVICE PLAN FOR YOUR CHILD AND FAMILY TAKEN INTO ACCOUNT YOUR ETHNICITY?			
3-5 YEARS OLD	3.71	1.45	39
6-12 YEARS OLD	3.58	1.39	201

	3-5 YEARS OLD		6-12 YEARS OLD	
	n	%	n	%
TITLE OF THIS PROFESSIONAL				
SOCIAL WORKER...........	13	33.3%	38	21.2%
PSYCHIATRIST............	2	5.1%	30	16.8%
PSYCHOLOGIST............	10	25.6%	68	38.0%
TEACHER.................	5	12.8%	9	5.0%
NURSE...................			2	1.1%
PHYSICIAN...............	1	2.6%	2	1.1%
CASE MANAGER............	1	2.6%	8	4.5%
OTHER...................	6	15.4%	18	10.1%
NOT APPLICABLE..........	1	2.6%	4	2.2%

SERVICE UTILIZATION CHECKLIST

	3-5 YEARS OLD		6-12 YEARS OLD	
	n	%	n	%
REGULAR CLASSROOM				
NEVER USED..............	15	39.5%	42	20.8%
USED....................	9	23.7%	62	30.7%
CURRENTLY USING.........	14	36.8%	98	48.5%
SPECIAL EDUCATION CLASSROOM/SERVICES				
NEVER USED..............	26	68.4%	97	47.3%
USED....................			35	17.1%
CURRENTLY USING.........	12	31.6%	73	35.6%
PSYCHIATRIST (M.D.)				
NEVER USED..............	15	39.5%	50	24.2%
USED....................	15	39.5%	82	39.6%
CURRENTLY USING.........	8	21.1%	75	36.2%
NURSE				
NEVER USED..............	29	78.4%	150	73.9%
USED....................	8	21.6%	47	23.2%
CURRENTLY USING.........			6	3.0%
LAWYER				
NEVER USED..............	29	78.4%	164	81.6%
USED....................	7	18.9%	27	13.4%
CURRENTLY USING.........	1	2.7%	10	5.0%
COUNSELOR				
NEVER USED..............	13	35.1%	37	18.1%
USED....................	15	40.5%	102	50.0%
CURRENTLY USING.........	9	24.3%	65	31.9%
SOCIAL WORKER				
NEVER USED..............	8	21.6%	65	31.0%
USED....................	20	54.1%	100	47.6%
CURRENTLY USING.........	9	24.3%	45	21.4%
PSYCHOLOGIST				
NEVER USED..............	13	34.2%	50	24.2%
USED....................	11	28.9%	93	44.9%
CURRENTLY USING.........	14	36.8%	64	30.9%

	3-5 YEARS OLD		6-12 YEARS OLD	
	n	%	n	%
MINISTER				
NEVER USED..............	22	57.9%	100	48.1%
USED....................	12	31.6%	80	38.5%
CURRENTLY USING.........	4	10.5%	28	13.5%
PSYCHIATRIC HOSPITALIZATION				
NEVER USED..............	35	94.6%	169	82.4%
USED....................	2	5.4%	31	15.1%
CURRENTLY USING.........			5	2.4%
RESIDENTIAL TREATMENT				
NEVER USED..............	31	86.1%	168	80.8%
USED....................	3	8.3%	29	13.9%
CURRENTLY USING.........	2	5.6%	11	5.3%
FOSTER CARE SERVICES				
NEVER USED..............	33	89.2%	189	90.0%
USED....................	4	10.8%	11	5.2%
CURRENTLY USING.........			10	4.8%
DAY TREATMENT PROGRAM				
NEVER USED..............	30	78.9%	175	85.4%
USED....................	1	2.6%	23	11.2%
CURRENTLY USING.........	7	18.4%	7	3.4%
ADVOCACY SERVICES				
NEVER USED..............	31	83.8%	181	90.5%
USED....................	6	16.2%	17	8.5%
CURRENTLY USING.........			2	1.0%
FINANCIAL ASSISTANCE				
NEVER USED..............	18	48.6%	110	53.7%
USED....................	8	21.6%	60	29.3%
CURRENTLY USING.........	11	29.7%	35	17.1%
SUPPORT OR SELF-HELP GROUP FOR PARENTS				
NEVER USED..............	27	73.0%	143	69.8%
USED....................	5	13.5%	49	23.9%
CURRENTLY USING.........	5	13.5%	13	6.3%

	3-5 YEARS OLD		6-12 YEARS OLD	
	n	%	n	%
SUPPORT OR SELF-HELP GROUP FOR SIBLINGS				
NOT APPLICABLE..........			1	.5%
NEVER USED.............	34	91.9%	176	85.4%
USED..................	2	5.4%	24	11.7%
CURRENTLY USING.........	1	2.7%	5	2.4%
CRISIS INTERVENTION				
NEVER USED.............	29	78.4%	164	81.2%
USED..................	7	18.9%	35	17.3%
CURRENTLY USING.........	1	2.7%	3	1.5%
RESPITE CARE				
NEVER USED.............	28	75.7%	174	87.9%
USED..................	6	16.2%	19	9.6%
CURRENTLY USING.........	3	8.1%	5	2.5%
OTHER SERVICES USED FOR CHILD				
NEVER USED.............			9	36.0%
USED..................	2	66.7%	5	20.0%
CURRENTLY USING.........	1	33.3%	11	44.0%

STRESS ITEMS

	Mean	Std Dev	# Cases
YOUR JOB OR CAREER (OR LACK OF SAME)			
3-5 YEARS OLD	3.52	1.75	40
6-12 YEARS OLD	3.38	1.62	213
CARING FOR YOUR HOME AND FAMILY			
3-5 YEARS OLD	4.40	1.39	40
6-12 YEARS OLD	4.00	1.31	218
YOUR MARRIAGE OR PRIMARY RELATIONSHIP OR LACK THEREOF			
3-5 YEARS OLD	3.50	1.66	40
6-12 YEARS OLD	3.47	1.63	214
FAMILY RELATIONSHIPS OTHER THAN YOUR MARRIAGE OR PRIMARY RELATIONSHIP			
3-5 YEARS OLD	3.25	1.27	40
6-12 YEARS OLD	3.15	1.56	216
YOUR CHILD(REN)			
3-5 YEARS OLD	4.07	1.57	40
6-12 YEARS OLD	3.95	1.45	218
YOUR SOCIAL LIFE AND RELATIONSHIPS WITH FRIENDS			
3-5 YEARS OLD	2.37	1.33	40
6-12 YEARS OLD	2.31	1.25	218
THE WAY YOU FEEL ABOUT YOURSELF			
3-5 YEARS OLD	3.37	1.67	40
6-12 YEARS OLD	3.13	1.56	217
FUN FROM PLEASURABLE ACTIVITIES SUCH AS MUSIC, MOVIES, HOBBIES AND SO FORTH			
3-5 YEARS OLD	2.10	1.51	40
6-12 YEARS OLD	1.78	1.19	216
YOUR PHYSICAL APPEARANCE			
3-5 YEARS OLD	2.85	1.65	40
6-12 YEARS OLD	2.66	1.45	217
YOUR WEIGHT			
3-5 YEARS OLD	3.15	1.81	40
6-12 YEARS OLD	3.07	1.62	217

	Mean	Std Dev	# Cases
THE WAY YOU MANAGE YOUR TIME			
3-5 YEARS OLD	3.05	1.64	40
6-12 YEARS OLD	2.89	1.39	217
YOUR PHYSICAL HEALTH			
3-5 YEARS OLD	2.75	1.67	40
6-12 YEARS OLD	2.77	1.49	216
YOUR LIFE IN GENERAL			
3-5 YEARS OLD	3.92	1.49	40
6-12 YEARS OLD	3.59	1.57	215

STRESS SCALE

	Mean	Std Dev	# Cases
TOTAL STRESS			
3-5 YEARS OLD	42.32	13.50	40
6-12 YEARS OLD	40.17	12.00	218

RESPONSIBILITY ITEMS

	Mean	Std Dev	# Cases
YOUR JOB OR CAREER			
3-5 YEARS OLD	2.39	1.16	28
6-12 YEARS OLD	2.26	1.05	142
CARING FOR YOUR HOME AND FAMILY			
3-5 YEARS OLD	2.35	.94	40
6-12 YEARS OLD	2.29	1.01	218
YOUR MARRIAGE OR PRIMARY RELATIONSHIP			
3-5 YEARS OLD	2.83	1.41	31
6-12 YEARS OLD	2.79	1.27	163
FAMILY RELATIONSHIPS OTHER THAN YOUR MARRIAGE OR PRIMARY RELATIONSHIP			
3-5 YEARS OLD	3.17	.87	40
6-12 YEARS OLD	2.79	1.07	212
YOUR CHILD(REN)			
3-5 YEARS OLD	2.30	1.01	40
6-12 YEARS OLD	2.33	1.02	218
YOUR SOCIAL LIFE AND RELATIONSHIPS WITH FRIENDS			
3-5 YEARS OLD	3.17	1.27	40
6-12 YEARS OLD	2.93	1.19	215
THE WAY YOU FEEL ABOUT YOURSELF			
3-5 YEARS OLD	3.22	1.27	40
6-12 YEARS OLD	3.01	1.21	216
YOUR ABILITY TO ENJOY PLEASURABLE ACTIVITIES SUCH AS MUSIC, MOVIES, HOBBIES AND SO FORTH			
3-5 YEARS OLD	3.22	1.45	40
6-12 YEARS OLD	2.87	1.19	217
TAKING CARE OF YOUR PHYSICAL APPEARANCE			
3-5 YEARS OLD	3.00	1.53	40
6-12 YEARS OLD	2.85	1.14	218

	Mean	Std Dev	# Cases
KEEPING YOUR WEIGHT AT APPROPRIATE LEVEL			
3-5 YEARS OLD	3.35	1.61	40
6-12 YEARS OLD	3.61	1.41	216
THE WAY YOU MANAGE YOUR TIME			
3-5 YEARS OLD	3.17	1.29	40
6-12 YEARS OLD	3.12	1.00	217
TAKING CARE OF YOUR PHYSICAL HEALTH			
3-5 YEARS OLD	3.10	1.39	40
6-12 YEARS OLD	3.09	1.06	217
YOUR LIFE IN GENERAL			
3-5 YEARS OLD	3.02	1.16	40
6-12 YEARS OLD	2.99	1.08	216

RESPONSIBILITY SCALE

	Mean	Std Dev	# Cases
TOTAL RESPONSIBILITY HANDLING			
3-5 YEARS OLD	38.50	11.52	40
6-12 YEARS OLD	37.16	10.08	218

PLEASURE ITEMS

SOME ITEMS OUT OF ORDER

	Mean	Std Dev	# Cases
YOUR JOB OR CAREER (OR LACK OF SAME)			
3-5 YEARS OLD	3.00	.95	32
6-12 YEARS OLD	3.00	1.04	179
CARING FOR YOUR HOME			
3-5 YEARS OLD	2.97	.86	40
6-12 YEARS OLD	2.68	.88	217
FAMILY RELATIONSHIPS OTHER THAN YOUR MARRIAGE OR PRIMARY RELATIONSHIP			
3-5 YEARS OLD	3.07	.91	40
6-12 YEARS OLD	2.82	.98	211
YOUR MARRIAGE OR PRIMARY RELATIONSHIP OR LACK THEREOF			
3-5 YEARS OLD	3.18	1.24	37
6-12 YEARS OLD	2.86	1.25	194
CARING FOR YOUR FAMILY			
3-5 YEARS OLD	2.45	.84	40
6-12 YEARS OLD	2.18	.87	214
YOUR CHILD(REN)			
3-5 YEARS OLD	2.20	.99	40
6-12 YEARS OLD	2.23	1.01	215
YOUR SOCIAL LIFE AND RELATIONSHIPS WITH FRIENDS			
3-5 YEARS OLD	2.90	.81	40
6-12 YEARS OLD	2.80	.93	214
THE WAY YOU FEEL ABOUT YOURSELF			
3-5 YEARS OLD	3.10	1.00	40
6-12 YEARS OLD	3.02	1.03	215
FUN FROM PLEASURABLE ACTIVITIES SUCH AS MUSIC, MOVIES, HOBBIES AND SO FORTH			
3-5 YEARS OLD	2.82	1.04	39
6-12 YEARS OLD	2.59	.94	216

	Mean	Std Dev	# Cases
YOUR PHYSICAL APPEARANCE			
3-5 YEARS OLD	3.17	1.17	40
6-12 YEARS OLD	3.07	.94	215
YOUR WEIGHT			
3-5 YEARS OLD	3.35	1.31	40
6-12 YEARS OLD	3.53	1.09	217
THE WAY YOU MANAGE YOUR TIME			
3-5 YEARS OLD	3.15	.92	40
6-12 YEARS OLD	3.04	.91	215
YOUR PHYSICAL HEALTH			
3-5 YEARS OLD	3.07	1.11	40
6-12 YEARS OLD	3.06	.93	215

PLEASURE SCALE

	Mean	Std Dev	# Cases
TOTAL PLEASURE SCORE			
3-5 YEARS OLD	38.42	7.56	40
6-12 YEARS OLD	36.97	8.14	216

DEMOGRAPHIC INFORMATION

	3-5 YEARS OLD		6-12 YEARS OLD	
	n	%	n	%
SEX OF CHILD				
MALE	20	50.0%	146	67.3%
FEMALE	20	50.0%	71	32.7%
DOES CHILD LIVE AT HOME?				
YES	39	100.0%	201	92.6%
NO			16	7.4%
YOUR RELATIONSHIP TO CHILD				
MOTHER	36	90.0%	175	80.6%
FATHER	3	7.5%	9	4.1%
OTHER	1	2.5%	33	15.2%
CHILD RELATIONSHIP TO RESPONDENT				
YOUR BIOLOGICAL CHILD	36	92.3%	184	87.2%
YOUR ADOPTED CHILD	3	7.7%	8	3.8%
YOUR FOSTER CHILD			10	4.7%
YOUR STEP CHILD			9	4.3%
NUMBER OF OTHER CHILDREN				
0	9	22.5%	30	13.8%
1	12	30.0%	84	38.7%
2	13	32.5%	47	21.7%
3	4	10.0%	32	14.7%
4	1	2.5%	13	6.0%
5			6	2.8%
6	1	2.5%	2	.9%
7			2	.9%
9			1	.5%

AGE OF OLDEST CHILD IN YOUR HOME

	3-5 YEARS OLD	6-12 YEARS OLD
Mean	7.43	11.40
Std dev	3.88	4.03
Minimum	2.00	5.00
Maximum	17.00	26.00
Valid cases	40	215
Missing cases	0	3

AGE OF YOUNGEST CHILD IN YOUR HOME

	3-5 YEARS OLD	6-12 YEARS OLD
Mean	3.71	7.13
Std dev	2.06	3.34
Minimum	1.00	1.00
Maximum	11.00	14.29
Valid cases	40	215
Missing cases	0	3

AGE OF RESPONDENT

	Mean	Std Dev	# Cases
3-5 YEARS OLD	32.48	7.58	40
6-12 YEARS OLD	36.45	8.65	213

	3-5 YEARS OLD		6-12 YEARS OLD	
	n	%	n	%
EMPLOYMENT STATUS				
Full Time	17	42.5%	96	44.4%
Part Time	9	22.5%	27	12.5%
Not Employed	14	35.0%	93	43.1%
PARTNER EMPLOYMENT				
Full Time	23	59.0%	107	51.7%
Part Time	1	2.6%	11	5.3%
Not Employed	3	7.7%	22	10.6%
Not Applicable	12	30.8%	67	32.4%
COMMUNITY SIZE				
LARGE CITY	7	17.9%	46	21.4%
SMALL CITY	15	38.5%	61	28.4%
TOWN	9	23.1%	44	20.5%
SMALL TOWN	1	2.6%	27	12.6%
RURAL NOT FARM	5	12.8%	31	14.4%
FARM	2	5.1%	6	2.8%
MARITAL STATUS				
MARRIED	21	52.5%	105	48.2%
WIDOWED			9	4.1%
DIVORCED	5	12.5%	52	23.9%
SEPARATED	8	20.0%	27	12.4%
NEVER MARRIED	5	12.5%	22	10.1%
OTHER	1	2.5%	3	1.4%
HIGHEST LEVEL OF EDUCATION				
Less Than 7th Grade			3	1.4%
Junior High	4	10.3%	13	6.0%
Some High School	5	12.8%	33	15.1%
High School Grad	10	25.6%	56	25.7%
Some College	5	12.8%	39	17.9%
Junior College	2	5.1%	25	11.5%
Vo-Tech	4	10.3%	32	14.7%
College Grad	5	12.8%	10	4.6%
Some Graduate School	1	2.6%	1	.5%
Graduate Degree	3	7.7%	6	2.8%

	3-5 YEARS OLD		6-12 YEARS OLD	
	n	%	n	%
PARTNER HIGHEST LEVEL OF EDUCATION				
Less Than 7th Grade.....	1	2.6%	12	5.6%
Junior High.............	2	5.1%	15	7.0%
Some High School........	2	5.1%	36	16.7%
High School Grad........	15	38.5%	59	27.4%
Some College............	4	10.3%	21	9.8%
Junior College..........	2	5.1%	8	3.7%
Vo-Tech.................	2	5.1%	7	3.3%
College Grad............	2	5.1%	7	3.3%
Some Graduate School....	1	2.6%	1	.5%
Graduate Degree.........	3	7.7%	9	4.2%
Not Applicable..........	5	12.8%	40	18.6%
RACIAL OR ETHNIC IDENTIFICATION				
American Indian.........			10	4.6%
Black...................	7	17.9%	69	31.8%
Hispanic................			2	.9%
White...................	32	82.1%	134	61.8%
Other...................			2	.9%
HOUSEHOLD'S ANNUAL INCOME BEFORE TAXES FOR 1989				
LESS THAN $5,000........	9	22.5%	47	22.3%
BETWEEN $5,000 AND $ 9,999..............	5	12.5%	21	10.0%
BETWEEN $ 10,000 AND $14,999..............	6	15.0%	44	20.9%
BETWEEN $15,000 AND $24,000..............	5	12.5%	49	23.2%
BETWEEN $25,000 AND $34,000..............	4	10.0%	30	14.2%
BETWEEN $35,000 AND $49,999..............	7	17.5%	12	5.7%
$50,000 AND OVER........	4	10.0%	8	3.8%
RELIGIOUS PREFERENCE				
PROTESTANT..............	27	69.2%	145	68.1%
CATHOLIC................	2	5.1%	9	4.2%
MUSLIM..................			1	.5%
BUDDHIST................	1	2.6%	1	.5%
OTHER...................	5	12.8%	41	19.2%
NONE....................	4	10.3%	16	7.5%

	3-5 YEARS OLD		6-12 YEARS OLD	
	n	%	n	%
FREQUENCY OF ATTENDING RELIGIOUS SERVICES DURING PAST YEAR				
REGULARLY...............	13	33.3%	82	37.6%
OCCASIONALLY............	14	35.9%	88	40.4%
ONLY ON SPECIAL DAYS....	4	10.3%	13	6.0%
NOT AT ALL..............	8	20.5%	35	16.1%
HOW RELIGIOUS ARE YOU?				
VERY RELIGIOUS..........	9	22.5%	47	21.8%
MODERATELY RELIGIOUS....	22	55.0%	119	55.1%
NOT VERY RELIGIOUS......	9	22.5%	44	20.4%
NOT RELIGIOUS AT ALL....			6	2.8%

APPENDIX B

NORTH CAROLINA FAMILY CAREGIVER SURVEY

Caring for a child can be both difficult and pleasant. Please indicate how much you agree or disagree with each of the following.

	Circle your response			
1. My child is why I met some of my best friends	Strongly Disagree	Disagree	Agree	Strongly Agree
2. My child is why I am a more responsible person	Strongly Disagree	Disagree	Agree	Strongly Agree
3. My child is the reason I've learned to control my temper	Strongly Disagree	Disagree	Agree	Strongly Agree
4. My child is responsible for my learning to be patient	Strongly Disagree	Disagree	Agree	Strongly Agree
5. My child is responsible for my increased awareness of people with disabilities	Strongly Disagree	Disagree	Agree	Strongly Agree
6. My child is fun to be around	Strongly Disagree	Disagree	Agree	Strongly Agree
7. My child is responsible for my being more aware and concerned for the future of humankind	Strongly Disagree	Disagree	Agree	Strongly Agree
8. My child is kind and loving	Strongly Disagree	Disagree	Agree	Strongly Agree
9. My child is helpful to other family members, which saves time and energy for me	Strongly Disagree	Disagree	Agree	Strongly Agree
10. My child is the reason I attend religious services more frequently	Strongly Disagree	Disagree	Agree	Strongly Agree
11. My child is the reason my life has better structure	Strongly Disagree	Disagree	Agree	Strongly Agree
12. My child is the reason I am more realistic about my job	Strongly Disagree	Disagree	Agree	Strongly Agree
13. My child is a source of pride because of his/her artistic accomplishments	Strongly Disagree	Disagree	Agree	Strongly Agree

Used with permission -- Positive Contribution - Behr, 1990

Circle your response

14. I consider my child to be helpful without having to be asked	Strongly Disagree	Disagree	Agree	Strongly Agree
15. I consider my child to be what gives our family a sense of continuity -- a sense of history	Strongly Disagree	Disagree	Agree	Strongly Agree
16. I consider my child to be an advantage to my career	Strongly Disagree	Disagree	Agree	Strongly Agree
17. I consider my child to be very affectionate	Strongly Disagree	Disagree	Agree	Strongly Agree
18. I consider my child to be what makes me realize the importance of planning for my family's future	Strongly Disagree	Disagree	Agree	Strongly Agree
19. I consider my child to be a great help around the house	Strongly Disagree	Disagree	Agree	Strongly Agree
20. I consider my child to be what gives me common ground with other parents	Strongly Disagree	Disagree	Agree	Strongly Agree
21. I consider my child to be responsible for my taking better care of myself	Strongly Disagree	Disagree	Agree	Strongly Agree
22. I consider my child to be responsible for my increased sensitivity to people	Strongly Disagree	Disagree	Agree	Strongly Agree
23. I consider my child to be the reason I am more productive	Strongly Disagree	Disagree	Agree	Strongly Agree
24. I consider my child to be the reason I budget my time better	Strongly Disagree	Disagree	Agree	Strongly Agree
25. I consider my child to be the reason I am able to cope better with stress and problems	Strongly Disagree	Disagree	Agree	Strongly Agree
26. I consider my child to be able to use good judgment	Strongly Disagree	Disagree	Agree	Strongly Agree
27. The presence of my child is an inspiration to improve my job skills	Strongly Disagree	Disagree	Agree	Strongly Agree
28. The presence of my child helps me understand people who are different	Strongly Disagree	Disagree	Agree	Strongly Agree

Used with permission -- Positive Contribution - Behr, 1990

	Circle your response			
29. The presence of my child confirms my faith in God	Strongly Disagree	Disagree	Agree	Strongly Agree
30. The presence of my child gives a new perspective to my job	Strongly Disagree	Disagree	Agree	Strongly Agree
31. The presence of my child is a reminder that all children, including those with disabilities, need to be loved	Strongly Disagree	Disagree	Agree	Strongly Agree
32. The presence of my child is a reminder that everyone has a purpose in life	Strongly Disagree	Disagree	Agree	Strongly Agree
33. The presence of my child helps me take things as they come	Strongly Disagree	Disagree	Agree	Strongly Agree
34. The presence of my child teaches others about unconditional love	Strongly Disagree	Disagree	Agree	Strongly Agree
35. The presence of my child is a source of pride because of his/ her athletic achievements	Strongly Disagree	Disagree	Agree	Strongly Agree
36. The presence of my child cheers me up	Strongly Disagree	Disagree	Agree	Strongly Agree
37. The presence of my child renews my interest in participating in different activities	Strongly Disagree	Disagree	Agree	Strongly Agree
38. The presence of my child is very uplifting	Strongly Disagree	Disagree	Agree	Strongly Agree
39. The presence of my child makes us more in charge of ourselves as a family	Strongly Disagree	Disagree	Agree	Strongly Agree
40. Because of my child my circle of friends has grown larger	Strongly Disagree	Disagree	Agree	Strongly Agree
41. Because of my child my social life has expanded by bringing me into contact with other people	Strongly Disagree	Disagree	Agree	Strongly Agree
42. Because of my child I learned about problems children may have	Strongly Disagree	Disagree	Agree	Strongly Agree

Used with permission -- Positive Contribution - Behr 1990

	Circle your response			
43. Because of my child I have learned to adjust to things I cannot change	Strongly Disagree	Disagree	Agree	Strongly Agree
44. Because of my child I am more accepting of things	Strongly Disagree	Disagree	Agree	Strongly Agree
45. Because of my child I have someone who shares responsibility for doing several tasks around the house	Strongly Disagree	Disagree	Agree	Strongly Agree
46. Because of my child I am more compassionate	Strongly Disagree	Disagree	Agree	Strongly Agree
47. Because of my child I learned more about emotional problems	Strongly Disagree	Disagree	Agree	Strongly Agree
48. Because of my child my family is more understanding about special problems	Strongly Disagree	Disagree	Agree	Strongly Agree
49. Because of my child I am grateful for each day	Strongly Disagree	Disagree	Agree	Strongly Agree
50. Because of my child our family has become closer	Strongly Disagree	Disagree	Agree	Strongly Agree
51. Because of my child I am more sensitive to family issues	Strongly Disagree	Disagree	Agree	Strongly Agree
52. Because of my child my other children have learned to be aware of people's needs and their feelings	Strongly Disagree	Disagree	Agree	Strongly Agree
53. Because of my child I have many unexpected pleasures	Strongly Disagree	Disagree	Agree	Strongly Agree

Used with permission -- Positive Contribution - Behr, 1990

Now we would like to know about the behavior of your child ________________.
(name of child)

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?			
	Circle your response				Circle your response			
B None								
a. ________________	Don't Know	Less Than Average	Average	More Than Average	Don't Know	Below Average	Average	Above Average
b. ________________	Don't Know	Less Than Average	Average	More Than Average	Don't Know	Below Average	Average	Above Average
c. ________________	Don't Know	Less Than Average	Average	More Than Average	Don't Know	Below Average	Average	Above Average

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?			
	Circle your response				Circle your response			
B None								
a. ________________	Don't Know	Less Than Average	Average	More Than Average	Don't Know	Below Average	Average	Above Average
b. ________________	Don't Know	Less Than Average	Average	More Than Average	Don't Know	Below Average	Average	Above Average
c. ________________	Don't Know	Less Than Average	Average	More Than Average	Don't Know	Below Average	Average	Above Average

III. Please list any organizations, clubs, teams, or groups your child belongs to.

	Compared to other children of the same age, about how much time does he/she spend in each?			
	Circle your response			
B None				
a. ________________	Don't Know	Less Active	Average	More Active
b. ________________	Don't Know	Less Active	Average	More Active
c. ________________	Don't Know	Less Active	Average	More Active

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?			
	Circle your response			
B None				
a. ________________	Don't Know	Less Than Average	Average	More Than Average
b. ________________	Don't Know	Less Than Average	Average	More Than Average
c. ________________	Don't Know	Less Than Average	Average	More Than Average

Used with permission - Achenbach, 1981

V. 1. About how many close friends does your child have? (Circle your response)
   a. None
   b. 1
   c. 2 or 3
   d. 4 or more

2. About how many times a week does your child do things with them? (Circle your response)
   a. less than 1
   b. 1 or 2
   c. 3 or more

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

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

VII. 1. Current school performance - If your child is aged 6 or younger please skip to the next page:

☐ Does not go to school

	Circle your response			
a. Reading or English	Failing	Below average	Average	Above aver[illegible]e
b. Writing	Failing	Below average	Average	Above aver[illegible]e
c. Arithmetic or Math	Failing	Below average	Average	Above average
d. Play and work by himself/ herself	Failing	Below average	Average	Above aver[illegible]e

2. Is your child in a special class? (Circle your answer)

   a. No

   b. Yes-what kind? ______________________

3. Has your child ever repeated a grade? (Circle your answer)

   a. No

   b. Yes-grade and reason? ______________________

4. Has your child had any academic or other problems in school? (Circle your answer)

   a. No

   b. Yes-please describe ______________________

   When did these problems start? ______________

Used with permission - Achenbach, 1981

12g

5. **Have these problems ended?** **(Circle your answer)**

a. No

b. Yes-when? ____________________

VIII. **Below is a list of items that describe children. For each item that describes your child <u>now or within the past 6 months</u>, please circle how true you feel it is.**

		Circle your response		
1.	Acts too young for his/her age	Not True	Sometimes True	Often True
2.	Allergy (describe): ______________ ______________________	Not True	Sometimes True	Often True
3.	Argues a lot	Not True	Sometimes True	Often True
4.	Asthma	Not True	Sometimes True	Often True
5.	Behaves like opposite sex	Not True	Sometimes True	Often True
6.	Bowel movements outside toilet	Not True	Sometimes True	Often True
7.	Bragging, boasting	Not True	Sometimes True	Often True
8.	Can't concentrate, can't pay attention for long	Not True	Sometimes True	Often True
9.	Can't get his/her mind off certain thoughts; obsessions (describe): ______________________ ______________________	Not True	Sometimes True	Often True
10.	Can't sit still, restless, or hyperactive	Not True	Sometimes True	Often True
11.	Clings to adults or too dependent	Not True	Sometimes True	Often True
12.	Complains of loneliness	Not True	Sometimes True	Often True
13.	Confused or seems to be in a fog	Not True	Sometimes True	Often True
14.	Cries a lot	Not True	Sometimes True	Often True
15.	Cruel to animals	Not True	Sometimes True	Often True
16.	Cruelty, bullying, or meanness to others	Not True	Sometimes True	Often True
17.	Day-dreams or gets lost in his/her thoughts	Not True	Sometimes True	Often True
18.	Deliberately harms self or attempts suicide	Not True	Sometimes True	Often True
19.	Demands a lot of attention	Not True	Sometimes True	Often True
20.	Destroys his/her own things	Not True	Sometimes True	Often True
21.	Destroys things belonging to his/her family or other children	Not True	Sometimes True	Often True
22.	Disobedient at home	Not True	Sometimes True	Often True
23.	Disobedient at school	Not True	Sometimes True	Often True
24.	Doesn't eat well	Not True	Sometimes True	Often True

Used with permission - Achenbach, 1981

		Circle your response		
25.	Doesn't get along with other children	Not True	Sometimes True	Often True
26.	Doesn't seem to feel guilty after misbehaving	Not True	Sometimes True	Often True
27.	Easily jealous	Not True	Sometimes True	Often True
28.	Eats or drinks things that are not food (describe): ______________	Not True	Sometimes True	Often True
29.	Fears certain animals, situations, or places, other than school (describe): ______________	Not True	Sometimes True	Often True
30.	Fears going to school	Not True	Sometimes True	Often True
31.	Fears he/she might think or do something bad	Not True	Sometimes True	Often True
32.	Feels he/she has to be perfect	Not True	Sometimes True	Often True
33.	Feels or complains that no one loves him/her	Not True	Sometimes True	Often True
34.	Feels others are out to get him/her	Not True	Sometimes True	Often True
35.	Feels worthless or inferior	Not True	Sometimes True	Often True
36.	Gets hurt a lot, accident-prone	Not True	Sometimes True	Often True
37.	Gets in many fights	Not True	Sometimes True	Often True
38.	Gets teased a lot	Not True	Sometimes True	Often True
39.	Hangs around with children who get in trouble	Not True	Sometimes True	Often True
40.	Hears things that aren't there (describe): ______________	Not True	Sometimes True	Often True
41.	Impulsive or acts without thinking	Not True	Sometimes True	Often True
42.	Likes to be alone	Not True	Sometimes True	Often True
43.	Lying or cheating	Not True	Sometimes True	Often True
44.	Bites fingernails	Not True	Sometimes True	Often True
45.	Nervous, highstrung, or tense	Not True	Sometimes True	Often True
46.	Nervous movements or twitching (describe): ______________	Not True	Sometimes True	Often True
47.	Nightmares	Not True	Sometimes True	Often True
48.	Not liked by other children	Not True	Sometimes True	Often True
49.	Constipated, doesn't move bowels	Not True	Sometimes True	Often True
50.	Too fearful or anxious	Not True	Sometimes True	Often True
51.	Feels dizzy	Not True	Sometimes True	Often True
52.	Feels too guilty	Not True	Sometimes True	Often True
53.	Overeating	Not True	Sometimes True	Often True

Used with permission - Achenbach, 1981

		Circle your response		
54.	Overtired	Not True	Sometimes True	Often True
55.	Overweight	Not True	Sometimes True	Often True
56.	Physically attacks people	Not True	Sometimes True	Often True
57.	Poor school work	Not True	Sometimes True	Often True
58.	Picks nose, skin, or other parts of body (describe): ________ ________	Not True	Sometimes True	Often True
59.	Physical problems without known medical cause:			
	a. Aches or pains	Not True	Sometimes True	Often True
	b. Headaches	Not True	Sometimes True	Often True
	c. Nausea, feels sick	Not True	Sometimes True	Often True
	d. Problems with eyes (describe): ________	Not True	Sometimes True	Often True
	e. Rashes or other skin problems	Not True	Sometimes True	Often True
	f. Stomach aches or cramps	Not True	Sometimes True	Often True
	g. Vomiting, throwing up	Not True	Sometimes True	Often True
	h. Other (describe): ________ ________	Not True	Sometimes True	Often True
60.	Plays with own sex parts in public	Not True	Sometimes True	Often True
61.	Plays with own sex parts too much	Not True	Sometimes True	Often True
62.	Poorly coordinated or clumsy	Not True	Sometimes True	Often True
63.	Prefers playing with older children	Not True	Sometimes True	Often True
64.	Prefers playing with younger children	Not True	Sometimes True	Often True
65.	Refuses to talk	Not True	Sometimes True	Often True
66.	Repeats certain acts over and over, compulsions (describe): ________ ________	Not True	Sometimes True	Often True
67.	Runs away from home	Not True	Sometimes True	Often True
68.	Screams a lot	Not True	Sometimes True	Often True
69.	Secretive, keeps things to self	Not True	Sometimes True	Often True
70.	Sees things that aren't there (describe): ________ ________	Not True	Sometimes True	Often True
71.	Self-conscious or easily embarrassed	Not True	Sometimes True	Often True
72.	Sets fires	Not True	Sometimes True	Often True
73.	Sexual problems (describes): ____ ________	Not True	Sometimes True	Often True
74.	Showing off or clowning	Not True	Sometimes True	Often True

Used with permission - Achenbach, 1981

		Circle your response		
75.	Shy or timid	Not True	Sometimes True	Often True
76.	Sleeps less than most children	Not True	Sometimes True	Often True
77.	Sleeps more than most children during day and/or night (describe): ____	Not True	Sometimes True	Often True
78.	Smears or plays with bowel movements	Not True	Sometimes True	Often True
79.	Speech problem (describe): ____	Not True	Sometimes True	Often True
80.	Stares blankly	Not True	Sometimes True	Often True
81.	Steals at home	Not True	Sometimes True	Often True
82.	Steals outside the home	Not True	Sometimes True	Often True
83.	Stores up things he/she doesn't need (describe): ____	Not True	Sometimes True	Often True
84.	Strange behavior (describe): ____	Not True	Sometimes True	Often True
85.	Strange ideas (describe): ____	Not True	Sometimes True	Often True
86.	Stubborn, sullen, or irritable	Not True	Sometimes True	Often True
87.	Sudden changes in mood or feelings	Not True	Sometimes True	Often True
88.	Sulks a lot	Not True	Sometimes True	Often True
89.	Suspicious	Not True	Sometimes True	Often True
90.	Swearing or obscene language	Not True	Sometimes True	Often True
91.	Talks about killing self	Not True	Sometimes True	Often True
92.	Talks or walks in sleep (describe): ____	Not True	Sometimes True	Often True
93.	Talks too much	Not True	Sometimes True	Often True
94.	Teases a lot	Not True	Sometimes True	Often True
95.	Temper tantrums or hot temper	Not True	Sometimes True	Often True
96.	Thinks about sex too much	Not True	Sometimes True	Often True
97.	Threatens people	Not True	Sometimes True	Often True
98.	Thumb-sucking	Not True	Sometimes True	Often True
99.	Too concerned with neatness or cleanliness	Not True	Sometimes True	Often True
100.	Trouble sleeping (describe): ____	Not True	Sometimes True	Often True
101.	Truancy, skips school	Not True	Sometimes True	Often True
102.	Underactive, slow moving, or lacks energy	Not True	Sometimes True	Often True
103.	Unhappy, sad, or depressed	Not True	Sometimes True	Often True

Used with permission - Achenbach, 1981

The community in which you live is important to raising children. Please indicate how much you agree with each of the following statements about your community and family.

		Circle Your Response			
1.	If I had an emergency, even people I do not know in this community would be willing to help	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
2.	I feel good about myself when I sacrifice and give time and energy to members of my family	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
3.	The things I do for members of my family and they do for me make me feel part of this very important group	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
4.	People here know they can get help from the community if they are in trouble	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
5.	I have friends who let me know they value who I am and what I can do	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
6.	People can depend on each other in this community	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
7.	Members of my family seldom listen to my problems or concerns; I usually feel criticized	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
8.	My friends in this community are a part of my everyday activities	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
9.	There are times when family members do things that make other members unhappy	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
10.	I need to be very careful how much I do for my friends because they take advantage of me	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
11.	Living in this community gives me a secure feeling	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
12.	The members of my family make an effort to show their love and affection for me	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
13.	There is a feeling in this community that people should not get too friendly with each other	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
14.	This is not a very good community to bring children up in	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
15.	I feel secure that I am as important to my friends as they are to me	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
16.	I have some very close friends outside the family who I know really care for me and love me	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
17.	Member(s) of my family do not seem to understand me; I feel taken for granted	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree

Used with permission - 1982 H.McCubbin, J. Patterson and Thomas Glynn, University of Wisconsin-Madison

Circle your response

104.	Unusually loud	Not True	Sometimes True	Often True
105.	Vandalism	Not True	Sometimes True	Often True
106.	Uses alcohol or drugs (describe): ____________________	Not True	Sometimes True	Often True
107.	Wets self during the day	Not True	Sometimes True	Often True
108.	Wets the bed	Not True	Sometimes True	Often True
109.	Whining	Not True	Sometimes True	Often True
110.	Wishes to be of opposite sex	Not True	Sometimes True	Often True
111.	Worrying	Not True	Sometimes True	Often True
112.	Withdrawn, doesn't get involved with others	Not True	Sometimes True	Often True
113.	Please write in any problems your child has that were not listed above: ____________________	Not True	Sometimes True	Often True
	____________________	Not True	Sometimes True	Often True
	____________________	Not True	Sometimes True	Often True

Used with permission - Achenbach, 1981

We would like to know more about your immediate family. Decide for your family whether you: STRONGLY DISAGREE; DISAGREE; are NEUTRAL; AGREE; or STRONGLY AGREE.

We cope with family problems by:

Circle your response

1.	Sharing our difficulties with relatives	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
2.	Seeking advice from relatives	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
3.	Doing things with relatives (get togethers)	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
4.	Seeking encouragement and support from friends	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
5.	Seeking information and advice from people faced with the same or similar problem	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
6.	Sharing concerns with close friends	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
7.	Sharing problems with neighbors	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
8.	Asking relatives how they feel about the problems we face	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree

Used with permission - 1982 H.I. McCubbin, A.S. Larsen & D.H. Olson

We would like to know which of the following you use in a difficult situation.

	Circle your response			
1. Trying to maintain family stability	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
2. Engaging in relationships and friendships which help me to feel important and appreciated	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
3. Trusting my spouse (or former spouse)to help support me and my child(ren)	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
4. Sleeping	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
5. Talking with the staff (nurses, social worker, etc.) when we visit the mental health agency/hospital	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
6. Believing that my child(ren) will get better	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
7. Working, outside employment	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
8. Showing that I am strong	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
9. Purchasing gifts for myself and/or other family members	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
10. Talking with other individuals/parents in my same situation	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
11. Eating	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
12. Getting other members of the family to help with chores and tasks at home	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
13. Getting away by myself	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
14. Talking with the Doctor about my concerns about my child(ren)	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
15. Believing that the mental health agency/hospital has my family's best interest in mind	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
16. Building close relationships with people	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
17. Believing in God	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
18. Develop myself as a person	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
19. Talking with other parents in the same type of situation and learning about their experiences	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
20. Doing things together as a family (involving all members of the family)	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
21. Investing time and energy in my job	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal

Used with permission - McCubbin, 1983

Circle your response

22. Believing that my child is getting the best care possible	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
23. Entertaining friends in our home	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
24. Reading about how other persons in my situation handle things	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
25. Doing things with family relatives	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
26. Becoming more self reliant and independent	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
27. Telling myself that I have many things I should be thankful for	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
28. Concentrating on hobbies (art, music, jogging, etc.)	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
29. Explaining our family situation to friends and neighbors so they will understand us	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
30. Encouraging child(ren) with emotional problems to be more independent	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
31. Keeping myself in shape and well groomed	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
32. Involvement in social activities (parties, etc.) with friends	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
33. Going out with my spouse on a regular basis	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
34. Being sure prescribed medical treatments for child(ren) are carried out at home on a daily basis	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
35. Building a closer relationship with my spouse	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
36. Allowing myself to get angry	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
37. Investing myself in my child(ren)	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
38. Talking to someone (not professional counselor/doctor) about how I feel	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
39. Reading more about the emotional problem which concerns me	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
40. Talking over personal feelings and concerns with spouse	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
41. Being able to get away from the home care tasks and responsibilities for some relief	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
42. Having my child with the emotional problems seen at the clinic/hospital on a regular basis	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
43. Believing that things will always work out	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal
44. Doing things with my children	Not Used	Used Somewhat	Used Quite A Bit	Used A Great Deal

Used with permission - McCubbin, 1983

Families who have children with emotional problems need a variety of services. This survey asks about family involvement and the relationship between professionals and families.

INSTRUCTIONS: Think of the professionals (such as social workers, psychologists, psychiatrists, teachers, or therapists) who are currently providing services to your child and/or family. Of these, please think of the professional with whom you have been the **most involved** and answer the following questions by circling your response.

	Circle your response				
1. Has this professional specifically asked you for your opinions about what treatment and services your child or family should receive?	A lot, from the first meeting	A lot, but after some contact	Somewhat	Only a little	Not all
2. Has this professional felt that your view of your child's disability has been useful in making decisions about treatment and services?	A lot, from the first meeting	A lot, but after some contact	Somewhat	Only a little	Not all
3. Has this professional included you and your family in defining goals for treatment and services for your child?	A lot, from the first meeting	A lot, but after some contact	Somewhat	Only a little	Not all
4. Has this professional discounted or ignored things that you or your family members have said?	A lot, from the first meeting	A lot, but after some contact	Somewhat	Only a little	Not all
5. Has this professional asked for your perceptions or opinions about the services that your child and family have been getting?	A lot, from the first meeting	A lot, but after some contact	Somewhat	Only a little	Not all
6. Has this professional made changes in his or her assessment of your child as a result of discussion and feedback from your family?	A lot, from the first meeting	A lot, but after some contact	Somewhat	Only a little	Not all
7. Has this professional regarded you and your family members' views of your child's disability or illness as important to assessing what problems need to be addressed?	A lot, from the first meeting	A lot, but after some contact	Somewhat	Only a little	Not all
8. Have you and your family members been involved in the development of the treatment or service plan for your child?	A lot, from the first meeting	A lot, but after some contact	Somewhat	Only a little	Not all
9. Has this professional specifically asked you for feedback about the way he or she is working with you and your family?	A lot, from the first meeting	A lot, but after some contact	Somewhat	Only a little	Not all
10. Has this professional treated you as a valuable asset in your child's treatment?	A lot, from the first meeting	A lot, but after some contact	Somewhat	Only a little	Not al
11. Has this professional made changes in treatment or services on the basis of feedback from you or your family members?	A lot, from the first meeting	A lot, but after some contact	Somewhat	Only a little	Not al
12. Has this professional talked with you and your family about how much your ethnicity or cultural background should be considered in developing services or treatment plans?	A lot, from the first meeting	A lot, but after some contact	Somewhat	Only a little	Not al

Used with permission - Portland Research and Training Center on Family Support and Childrens Mental Health, 1990

	Circle your response				
13. In actuality, has the service plan for you child and family taken into account your ethnicity	A lot, from the first meeting	A lot, but after some contact	Some-what	Only a little	Not all

14. What is the title of this professional?

1. Social Worker
2. Psychiatrist
3. Psychologist
4. Teacher
5. Nurse
6. Physician
7. Lawyer
8. Case manager
9. Other: ____________________

Please tell us about the services you have used for your child with emotional problems.

Type of Service	Circle your response		
Regular Classroom	Never used	Used	Currently using
Special Education Classroom/ Services	Never used	Used	Currently using
Services of a Psychiatrist (M.D.)	Never used	Used	Currently using
Services of a Nurse	Never used	Used	Currently using
Services of a Lawyer	Never used	Used	Currently using
Services of a Counselor	Never used	Used	Currently using
Services of a Social Worker	Never used	Used	Currently using
Services of a Psychologist	Never used	Used	Currently using
Services of a Minister	Never used	Used	Currently using
Psychiatric Hospitalization	Never used	Used	Currently using
Residential Treatment	Never used	Used	Currently using
Foster Care	Never used	Used	Currently using
Day Treatment Program	Never used	Used	Currently using
Advocacy Services	Never used	Used	Currently using
Financial Assistance	Never used	Used	Currently using
Support or Self-Help Group for Parents	Never used	Used	Currently using
Support or Self-Help Group for Siblings	Never used	Used	Currently using
Crisis Intervention	Never used	Used	Currently using
Respite Care (child care to give parents relief)	Never used	Used	Currently using
Other: ______________________________	Never used	Used	Currently using

Used with permission - Portland Research and Training Center on Family Support and Childrens Mental Health, 1990

We all experience some degree of distress in our lives. Think about your level of stress - the extent to which you experience pressure in each of the following areas. For each area please circle the response indicating how much stress you experience.

	Circle your response					
Your job or career (or lack of same).	None	A little stress	Some or occasional stress	Moderate stress	Quite a bit of stress	High or extreme amount of stress
Caring for your home and family.	None	A little stress	Some or occasional stress	Moderate stress	Quite a bit of stress	High or extreme amount of stress
Your marriage or primary relationship or lack thereof.	None	A little stress	Some or occasional stress	Moderate stress	Quite a bit of stress	High or extreme amount of stress
Family relationships other than your marriage or primary relationship.	None	A little stress	Some or occasional stress	Moderate stress	Quite a bit of stress	High or extreme amount of stress
Your child(ren).	None	A little stress	Some or occasional stress	Moderate stress	Quite a bit of stress	High or extreme amount of stress
Your social life and relationships with friends.	None	A little stress	Some or occasional stress	Moderate stress	Quite a bit of stress	High or extreme amount of stress
The way you feel about yourself.	None	A little stress	Some or occasional stress	Moderate stress	Quite a bit of stress	High or extreme amount of stress
Fun from pleasurable activities such as music, movies, hobbies and so forth.	None	A little stress	Some or occasional stress	Moderate stress	Quite a bit of stress	High or extreme amount of stress
Your physical appearance.	None	A little stress	Some or occasional stress	Moderate stress	Quite a bit of stress	High or extreme amount of stress
Your weight.	None	A little stress	Some or occasional stress	Moderate stress	Quite a bit of stress	High or extreme amount of stress
The way you manage your time.	None	A little stress	Some or occasional stress	Moderate stress	Quite a bit of stress	High or extreme amount of stress
Your physical health.	None	A little stress	Some or occasional stress	Moderate stress	Quite a bit of stress	High or extreme amount of stress
Your life in general.	None	A little stress	Some or occasional stress	Moderate stress	Quite a bit of stress	High or extreme amount of stress

Used with permission - Preventive Measures, Inc. - Press, 1986-1990

As you think about your life over the last few months, consider how well you have handled your responsibilities in each of the following areas? For each area please circle the response indicating how well you handle your responsibilities.

Circle your response

Your job or career (if you have one. Otherwise leave blank.)	Extremely well	Very well	Well	Somewhat poorly	Poorly	Very poorly
Caring for your home and family.	Extremely well	Very well	Well	Somewhat poorly	Poorly	Very poorly
Your marriage or primary relationship (if you have one. Otherwise leave blank.)	Extremely well	Very well	Well	Somewhat poorly	Poorly	Very poorly
Family relationships other than your marriage or primary relationship.	Extremely well	Very well	Well	Somewhat poorly	Poorly	Very poorly
Your child(ren).	Extremely well	Very well	Well	Somewhat poorly	Poorly	Very poorly
Your social life and relationships with friends.	Extremely well	Very well	Well	Somewhat poorly	Poorly	Very poorly
The way you feel about yourself.	Extremely well	Very well	Well	Somewhat poorly	Poorly	Very poorly
Your ability to enjoy pleasurable activities such as music, movies, hobbies and so forth.	Extremely well	Very well	Well	Somewhat poorly	Poorly	Very poorly
Taking care of your physical appearance.	Extremely well	Very well	Well	Somewhat poorly	Poorly	Very poorly
Keeping your weight at an appropriate level.	Extremely well	Very well	Well	Somewhat poorly	Poorly	Very poorly
The way you manage your time.	Extremely well	Very well	Well	Somewhat poorly	Poorly	Very poorly
Taking care of your physical health.	Extremely well	Very well	Well	Somewhat poorly	Poorly	Very poorly
Your life in general.	Extremely well	Very well	Well	Somewhat poorly	Poorly	Very poorly

Used with permission - Preventive Measures, Inc. - Press, 1986-1990

As you think about your life over the last few months, consider the amount of pleasure you experience in each of the following areas. For each area please circle the response indicating the amount of pleasure you experience.

	Circle your response				
Your job or career (or lack of same).	Extreme pleasure	Very much pleasure	Some pleasure	Some discomfort	Discomfort
Caring for your home	Extreme pleasure	Very much pleasure	Some pleasure	Some discomfort	Discomfort
Caring for your family	Extreme pleasure	Very much pleasure	Some pleasure	Some discomfort	Discomfort
Your marriage or primary relationship or lack thereof.	Extreme pleasure	Very much pleasure	Some pleasure	Some discomfort	Discomfort
Family relationships other than your marriage or primary relationship.	Extreme pleasure	Very much pleasure	Some pleasure	Some discomfort	Discomfort
Your child(ren).	Extreme pleasure	Very much pleasure	Some pleasure	Some discomfort	Discomfort
Your social life and relationships with friends.	Extreme pleasure	Very much pleasure	Some pleasure	Some discomfort	Discomfort
The way you feel about yourself.	Extreme pleasure	Very much pleasure	Some pleasure	Some discomfort	Discomfort
Fun from pleasurable activities such as music, movies, hobbies and so forth.	Extreme pleasure	Very much pleasure	Some pleasure	Some discomfort	Discomfort
Your physical appearance.	Extreme pleasure	Very much pleasure	Some pleasure	Some discomfort	Discomfort
Your weight.	Extreme pleasure	Very much pleasure	Some pleasure	Some discomfort	Discomfort
The way you manage your time.	Extreme pleasure	Very much pleasure	Some pleasure	Some discomfort	Discomfort
Your physical health.	Extreme pleasure	Very much pleasure	Some pleasure	Some discomfort	Discomfort

Used with permission - Preventive Measures, Inc. - Press, 1986-1990

1. What is the sex of the child you had in mind as you answered the questions in this booklet? (circle 1 or 2)

   1. MALE
   2. FEMALE

2. What is that child's birthdate?

   In what MONTH __________ In what YEAR __________

3. What is your child's grade in school? __________

4. Does that child live in your home? (Circle 1 or 2)

   1. YES
   2. NO
      If NO, where living ________________________________

5. What is your relationship to that child? (Circle 1, 2, or 3)

   1. MOTHER
   2. FATHER
   3. OTHER (specify)______________________

6. Is that child? (Circle <u>one</u>)

   1. YOUR BIOLOGICAL CHILD
   2. YOUR ADOPTED CHILD
   3. YOUR FOSTER CHILD
   4. YOUR STEP CHILD

7. How many other children do you have? _______________

8. What is the age of the oldest child in your home? ______________
   What is the age of the youngest child in your home? _______________

9. What is your age? ______ years

10. What is the amount of time you are employed? Employed means working for salary or wages. (Circle only one number)

    1. EMPLOYED FULL-TIME
    2. EMPLOYED PART-TIME
    3. NOT EMPLOYED AT THIS TIME.

11. What is the amount of time your child's other parent is employed? (Circle only one number)

    0. NOT APPLICABLE
    1. EMPLOYED FULL-TIME
    2. EMPLOYED PART-TIME
    3. NOT EMPLOYED AT THIS TIME.

12. In which county of North Carolina do you presently live?

    ____
    (Write the name of your county on the line)

13. Which of the following best describes the type of community in which you live? (Circle only <u>one</u> number)

    1. LARGE CITY (Population greater than 100,000)
    2. SMALL CITY (Population between 25,000 and 100,000)
    3. TOWN (Population between 2,500 and 25,000)
    4. SMALL TOWN (Population 2,500 or less)
    5. RURAL (Not farm)
    6. FARM

14. Which of the following best describes your current marital status? (Circle only one number)

1. MARRIED
2. WIDOWED
3. DIVORCED
4. SEPARATED
5. NEVER MARRIED
6. OTHER (Please specify) ______________________________

15. What is the highest level of education YOU personally have completed? (Circle only one number)

1. LESS THAN 7th GRADE
2. JUNIOR HIGH SCHOOL (9th GRADE)
3. PARTIAL HIGH SCHOOL (10th OR 11th GRADE)
4. HIGH SCHOOL GRADUATE
5. PARTIAL COLLEGE (AT LEAST ONE YEAR)
6. COMMUNITY OR JUNIOR COLLEGE
7. VOCATIONAL/TECHNICAL SCHOOL
8. COLLEGE OR UNIVERSITY GRADUATE (BACHELOR'S DEGREE)
9. PARTIAL GRADUATE EDUCATION (AT LEAST ONE YEAR)
10. GRADUATE PROFESSIONAL TRAINING (GRADUATE DEGREE)

16. What is the highest level of education your child's other parent has completed? (Circle only one letter)

0. NOT APPLICABLE
1. LESS THAN 7th GRADE
2. JUNIOR HIGH SCHOOL (9th GRADE)
3. PARTIAL HIGH SCHOOL (10th OR 11th GRADE)
4. HIGH SCHOOL GRADUATE
5. PARTIAL COLLEGE (AT LEAST ONE YEAR)
6. COMMUNITY OR JUNIOR COLLEGE
7. VOCATIONAL/TECHNICAL SCHOOL
8. COLLEGE OR UNIVERSITY GRADUATE (BACHELOR'S DEGREE)
9. PARTIAL GRADUATE EDUCATION (AT LEAST ONE YEAR)
10. GRADUATE PROFESSIONAL TRAINING (GRADUATE DEGREE)

17. Which of the following best describes your racial or ethnic identification? (Circle only one number)

1. AMERICAN INDIAN
2. ALASKAN NATIVE
3. ASIAN OR PACIFIC ISLANDER
4. BLACK, NOT OF HISPANIC ORIGIN
5. HISPANIC
6. WHITE, NOT OF HISPANIC ORIGIN
7. OTHER (specify) ______________________________

18. What was your household's total annual income BEFORE TAXES for the year 1989? Be sure to include income from all sources. (Circle only one number)

1. LESS THAN $5,000
2. BETWEEN $5,000 AND $9,999
3. BETWEEN $10,000 AND $14,999
4. BETWEEN $15,000 AND $24,999
5. BETWEEN $25,000 AND $34,999
6. BETWEEN $35,000 AND $49,999
7. $50,000 AND OVER

19. What is your religious preference? (Circle only <u>one</u> number)

1. PROTESTANT
2. JEWISH
3. CATHOLIC
4. MUSLIM
5. BUDDHIST
6. OTHER (Specify) ______________________________
7. NONE

20. How frequently did you attend religious services in a place of worship during the past year? (Circle only <u>one</u> number)

1. REGULARLY (Once a week or more)
2. OCCASIONALLY
3. ONLY ON SPECIAL DAYS (Christmas, etc.)
4. NOT AT ALL

21. How religious do you consider yourself to be? (Circle only <u>one</u> number)

1. VERY RELIGIOUS
2. MODERATELY RELIGIOUS
3. NOT VERY RELIGIOUS
4. NOT RELIGIOUS AT ALL

If there is anything else you would like to tell us about raising your child please use this space.

Will you be willing to participate in a follow up study and/or talk with us at a later time?

☐ Yes ☐ No

Professionals do not know enough about what it is like to parent a child with difficulties. You are one of a small number of people who is being asked to help us by sharing your parenting experiences. In order for the results to be helpful to professionals and other parents it is important that each questionnaire be completed and returned.

If you have any questions please write or call. The telephone number is (913) 864-8950.

Sincerely,

Tom McDonald
Tom McDonald
Project Director

Richard Donner
Richard Donner
Research Assistant

Family Caregiving for Children with a Serious Emotional Disability

Phase One
Technical Report

EVALUATION FORM

1. Who used the report? (Check all that apply.)

___Parent ___Educator ___Child Welfare Worker

___Juvenile Justice Worker ___Mental Health Professional

Other (Please Specify)________________________________

2. Please describe the purpose(s) for which you used the report:

____

____

3. Would you recommend use of the report to others? (Circle one)

Definitely Maybe Conditionally Under No Circumstances

Comments:________________________________

4. Overall, I thought the report was: (Circle one)

Excellent Average Poor

Comments:________________________________

5. Please offer suggestions for the improvement of subsequent editions of this report:

____

____

____

____

We appreciate your comments and suggestions. Your feedback will assist us in our effort to provide relevant and helpful materials. Thank you.

Please fold, staple and return this self-mailer to the address listed on the reverse side.

fold and staple

NO POSTAGE
NECESSARY
IF MAILED
IN THE
UNITED STATES

BUSINESS REPLY MAIL

FIRST CLASS PERMIT NO. A75 PORTLAND, OREGON

POSTAGE WILL BE PAID BY ADDRESSEE

RESEARCH AND TRAINING CENTER
REGIONAL RESEARCH INSTITUTE FOR HUMAN SERVICES
PORTLAND STATE UNIVERSITY
P.O. BOX 751
PORTLAND, OR 97207