THE INFLUENCE OF INFORMAL SOCIAL SUPPORT ON COPING, STRESS AND LIFE SATISFACTION IN MOTHERS OF CHILDREN WITH SEVERE DEVELOPMENTAL DISABILITIES

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BY

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ABSTRACT

— The trend towards family care of children with developmental disabilities has lead us to examine ways to support families. One source of help primary caregivers have available to them is informal social support. Ninety mothers of children with severe developmental disabilities, residing in four Michigan counties (two urban and two rural) were interviewed face-to-face to determine the nature and extent of their informal social support systems. The types of support investigated were perceived, instrumental, emotional, informational and network. Data were analyzed using bivariate and multivariate techniques. The findings indicate that mothers are primarily responsible for the day-to-day care of their children. However, the help they do receive is important to them. Assistance proffered to mothers comes mostly from immediate family members. Although married and working women perceive greater support from some family members, when help with daily tasks was measured, these women did not actually receive any greater assistance. Multivariate analysis revealed that perceived informal social support was associated with better ability to cope and lower levels of stress. The influence of informal social support on life satisfaction was less certain. Ability to cope was significantly correlated with decreased stress and increased life satisfaction. None of the various types of informal support explained coping, stress or life satisfaction. However, emotional support turned out to be a proxy for emotional problems, and so it was associated with higher stress, and lower coping and life satisfaction. None of the other independent variables included in the model (severity of handicap, formal support or life stress) explained the variance in the dependent variables. When actual regression coefficients were examined, it was concluded that increasing the amount of social support to mothers is not a very efficacious approach to helping them reduce their stress and improve their coping. The implications of these findings for women and for social policy and social work practice are discussed.

RÉSUMÉ

La tendance de la famille de s'occuper des enfants présentant des difficultés de développement nous a amenés à examiner les moyens de leur venir en aide. Une des sources disponibles a ceux s'occupant de ces enfants, est l'aide provenant de la famille, des amis, etc. Quatre-vingt-dix meres, avec enfants présentant des difficultés sévères de développement et résidant dans quatre comtés du Michigan (deux urabains et deub ruraux), furent interviewées, afin d'identifier la nature et l'étendue de cette aide reçue. Cinq types d'aide furent examinés: l'aide perçue, l'aide fonctionnelle, l'aide émotionnelle, l'aide informative ainsi que l'aide issue du réseau de connaissances. Les données furent analysées par les techniques d'analyse de variance multiple et de bivariance. Les résultats ont démontré que sur une base quotidienne les mères sont les principales responsables de leurs enfants. Cependant l'aide qu'elles peuvent recevoir demeure importante. Cette aide leur provient principalement des membres de la famille immédiate. Les femmes mariées et travaillant a l'extérieur du foyer percevaient l'aide que d'autres membres de la famille leur donnaient comme étant plus importante, ce qui en réalité n'était pas le cas. L'analyse de variance multiple démontra que la perception d'aide de certains membres de la famille était associée à un niveau plus élevé d'adaptation et à un niveau plus bas de stress. Le lien entre l'aide ou le support familial et la satisfaction de vie était moins certain. L'habileté de s'adapter était significativement reliée à un plus bas niveau de stress et une plus grande satisfaction de vivre. D'autre part aucun des différents types d'aide familiale n'a expliqué l'adaptation, le stress ou la satisfaction de vivre. Cependant, l'aide emotionnelle se révéla un substitut important vis-à-vis des problèmes émotionnels et était reliée à un niveau supérieur de stress et à un niveau plus bas d'adaptation et de satisfactien de vivre. Aucune des variables indépendantes incluses dans le modèle (severite du handicap, l'aide familiale ou le stress de la vie) ne purent expliquer la variance des variables dépendantes. Apres analyse des coefficients de regression on a conclu que l'accroissemvent de support social aux mères n'est pas une approche efficace de leur venir en aide, de réduire leur stress ou d'améliorer leur niveau d'adaptation. Nous présentons les implications de cette recherche pour les femmes, pour les politiques sociales ainsi que pour la pratique en service social.

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CHAPTER I

THE RESEARCH PROBLEM

Introduction

For the first time since the inception of institutions for persons with developmental disabilities[1] at the beginning of this century, families are being encouraged to care for their children with severe handicaps at home. In the past decade a number of policies, programmes, and practices have been introduced in both Canada and the United States to assist families with a disabled member. Families and their handicapped children have benefited from mandatory special education (P.L. 94-142, 1975), state sponsored family support services, limited availability of cash subsidies, positive attitudes of many health professionals towards home care, and better societal acceptance of persons with disabilities. This represents a significant shift from the experiences of parents who previously opted to maintain their disabled member at home. Prior to this period, virtually no special services were available to the family with a handicapped person remaining in the home. Public resources were expended almost exclusively for people living in institutions. This was true despite the fact that family-based care has always been the most prevalent form of care for persons with developmental disabilities.

It is estimated that the noninstitutionalized developmentally disabled population in the United States numbers 2.5 million (Boggs & Henny, 1979). However, only 243,699 persons actually live in out-of-home arrangements such as an institution or community based facility (Hauber, Bruininks, Hill, Larkin, & White, 1982). Yet public expenditure data indicate that more money is spent on the 5% of the mentally retarded population in institutions than the 95% residing in the community (Baumeister, 1970).

A number of recent events demonstrate the growing commitment of state and federal government to turn the tide away from institutional care and towards community care. In 1975 in the United States only four states provided support to families with a disabled member. Pennsylvania provided a statewide programme of family services; California and Montana had a cash subsidy programme combined with support services; and South Carolina had a cash subsidy programme alone. By 1985, there were 22 states providing support services and/or cash subsidies to families with developmentally disabled children (Bates, 1985). On the federal level there has also been a move afoot to shift financial incentives from institutional to community care. For example, the proposed Community and Family Living Amendments Bill would reallocate Medicaid dollars from institutional to community and family care by creating substantial fiscal penalties in the federal financial support for residential facilities with over 15 persons (Agosta & Bradley, 1985).

Bradley (1984) points out that the ideologies of normalization and mainstreaming, plus a number of forces which have emerged from the professional community, parent groups, and the political process, have converged to provide the impetus for deinstitutionalization. Factors important to promoting this historical shift in the field of developmental disabilities include increased evidence that (1) parents can be taught specialized skills; (2) persons with handicaps can grow and learn; (3) institutionalization has debilitating effects and is more expensive than community based care; as well as, (4) improvement in the instructional technologies for persons with disabilities; (5) the growth of politically active parent groups; and, (6) broad scale litigation brought against institutions. Thus, with the advent of deinstitutionalization has come greater emphasis on home-based care where, with specialized assistance such as financial support, respite care and parent training, families are viewed as capable caregivers (Bradley, 1984).

Certainly the movement away from institutions has not been without controversy. Bachrach (1981) notes that this social policy has been supported by both liberal and conservative forces, albeit for different reasons. On the liberal front has been a belief in and commitment to protecting the civil rights of mentally retarded individuals. Rothman (1978) refers to this as the "liberty model" which recognizes that paternalistic state intervention in the name of the common good has all too often worked against disadvantaged people by denying them their autonomy. The goal of the liberty model is "to reduce state power, to define the groups' aims in terms of rights that should be immune from interference, not the needs that ought to be fulfilled" (Rothman, 1978, pp. 91-92). For mentally retarded individuals these rights can be defined as: the right to education; the right to treatment; the freedom from peonage (Roos, 1975); and the right to live in the least restrictive environment (Turnbull, Ellis, Boggs, Brooks, & Biklen, 1981).

For more conservative factions, the appeal of deinstitutionalization has been in the ability to cut costs through what is believed to be more cheaply provided care in the community. Rothman (1978, p. 94) states, "a focus on rights may well give a new legitimacy to neglect, allowing conservatives to join in the chorus for rights, not for the sake of maximizing choice but for reducing tax-based expenditures." Bachrach (1981) suggests that this coalition of contradictory political streams may prove to be short-lived, especially during times of fiscal restraint. There is already a consensus, at least among those most concerned with the rights of developmentally disabled individuals, that the existing system of community supports is inadequate (Bradley, 1984). The battle to increase or even maintain those services and programmes currently available may be hard fought as state and federal governments attempt to contain or reduce social spending.

The State of Michigan serves as a case example of the response of states to the deinstitutionalization movement. The political stage was set for increases in family support programmes when Governor Blanchard made it a goal in his 1984 "State of the State Address" that all developmentally disabled children currently living in institutions would be returned to the community by 1986. In December 1983 he signed into law the Family Support Subsidy Act (Public Act 249) which provides a cash subsidy of $225 per month to families with severely mentally impaired, severely multiply impaired and autistic impaired children living at home. Families bringing a child home from placement can receive a one-time payment of twice the monthly subsidy amount ($450) for the purpose of preparing to return the child home. The only financial criterion is that the taxable family income not exceed $60,000 per year. Simultaneously, the state committed 2 million dollars in its 1983-84 budget for the expansion of family support services through community mental health agencies on a statewide basis.

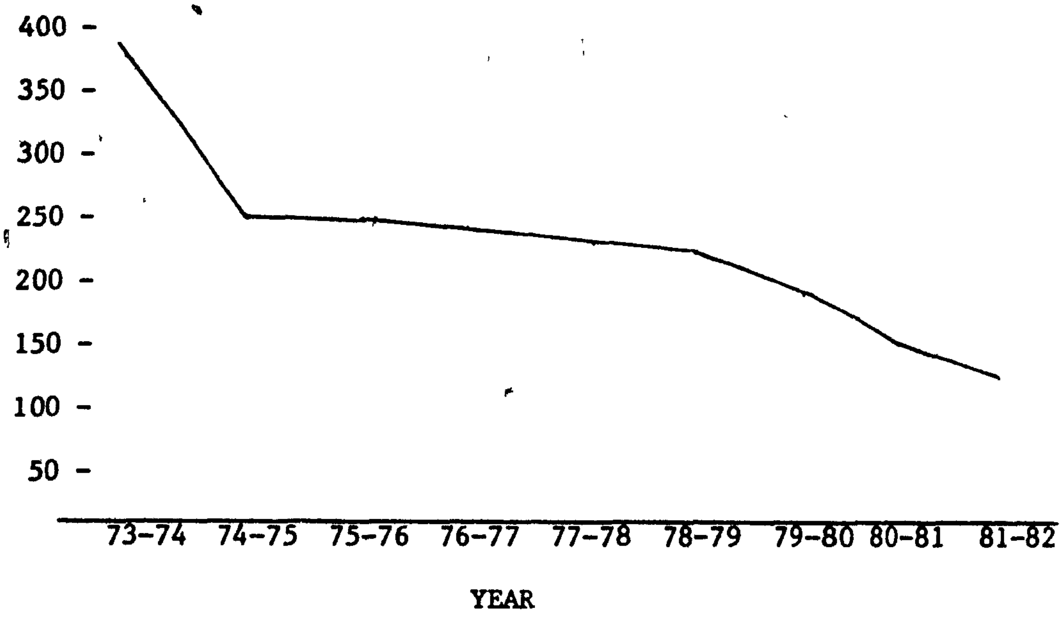
The rationale for these programmes took on both a humanitarian and cost containment argument. The following quote from an information sheet about the Family Support Subsidy Act points to both of these rationales (Stabenow, 1983).

> The Act begins to fill a gap in state funding policy which actually encourages the breakup of families. Michigan taxpayers pay expensive institutions which provide for the total needs of disabled children--health, food, shelter, clothing and special needs--and pay foster parents hundreds of dollars a month to care for other people's children. Yet, the State gives no help to parents who want to keep their own children home. Family support subsidies not

> only are more cost-effective than these out-of-home placements, but are beneficial to the child and family (p. 1).

Although the State of Michigan is now beginning to recognize the need for a statewide programme of support services for families with handicapped children, the fact is that admissions to state centres for developmentally disabled children have decreased dramatically over the past ten years. Unpublished data from the Michigan Department of Mental Health indicate that in 1973-74, 390 children were admitted to centres for the developmentally disabled while only 102 were admitted in 1981-82. During this time period, the number of children with handicaps surviving actually increased (Gortmaker & Sappenfield, 1984) therefore understating the decrease in admissions. No data are available regarding the numbers of children who are living in settings other than state institutions. It is likely, however, that some children who would have previously resided in regional centres are in foster care, nursing homes or with the biological family. Figure 1 shows the number of handicapped children admitted to Michigan Regional Centers over a ten year period (Unpublished Michigan State Department of Mental Health Data).

Figure 1.1. Admissions of children 0 to 17 years to regional centres, 1973-82.



Clearly, there is considerable effort, both at the state and federal level, aimed at encouraging care of children with developmental disabilities in the natural family. The rationale for these programmes, consistent with the deinstitutionalization movement generally, exists in two realms. The first contains the humanitarian argument which recognizes that handicapped children have the same right to be raised by their natural parents as other children, even if this requires special services and supports to be achieved. Furthermore, it is believed that parents of handicapped children should have the option of raising their children at home. Moroney (1983) reminds us that:

> Despite the rhetoric of choice and preferences for the disabled and their families, priority (resources) has been given to institutional care. And yet, the evidence is that most families favor home care over institutional care, that they actually are providing a supportive environment for their disabled members whether they are

> severely retarded or elderly parents, and that they are doing so with little support from the organized health and welfare system (p. 212).

The second rationale for these programmes is the belief that family based care is cheaper than that provided in institutions or other out-of-home placements and therefore should be promoted. However, home care will only be cheaper as long as the state does not establish a system of community services to families which reaches the level of funding previously allocated to institutions. The argument presented by Representative Stabenow is that the state pays for food, shelter, clothing and health care when the child is institutionalized. The state can presumably save money by returning a child home where the family then assumes responsibility for these basic needs. Consequently, home care is potentially less costly for the state and more financially expensive for the family.

This reshaping of state policy regarding persons with developmental disabilities is occurring, however, at a time when families are smaller, more mobile and more likely to have a mother who is working outside the home. All of these factors potentially make home care more taxing because families have fewer internal resources such as siblings, extended family or a caregiver who does not hold another job upon which to draw. As a result of the state policy to promote family care, women, who usually take primary responsibility for the care of children, may be exploited because of their dual role as primary caregiver and wage earner. Furthermore, those women who do not work outside the home are providing a service for which they do not receive compensation and which may prevent them from pursuing employment. On the other hand, if families have always preferred home care, even when they had to manage with few formal resources, a state policy to provide those resources could be viewed as supporting the preferences of families. Of course, the latter view assumes that parents do not place their children because they prefer not to, as opposed to reasons such as absence of acceptable community placements or lack of awareness of residential services. Finch (1984) argues that is is "profoundly insulting" to assume that the many women caring for their dependent relatives are doing so out of choice. Rather, she states that if a range of alternatives really existed some women as well as some men would choose to care for their vulnerable family members.

While it is well documented that raising a child with handicaps creates financial, social and psychological stress for the family, there is no clear consensus on how to ameliorate this stress. The goal of family support services to this population is to enable families to care for developmentally disabled members by providing the necessary social and financial supports to sustain the family structure, foster healthy family relationships, and reduce the burden of care (Herman, 1984). An underlying assumption of this goal is that family support services will forestall or prevent out-of-home placement. Yet, the question remains as to which services, provided in what amounts, in what format, will make it possible for families to maintain their children at home while at the same time preserving the quality of life for the entire family.

There are a number of services which generally fall under the rubric of family support. They include: respite care; counselling; transportation; homemaker services; and cash subsidies. Few studies have been conducted to test the efficacy of these interventions. In part this is due to the fact that the unit of attention has just recently been defined as the family. When institutional care dominated little attention was paid to the needs of the family; consequently interventions were almost always directed at the individual. As is often the case, families cannot wait for researchers to decide which interventions will best meet their needs. Commonsense dictates that a core set of supports, such as those mentioned above, should be available. However, much work must be done to determine the best mechanisms for delivering those services.

Yet there is evidence that many families do not receive support services and when they do, services alone do not contribute greatly to improved quality of life for the family. A recent study of 100 Michigan families with severely handicapped children examined family use of both formal and informal supports.[2] Those services most often used were provided directly to the handicapped child and were usually part of the school programme such as speech, physical and occupational therapies. Also among frequently used services was health care which can be viewed as a necessity, especially for severely handicapped youngsters. Only a handful of families (0-10%) reported using what are typically family support services, that is respite care, training in how to care for the child, counselling and homemaker services. In fact, respite care, which is considered the cornerstone of family support services, had not been used by 95% of the families in the past month and 88% said that they had not used respite care in the past year. However, the number of services received did not positively influence quality of life, coping or stress. The only factor which significantly moderated the amount of perceived stress the mother was experiencing was the amount of informal support used by the mother.[3] On all measures of stress and coping, there were no significant differences by marital status, income level, level of child's functioning or age of mother (Marcenko & Meyers, 1985).

If these findings are true, then an important determinant of family functioning may be the degree to which family, friends, neighbours, parent groups, and co-workers provide support to mothers. Viewing family support from this broad perspective adds to the complexity and possible variations which exist among families with a disabled member. Designing policies and programmes which address the needs of families, while at the same time recognizing the differences among families, presents a substantial challenge to the field. Creating an effective system of support requires an understanding of the ways in which families construct their own system of support. The purpose of the formal system should be to build upon the existing strength of the family and augment the naturally occurring system where necessary. Professionals can be guided by the family's definition of their own needs rather than the service system's standardized approach to meeting needs. Formal interventions, to be beneficial, must account for the variations in the ways in which families organize their lives to cope with the demands of a child with special needs. This requires maximum flexibility in the delivery of family support services and active involvement on the part of families. Programmes which are rigid in their criteria for admission and implementation run the risk of excluding families in need or being rejected by the families themselves.

Due to the recent trend towards natural family care and away from institutional or out-of-home placement for children with handicaps, and the concomitant availability of resources which had previously been committed to institutional care, an opportunity to address the needs of this population in innovative ways is presented. Yet little is known about families' own system of informal supports and their personal strategies for coping with the demands of a child with special needs. These strategies are influenced by social, cultural, psychological and economic factors, and are important when considering how the formal system of supports should interface with the informal system. However, the process of providing social support, and how it operates to enhance functioning is not well understood. Data which explore both the relationship between social support and coping, and the processes by which support is given, are needed in order to guide intervention strategies (Brownell & Shumaker, 1985).

The research questions which emerge from this discussion are:

> How important is the informal social support system in promoting coping moderating stress and enhancing life satisfaction for the primary caregiver of a severely handicapped child? and

What is the nature of the informal social support system of the primary caregiver with a severely developmentally disabled child?

The Yield and It's Relevance to Social Policy

If policies and programmes in the area of support to families are to help families maintain their disabled children at home and improve the quality of life for all family members, knowledge of how families actually manage on a day-to-day basis with the demands of a handicapped member is essential. Data about the potentially powerful system of informal supports mothers avail themselves of, and the relationship of that system to stress, coping and life satisfaction, are lacking in the literature. The proposed research will inform public policy by identifying various aspects of the informal support system and the degree to which they act to moderate stress and enhance life satisfaction. Furthermore, the study will produce information about how families cope which will prove useful to policy makers, programme planners, social work practitioners and advocates for persons with developmental disabilities.

Policy makers and programme planners concerned with the development of policy and the design of services for this population will be able to utilize data about the relative strengths and limitations of the informal support systems families employ. These data will assist them in formulating policy and programmes which more appropriately address the needs of families. Furthermore, information regarding families' current use of formal services, and the barriers they experience to taking full advantage of services, will help them fashion a more effective system of care.

The major role of the social work practitioner working with families who have a severely disabled member is case management. This important social work function attempts to assist families in bringing together informal and formal supports necessary to care for a handicapped person. From this study, the practitioner will learn about the role of informal support in moderating stress and enhancing life satisfaction for the primary caregiver of a handicapped child. The practitioner will have a better understanding of the needs and coping styles of various family constellations, such as the single parent family as compared to the two parent family. The characteristics of families at risk for low social support will also be identified, providing the social worker with practical mechanisms for targeting social work intervention to those with the greatest probability of need. Furthermore, the advocate will be presented with evidence about the needs and stresses of families caring for a handicapped child, the gaps and limitations of the informal system, and the areas in which families need assistance from the formal system.

The Broader Implications of the Social Policy to Promote Family Care of Severely Disabled Children

Explored in greater detail in this study will be the relationship between social policy and the consequences of policy for those it is meant to serve. Specifically, the policy of providing state support to encourage family care of severely disabled children will be examined in terms of its implications for the family and particularly the female caregiver. For instance, the state preference for providing care for persons with developmental disabilities only when they resided in an institutional setting resulted in removal of many handicapped persons from their families and often severed family ties. Similarly, the practice of maintaining children with handicaps at home has implications for the family unit and the primary caregiver. Severely disabled children do not achieve independence as other children do. As a result, the primary caregiver may find herself in a position of providing long-term care to her dependent child while sacrificing her own goals and aspirations.

The shift in public policy from institutional to family care at this point in history is especially noteworthy. Our notion of what constitutes a typical family has changed. There are at least four prototypes of the American or Canadian family; the traditional two parent family; the single parent family; the blended family consisting of children from two previous marriages; and the teenage parent family. Each of these family constellations carries with it special needs, problems and strengths. One approach to assisting such a diverse group of families is inadequate. Data about how these various family types cope are required to determine what additional support they would find most beneficial in their attempts to provide a growth promoting environment for themselves and their handicapped member.

At the same time as the family is being redefined, medical advances are saving the lives of infants who previously would have died.

Concomitant with the deinstitutionalization movement and consistent with its aims is home care for medically challenging and often technology dependent children. These children, had they survived in the past, would have typically been cared for in an acute care setting such as a hospital or a skilled facility like that of a nursing home. Home care of these very sick and dependent children, many of whom will live to adulthood, creates a need for information about how to support the family caring for such a child across the life cycle. The current study will shed light on how the primary caregiver uses her informal social supports to deal with the often extraordinary demands of a severely disabled youngster.

FOOTNOTES

[1] The term "developmental disabilities" is defined by United States Federal Law (PL 95-602, Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978) and refers to substantial functional limitation in three or more areas of major life activity. The most common developmental disability is mental retardation. Other developmental disabilities include cerebral palsy, epilepsy, and autisim if they result in functional limitations in three or more spheres. Throughout this document the terms disabled, handicapped and child with special needs will be used interchangeably with developmental disabilities. For a full definition of developmental disabilities, see page 119.

[2] These findings emerged from a longitudinal study of the impact of a Michigan programme of cash subsidies for families with severely developmentally disabled children. The study will be discussed in greater depth in Chapter III.

[3] Throughout this document the terms "female primary caregiver" and "mother" will be used interchangeably. Actually, five of the primary caregivers are not the biological mother of the child, but a grandmother or sibling.

CHAPTER II

REVIEW OF THE IMPACT ON FAMILY LITERATURE

Introduction

The purpose of this chapter is to establish that caring for a child with severe developmental disabilities is stressful for the family. The body of literature which examines the impact upon the family caring for a child with developmental disabilities spans more than thirty years. During that period several factors have changed including the availability of family support services, general acceptance of deinstitutionalization and community or family-based care, the attitudes of professionals regarding the feasibility and benefits of family care, and passage of legislation such as that which mandates education for all handicapped children. These factors have meant greater support for families raising a child with developmental disabilities at home and more opportunities for children to grow and develop within the natural family unit or community. Therefore, in a critical look at the literature on the consequences for families with a handicapped child, it must be kept in mind that earlier research does not accurately reflect the environment which exists today and may thus overstate the feelings, perceptions and hardships which family members express or experience.

Research which examines the stress of raising a handicapped child has documented the adverse social, psychological, physical and financial consequences for the family. This review will focus on literature which deals with the impact upon the family caring for a disabled child from the standpoint of: burden of care and psychological stress, especially for the primary caregiver; financial strains; time constraints; the marital relationship; consequences for the siblings; labour force participation of the mother; and concerns and worries of the parents regarding their handicapped child.

There is another body of literature which identifies the differences between families of institutionalized children and those whose children are living at home. This research highlights the factors which increase the risk of children being placed out of the home. Presumably there is greater stress in families electing placement which makes the topic of study worthy of inclusion within this review of the literature.

The Impact Upon the Family Caring for a Child with Developmental Disabilities

This subsection will consider both how the family experiences caring for a handicapped child, and to a lesser extent, how the family milieu influences the development of a handicapped child. The areas to be reviewed include the general impact of the child on family plans, social activities and leisure time, in addition to the influence of the child's condition upon the marital relationship, siblings, parental mental health and maternal labour force participation. Special attention will be paid to child characteristics which contribute to stress in the spheres of family life mentioned above.

Much of the early research on developmental disabilities was retrospective and descriptive, exploring broadly the impact upon the family caring for a handicapped child (Blacher, 1984). Furthermore, the devalued position of persons with developmental disabilities was emphasized in this beginning work as it dealt primarily with the negative impact upon the other family members to the exclusion of the consequences for the disabled child. For example, a 1956 survey of 50 Australian families which examined the effect of moderately (IQ = 55 to 35) and severely or profoundly (IQ 35) retarded children between the ages of 5 and 15 upon the family unit, focused on the following variables: first observations of the retardation; behaviour difficulties; type of assistance desired by the family; understanding of the child's retardation; the effect of the mentally retarded child on family plans, leisure time, home management and routine; school adjustments; housing; and adjustment to work (Schonell & Watts, 1956).

The families had registered with Queensland Subnormal Children's Welfare Association, and their children were living at home and not attending school. The researchers found that the presence of a retarded child had a negative impact upon family members. In terms of family plans, the areas of greatest inconvenience were mothers' shopping arrangements and curtailment of visits to the homes of other people with 58% and 50% respectively reporting these difficulties. Twenty-eight percent of the families had relocated to accommodate the educational, medical and special environmental needs of the child. Evening leisure activities were affected for 28% of the families, while 52% found it impossible to indulge in daily social activities. Thirty-two percent of mothers said they had no help of any kind with their children and 36% stated the desire to call upon someone else occasionally to gain relief from the constant caring demands placed on them. The most pressing worry for 27% percent of mothers was what would happen to their mentally retarded child once the parents were unable to care for him or her.

Although this survey was one of the first systematic investigations into the areas of family life affected when a mentally retarded child is present, it suffers from some methodological limitations. First, the results of this study are not easily generalized due to the method of sample selection. The authors allude to the fact that many of the parents who became members of the Association did so because of the announced opening of a centre for children sponsored by this organization. Therefore, the families participating in the study may differ in significant ways from all families with mentally retarded children residing in Brisbane, Australia. Second, the exclusion of a control group of similar families with nonhandicapped children leaves open to question the extent to which all families are disrupted by the presence of a child 5 to 17 years of age and how much disruption is actually attributable to the mental retardation. In spite of these criticisms, this study outlined the areas of greatest concern to parents, serving as a guide to subsequent research.

Another early study explored the extent to which the birth of a child with a developmental disability caused parents to limit subsequent births (Holt, 1958). All families of a mentally retarded child born after 1939 and residing in Yorkshire, England were contacted. Of 201 families interviewed, additional pregnancies were possible for 160 families; of those, 20 were said to be indifferent, 39 desired more children and 101 did not. Ninety of the 101 who stated they did not want additional children attributed their decision to the presence of a retarded child. Those parents most willing to have more children were under 30 years of age and those for whom the retarded child was the first-born. The reasons given by those parents who had decided to limit their family size included: no more children were wanted anyway (n=11); fear that subsequent children would be similarly affected (n=33); and amount of work required to care for the disabled child (n=57).

Although it is clear that the presence of a mentally retarded child influenced parents' decision to limit family size, it is not known how many fewer children are actually born to these families compared to their counterparts in the general population due to the lack of a control group. Furthermore, the results of this early study are not fully applicable to our current situation because of advances in the field of genetics. For those 33 parents who feared that other children born to them would be retarded, genetic counselling could have proven extremely helpful.

McAllister, Butler, and Lei (1973) explored differences between families with and without a behaviourally retarded child along two dimensions of familial interaction, the social activity of parents with children in nuclear families, and the interaction of parents with the neighbourhood and community. The sample was selected through a stratified random sample of a California city with an approximate population of 100,000. Included were 1,065 Anglo families with at least one child under 16 years of age living at home. Of the 2,305 children identified, 360 were judged to be behaviourally retarded. To determine intrafamilial social activity, parents were asked how often they read stories and talked with their children about friends and problems. The data support the hypothesis that in families where there is a behaviourally retarded child present, interaction between parent and child is less frequent. Extrafamilial interaction of parents was measured by membership in voluntary organizations and interaction with relatives, friends, and co-workers. There were no significant differences between the families compared in terms of participation in formal community organizations or frequency of visits with friends and co-workers. However, parents of behaviourally retarded children were less likely to visit relatives and neighbours.

Although the sample was large and randomly selected, this study draws conclusions regarding intrafamilial social activity which are based on weak data. There is no evidence that reading stories to children or talking with children about problems and friends are valid measures of internal social solidarity. Indeed, families may engage in any number of activities which are satisfying to its members but are not reflected in the data available here. Even in situations where parents frequently discuss problems with their children, this may not predict group cohesion.

Another issue which the authors admit but dismiss as not important, is the fact that behavioural retardation may be a manifestation of the lack of family interaction instead of being specifically attributable to the presence of a retarded child. An additional weakness of this research lies in its inability to control for confounding variables such as socioeconomic status, age and family size. These demographic factors may influence the degree to which families engage in the activities measured. Furthermore, behavioural retardation could be linked to socioeconomic status, again confounding the results. In summary, the findings of this study may be specious due to substantial methodological limitations.

Several authors have considered the impact of having a developmentally disabled child on the marital relationship. In one such study, Tew, Payne, and Laurence (1974) found that the marital relationship was negatively effected in their longitudinal research comparing 59 families with a child having a major neural tube malformation to 58 families without a handicapped child. Families were matched for community of residence, social class, sex of the child and family size. At the time of the child's birth, 70% of both groups of parents reported a satisfactory marital relationship. By the time the children were nine years old, 46% of parents of handicapped children and 79% of the control group parents had satisfactory relationships. The difference was found to be highly significant. Severity of the child's condition was also found to affect marital harmony. There was more marital strife in families with severely disabled children as compared to families with moderately impaired children. Among the families with disabled children there had been seven divorces while only three divorces had occurred in the control group. Furthermore, all three of the mothers without a handicapped child had subsequently remarried and only one of the mothers of the handicapped children had remarried. This suggests that mothers caring for handicapped children may have difficulties remarrying.

In another study, Korn, Chess, and Fernandez (1978) looked at the impact of children's physical handicaps on marital quality and interaction in families with children who had sequelae of congenital rubella between three and six years of age. Forty families, classified as experiencing distress as measured by evidence of parental discord, serious disruption in such family routines as social and recreation activities, or deterioration of interpersonal relations, were compared to 40 other families with children having the same condition but not experiencing difficulties in family life style. Handicapping characteristics of the child were the most significant predictors of family distress. These characteristics included type and number of physical handicaps, mental retardation, behaviour disorder or whether the child was temperamentally a difficult child. Analysis by sociofamilial attributes showed that impaired marital quality and family interaction was somewhat higher among Black and Jewish families; where the family was middle class by income levels; where services for the family and children are seen as inadequate by the parents; and where there is a favourable attitude towards abortion.

The results of this study suggest that degree of child disability may be an important a predictor of marital quality and interaction. Yet the researchers report that in the larger sample of 162 families from which the two groups of 40 families were taken, only two families reported the onset of severe marital discord after the handicapped child was born. Therefore, the birth of a handicapped child may not have caused marital distress but may have exacerbated an already existing problem. The authors suggest that professionals often focus on pathology and neglect to see that the impact of a disabled child is not necessarily distressing or degenerating to the family unit. In terms of the sociofamilial characteristics which predicted marital difficulties, correlations did not provide much guidance in identifying families at-risk as significant characteristics could have been confounded by other variables.

In contrast to studies which indicate a negative or neutral impact, some research has shown that the marital relationship is strengthened when a child with handicaps is present. Kazak and Marvin (1984) compared 56 families with a child having a major diagnosis of spina bifida with a group of 53 families matched for age of child. The only significant difference between the two groups of families was in income with the study group having a lower family income ($17,900 versus $29,500). Analysis of the subscales of the Dyadic Adjustment Scale indicated that those parents with a handicapped child felt there was significantly greater affection and concensus in the marriage.

There have been a series of studies which measure the psychological implications for the mother with a handicapped child, many controlling for the type or severity of the child's disability. In one such study, Cummings, Bayley, and Rie (1966) studied four separate groups to determine the effect of various types of child difficulties upon the personality of the mother. Included were four samples of 60 mothers, each of whose child was either mentally retarded, chronically ill, neurotic or healthy. Those who met the criteria for acceptance into the study were: part of an intact family; natural mother of the child; mother of more than one living child, with half or more of her children in a healthy status; families with a handicapped child in the age range 4 to 13; white or Black; and upper middle to upper-lower socioeconomic status. Maternal personality traits measured were: general self-esteem; esteem related to the maternal role; concern about the child's health; discomfort in caring for the child; child-rearing orientation; and interpersonal satisfaction. Results indicate that mothers of children with any deficiency, whether it be illness, neuroses or mental retardation, were at greater risk for psychological stress than were mothers of healthy controls. Those showing the most marked signs of distress were mothers of neurotic children, possibly reflecting the interaction between maternal and child neuroses. Mothers of mentally retarded children fared slightly better psychologically, but when compared to healthy controls, they were much more depressed, preoccupied with their child and displayed difficulty handling anger at the child. They also felt much less competent in their maternal role and gained less enjoyment from their child. Age and sex differences of the children did not yield any significant differences in maternal psychological states.

This study is well designed, using standardized, reliable tests, with adequate sample sizes. However, bias has been introduced in that mothers of mentally retarded children were recruited from parent associations. The researchers state that these parents are more militant and may actually possess higher morale than the general population of parents with retarded children. Thus, the findings of this research may understate the actual psychological stress experienced by mothers of mentally retarded children.

In a study of 51 mothers of children with spina bifida, Tew and Laurence (1971) also considered the relationship between severity of the child's handicapping condition and maternal stress. At the severe end of the continuum were children who were incontinent, were unable to ambulate, had an IQ less than 80, and were attending a special school. The mild category consisted of children who ambulated unaided and who were totally continent, while the moderate group was made up of children who ambulated with aids and who were only partially continent. Children ranged in age from 9 to 15 years. Mothers were asked to complete a 24 question malaise inventory which measures emotional states including stress and depression. The researchers found that when the children were severely disabled, their mother's emotional state was significantly affected. Mothers of those children judged to be moderately handicapped did not register higher scores on the malaise inventory than those who were classified as mildly handicapped. A control group was not available; consequently, it is not known whether mothers of moderately and mildly involved children are negatively affected when compared to mothers of normal children. The child characteristics most significantly related to maternal distress were incontinence and an IQ below 80. The authors hypothesize that incontinence creates a particularly stressful set of circumstances for the mother due to prolonged dependency of the type often associated with infancy.

Dorner (1975) researched the relationship of physical handicaps to stress and depression in mothers with an adolescent with spina bifida. Using the malaise inventory with 63 mothers of children between 13 and 19 years, Dorner found this group to score twice as high as would be expected for the general population. Divorce, however, did not occur more frequently within the group of families having a physically handicapped child than for the general population. Mothers who admitted to being depressed did not associate their depression with the demands of a handicapped child but cited reasons such as bereavement, illness, and menopause. The author explains this finding by suggesting that mothers with a disabled child may be more vulnerable to stress than other mothers. In other words, although mothers with handicapped children are not expected to experience stressful life events more frequently than mothers of nonhandicapped children, when a stressful event occurs it exacerbates an already difficult life situation.

Bradshaw and Lawton (1978) also used the malaise inventory with 303 mothers randomly selected from a population of 25,000 families who had applied to the Family Fund in England between 1972 and 1977. The Family Fund was established to relieve stress in families with a handicapped child by providing cash subsidies. The mean malaise scores of the mothers studied was more than twice the mean score for the general population. However, contrary to Tew and Laurence's findings, mother's malaise scores did not differ by the severity of the handicapped child's condition. Furthermore, there was no significant variation between one and two-parent families. Mothers who did score significantly lower on the malaise inventory were those who were able to do paid work, while mothers who wanted to work but could not and those who stayed at home and did not want to do paid work, had higher scores. The variations between working and non-working mothers was the largest observed in the analysis. The amount of informal support in assisting in the care of the handicapped child was also an important factor in reducing stress as measured by the malaise inventory. Yet, contact with a social worker, a type of formal support, was associated with higher scores. The authors speculate that either social workers are concentrating their efforts where they are most needed, with mothers who are depressed, or their interventions are ineffective and may in fact increase stress.

Bradshaw and Lawton (1978) conducted a second study to validate these results. They asked 199 mothers to complete the malaise inventory before application to the Family Fund and again after financial help was received. The mean malaise score was the same for this sample as it was for the first group of 303 mothers. Furthermore, there was no significant difference between scores before and after receipt of the money, demonstrating that money as an intervention alone may not reduce depression in mothers.

Although not using the malaise inventory, Beckman (1983) considered the relationship between characteristics of the handicapped child and stress experienced by the family in 31 parents of developmentally disabled infants. Mothers were interviewed to determine if the amount of stress reported was related to: a slower rate of development; less social responsiveness; more difficult temperament; more repetitive, stereotypic behaviour patterns; and additional or unusual caregiving demands. Two separate instruments were used to measure stress, the Questionnaire on Resources and Stress and the Holmes and Rahe Schedule of Recent Experience. Findings indicate that maternal stress was significantly related to all negative child characteristics except the rate of developmental progress. Scores obtained on the Holmes and Rahe Scale, however, bore no significant relationship to child characteristics. The author comments that the two instruments may measure different types of family experiences but she does not discuss what those experiences are. One might assume that recent life changes are not any more likely to occur in families with infants who have severe developmental disabilities. Beckman did find that the only demographic variable significantly related to stress was single parent status. She hypothesizes that since stress is associated with the total number of caregiving demands, single parents are more vulnerable because they do not have the assistance of a spouse.

Research in the field of developmental disabilities has seldom taken an interactional approach to understanding the relationship between the severity of the child's handicapping condition and family stress. An exception is a study by Nihira, Meyers, and Mink (1980) which examined the interaction between mentally retarded children; their home environment; and family adjustment. The sample consisted of 114 trainably mentally retarded (TMR) children and 152 educable mentally retarded (EMR) children and their families. Both groups of families were comprised of 75% whites and 25% minorities. All children were residing in their natural homes with married parents. Data were collected using standardized instruments and structured interviews. It was found that the more socially and adaptively competent the child, the better the coping skills of the parents. Concomitantly, when parents felt that the mentally retarded child had not had a negative impact on the family, children displayed greater social and adaptive competence.

Conceptually, this study establishes the mutual and interactional aspects between child behaviour and family coping. Other research has placed coping in a framework which focuses on the impact of child characteristics upon family stress and coping. Using an interactional framework allows for the influence of the family's ability to cope upon child social and adaptive behaviour.

Waisbren (1980) investigated the difference in parents' reactions after the birth of a developmentally disabled child and a nonhandicapped child. Thirty families with a developmentally disabled child less than 1.5 years old were compared with 30 families with a nonhandicapped child. Subjects were drawn from both California and Denmark and matched on socioeconomic status and the child's birth order, sex and age. All subjects were white. Parents completed written questionnaires and were interviewed. This is a departure from most other studies which are based primarily on interviews with mothers and it consequently contributes a more balanced picture of parental perceptions. Waisbren found that parents with and without a developmentally disabled child were similar in their reports of their physical health, social activities, activities with the baby, marital relationships, and plans for the future. However, parents of a handicapped child evaluated themselves more negatively after the baby's birth and expressed more negative feelings about their child compared to parents with nonhandicapped children.

The strength of this study lies in the fact that cases and controls were well matched and the data actually reflect the thoughts and feelings of both parents. As with any retrospective study, one cannot be certain that the reported differences were not present before the birth of the developmentally disabled child. However, there is no reason to believe that for well matched groups that the differences are not associated with the birth of a handicapped child.

Although it is generally believed by professionals that mothers with a developmentally disabled child will be impeded in their ability to participate in the labour force, few controlled studies have been done to test this assumption. However, Breslau, Salkever, and Saruch (1982) investigated the relationship between presence of a disabled child in the home and maternal employment. Included in the study were 369 families of children with cystic fibrosis, cerebral palsy, myodysplasia, and multiple physical handicaps who were attending specialty teaching clinics in Cleveland, Ohio. A control group was comprised of 456 Cleveland families with children in the same age range as the experimental group. Data were obtained through structured interviews with mothers. Analysis showed that among married women caring for a child with a disability there was an interaction with race and income. For Black women, and low-income families, it reduced the probability of labour force participation while increasing the probability of employment among white women and high-income families. However, low income and Black wives who were employed outside the home worked longer hours, as compared to high income and White mothers. Labour force participation of single mothers was not significantly affected by child disability either alone or in interaction with income or race.

The Cleveland study supports the theory that low income and Black wives caring for a handicapped child will be negatively affected in their ability to participate in the labour force, yet upper income and white mothers will participate in greater numbers than their counterparts without a handicapped child. It is difficult to interpret the results of this study without further knowledge of the public programmes for handicapped children in Ohio and Cleveland, the cultural issues which may be operating, and the financial costs of caring for severely physically handicapped children. Reduced employment on the part of low income wives may have more to do with the criteria for inclusion into public programmes such as Medicaid than the extra demands of a severely handicapped child. If mothers must forego the benefits of means tested programmes, such as Medicaid, when they enter the work force, this could act as an important disincentive to working outside the home. Children with handicaps are likely to require frequent and ongoing health services, thus mothers must weigh the risks of being without Medicaid against the benefits of employment.

On the other hand, upper income women may participate in the labour force more frequently than their counterparts without a disabled child for any number of reasons. The financial drain of a handicapped child could necessitate another income to maintain the standard of living they desire, or working may be a way of coping with the demands of a dependent child. The latter explanation is consistent with Bradshaw and Lawton's (1978) finding that women who worked were less depressed than those who did not work outside the home. Regarding the finding that Black wives worked more hours than their white counterparts, it is hypothesized that this phenomenon relates to the lower earnings of Black men as compared to white men. Consequently, Black women have to work more hours than white women to offset the lower income of their husbands. A limitation of this study is that only family income is reported instead of female and male contribution to the total.

Therefore, it is not possible to test this hypothesis. Nonetheless, it appears that low-income women and Black women may enter the labour force less frequently when a handicapped child is present, while upper-income and white women to join the labour force in greater numbers. More quantitative and qualitative data are needed to determine the extent, meaning and consequences of these findings. It can be concluded that women with disabled children will respond to a host of social, psychological and economic factors when making a decision to enter the work force. It cannot be assumed that the demands of a handicapped child will impede labour force participation for all women, in fact, some groups of women may actually experience incentives to working outside the home.

Much of the research on families with handicapped children reports the experiences of white, middle class, two-parent families. Little data are available on the impact upon poor, single-parent families who are members of ethnic minorities. The exception is a study by Eheart and Ciccone (1982) which considered the special needs of thirty-six low-income mothers of developmentally delayed children ranging in age from 12 to 56 months. Approximately 50% of the children were severely to profoundly delayed, while the other half of the sample consisted of children who were mildly to moderately delayed. Using a largely open-ended questionnaire to interview mothers, the researchers probed issues of time, finances, parenting, relationships and other general concerns. They found that 80% of mothers reported their children took extra time, especially for basic care. Only mothers with severely delayed children stated that they had financial problems related to their child. The majority (81%) of mothers felt they were good or very good parents. Most said they had someone to talk with about their child and 75% of those mothers who were married felt the child had no impact or a positive influence on their marriage. The greatest area of concern to parents was help in understanding their child's potential development.

The small sample size, coupled with the lack of a comparison group of either low-income mothers without a handicapped child or high-income mothers with a delayed child makes it difficult to draw any meaningful conclusions from this study. The concerns and issues voiced by this group of low-income mothers echo the concerns of all mothers with a developmentally delayed child.

That children living in poverty are more likely to show developmental retardation is well established (Deutsch & Brown, 1964). In an attempt to measure the differences in home stimulation by mothers of infants living in poverty relative to those living in more economically advantaged situations, Ramey, Mills, Campbell and O'Brien (1975) compared two groups of families. A low-income group of 30 mothers and children was compared to 30 mother-child dyads from a stratified random sample drawn from the general population. Subjects were matched on age and sex of infants, and live birth parity. Demographically, the high-risk group consisted of all Black families, the majority of whom did not have a high school education and for whom the average annual income was $1,500. The general population sample was predominately white, mostly college graduates, with an average annual income of $10,780. An instrument which required direct home observation and interviews measured maternal warmth, absence of punishment, organization of environment, appropriate toys, maternal involvement and opportunity for variety. The data revealed that the general population group scored significantly better on all factors.

The difficulty with studies such as this is not in the methodology or the reliability of the measure but in the narrowness of the focus. Research which specifically links maternal behaviour to developmental retardation fails to recognize the social, psychological, cultural and economic factors which contribute to the ways in which mothers behave towards their infants and also the influence of poverty on the child and family. It is instructive to contrast the demographic characteristics of both groups. The control parents earned an average income which was seven times that of the poverty group. One could assume that families with an income of $1,500 are having difficulty meeting even basic needs whereas the control parents have many more material resources. Furthermore, without so much as a high school education, the opportunities for employment and consequently freedom from poverty are limited. Men who are not employed and unable to adequately support their families are viewed negatively by the larger society and may have feelings of frustration and anger. These factors potentially create additional stress for fathers and the entire family. Focusing on the larger social context as opposed to the phenomenon of maternal-child interaction allows an evaluation of the social factors which contribute to developmental retardation and reside outside the family unit but nonetheless impinge on maternal behaviour. Furthermore, interventions which are designed to address home stimulation alone miss important social issues.

Schilling, Kirkham, Snow and Schinke (1986), studied 33 single - and 48 married mothers of handicapped children to determine if the two groups differed with respect to stress, life satisfaction and perception of the child. Mothers with handicapped children between the ages of 2 and 10 were recruited as volunteer participants and asked to complete questionnaires and to be interviewed. The two groups of mothers differed significantly in that single parent families had fewer children, less living space, lower incomes, were less likely to own their homes and were in occupations with lower prestige than mothers in two parent families. There were no differences in age and education of mothers or in the age and race of the handicapped child. Total scores on all subscales did not reveal any significant differences between single and married mothers. Holroyd's short form Questionnaire on Resources and Stress, which measures parent and family problems, pessimism, child characteristics and physical incapacitation, did not distinguish the two groups. Total scores on the Feetham Family Functioning Survey (FFFS) or Quality of Life also did not differentiate the groups, although several individual items on both scales reached significance. The FFFS items which separated single mothers from married mothers suggest that single mothers have more time pressures and feel unsatisfied and estranged from significant others. On the Quality of Life Survey, single mothers differed from married mothers on items related to social and economic factors. The authors conclude that single mothers experience social, familial and economic pressures which are generic in nature and not necessarily related to the burden of care posed by a handicapped child. They assert that family support interventions cannot overcome inadequate economic and institutional supports.

To this point in the literature review, studies which illuminate the relationship between the presence of a developmentally disabled child and parental reactions have been discussed. However, an area also explored in the literature has been the experience of the siblings of children with handicaps. In one such study, 71 siblings of children with Down's Syndrome or cleft palate were compared with 71 individually matched school age children to determine if siblings of handicapped children displayed more emotional and behavioural problems than other children (Gath, 1972). Analysis of interviews with mothers and behavioural ratings by teachers did not distinguish the two groups of children. The author notes that children with cleft palate are not usually considered handicapped because the condition can be surgically corrected early in the infant's life. Children with Down's Syndrome, however, have an impairment which is not correctable, is associated with mental retardation and is visually identifiable. Yet siblings of children with Down's Syndrome did not show an increase in emotional problems over those siblings of children with cleft palate or controls. It is difficult to make generalizations from this study since the sample of children with a sibling with Down's Syndrome is small (n=36), and families who maintained their handicapped children at home during a time when institutionalization was common may differ in significant ways from those who placed their children. Still the evidence supports that siblings of handicapped children do not necessarily manifest more emotional problems then other children.

In a descriptive study of 86 families with a child having spina bifida, Richards and McIntosh (1973) also found that the majority of siblings were not negatively affected by the presence of a handicapped child. The researchers were able to interview all families with a surviving child born with spina bifida between 1964 and 1968 and still residing at the time of the study in Glasgow, Scotland. In 70 families with children in addition to the handicapped child, 63 parents described siblings as understanding and helpful and 7 saw their nonhandicapped children as resentful, jealous or cruel. In 17 of the families, the diminished amount of attention given to siblings was said to affect their behaviour negatively, however, researchers judged only brothers and sisters in six families to be deprived. In no instances were friends of siblings found to restrict their visiting.

Consistent with the the studies previously cited, Gayton, Friedman, Tavormina and Tucker (1977) found that siblings of children with cystic fibrosis did not suffer any negative psychological consequences in terms of their own development. Forty-three families with children having cystic fibrosis ranging in age from 5 to 18 years were selected from a patient list of 73 families at the University of Rochester Medical Center. Psychological tests administered to both the children with cystic fibrosis and their healthy siblings did not reveal personality dysfunction in either group of children. Furthermore, when the chronically ill children were compared to their siblings, no significant differences were found with the exception of one of 22 variables on one test. The researchers note that this difference is questionable given the number of comparisons made.

Summary of Impact Literature

Research into the characteristics and experiences of families caring for developmentally disabled members is extensive. Studies document that family members often feel the impact through increased social and psychological stress, social isolation and financial strain. Women, due to their role as primary caregiver, appear to sacrifice the most both personally and professionally. A number of studies have shown that mothers caring for a child with developmental disabilities shoulder a great deal of the physical and emotional burden in meeting the special needs of their children on a day-to-day basis. Concomitantly, they can be expected to manifest more symptoms of depression than would be expected in the general female population. Working outside the home has been associated with a healthier psychological state in one study, but when maternal labour force participation was considered in another study it was found that Black and low-income wives with handicapped children worked outside the home less often than their counterparts with a nonhandicapped child. White and high-income mothers, on the other hand, worked more frequently than matched controls. This is an interesting and largely unexplored line of inquiry in the mental retardation literature. It is often assumed by professionals that mothers with a handicapped child will be impeded in their ability to participate in the labour force due to the caregiving demands placed upon them. At least one study indicated that this may only be true for some mothers. More research is needed to determine how, and under what circumstances, mothers are affected in their opportunities for employment and further education and training.

It is difficult to draw conclusions with any certainty about the specific impact of a child with developmental disabilities on the family based on a review of the literature. Research has sometimes yielded contradictory and confusing findings due to the exclusion of control groups and the use of instruments which are of unknown reliability and validity (Crnic, Friedrich, & Greenberg, 1983). Additionally, the method of sample selection usually employed has made it difficult to make generalizations to the entire population of families with developmentally disabled children. Parent associations, volunteers, and hospital clinics have served as a ready source of subjects. Few studies have actually drawn samples from the general population of handicapped children and their families. Consequently, bias as a product of self-selection is a nagging problem. The usual method of sample section has led to a plethora of research on white and middle-class families and a dearth of research on the problems confronting minority and low-income families. It seems fairly clear, however, that mothers of severely handicapped children will experience more stress than those mothers of less involved children or nonhandicapped children. Specifically, greater functional limitations such as the child's inability to toilet, feed, ambulate and speak is associated with elevated levels of maternal stress. This is logical in light of the fact that these child characteristics require mothers to meet basic dependency needs of their children over a prolonged period of time.

Research into the influence of a child with special needs upon the marital relationship has produced conflicting results. Basically, we know that some parents report increased tension in their relationship while other parents feel that they have been drawn closer together. It is probably safe to conclude that under most circumstances the presence of a handicapped child will exacerbate already occurring marital problems but not necessarily create problems where they had not previously existed. Furthermore, the single mother confronted with caring for her handicapped child alone will usually experience more stress than married women and the single mother will likely find her opportunities for remarriage diminished over other single parents.

Much of the research to date has been cross-sectional, providing data about the life circumstance of families at one point in time. This approach has not yielded information about how families cope with the demands of a handicapped child over the life cycle. A developmental framework which samples family experiences at various points in the handicapped child's life would contribute to our understanding of issues confronting families and the coping strategies they employ longitudinally. Another obvious void in the literature is research which seeks to understand the direct impact upon the father with a handicapped child. Some research has been done in this area (Tallman, 1965; Waisbren, 1980; Erickson, 1976) but much more is known about the experiences of mothers rather than fathers. This phenomenon can be attributed to the fact that women have traditionally assumed the role of primary caregiver and as such have been the focus of concern. Furthermore, since they are usually responsible for taking their children to appointments and because they are home with their children and available for interviews, they have generally been more accessible to researchers.

The literature supports that siblings of children with handicaps do not necessarily exhibit greater psychological or behavioural problems. In all of the studies cited, siblings of handicapped children did not show an increased risk for emotional difficulties or score more poorly on psychological tests than control groups of children without a handicapped sibling.

Finally, from a conceptual perspective, this literature has not sought to explain the various interrelated factors which contribute to family stress and coping. By and large, only a few dimensions of the problem have been studied to the exclusion of other possible intervening factors such as the availability of informal and formal support, developmental stage of the child and family, or cultural and ethnic characteristics. Furthermore, the mutual interaction of child characteristics and family stress has not been considered. The direction of the relationship has been assumed to be from child to family and not from family to child. It was noted earlier that this conceptual approach may be indicative of the devalued position of people with handicapping conditions in society. Farber (1968) has suggested that a study of family life from the perspective of persons with mental retardation may provide many insights into the nuances of family life and kinship.

Family and Child Characteristics Associated with Out-of-Home Placement of Children with Developmental Disabilities

There is a considerable body of literature which considers the differences between families with children who are placed out-of-home and families with children who are cared for at home. Much of the early work was exploratory and documented the price families pay for maintaining their handicapped member at home. As stated previously, conditions, attitudes, and the availability of services were quite different in the 1950's than they are now, therefore limiting the degree to which the results from these early studies can be generalized to current families. Nevertheless, the data contribute to our understanding of the areas of family life potentially affected when a child with developmental disabilities is living with or apart from the family. Later studies on this topic are better controlled and more focused. Yet much of the research comparing institutionalized and non-institutionalized populations has been done retrospectively, that is, after the family member has been placed. This approach does not permit comparisons of families while the developmentally disabled individual is actually in the home, nor does it illuminate the conditions and issues which led to institutionalization. Ideally, longitudinal research which follows a cohort of developmentally disabled people over time would identify factors contributing to institutionalization. However, with a low incident event this design is unrealistic and expensive because it requires following a large cohort for several years.

An early social survey investigated the problems faced by parents of severely and profoundly retarded individuals residing in London, England between 1950 and 1954 (Tizard & Gard, 1961). A stratified random sample of families with a retarded individual living at home was compared with 100 families with a similar member who had been institutionalized between one and five years. Subjects were stratified by age and sex and information was collected through an interview, usually with the mother, and from records. Although there were no differences in social class as measured by the occupation of the principal wage earner, 25% of the home group was classified as poor compared with 13% of the institutionalized group ($p < .001$). There were two reasons for this difference. First, the presence of an additional dependent drained family resources even after accounting for government subsidies. Second, in 22% of the home families, the presence of a retarded family member prevented mothers from participating in the labour force. In terms of family size, approximately one-third of mothers intended to avoid having additional children, a decision they attributed directly to the birth of the mentally retarded child. Social contacts were severely limited for 15% and limited for 30% of those with a mentally retarded person at home. The corresponding figures for the institutional group were 2% and 24% ($p < .01$). The study also compared overall family problems including housekeeping, money, housing, overcrowding, family structure, social contracts, mother's mental and physical health, and health of father and siblings. In families with a retarded member at home, 66% had three or more of the above problems compared with 45% of those receiving institutionalized care ($p < .001$). In summary, those parents who maintained their mentally retarded offspring at home were more likely to be poor, have mothers whose labour force participation was restricted, limit family size, be confined in their number of social contacts, and have three or more family problems.

Hobbs (1964) studied differences in family characteristics and attributes of the mentally retarded person in 27 institutionalized and 23 non-institutionalized individuals. The two groups were compared in the following areas: anti-social behaviour; special education opportunities; family conformity to societal standards; broken home; educational background of parents; rejecting attitudes of parents; and family size. Subjects ranged in age from 13 to 25 years and had IQs from 45 to 78. Hobbs found that the institutionalized group had a significantly higher incidence of anti-social behaviour, fewer opportunities for education, and more often came from single parent families which suffered from unemployment, alcoholism, and family quarrelling. Conclusions from this early study must be regarded as tenuous since the purpose was exploratory and no attempt was made to control for confounding variables such as socioeconomic status. Furthermore, sample sizes were small and this retrospective study does not measure the effect of institutionalization upon the family or the developmentally disabled individual. For instance, more frequent anti-social behaviour exhibited by the institutionalized group may be a manifestation of the institutional experience rather than a pre-existing characteristic which led to out-of-home care.

In an effort to understand the relationship between the family conditions prior to institutionalization of the mentally retarded member and the probability that the member would be released to his family, Mercer (1966) studied two groups of families. A group of patients who had been released to their families after a period of institutionalization was compared to a matched group of patients who remained in the hospital setting. Sixty-three cases (released) and 70 controls (institutionalized) were matched on age, sex, IQ, length of hospitalization and ethnicity. Findings indicate that the only significant difference prior to institutionalization between the still-institutionalized and released groups were in the category of burden of care, with the families of the institutionalized group reporting the higher burden. Included in this catagory were variables such as mother exhausted by care, required constant attention, cost of support, medical care, and frequent seizures requiring attention. Although the relationships were in the expected direction, there were no significant differences between the two groups on such issues as interpersonal conflict, concern about the welfare of the patient, and structural stress in the family or marital status. This study is much better controlled than Hobb's (1964) research since groups were matched on several variables. Therefore, conflict within the family, single parent status and degree of disability were not shown to be as important as burden of care in contributing to prolonged institutionalization.

Research has also attempted to measure differences between families with and without an institutionalized member in terms of the marital relationship and tension experienced by the siblings of the mentally retarded person. Fowle (1968) compared 35 families in which the mentally retarded child had been placed in an institution with 35 matched families who had retained their child at home. Matched variables included chronological age and sex of the child, socioeconomic status and background of the family and geographic location of the family dwelling. The children ranged in age from 3 to 17 years and all families were residents of two adjoining counties in California. Both groups of families were measured on marital integration and sibling role tension. The data indicate that marital integration for both groups was remarkably similar. However, when the Farber Sibling Role Tension Index was used with siblings between the ages of 6 and 17, it was discovered that sibling stress was significantly greater in those families who maintained their retarded child at home ($p < .003$). When the data were analyzed by sex of the oldest sibling at home, the oldest female sibling of the home group manifested significantly higher tension than the oldest female controls. For oldest male siblings there were no significant differences between cases and controls. Fowle concludes that the presence of a retarded child has a more profound effect on the oldest daughter than the oldest son. It is not clear what family dynamics contribute to greater role tension for the oldest daughter since this was not a focus of the study. One might hypothesize that the eldest female child would bear disproportionate responsibility for the care of her mentally retarded sibling resulting in role tension.

In one of the few cohort studies which has been conducted on this topic, Eyman, O'Connor, Tarjan and Justice (1972) followed a group of 143 mentally retarded children for five years to determine which factors were associated with institutionalization. The children who were admitted to placement differed significantly on five variables from those who were not. The institutionalized group generally had IQs less than 53, were younger, had more physical disabilities and adaptive behaviour failures, and were of Anglo background. However, this study was potentially biased by a drop-out rate of approximately 40% and a resultant small sample size, especially of institutionalized children, which equalled only 30 subjects who were available for study upon follow-up.

Other researchers have also discovered a relationship between behavioural problems and placement. A recent study compared case record material of families requesting out-of-home placement with those requesting increased services but not placement (Tausig and Epple, 1985). The sample was divided into two groups for the purposes of analysis, those persons 21 years old or younger and persons 22 years old or over. Independent variables studied included degree of disability, stress in the family, and family structure. Income and race were not recorded. Results show that for those 21 years and under, the presence of behaviour problems is the most significant predictor of placement requests. Other important factors contributing to placement included, age (older individuals), number of diagnosed disabilities, disruption of family relations, family mental health problems, and number of children under six years old (fewer children, more requests).

This study is important for the number of interrelated variables which were simultaneously explored. Research into individual and family characteristics and other stressors increases our knowledge of the relative importance of each of these factors. Furthermore, a comprehensive examination of the family and disabled child permits the development of a profile representing families at risk for placement, a potentially useful guide to programme planners, providers and consumers.

The major limitations in this study are related to the secondary characteristics of the data. These data may not address the questions which the research seeks to answer. Case records generally suffer from inconsistencies, inaccuracies, and missing information. An example in this study is the absence of income and race data. It may be assumed that the researchers would have preferred to collect this information and it was not available to them.

Summary of Impact and Placement Literature

The literature to date strongly supports that the child characteristics associated with out-of-home placement and increased family stress are severe disability and disruptive behaviour. The data are mixed with regard to age and sex of child, but the evidence suggests that these are far less important issues for families. However, it may be that behaviourally difficult children are at greater risk for placement as they reach adolescence because parents find management more problematical due to size and strength of the child. Since most of the research comparing institutionalized and non-institutionalized populations is retrospective, it is not possible to determine whether observed differences between persons with developmental disabilities are a result of the venue of care or if the differences existed prior to out-of-home placement. For example, there is ample evidence to support that institutional care can have deleterious effects on people with mental retardation (Conroy & Bradley, 1985). Institutionalized individuals may therefore appear to be more severely disabled or behaviourally disruptive then they would have had they been cared for by the natural family or in a community placement.

Family characteristics associated with out-of-home placement include single parent status, mental or physical health problems of other family members or internal family problems. Another factor which may explain differences between families with and without an institutionalized member is local policies and practices regarding placement. For instance, it was the policy at a major institution in Michigan to allow admission of severely or profoundly retarded children simply because they were part of a single parent family (Jaslow, Kime, & Green, 1966). The rationale for this policy was that "the limit of parental attention would probably not help him (the retarded child) in self-care training with the resources today available to a working single parent" (p. 4). Thus, one would expect to find more children of single parents institutionalized at this facility. Many practices in organizations are not made explicit but nonetheless influence the population served. It is unknown to what extent such practices may have biased the results of the studies reported here. Some caution should be exercised in making the logical theoretical leap that out-of-home placement occurs only in families where there is greatest stress and that the demographic differences between the groups point to the sources of that stress.

In terms of the variation in impact upon the family having a child with developmental disabilities living either with or apart from the family, several issues have been identified. Consistent with studies cited earlier. the marital relationship is not negatively affected when a mentally retarded child is cared for at home as opposed to an out-of-home setting. However, Fowle (1968) found that the eldest female child experienced greater stress when her handicapped sibling lived at home, possibly reflecting increased responsibility placed upon her. Financially, those with their disabled child at home suffer due to their responsibility for meeting the basic and special needs of their child. When the family member is placed out-of-home, many of these needs are assumed by the state. Furthermore, to the extent that mothers or other primary caregivers are unable to work outside the home, family income is reduced.

A few central themes regarding how the family is affected by a developmentally disabled member have emerged in the first two sections of this review. Children who are more functionally limited and exhibit greater behavioural problems contribute to family stress and are more likely to be placed out-of-home. This is logical since these factors mean increased burden of care for the primary caregiver, usually persisting over the life cycle of the handicapped person. At the same time, single parent families experiencing internal conflict often have fewer emotional, physical, and financial resources to deal with the extraordinary demands of a severely disabled member. Consequently, if these family and individual characteristics are both present there is a substantial risk of high family stress or out-of-home placement. Formal and informal support to these families at risk are potentially important factors in reducing family stress and preventing out-of-home placement. Subsequent sections of the review will examine the relationship between informal social support and family stress.

CHAPTER III

REVIEW AND CRITIQUE OF THE THEORETICAL MODEL

Introduction

The purpose of this chapter is to present and critique the Double ABCX Model of Adjustment and Adaptation, the theoretical framework which will be employed in this research to explain the relationship between family stress, social support and adaptation. Following a review of the theoretical framework, will be a review of two bodies of literature. Reviewed first will be research which attempts to test the Double ABCX Model. Secondly, research which examines the role of informal social support and its various forms in promoting adaptation, will be reviewed. Next, the issue of causality between informal social support and health outcomes will be examined. The chapter will conclude with specific research questions and hypotheses which emerge from the literature review, and a concise statement regarding the operationalization of the Double ABCX Model.

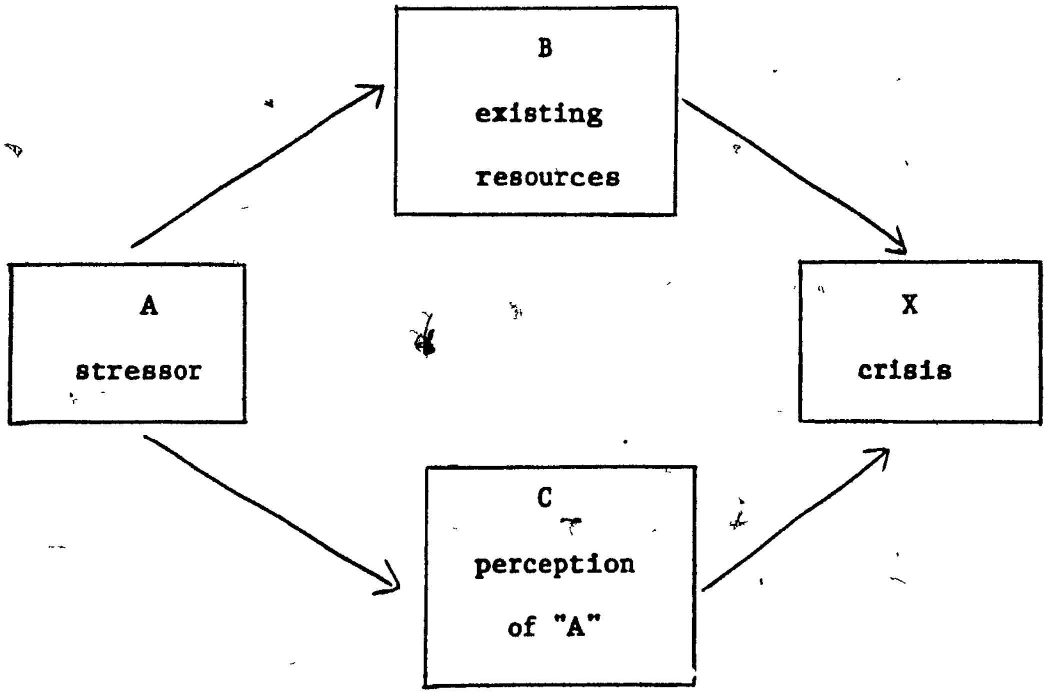
Theoretical Framework

Based upon a review of the impact on family literature, it has been firmly established that caring for a child with severe developmental disabilities creates stress for the family unit. Although the initial discovery that the child has a handicap produces an acute crisis for the family, it is expected that the family will continue to experience stress due to the constant caregiving demands of its dependent member. Olshansky (1962) has used the term "chronic sorrow" to describe the feelings families experience over time regarding the child with handicaps. Having established the stressor, it is now necessary to focus the concepts of stress and adaptation within a theoretical framework which explains the relationship between these two variables. In the field of developmental disabilities, crisis theory has been widely used as a theoretical model to explore family adaptation to the strain of caring for a child with disabilities. This theory will be used as the basis for the design and study of the research questions which emerge from the review of the literature.

Rueben Hill (1958) was the forerunner in the conceptualization of a model for understanding the reactions of families to social stresses. His theoretical framework grew out of a longitudinal study of families where the husband/father was separated due to armed services duty during World War II. Hill's model has been useful to mental health professionals because it offers an explanation of the factors which lead to a stressful event ultimately being experienced as a major or minor crisis for the family.

To consider this model carefully, it is first necessary to define the family. Hill (1958) views the family system as "an interacting and transacting organization" (p. 139). It consists of individuals interacting and organized around positions, norms and roles, engaged in transactions with groups and associations outside of its boundaries. Given this definition of the family, the notion of a crisis-precipitating event is introduced. Hill calls this a stressor (A), or a situation for which the family has had little or no preparation. The stressor (A) interacts with the family's crisis-meeting resources (B) which in turn interacts with the definition the family makes of the event (C) to produce the crisis (X). Hill's model is presented in Figure 2.1.

Figure 3.1 The Hill ABCX family crisis model.

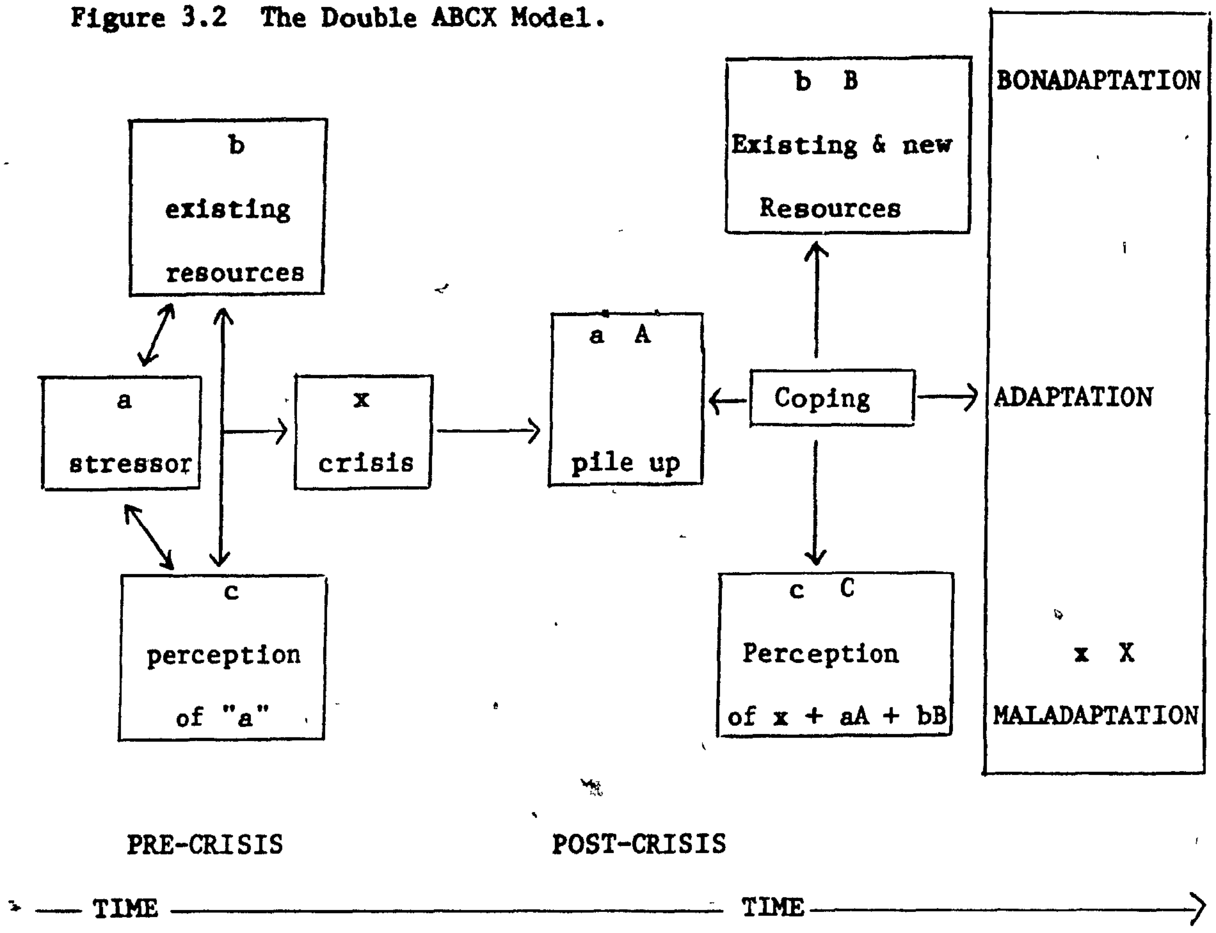


Resources and perception of the event are seen as internal attributes of the family. The resources which a family possesses include family integration, affection, and a sense of economic interdependence. Informal social support also falls under the rubric of resources. These family strengths provide resistance to stressors. To decipher how the A and B factors influence the magnitude of the crisis one must closely examine the amount and type of resources available and the meaning family members attach to the stressor. With regard to the B factor, or perception of the stressor, not all families view an event in the same way; therefore, in order for a crisis to ensue, the precipitating factor must be seen as stressful. Family perceptions are shaped by values, norms and cultural background. The initial crisis and its attendant hardships are seen as lying outside the family. Hill's work, while establishing a basic framework for understanding the family in crisis, lacks the power to fully explain why families will react differently to a crisis. Furthermore, the Hill model does not account for the multitude of other factors affecting the family's response nor does it provide a view of family adaptation longitudinally.

McCubbin and Patterson (1983b), building on the work of Hill, have developed the Double ABCX Model, a multivariate theoretical framework for understanding family adaptation to stress. It is called the "Double" ABCX Model because it adds a second post-crisis factor to all four parts of the original Hill Model. This conceptualization seeks to guide the family researcher through the process of identifying "how much and what kinds of stressors; mediated by what personal, family and community resources and by what family coping responses; and what family processes shape the course and ease of family adjustment over time" (p. 7). McCubbin and Patterson define a stressor as a life event which results in actual or potential change for the family system. This differs slightly from Hill's concept of a stressor as a situation for which the family is not prepared. The Double ABCX Model also expands Hill's original framework by adding a longitudinal perspective to the family in crisis. It incorporates both a retrospective or pre-crisis component and a post-crisis component. The four post crisis variables include: (a) the additional life stressors which shape family adaptation; (b) the psychological, intra-familial, and social resources families employ to manage crises; (c) the change in meaning families develop to make sense out of the predicament; (d) the coping strategies families use; and (e) the possible outcomes of these family efforts.

While Hill developed the original ABCX Model from his observations of families where the husband/father was separated during World War II, McCubbin and Patterson (1983b) expanded the concept to the Double ABCX Model based on their study of 216 families experiencing the same phenomenon during the Vietnam War. Conceptually, Double ABCX is a dynamic model which accounts for changes in structure, perception, and outcome families make pursuant to the initial crisis. A schematic representation of Double ABCX is pictured below and should serve to guide the reader through an explanation of the model.

Figure 3.2 The Double ABCX Model.



<u>Family Demand: Pile-up (aA Factor)</u>

In addition to the crisis at hand, families have in the past and will in the future continue to experience crises. To reflect this reality of family life, the Double ABCX Model adds the pile-up factor to the initial crisis. Other crises can be precipitated by demands from (a) individual family members, (b) the family system, and (c) the community. Five general types of stressors have been identified, (a) the initial stressor and its hardships, (b) normative transactions, (c) prior strains, (d) the consequences of family efforts to cope, and (e) ambiguity, both intra-family and social. The initial stressor is that situation which requires change or adaptation on the part of the family or the (A) factor. Normative transactions include the normal growth and development issues which confront the family and its members over the life cycle. Prior strains are unresolved difficulties from previous crises. These pre-existing strains are often exacerbated when a new crisis is introduced. A fourth source of pile-up stressors is a result of coping strategies which have been employed to deal with past crises. An example would be a mother returning to the work force due to a family financial crisis. While assisting in meeting the crisis, this method of coping carries with it potential stresses and strains for the mother and family. The final pile-up stressor, intra-family and social ambiguity, refers to uncertainty about the future which families in the process of change experience. For instance, a mother assuming a job outside the home may lead to some ambiguity for family members about her role and responsibilities within the family unit.

Family Adaptive Resources (bB Factor)

Resources which assist the family in meeting the demands of a crisis exist within the individual family members, the family unit and the community. Resources are of two types, existing and expanded. Resources which families develop to meet the demands of the initial crisis are considered expanded. Social support is an integral part of the bB factor since theoretically those with adequate social support will be better prepared to deal with the crisis situation. McCubbin and his colleagues have adopted Cobb's (1976) definition of social support which states that support is information that a family (a) is cared for and loved, (b) is esteemed and valued, and (c) belongs to a network of mutual obligation and understanding.

Family Definition and Meaning (cC Factor)

The cC factor includes the meaning the family attaches to the initial stressor (C) along with meaning of prior stress and strains (c). In order to redefine the crisis and give it new meaning, the family must (a) "clarify the issues, hardships, and tasks so as to render them more manageable and responsive to problem solving efforts; (b) decrease the intensity of the emotional burdens associated with the crisis situation; and (c) encourage the family unit to carry on with its fundamental tasks of promoting member social and emotional development" (p. 16).

Family Adaptive Coping: Interaction of Resources, Perceptions, and Behaviours

Within the Double ABCX Model, coping is viewed as a dynamic process where resources, perceptions and behavioural responses interact to produce family functioning. Family coping is seen as a process which attempts to (a) eliminate or avoid stressors and strain; (b) deal with hardships of the situation; (c) maintain the family system's integrity and morale; (d) mobilize resources to meet demands; and (e) implement structural changes in the family system to accommodate the new demands.

Family Adaptation Balancing (xX Factor)

The X factor in Hill's model refers to the degree of family crisis which is precipitated by the stressor. McCubbin and Patterson (1983b) suggest that family adaptation is a more useful concept for explaining the outcome of the family's attempts at coping. Adaptation or balance can be viewed on three levels (a) the individual family member, (b) the family system, and (c) the community within which the family resides. At the level of the individual, a balance is sought between the member and the family unit. Difficulties arise when the demands placed upon the family by one of its members exceeds the family's capacity to meet those demands. Balance is also strived for between the family and the community. Tension is created when the two systems are not in mutual agreement. For instance, the family with a handicapped child may expect resources such as respite care which the community is not prepared to offer, resulting in an imbalance.

Outcomes in the Double ABCX Model are viewed along a continuum from bonadaptation to maladaptation. Bonadaptation is a product of balance at the level of the individual and family as well as balance between family and community. The result of bonadaptation is (a) maintenance or strengthening of family integrity; (b) promotion of individual member and family unit growth; and (c) maintenance of family independence and control over its environment. Family maladaptation, on the other hand, is seen as an imbalance at either the individual/family or family/community level or a balance which results in (a) deterioration of family integrity; (b) lack of individual or family unit growth and development; or (c) loss of family independence and autonomy.

The Double ABCX as a theoretical model has appeal to social workers in the field of developmental disabilities because it takes into account the multiplicity of factors which come to bear on family adaptation. In the study under discussion, the primary focus is the role of informal social support in helping mothers cope with the often extraordinary demands of a severely handicapped child. The Double ABCX is employed in this research due to its ability to explain social support and family adaptation. The model also allows for changes in adaptation longitudinally, making it particularly well-suited for use in situations of chronic stress. However, the Double ABCX in its entirety is almost impossible to test in a quantitative study due to the number of potential factors for inclusion in the model, and the measurement problems associated with these factors. Single subject design would probably be a more appropriate methodology for a study incorporating all of the nuances of the model. I am concentrating on one aspect of the model, the influence of informal social support resources on coping, stress and life satisfaction from the perspective of the female primary caregiver. The relative strengths and limitations of the Double ABCX will be addressed in the following section.

Critique of the Double ABCX Model

Both Hill's original model of family stress and adaptation and the augmented Double ABCX Model are based on systems theory. Consistent with a systems framework, the theory identifies three distinct yet interacting systems, the individual, the family and the community, all of which experience the impact when a stressor is introduced. Although the family system is the focal point of the model and the primary system of concern, both the individual and community are recognized as important systems. Essentially, the stressor interacts with family resources and the meaning the family attaches to the event to produce an outcome which is felt at all three system levels, individual, family and community. McCubbin and Patterson (1983b) refer to the outcome of a stressor on family functioning as balance or adaptation which occurs along a continuum from maladaptation to bonadaptation.

Burrell and Morgan (1979) outline several general principles which are typically found in theoretical frameworks based on systems theory. The Double ABCX Model meets most of these criteria in the following ways. First, there are boundaries around the primary system or family which distinguishes it from the environment or community. Second, the system is processual in nature as evidenced by the various interactions between stressor, resource, meaning and outcome. Third, the outcome is seen as a balance, often referred to as homeostasis in other systems models. Fourth, there exists mutual interdependence between the individual family members, family system and the environment or community. Finally, the family system can be observed in terms of the behaviour of its constituent parts or individual members.

General systems theory is widely applied as a framework in social work practice both in the United States and Canada (Drover & Shragge, 1977). Uncritical acceptance of systems theory in social work practice does not allow the practitioner to assess the relative strengths and limitations of the model. This section will review the Double ABCX Model in terms of its strengths and weaknesses as a conceptual framework for understanding the relationship between caring for a child with developmental disabilities and family adaptation. It will be argued here that the Double ABCX Model has a certain usefulness conceptually;

however, it possesses inherent biases and shortcomings which limit its effectiveness as a tool for social work practice.

Systems theory as a conceptual framework has great appeal to social workers. Of the helping professions, social work is the only one which sees its purview as the enhancement of social functioning. Hollis (1972) defines social functioning as the interplay between the social environment and the individual. The psychoanalytic approach, which has also significantly influenced social work practice, is constrained by its emphasis on individual drives and defenses to the almost total exclusion of the social environment. Systems theory, by contrast, recognizes the individual and his or her psychological state while at the same time incorporating the influence of the environment upon the individual. Such a theoretical framework serves to legitimize social work as a profession by placing importance on the "system" which social work considers its area of concern, the social system.

Ludwig Von Bertalanffy (1968), who is commonly thought of as the father of general systems theory, points to several strengths of the theory, two of which have particular application to social work practice with families having a developmentally disabled child. The first is that the theory is multivariate, allowing for an explanation of social problems which are multifaceted. This is an important characteristic of the Double ABCX since it integrates a number of variables including both pre- and post-crisis stressors, resources and perceptions. In addition to being multivariate, Double ABCX is longitudinal, taking into account that families change over time as they struggle for adaptation to a stressful event. Concomitantly, the model fits well with a developmental approach, recognizing that the family system evolves through a series of normative developmental stages as does the individual (McCubbin & Patterson, 1983a). A developmental approach is preferable to the medical model which looks to cure the problem, because developmental disabilities are usually permanent, expected to persist indefinitely, and therefore not likely to be cured. Conceptualizing the family and its members as growing and evolving systems provides the practitioner with a framework for evaluating and intervening to meet the system's needs across the life span. Therefore, Double ABCX is not only multivariate but incorporates change and developmental processes resulting in a model which is well-suited to social phenomena that are highly variable and change oriented.

The second factor Von Bertalanffy identifies as a strength, useful to practitioners working with this population of families, is that it is interdisciplinary. Children with developmental disabilities and their families require interventions from a number of disciplines. Systems theory, due to its wide application and flexibility, is familiar and understandable to providers spanning social work, psychology, occupational therapy, physical therapy, speech, nursing and medicine. This common framework facilitates the interdisciplinary process, potentially resulting in a more coherent and coordinated intervention plan for the family and child.

Bristol (1984), one of the few researchers to test the efficacy of the Double ABCX, has also identified factors which she considers strengths. She points out that the model allows for assessment of positive adaptation to the presence and care of a child with special needs. By providing a framework for assessing active coping and positive support, the model helps the practitioner focus on healthy adaptation as well as maladaptation. Furthermore, recognition is given to the social and contextual nature of adaptation, which as mentioned before is a departure from intrapsychic models.

Other authors have criticized systems theory on several fronts (Burrell & Morgan, 1979; Cloward & Piven, 1975; Drover & Shragge, 1977; Gouldner, 1970). Drover and Shragge (1977) take issue with Von Bertalanffy's view that a strength of the theory is its multivariate perspective. Indeed, the framework is multivariate but the possible factors for consideration are so numerous that one cannot comprehend the multiplicity of interrelationships. Therefore, the practitioner is forced to make judgements about which variables will be included in the analysis. The resultant process is an individual decision which carries with it the values and biases of the social worker. Although the theory appears on the surface to possess scientific neutrality, the very fact that certain factors are excluded from analysis is a value-ladden decision. When considering how the social worker might arrive at a decision about which variables to include, it is likely that those which are more amenable to change would remain in the analysis. Systems which are more powerful and therefore less malleable would probably be dropped. For example, in the case of designing services to a family with a child having developmental disabilities, the social worker might include the school in the framework while leaving out the State

Department of Mental Health because intervention at the school level is manageable whereas the State Department would be thought of as too powerful for one worker to impact. Furthermore, the family, usually the least powerful system in the equation, is often counselled to adapt and cope with their problems rather than work to change the other systems which impinge upon them. Under this model, the consumer movement, which spurred policies such as deinstitutionalization and mandatory special education, would have never succeeded.

Drover and Shragge (1977) also remind us that a basic assumption of the model is that all systems are working toward the same goal. There is no acknowledgement that systems act according to different motivations and interests. For instance, the state may be concerned with cutting costs and therefore support deinstitutionalization, while parent groups support the same social policy for humanistic reasons. On a similar theme, Cloward and Piven (1975) state that systems theory leads social workers to view clients as interacting with a variety of systems when, in fact, clients do not interact with systems but are oppressed by them. They assert that social agencies dictate the nature and content of the relationship with clients rather than interact with them from a mutual power base with mutual goals. Cloward and Piven (1975) advocate that social workers resist agencies representing the welfare state, an intervention inconsistent with systems theory which seeks to reduce conflict and promote adaptation. Under systems theory, intervention is aimed at making systems work better rather than devising alternatives (Gouldner, 1970).

Systems theory is also conservative in that it perpetuates the status quo by accepting society's institutions as a given (Gouldner, 1970). For example, the Double ABCX Model does not question whether the family is the most beneficial environment for a child. The theory merely accepts the family form it is asked to analyze. With respect to the Double ABCX Model, McCubbin and Patterson (1983a) state that "the important characteristic of the family before the impact of a stressor event or transition is the general sense of satisfaction and stability about the family structure and patterns of interaction" (p. 19). However, families experiencing chronically stressful life situations may not have a general sense of satisfaction and stability prior to a crisis. In fact, some families may be vulnerable to chronic crises due to the conditions under which they live. Consider the single parent family, living in poverty, with a developmentally disabled child. The lack of financial resources, coupled with the absence of a spouse and the presence of a handicapped child puts this family at risk for chronic stress and crisis. The model, therefore, may be limited in its ability to address some family configurations and life styles.

In summary, systems theory generally, and the Double ABCX Model specifically, have been widely applied as a theoretical model for explaining the relationship between stress, coping and adaptation in families with developmentally disabled children. Although the Double ABCX is useful conceptually, it carries with it some inherent deficiencies which should be made explicit to the social work practitioner. On the positive side, the model incorporates social functioning as an important component of overall functioning. It is multivariate, easily applied longitudinally, and understandable to the cadre of professionals involved with families and children with developmental disabilities. Furthermore, it recognizes positive as well as poor adaptation to the presence of a handicapped child.

However, social workers should be aware that the model is inherently conservative, value-ladden, and difficult to comprehend due to the multiplicity of possible variables for consideration. The Double ABCX Model appears to be better suited to generally stable family situations since it assumes equilibrium prior to a stressor event. Social workers will also find the Double ABCX helpful in analyzing social phenomena such as the family in crisis as opposed to prescribing interventions. Goldstein (1975) points out that systems theory cannot be practiced in the way Behaviour Modification or Gestalt Therapy are applied. The Double ABCX is used in the current study because of its descriptive and explanatory power. The model as it is applied in the current study will test whether informal social support moderates the stress of caring for a severely disabled child and enhances life satisfaction for the primary caregiver. Interventions with children and families which result from this study will be informed by the model but not prescribed by it. The purpose of the research described here is not to test the effect of an intervention strategy but to better understand the relationships between informal social support and stress, coping and life satisfaction in the female primary caregiver of a handicapped child. The Double ABCX Model is both appropriate and useful under these circumstances.

The Role of Informal Social Support in Moderating Stress and Preventing Out-of-Home Placement in Families with Developmentally Disabled Children

Informal social support and its stress moderating and health-promoting properties have received significant attention in the social science and medical literature. However, the influence of community and social supports upon decisions to institutionalize, or as a mediator of stress in families with a developmentally disabled member, is not well understood due to a dearth of research in this area (Sherman & Cocozza, 1984). Research to date has largely focused on the impact upon the family with a disabled member and little attention has been paid to the supports which assist families with coping. This is probably attributable to the fact that until recently emphasis has been placed on institutional care of persons with developmental disabilities as opposed to family and community care. This section of the review will critique the limited literature on informal social support to families with handicapped children.

Marie Bristol and her colleagues have made a significant contribution to our understanding of families with children who have developmental disabilities through their research with autistic children and their families. Bristol (1984) is one of the few family researchers to empirically test the ability of the Double ABCX Model to predict healthy adaptation in families with handicapped children. She studied 45 families with autistic or autistic-like children between the ages of 2 and 10 years to determine whether the Double ABCX was an effective framework for conceptualizing the process of adaptation in these families. The model was operationalized in the following way: (A) the severity of the handicap and (a) the pile-up of other stresses; (B) family cohesion and (b) social support; (C) the externalization of blame and (c) the definition of the handicap as a family crisis; the interaction of (B) plus (C) the patterns of coping; and healthy adaptation (xX) was measured by frequency of maternal depressive symptoms, a general rating of family adaptation and marital adjustment. Mothers who had taken medications continuously for a month were analyzed separately and compared to mothers who had not taken medication to see if these two groups differed in terms of the ABC variables.

Demographically, families proved to be a very heterogeneous group. All five of the social status groups as measured by the Hollingshead Index were represented. Mothers' education ranged from junior high school to graduate school. Thirty-five of the mothers were part of a two-parent family and 10 mothers were single parents. The children also proved to be a diverse group, with IQs ranging from 9 to 91. Race was not reported. Participants were consecutive referrals to a statewide programme for autistic children. Data were collected through self-administered questionnaires, home observations, structured interviews with mothers, and psychometric testing of children.

It was hypothesized that the Double ABCX Model would predict healthy adaptation in families with autistic and autistic-like children. Canonical correlation was used to test whether child characteristics (A), family resources (B), and maternal beliefs (C), significantly predicted adaptation in the form of maternal depression and observer ratings of acceptance and quality of parenting with the handicapped child. Analysis yielded a canonical correlation of .67, with $p < .006$, indicating that the A, B, and C factors together significantly predicted healthy adaptation in the families studied. Because canonical correlation did not identify whether maternal depression or acceptance and quality of parenting were predicted, multiple regression was performed separately for these two dependent variables. The model proved to explain 55% ($p = .001$) of the variance in observer rating of family adaptation, 33% ($p = .04$) of the variance in mother's depressive symptoms, and 53% ($p = .01$) of the variance in marital adjustment ($n = 35$). The predictor variables included: (a) severity of the handicap; (b) pile-up of other stressors; (c) family cohesion; (d) informal support; (e) formal support; (f) self-blame; (g) definition as a family catastrophe; and (h) coping patterns. When multiple regressions were run with all of the predictor or independent variables considered for each adaptation or dependent variable, only pile-up of other stressors and informal support were significant factors in each regression equation. Analysis by whether or not a mother had regularly taken medication in the past year revealed that those who had not taken medication were more likely to seek out and utilize informal and formal supports than those who had continuously used medication.

The Bristol study lends credence to the Double ABCX Model as a way to conceptualize healthy adaptation of families under the stress of caring for a handicapped child. The model significantly predicted healthy adaptation, mother's depressive symptoms and marital adjustment. Furthermore, the model was least effective in predicting maternal depression (33% of the variance), which is curious in light of the plethora of studies on this topic. Pile-up of other stressors was the only variable which significantly predicted maternal depression. In a previously cited study by Dorner (1975), it was found that mothers of physically handicapped children had malaise scores which were twice as high as would be expected from the general population. Mothers who admitted to being depressed, however, did not link their depression to the handicapped child but attributed it to other normative pressures. These findings indicate that maternal depression may be attributable to other life stresses, not the actual care of the handicapped child. However, it may also be true that the caregiving demands of a child with handicaps make mothers more vulnerable to depression. A further limitation of the Bristol study has to do with making generalizations about family adaptation based on data solely from mothers. Although this is characteristic of the majority of family research, caution should be exercised in drawing conclusions about family functioning when data are available for only one family member.

Only informal support and recent life changes were significant predictors of adaptation across all dependent measures in Bristol's study. Throughout the literature, informal support consistently surfaces as an important factor in adaptation of families experiencing stress. Yet little is known about the interaction between social support and stress. In this study, for instance, the Carolina Support Scale, which yields a summary measure of support, and its perceived usefulness from family, friends, neighbours and other parents of handicapped children, was used. Consequently, it is not known whether these people provided information about programmes, services or child rearing; assistance such as babysitting or help with household chores; or if they were emotionally supportive. Since the Carolina Parent Support Scale provides a global measure of support, programme planners and practitioners interested in designing and delivering services to this population do not have adequate information regarding the content or nature of the support families find most helpful. Another unanswered question pertains to the characteristics of families best able to construct satisfying networks of support. Bristol's study consisted of a demographically broad sample, but did not control for education or income which may be associated with access to informal support. It would be useful to know if certain features predispose families to develop their own networks of informal support. These data would help identify mothers who are potentially at risk for poor systems of informal support and provide clues as to the traits and conditions which lead mothers to amass their own support. Two exploratory research questions emerge from this analysis:

> Is informational, instrumental or emotional social support important in promoting healthy adaptation in families with a developmentally disabled child? and
>
> What are the demographic variables which discriminate families with strong networks of informal social support from those with weak networks?

Families of children with handicaps, like other families, progress through developmental stages. Consequently, families throughout the life cycle will possess the need for different constellations of formal and informal supports. Suelzle and Keenan (1981) collected data through mail questionnaires to 330 families with mentally retarded children ranging in age from birth to 21 years old. The population consisted of parents with developmentally disabled children, residing and receiving services in Lake County, Illinois. The response rate was 43.9%. The sample is likely to be biased towards better educated, English speaking and verbal parents since the questionnaire required self-administration and was 57 pages long. Regarding the utilization of services, parents of younger children tended to look to physicians for recommendations, while parents of older children were more likely to rely on the advice of school personnel. Social support from family members, friends or paid babysitters declined significantly over the life cycle of the children. Whether this reflects diminishing need for support over the life cycle or decreased willingness to provide support on the part of significant others is not known. Differences were observed in the sources of babysitting services. Single mothers who were members of ethnic minorities and who had less than a high school education, used family and friends for babysitters. Higher income, white and better educated mothers more often utilized paid babysitters. It is unknown whether the decision to employ a paid sitter or to utilize a family member is based on economic resources or some other factor.

To determine the influence of social support upon placement of the child, German and Maisto (1982) interviewed three groups of mothers, those with a mentally retarded child placed out-of-home, those using respite care, and those keeping their child at home. Family support was defined as those social, financial and emotional systems which mediate family stress. Significant differences were found among the three groups in several areas. Those keeping their child at home had a higher level of education, were more often white and married, and less likely to have another mentally retarded child. Results showed that emotional support in the form of another parent, grandparents and extended family was very important to families caring for their children at home. In the absence of support from these significant others, there was a greater likelihood of out-of-home placement. The researchers do not report on the relative socioeconomic status of the three groups. However, if single parent status is associated with lower income, it is safe to assume that the residential group includes a higher proportion of this economic class. Although it is clear that those in the home group had greater access to social support, it is unclear how significant the effects of low income status are. Also, since this study was conducted after the child was placed, it is not possible to know how much support actually existed for parents prior to placement. It is conceivable that previously supportive family members withdrew after placement due to a lessening of need.

The effects of stress and social support were the subject of study of 52 mothers of pre-mature infants and 53 mothers of full-term infants (Crnic, Greenberg, Ragozin, Robinson & Brasham, 1983). The sample consisted of primarily white, middle-class, two-parent families in which the mother did not work outside the home, although one third of the families received some public assistance. Data were collected through in-depth structured home interviews when infants were one month old, and video-taped behavioural observations made at four months of age in the clinic setting. Measured in the home interviews were life stress, social support, general life satisfaction and satisfaction with parenting. The behavioural observations yielded a global measure which rated dimensions of child behaviour, including satisfaction from interaction, responsiveness and affective tone. No significant group differences were found between mothers with a pre-mature infant and those with a full-term infant. The data were subsequently pooled and divided into high versus low support and life stress. A 75%-25% split was employed because most mothers scored high on support and low on life stress. The three sources of social support measured were intimate, friendship, and neighbourhood or community. Presence of intimate and community support and lower life stress were highly significant predictors of life satisfaction while friendship support was not. Regarding satisfaction with parenting, intimate and friendship support and lower life stress were highly predictive of a positive maternal attitude. However, it was not the presence or absence of intimate support which was a significant factor in predicting satisfaction with parenting, but the satisfaction with the support. This finding suggests that it may not be enough to measure whether or not a source of support exists for an individual: but the degree to which the relationship is valued may have greater impact. Social support was also found to significantly affect both maternal and infant behaviour. Generally, intimate support was found to have the most positive effects on life satisfaction.

In another study, Bristol and Schopler (1984) examined stress and coping in families with an autistic adolescent. Two groups of ten families each, one group with high stress and one with low stress, were compared. The groups were similar with respect to mother's age, family income, number or age of children in the family, percent of first born children, percent of children who were more severely autistic, and number of mothers employed outside the home. The lower stress group consisted of children who had fewer behavioural problems and where more self-help skills, activities and services were available to the family. Contrary to Bradshaw and Lawton's (1978) finding that only working mothers were less depressed, Bristol and Scholper discovered that mothers in the low stress group reported greater satisfaction with their status regardless of whether they were working outside the home or not. Low stress mothers also reported more support from husbands, relatives, friends, and other parents of handicapped children. Again, this study examines a small sample of parents, making generalizations impossible. In addition, the support scale used does not measure the type of support received from informal sources. It is not known, for instance, whether emotional, instrumental, or informational support is provided and how important each category of support is in moderating stress.

The nature of social support networks in families with handicapped children was studied by Kazak and Marvin (1984). Fifty six families with a child having spina bifida were compared with 53 families with a nonhandicapped child. The only significant demographic difference between the families was in income, with the study group earning an average of $17,900 compared to $29,500 for controls. There were no differences between families in the size of family networks; however, parents with a handicapped child had significantly fewer persons in their friendship network. Furthermore, families with a handicapped child had denser social networks than controls, meaning that network members were more likely to know and interact with each other. This study supports the fact that families with handicapped children are more likely to be isolated than parents of nonhandicapped children. The authors state, however, that additional analysis of the data did not reveal a correlation between family or friendship network size and stress. Therefore, satisfaction with relationships and quality of support may prove to be better predictors of reduced stress than size of network.

In a recent work, Dunst, Trivette and Cross (1986) considered the mediating influence of social support in a study of 137 parents of mentally retarded, physically impaired and developmentally at-risk children. The outcomes measured included personal well-being, parental attitudes toward their child, family integrity, parental perceptions of child functioning, parent-child play opportunities, and child behaviour and development. Subjects were 96 mothers and 41 fathers of preschool children who were participants in an early intervention programme for children with or at-risk for a developmental disability. The three groups of families did not differ in age, education of parents or marital status. Differences were found in socioeconomic status, with those having a developmentally at-risk child scoring lowest on the Hollingshead Five-Level Model of Social Status followed by those families with a mentally retarded child. The three groups of children did not differ in age or sex but the groups were significantly different in developmental measures such as IQ and social-adaptive age. Results showed that when controlling for socioeconomic status and income, child sex, age, developmental quotient and diagnosis, both satisfaction with support and number of sources of support were significantly related to all sets of outcomes. Parents with more satisfying social networks reported better personal well-being, more positive attitudes, and more positive influences on parent-child play opportunities and child behaviour and development. The only area social support did not influence was family integrity.

The authors conclude that social support has differential impacts and effects. They recommend that future investigators identify the types and dimensions of support that have particular impacts in order to further our understanding of the differential influences of support on the parent, family and child.

Summary of the Relationship Between Informal Social Support and Family Adaptation

The developmental disabilities literature on the topic of informal social support is not extensive. Research to date indicates that social support is an important factor in moderating the stress of caring for a handicapped child. Furthermore, in the absence of such support, there is a greater likelihood of stress and out-of-home placement. There is some indication that support decreases over the life cycle; however, it is not clear whether this reflects diminishing need or fewer people willing to provide such support. It has been shown that the size of the social network is less important than the degree to which the relationships are valued. Consequently, quality of social support should be considered over quantity. Also, families with children having developmental disabilities often have fewer friends in their social network than families with nonhandicapped children, furthering the contention that the former families are more socially isolated. It was also shown that greater support to parents is associated with more positive parent-child interaction and better child behaviour and development.

Absent from the literature are data on the type of social support that families caring for a handicapped member find beneficial. Determining the extent to which instrumental, informational or emotional support are helpful to families would make a substantial contribution to the research in this field. Furthermore, data regarding the characteristics of families at risk for inadequate social support would assist professionals in targeting interventions to families with the greatest need.

A conceptual issue of concern is whether or not there is a causal relationship between informal social support and the outcomes cited in the preceding studies. It is possible, for instance, that those reporting less stress and better adaptation possess important psychological characteristics which allow them to build a strong system of support. People who are emotionally healthy may possess the personal resources and interpersonal skills to maintain positive relationships with family, friends and neighbours. Given this interpretation, the causal relationship goes from adaptation to social support instead of the other way around. If social policy and programmes are to be influenced by past research and the current study, there must be greater evidence of the independent effect of social support on emotional well-being. The next section will attempt to bring the literature together in a way which lends credibility to the view that social support leads to positive adaptation.

Establishing Causality Between Informal Social Support and Health Outcomes

This sub-section will examine the issue of causality and argue that there is sufficient evidence to conclude that informal social support moderates the impact of a stressor. Since little of the developmental disabilities research has studied the stress-moderating role of social support, it is necessary to review key studies which document the physical and emotional health promoting properties of informal support. This line of theory has its beginnings in the study of the relationship between life stress and illness. Through the seminal work of Seyle (1956), and later Holmes and Rahe (1967), among others, the association between stressful life events and ill health was established. Since that time a plethora of research has been conducted on factors which potentially moderate the impact of a particular stressor. Moderators can be psychological, physiological or social factors (Dohrenwend & Dohrenwend, 1974). Yet a problem which continues to plague researchers is one of causality. It is difficult to establish causality in most social science research because strict experimental conditions are not possible. In the study of informal social support there is always a question about the direction of the influence between social support and the dependent variable, whether it be physical or emotional health. If social work interventions are to be predicated on the results of this research, there must be strong reason to believe that social support has a positive influence on health.

Two approaches have been used to test the effect of informal support on health outcomes. The first is an experimental design where individuals are randomly assigned to an intervention group that provides various types of support and a control group which receives no intervention. With an adequate sample size, it is possible to control for psychological and physiological processes which mediate against life stress in order to measure the independent effect of social support. Although intervention studies are expensive and often difficult to implement, the contribution to the field is potentially substantial. Yet there is one major dilemma for researchers attempting intervention studies in the area of informal support. By definition, informal social support operates outside the formal system of services, making it difficult to conceive of an intervention which preserves the essential elements of the informal system. An example of an intervention study which fell victim to this problem is one which introduced a supportive companion for women admitted for delivery in a Guatemala hospital (Sosa, Kennell, Klaus, Robertson, & Urrutia, 1980). Mothers were randomly assigned to the companion group and a control group which followed regular hospital procedures. Those mothers receiving the intervention differed significantly from controls in that the length of time from admission to delivery was shorter, they were awake more after delivery, and they stroked, smiled at and talked to their babies more than control mothers.

Although this study establishes the positive influence of a lay person for mothers experiencing the stressful event of delivery, it is questionable whether the intervention qualifies as informal social support. Using Gottlieb's (1983) definition of social support which states that the support is proffered by social intimates, it is clear that the supportive companion is not part of the woman's social network. Furthermore, the intervention violates another element of an informal system in that the support is not mutual, but one way, flowing from companion to mother. Intervention studies are typically difficult to manipulate within the informal system. Cohen and Syme (1985) caution that the effectiveness of intervention studies "depends on the appropriateness of the resources provided by the system, the interpersonal context in which those resources are made available, and whether persons perceive access to these resources in the way intended by the intervenor" (p. 17).

A more promising approach to dealing with the question of causality may lie in longitudinal research which establishes a baseline of psychological, physiological and social characteristics and follows a cohort over time to observe how social support assists individuals experiencing stress. As new stressors are introduced into the life of an individual it is possible to determine whether the amount of informal social support available to the individual predicts better outcomes. One of the most important prospective studies of social support and its influence on health was the work of Nuckolls, Cassel and Kaplan (1972). In a study of 170 pregnant women, Nuckolls et al. explored the relationship between psychosocial assets, social stress and the

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psychological symptoms and morale, and physical health in a sample of 100 persons 45 to 64 years of age. Participants in the study were interviewed in their homes for 12 consecutive months and completed self-report questionnaires between interviews. Cross-sectional analysis using multiple regression indicated that lack of tangible and emotional support were significant predictors of depression. Life events and loss events did not explain a significant amount of the variance in depression. In the analysis of morale, nonloss life events significantly predicted morale. Of the support measures, only absence of tangible support contributed significantly to the explained variance in negative morale. There were no significant correlations between the independent variables and physical health status.

Prospective analysis supported the findings of cross-sectional analysis. When depression was compared over the course of the study, it was found that there was a significant correlation between depression at time 1 and 2 ($r = 0.71$, $p < .001$). However, neither social support nor social network size was significantly predicted by life events, earlier depression or morale. The authors conclude that this finding offers support for depression and morale being dependent variables. This finding also argues against the premise that the relationship between support and depression results from the effects of psychological symptoms on interpersonal relationships. In other words, their results suggest that social support influences morale rather than morale influencing social support. This is an important point for the proposed research on the role of social support in moderating stress and life satisfaction in mothers with severely handicapped children. It is assumed that social support buffers stress, thereby leading to better adaptation. If in fact positive outcomes significantly affect one's ability and predilection to build networks of informal social support, then social support is the dependent variable.

On the other hand, it is naive to assume that there is not reciprocal causation between informal social support and adaptation. Certainly, severely depressed individuals are likely to experience considerable difficulty maintaining positive relationships with others. However, most people are not at the severe end of the depression continuum but are coping fairly effectively, even in the face of chronic stress. Yet, some people seem to be more adept at building good interpersonal relationships. Part of this dynamic can be attributed to a positive feeling about self and satisfaction with one's life situation.

It is especially difficult to ferret out the relationship between support and adaptation when considering the role of a chronic stressor (Kessler, 1983). At least with an acute, time-limited stressor it is possible, theoretically, to measure the ability of social support to moderate the negative impact since we are able to study individuals before and after they experience the event. As if these methodological problems were not difficult enough, we usually have to rely on measures which are not objective but which require self-report. The respondent's level of stress might colour her perceptions and yield artificially strong relationships between social support and the outcome variables (Kessler, 1983).

Given these limitations, why would one want to study the role of informal social support? It is in part because we know, based on personal experience, that support from the people close to us is important during times of stress. Furthermore, social support has been associated with positive health outcomes in numerous studies. In a previous study (Marcenko & Meyers, 1985) I found that social support was the only variable significantly related to reduced stress and enhanced coping. In light of this finding, my curiosity about the nature and type of support most helpful to mothers caring for severely handicapped children was piqued. If social workers knew more about how social support assists mothers of handicapped children, they could better design their interventions.

In addition to these reasons, it has been reported in the literature that mothers with handicapped children experience a unique set of circumstances which complicates their ability to engage in social relationships. For instance, families with handicapped children are at-risk for inadequate social support since they typically experience greater social isolation than their counterparts in the general population (Davis & MacKay, 1973). Therefore, this may be a characteristic of families with handicapped children irrespective of the psychological strengths of parents. The barriers they encounter to establishing adequate networks of social support are not always of a psychological nature but are inherent in the life situation they confront. In addition to environmental conditions such as social isolation which inhibit support, it has been shown that mothers with handicapped children experience depression more often than their counterparts with nonhandicapped children (Dorner, 1975; Bradshaw & Lawton, 1978). This psychological factor could further impede one's ability to develop and maintain social support networks. Therefore, mothers caring for handicapped children may need assistance in overcoming both environmental and psychological barriers to accessing informal social support.

While the stress-buffering effect of social support is the hypothesis employed in the study under discussion, there is also a hypothesis which asserts that support enhances health regardless of stress level. The former hypothesis is referred to as the stress buffering effect and the latter as the main effect (Dooley, 1985). Cohen and Syme (1985) argue that comparisons of main and buffering effect models will not contribute substantially to our understanding of the relationship between social support and health. Rather, they encourage research which illuminates how support relates to various behavioural, emotional and physiological mediators of health. Data about the type and source of help most beneficial would assist in fashioning a system of support to families with severely handicapped children which is efficacious to both children and families.

Cassel (1976) asserts that there is ample evidence in studies of both animal and human populations that social support provided by those from the primary group important to the individual will have a stress-buffering effect, thereby offering some protection against disease. He suggests that a one-dimensional concept of psychosocial processes as stressful or non-stressful is inadequate. A more accurate framework includes two dimensions, the stressful event, plus the beneficial effects of social support. Conceptually Cassel's formulation is straightforward and consistent with both Hill's and McCubbin's crisis models. All three theories purport that certain conditions or circumstances within the social environment can be stressful for an individual; however, social support has a moderating effect on the degree to which the stressor is negative in its impact.

Thus, evidence for the role of informal social support in moderating stress exists in the literature. This, coupled with the special social and psychological circumstance mothers with handicapped children find themselves in, makes the study of the nature of the informal support systems which assist mothers to care for a severely handicapped child, an important subject of inquiry. It is recognized, however, that causation cannot be definitively established and, in fact, there is probably some reciprocal causation between informal social support and adaptation. Consequently, the purpose of this study is not only to determine the relationship between support and stress, but to illuminate the nature and type of help most important for mothers of handicapped children. Future research should focus on both intervention studies which attempt to utilize helpers from mother's already existing network or introduce new network members and longitudinal studies which examine the role of social support as new stressors are experienced.

Informal Social Support and the Single-Parent Family

The single-parent family, which usually means single mothers, deserves special attention with regard to informal social support due to the lack of a spouse who potentially assists in the caregiving demands of a child with developmental disabilities. Wikler, Haack and Intagliata (1984) sum up the position of the single mother with a handicapped child in this way:

> The unrelieved responsibility of raising a chronically dependent person can drain the single mother's energy from such critical activities as developing new social relationships or managing a household routine. This strain combined with the perception that it may never cease, places the single parent at increased risk for stress. The child-care related stresses cannot be underestimated when working clinically to support the single parent of a child with mental retardation (p. 47).

McLanahan, Wedemeyer and Adelberg (1981) examined the relationship between network social support and psychological well-being in the single parent family. In-depth, semi-structured interviews were conducted with 45 divorced mothers. Subsequent to the interview, mothers were contacted by telephone twice weekly for six weeks to discuss their daily stress and how their networks served to support them. Subjects ranged in age from 22 to 52 years and had yearly incomes ranging from $4,500 to $50,000, although almost all were employed.

Three major types of networks were identified: (1) a family of origin network; (2) an extended network; and (3) a conjugal network consisting of two subtypes. The family of origin type is typified by support from family members with few or no non-related friendship ties. The network members are in frequent contact and are known to each other. An extended network is usually large and composed of new friends who are not necessarily in contact with other members of the network. Lastly, conjugal networks consist of a key male figure and may be one of two subtypes. In the first type the remainder of the network includes family members and old friends, while the second subtype includes the key male figure and new friends. Analysis of qualitative data revealed that the effects of support were moderated by a third factor, role orientation of the mother. Two orientations were identified, stabilizers and changers. Stabilizers were attempting to maintain their pre-divorce roles, while changers were interested in establishing a new identity as a single person. The study found that mothers who were psychologically distressed were either change oriented and had closely-knit, family of origin supports or stabilizers, and had supports which were loosely-knit friendships.

Conclusions about the nature and satisfaction of network support for single parents are not advisable from this study given the small sample size, non-random selection of mothers and the heterogeneity of the sample. However, the authors have generated hypotheses about how various types of support are related to psychological well-being in single parents. Their three major hypotheses are that loose-knit networks are supportive for women establishing a new identity; close-knit networks assist women attempting to maintain their existing identity; and the orientation and network type may change over time.

The single mother of a child with developmental disabilities, depending upon the functional limitations of her child, will have instrumental needs which far exceed those of a single parent with a nonhandicapped child. Babysitting for the handicapped child is a problem often mentioned in conversations with parents because neighbourhood teenagers, the usual source of sitter, are often not capable of handling the responsibility of a child with special needs. Furthermore, babysitting is a need which persists throughout the lifetime of a severely handicapped individual. Consequently, mothers of handicapped children never gain independence from the constant caregiving demands of their children.

A second difference between mothers of handicapped and nonhandicapped children is the degree to which they are able to establish new social relationships. Parents of handicapped children have been shown to be more socially isolated (Schonell et al., 1956; Davis & Mackay, 1973; McAllister et al., 1973). Consequently, parents may have limited opportunities for establishing new relationships. Furthermore, the supportive needs of the single parent may be so numerous and sustaining that friends are unwilling to meet those needs on a continuous basis. Family members, however, may be more committed and perceive an obligation to provide support to the parent of a handicapped child. Therefore, it is expected that parents of children with severe developmental disabilities will receive support primarily from family members rather than friends or neighbours.

The effects of stress and social supports on mother-child interaction in single- and two-parent families was the subject of an exploratory study by Weinraub and Wolf (1983). The sample consisted of 28 mother-child dyads including 14 single parents matched with 14 mothers in two-parent families. Mothers were matched on age, education, race and family income. The children ranged in age from 27 to 54 months. Mothers were an average age of 32 years with a mean educational level of 16 years. Measures of stressful life events, social networks and perceived maternal coping were obtained by a questionnaire. Quality and frequency of mother-child interaction were assessed through a structured laboratory task which was video-taped. The study found that single-parents had more life changes, fewer social supports and community ties and were more socially isolated than mothers in two-parent families. Furthermore, single mothers worked longer hours and received less emotional and less parental support. Despite these differences, single mothers did not report any greater difficulty in coping, nor were there any significant differences observed between the two groups in mother-child interactions. When the two groups were considered separately, fewer stressful life events, reduced social contact, increased parenting support, and more hours worked predicted optimal maternal-child interaction in single-parent families. In two parent families, fewer stressful life events, satisfaction with emotional support and availability of household help predicted optimal interaction.

The results of this exploratory study suggest that single- and two-parent families may differ in the amount of social support utilized and the number of stressful life events experienced. Yet, mother-child interaction did not differ between married and single mothers. Only when the sample was dichotomized into those with more or less optimal interaction did support prove to be an important intervening variable among marrieds and singles. The number of parents in less optimal categories was extremely small, including only four single-parents and three married mothers. Consequently, more research is needed to validate the significance of social support in promoting positive mother-child interaction.

Brown and Gray (1985) considered the differences in social networks between 91 married and 183 nonmarried Black females in a study of women residing in Richmond, Virginia. Data on marital status, social network, sources of social support and psychological well-being were gathered through structured interviews. Comparisons on demographic variables between the two groups of women revealed no significant differences in education, employment or number of children. Married respondents differed significantly in that they were older and had higher family incomes than nonmarried women. Analysis revealed that there were no differences by marital status in the number or range of social support network relationships. However, when asked to name their closest relationships, married women tended to distribute their first close relationships among family members, female friends and husbands. Nonmarried women cited family members, especially mothers, siblings and children as their most important close relationships. In terms of source of emotional support, married females split equally between husbands and formal services or family members. Nonmarried women, on the other hand, stated they would seek emotional support primarily from family members. There were no differences between the two groups in the amount of reported instrumental social support, or in perceived satisfaction with support in general. Nonmarried Black females did, however, have higher levels of psychological distress than their married counterparts. The researchers attribute this difference to the younger ages and lower incomes of nonmarried respondents.

Hirsch (1979) considered the psychological characteristics of personally satisfying networks of social support and the relationship between social support and coping with final exams in 16 male and 16 female college students. Findings from this study indicate that multidimensional relationships are associated with greater satisfaction with social networks. Multidimensionality was defined as networks in which the individuals engage in a variety of activities as opposed to only one type of behaviour. Regarding the stressful period of final exams, students reported less support before and during finals than they received after finals. These results might be expected, since amount of support is measured in terms of time spent with individuals providing this support. Clearly, students would have much more time available to receive support after finals than either before or during exams. It cannot be concluded that during times of stress people will withdraw from support based on these data, but rather the finding is a result of the way in which support is measured and the type of stress studied.

In another exploratory study, Hirsch (1980) looked at the relationship between natural support system and coping with major life change in 20 recent widows and 14 mature women returning to college. Subjects in both groups were similar on most demographic variables, life changes and natural support system variables. They were, therefore, treated as one generic group for the purposes of analysis. Social support measures included the following five categories: (1) cognitive guidance, such as information and advice; (2) social reinforcement, defined as praise or criticism regarding some behaviour; (3) tangible assistance, in the form of help with such things as chores or child care; (4) emotional support, defined as communication with a friend which made one feel better or worse when one has already been feeling upset; (5) socializing, which is self explanatory. Both recent life changes and mental health were also measured. Findings indicated that greater satisfaction with cognitive guidance is significantly related to less symptomatology, as measured by the Hopkins Symptom Checklist, and better mood a measure derived from the Profile Mood States. Higher self-esteem was significantly correlated with greater satisfaction with socializing experiences. There were no other significant correlations between support and mental health. Hirsch did find that nuclear family-friendship density was related to less satisfaction with one's social support, poorer mood and low self-esteem. Density refers to the number of relationships between family members and friends as a proportion of the total number of relationships. Having a network of support which consisted of a broad spectrum of people was found to have a more positive affect on mental health than tightly knit systems. This finding suggests that the type of social network is an important factor in mental health.

Although this research is instructive, the type of stress considered in both Hirsch studies is normative and pales in comparison to the stress experienced by mothers of severely handicapped children. However, the issue of multidimensionality is an interesting one as mothers of handicapped children, due to the chronicity of the crisis they experience and their characteristic social isolation, may find that friends drop out of the support network leaving only a nucleus of family members. The current study will explore the source of support to mothers with a severely developmentally disabled child, thereby determining the degree of multidimensionality present in their networks.

The research to date on social support and its relationship to health has dealt with acute crises or stressful events that serve as the precipitator which support then buffers against. Lacking in the literature are data about the impact of support by those confronting a chronic stressor such as care of a severely handicapped child. Cobb (1976) has suggested that this is a neglected subject of study and he questions whether social support has the ability to moderate the effects of chronic stress. Furthermore, with few exceptions, recent studies of social support have not considered the nature or content of the support provided and its relative effect on stress. House and Kahn (1985), in their recent review of measures and concepts of social support, suggest that studies in this field should attempt to measure three aspects of social relationships: (a) their existence and quantity, (b) aspects of network structure, and (c) the functional content and quality of relationships. House and Kahn point out that it is necessary to measure all three aspects of social relationships - quantity, structure and function - because they are logically and empirically interrelated. For instance, relationships must first exist, to form a structure, which in turn fulfills certain functions, which then has an impact on health.

Of particular interest in the area of developmental disabilities is the structure and function of social support since parents caring for a handicapped child will have many supportive needs, persisting over the life cycle of the child. Research has not examined the function of social support the primary caregiver receives and the differential impact of that support based upon whether it is informational, instrumental, or emotional. Interventions designed to bolster the network of informal social support to parents of handicapped children could be more effectively planned if professionals and parents were armed with data about the most efficacious types of support. Furthermore, practitioners would be better equipped to identify families at risk of poor coping if they understood more about the stress reducing types of social support.

Emergent Hypotheses and Research Questions

In Chapter I two broad research questions were posed:

> How important is the informal social support system
> in promoting coping, moderating stress and enhancing
> life satisfaction for the female primary caregiver
> of a severely handicapped child? and
>
> What is the nature of the informal social support system
> of the primary caregiver with a severely developmentally
> disabled child?

This review of the literature reveals that informal social support provided by family, friends, neighbours, co-workers or parent groups moderates stress and promotes healthy adaptation in families caring for a handicapped child. Although research points to the stress-buffering role of informal support, data are not available about the nature and content of that support. Informal social support has been defined as "verbal and/or nonverbal information or advice, tangible aid, or action that is proffered by social intimates or inferred by their presence and has beneficial emotional or behavioural effects on the recipient" (Gottlieb, 1983, p. 28). Three types of informal social support are mentioned in this definition and usually recognized in the social support literature, instrumental, informational and emotional. Instrumental support is assistance with daily tasks such as household chores, babysitting, or a ride to the store. Informational support is assistance in the form of information which is helpful in caring for a handicapped child. Examples include information about parent groups or child development. Emotional support is that which assists one in expressing and confronting feelings. The content of emotionally supportive acts includes listening, concern, esteem and trust. In addition to the three types of support identified above, House and Kahn (1985) state that it is also important to measure network size. It is their contention that it is necessary to establish that a network exists, before measuring the impact of those relationships.

This section will present a rationale for hypotheses and questions regarding the relationship between informal social support in its various forms, and coping, stress and life satisfaction. In hypothesizing about the importance of each type of social support, several factors must be considered. The female primary caregiver of a child with severe developmental disabilities will have instrumental needs which persist over the life cycle of the child. Severely handicapped children often do not toilet independently, ambulate or have speech. They may also have medical and physical conditions such as cerebral palsy or epilepsy which complicate their daily care. Consequently, it is hypothesized that instrumental social support will significantly enhance coping, moderate stress and lead to greater life satisfaction for mothers of a severely handicapped children.

Informational support, while potentially important, will probably be needed only periodically by the primary caregiver. Furthermore, this type of support is usually not critical to the care of the child on a day-to-day basis. Therefore, it is hypothesized that informational support will not significantly moderate stress or enhance coping and life satisfaction.

Mothers of handicapped children experience the greatest burden of care for their children. They have also been shown to be depressed more frequently than mothers of nonhandicapped children. In view of the stress they encounter, it is hypothesized that emotional social support will result in significantly better coping, less stress, and higher life satisfaction.

With respect to network size, the literature has pointed to the fact that quality not quantity of network relationships is the more important moderator of family stress (Kazak and Marvin, 1984). Therefore, it is hypothesized that network size will have no effect on coping, stress or life satisfaction.

Also worthy of consideration is a global measure of perceived informal social support. Given that perceived level of support may be more crucial than the amount of support given, it is expected that perceived support will correlate with high coping and life satisfaction and reduced stress.

In addition to understanding the types of social support which assist mothers of handicapped children, professionals would benefit from knowing the characteristics of mothers at-risk for poor support. For instance, some research has indicated that single mothers have less support due to the absence of a spouse (Beckman, 1983). Other research has shown that as children get older, parents have less support (Suelzle & Keenan, 1981). Data regarding the sociodemographic characteristics of parents most likely to lack social support would help professionals target their efforts towards families in greatest need.

As mentioned, considerable attention has been paid to the single mother of a handicapped child due to the extraordinary demands placed upon her. Yet it is unclear if the single mother uses support from other sources to compensate for the absence of a spouse. Consequently, married and single mothers will be compared to determine how the two groups differ in their sources and types of informal support.

Also of interest is the difference between mothers working outside the home and those who are not, with respect to their use of informal support. Employed mothers potentially have greater instrumental needs because of their dual role as primary caregiver and worker. On the other hand, mothers not working outside the home may experience greater social isolation and therefore have more need for emotional support. These two groups of mothers will be compared to explore the relationship between employment status and amount, type and source of informal support.

To summarize, help in the form of concrete assistance and emotional support, which comes from persons in the informal network directly to mothers is expected to produce healthy maternal adaptation. Informational support and network size, although periodically of same importance, should not explain the variance in mothers' coping, stress or life satisfaction. The chronic stress of caring for a severely handicapped child is expected to be moderated by the quantity and quality of certain types of support proferred to mothers. For the purpose of clarity, the research questions and hypotheses are outlined in the following section.

Research Hypothesis and Questions

Primary Hypothesis

Female primary caregivers who report high informal social support will also report higher coping, lower stress and greater life satisfaction than those women with low informal social support.

Expectations

1. High Perceived Support - high coping, low stress, high life satisfaction.
2. High Instrumental Support - high coping, low stress, high life satisfaction.
3. High Emotional Support - high coping, low stress, high life satisfaction.
4. High Informational Support - no significant effect on any measures of coping, stress and life satisfaction.
5. High Network Support - no significant effect on any measures of coping, stress and life satisfaction.

Primary Descriptive Research Question

What is the nature of the informal social support system of the primary caregiver with a severely developmentally disabled child?

Descriptive Research Questions

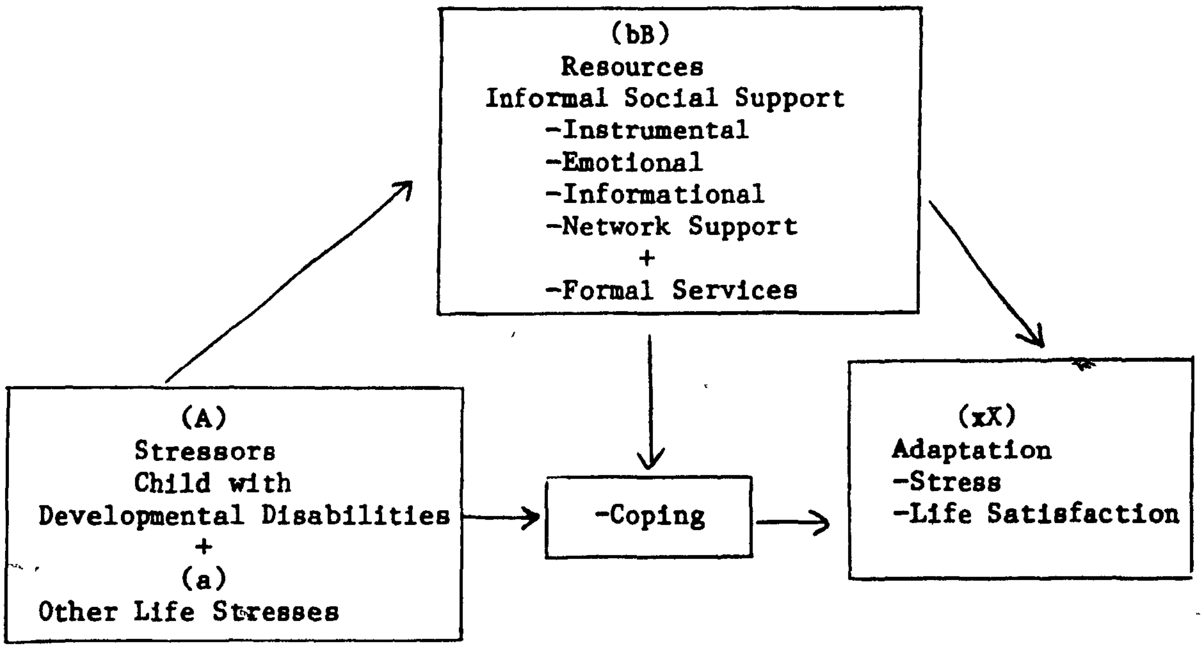
1. What are the demographic factors which discriminate mothers who have high levels of informal social support from those who have low levels of support?
2. Do single women differ from married women in their informal social support system?
3. Do mothers who are working outside the home differ from those who are not in their informal social support system?

The Research Question Applied to the Double ABCX Model

It will be recalled that the Double ABCX Model (McCubbin and Patterson, 1983b) is a multivariate theoretical framework for understanding family adaptation to stress. The model seeks to identify how stressors are mediated by individual, family and community resources and family coping responses to produce family adjustment over time. The complete model can be found on page 61.

Although the model is longitudinal, this research is cross-sectional and looks at the families at one point in time. Therefore, it is not known how families were adapting prior to the birth of their child with developmental disabilities. As Figure 3.3 indicates, the stressor (A) is the stress of caring for a child with severe handicaps. This stressor differs from many others a family may experience in that it is chronic and not expected to be resolved. In fact, care is often more difficult as the child matures because of the child's size and strength, coupled with ongoing dependency. Pile-up (aA) is defined as the initial stressor plus other life stresses the family may experience. Both the degree of dependency presented by the child and other life stresses will be measured in the study. Resources (bB), for purposes of this research, are defined as informal social support either perceived, instrumental, emotional, informational or network, and formal support. These independent variables, level of child functioning, stressful life events, perceived informal social support and formal services are expected to explain the variance in coping, stress and life satisfaction. No measures of the definition and meaning the family attaches to the stress of caring for a child are proposed. However, coping, which is seen as a product of the interaction between resources such as informal and formal social support, and perception of the crisis, is measured. It is expected that level of coping will be explained by the independent variables in the model. Coping, in turn, is expected to predict the outcome variables, stress and life satisfaction. The operationalized model is charted below.

Figure 3.3 The Double ABCX Model operationalized.



Underlying Presumptions of the Research

Inherent in any research are underlying presumptions about the population under study and the relationship between this group and the larger society. In this case, the research makes presumptions about the best way for children with severe developmental disabilities to grow up and the responsibility of the state to these children and families. These presumptions are enumerated below.

1. In Canada and the United States, community and professional judgement supports the notion that it is preferable for all children to grow up in a family situation.

2. It follows that family care for children with developmental disabilities in the natural home is preferable to out-of-home placement.

3. It is the judgement of professionals dealing with this population that most families, when given adequate supports, can care for their disabled children at home.

4. Furthermore, families indicate to professionals that they prefer to care for their children with developmental disabilities at home.

5. Available evidence supports that children with severe developmental disabilities can grow, intellectually, emotionally and socially, and that they are able to learn new skills.

6. The state has a responsibility to provide assistance in meeting the basic needs of vulnerable populations, including children with developmental disabilities. However, the responsibility of the state is by no means static and in fact it often comes under attack, especially at times of fiscal constraint.

Presumptions 2, 3, and 5 are fairly new beliefs in the field of developmental disabilities and are the product of the community living movement.

CHAPTER IV

METHODOLOGY

Introduction

This is a study to determine the influence of informal social support on stress and life satisfaction in the mothers caring for a severely developmentally disabled child. The research is part of a larger longitudinal study conducted by myself and co-investigator, Judith Meyers, to evaluate the impact of a cash subsidy programme on recipients. On July 1, 1984, Michigan implemented the Family Subsidy Act which provides a cash subsidy of $225.00 per month for families with severely mentally impaired, severely multiply impaired and autistic impaired children under the age of 18 who are living in the natural family home. In order to be eligible for the subsidy, the taxable family income for 1983 could not exceed $60,000 dollars per year. The subsidy is not considered in the income ceiling for other public programmes or for the purposes of subsequent state and federal income taxes.

In order to evaluate the extent and manner in which this new programme is helpful to families, 100 female primary caregivers, residing in one of four Michigan counties, were interviewed prior to receiving the subsidy (June, 1984) and then re-interviewed one year later (June, 1985). Analysis of time 1 interviews revealed that informal social support was the only factor which significantly moderated stress and enhanced coping for the primary caregiver. Since only one global measure of informal support was included at time 1, three additional instruments which elaborate the type and source of informal support were added to the time 2 protocol. These instruments will serve as the basis for the research on the relationship between informal support and stress. Because this research is part of a comprehensive longitudinal study, other data which corroborate the primary instruments utilized are available. Also, the global measure of informal support and all measures of stress, coping and life satisfaction are part of the study at both time 1 and time 2.

The purpose of this chapter is to outline the research design, method of sample selection, protocol for interviewing, conceptually and operationally define the terms employed, and describe the instruments utilized. Furthermore, reliability and validity of the instruments will be presented along with details of the data analysis.

Research Design

This is essentially a cross-sectional study describing the characteristics of the informal social support system of a sample of mothers with severely developmentally disabled children. The larger study which serves as the context for this research is a longitudinal intervention study. The purpose of the larger study was to determine the impact of receiving a cash subsidy upon eligible families. A control group was not used because all families within the State of Michigan with severely handicapped children were eligible for the subsidy, making it impossible to select an unbiased sample of families not receiving the subsidy. Consideration was given to selecting a control group of families with less severely handicapped who would not be receiving the subsidy. However, it was felt that the conditions were sufficiently different for these families to make comparisons invalid. Thought was also given to contacting a neighbouring state as a control group source. Again, economic and social factors would have been difficult to duplicate; in addition, costs would have been prohibitive. We decided to select a sample of 100 families because we were constricted by our budget. In retrospect, however, it would have been judicious use of our resources to interview 120 families, realizing that we would probably experience a drop out rate around 20%.

Population

The population under study consists of families residing in one of four Michigan counties - two urban and two rural - who have children with severe developmental disabilities residing in the family home. Children range in age from 4 to 17 years and the yearly taxable family income for 1983 did not exceed $60,000. Children are also enrolled in the public special education programme and classified as either severely mentally impaired, severely multiply impaired or autistic.

Sample Selection

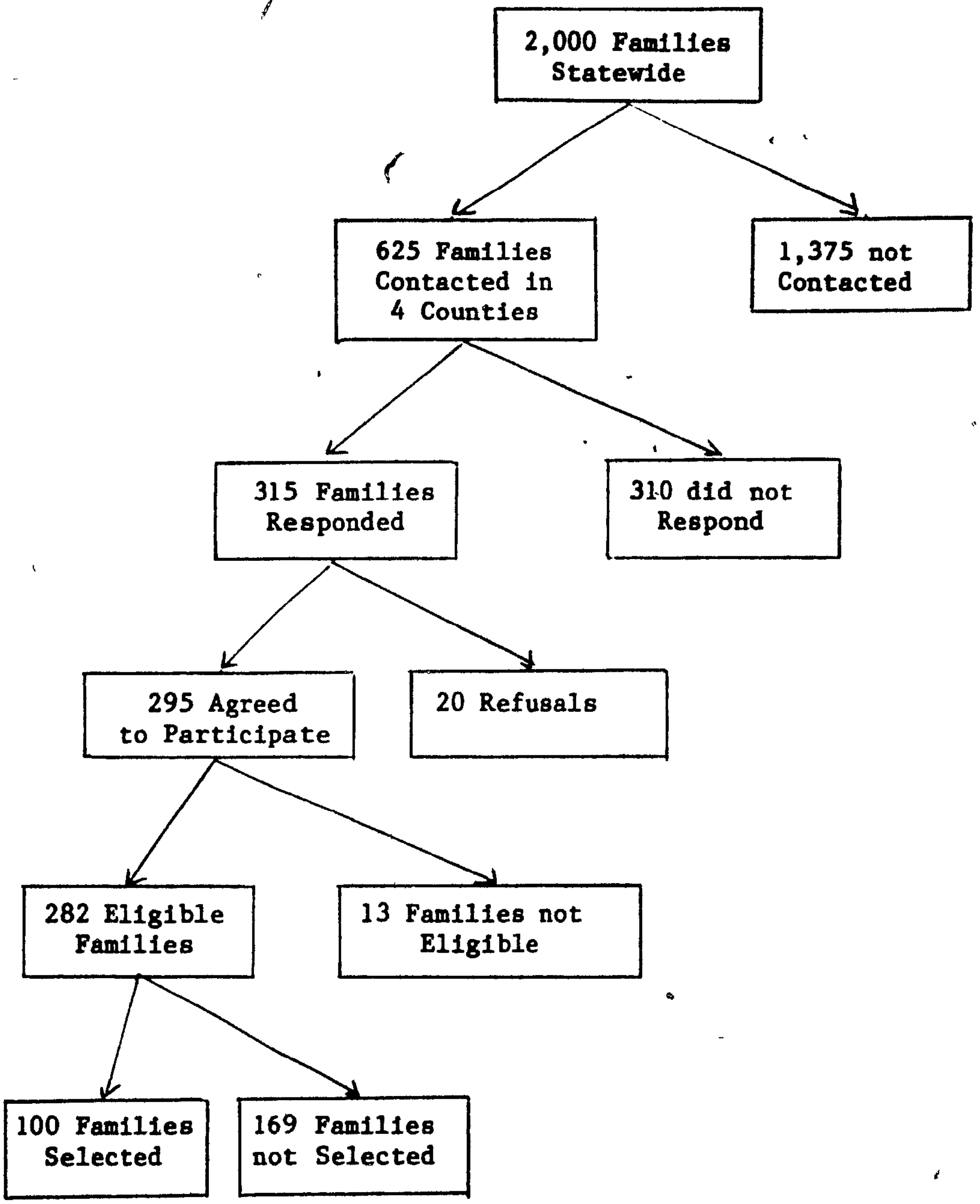
The sample population of 100 families was selected from two urban and two rural Michigan counties. Eighty-five families residing in urban counties (Wayne, N = 60 and Genessee, N = 25) and 15 families living in rural counties (Shiawassee and Tuscola, N = 15) were accepted into the study. Counties were selected with the assistance of experts from the Michigan Department of Mental Health which had just completed a baseline study of family support services by county (Herman, 1984) and based on data regarding the percentage of farm and non-farm population and per capita income as reported in The County and City Data Book (1983). The number of families interviewed in each of these areas approximates the distribution of the population of eligible families among these two types of counties in the state.

Families with a child who met the special education criteria of either severely mentally impaired, severely multiply impaired or autistic impaired were contacted through the Intermediate School Districts (ISDs). The ISDs in each county are responsible for special education services. Consequently, they have a complete listing of the children in the three impairment categories for their county. The ISDs sent letters prepared by the researchers to all families with a child who fit the diagnostic criteria for the Family Support Subsidy Programme describing the study and enlisting their participation. Confidentiality was assured, as no names were released to the researchers. A pre-stamped postcard addressed to the research team was included with the letter requesting address, telephone number, and age of the handicapped child. Parents could also opt to request further information about the study without providing any information beyond telephone number by checking the appropriate box on the postcard. It was also explained in the letter that the study was independent of the subsidy and that families would be paid $5.00 for each interview in appreciation for their time.

Figure 4.1 describes the sample selection process. Approximately 625 letters were sent, 500 in Wayne County, 100 in Genessee County and 25 in Shiawassee and Tuscola Counties. A total of 315 postcards were returned, yielding a response rate of 50%. Twenty families refused to be interviewed, leaving 295 families who agreed to participate. Thirteen families were excluded for reasons that included: the child was over 16 years old (N = 10); there was more than one severely handicapped child in the family (N = 2); or the father was the primary caregiver (N = 1). From the 282 eligible families responding, a stratified sample based on age of the handicapped child was selected. Stratification was determined by state data which indicated that approximately 30% of the population was four to six years of age; 24% was seven to nine years old; 25% was ten to twelve years; and 31% was between thirteen and seventeen years. In Wayne County, the researchers drew approximately thirty families from suburban cities and another thirty from the City of Detroit to assure a mix of families from different income and racial groups, since data were not available regarding these characteristics prior to sample selection.

At time 2, 90 families were available for follow-up. Ten families were not re-interviewed for the following reasons: three families moved

Figure 4.1. Sample selection flow chart.



out-state; one family placed their child out-of-home; one had a seriously ill child; one child was not living with the same primary caregiver; one child died; one mother refused to be re-interviewed because she found it too demanding the previous year; another mother was excluded because her command of English was not adequate to comprehend the questionnaire; and one family could not be contacted at follow-up. Table 4.1 compares the ten families who dropped out of the study to the 90 families who were available at both times 1 and 2. I decided not to test whether the demographic characteristics of those not available at follow-up are statistically different from those available for re-interview, due to the small number of non-respondents at time 2. However, 70% of those not re-interviewed were Black, 90% were living in urban counties, 60% had incomes of $10,000 or below, and 90% of the mothers were not working outside the home.

Representativeness

The sample selected in each county was compared to the population of families in that county who were enrolled in the Family Support Subsidy Programme by diagnosis, sex, age and race of handicapped child and family income. The total sample was then compared to the statewide population of families enrolled in the programme. However, we were not attempting to select a sample which was representative of the state but of the counties included in the study. Therefore, the population of statewide enrollees is compared to the entire sample for general information, not because it was our intention to select a sample representative of the state.

Table 4.1

Demographic Characteristics of Respondents Available at Follow-up Compared to those not Available

	Percentage	
	Available (N=90) %	Not Available (N=10) %
Diagnosis		
Severely Mentally Impaired	41	10
Severely Multiply Impaired	36	50
Autistic Impaired	23	40
Sex of Children		
Male	51	60
Female	49	40
Age of Handicapped Child		
4 - 6	27	30
7 - 9	23	10
10 - 12	24	10
13 - 17	26	50
Race of Children		
Black	47	70
White	49	30
Other	4	0
Marital Status of Mother		
Married	56	30
Single	44	70
Educational Level of Mother		
High School	21	20
High School	50	60
College	29	20
Income		
≦ $5,000	13	20
5,001 - 10,000	26	40
10,001 - 20,000	18	20
20,001 - 40,000	21	10
40,001 - 60,000	4	10
Employment Status of Mother		
Employed Outside the Home	34	10
Not Employed Outside the Home	66	90
County of Residence		
Urban	84	90
Rural	16	10

According to Table 4.2, the sample is significantly different from the population in Wayne County by diagnosis only. There is a higher proportion of severely multiply impaired children in the population than in the sample. In Genessee County, the sample differs significantly from the population of Genessee families enrolled in the programme by diagnosis and sex of the child. The sample contains a greater percentage of children who are severely multiply impaired and female, than the population for that County. In Tuscola and Shiawassee Counties, there are no significant differences between the population and sample. However, statistical analysis was not performed for race since three cells did not contain any subjects. Looking at the four counties as compared to the entire population of families enrolled in the state, the sample has significantly more Blacks than the enrolled state population. There are no other significant differences between the population and sample. Although there were some minor differences between the population and sample in each county, this might be expected given the small sample size. With respect to generalizations to the State of Michigan, caution should be exercised as race may be an important determinant of family reaction and adaptation to having a severely handicapped child.

Data Collection

During the months of June and July, 1984 and then again during the same months in 1985, interviews were arranged by telephone and conducted with the female primary caregiver at a time and place of her convenience. Experienced interviewers were hired and trained by the researchers. A one-day training session was held at times 1 and 2 and

Table 4.2

Demographic Characteristics of the Sample Population Compared to the Total Population Enrolled in the Programme by County

	County (%)							
	Wayne		Genessee		Tuscola/Shia.		Total	
	Pop. (N=614) %	Sample (N=54) %	Pop. (N=129) %	Sample (N=22) %	Pop. (N=29) %	Sample (N=14) %	Pop. (N=2477) %	Sample (N=90) %
Diagnosis								
SMI[a]	28*	33	74**	59	52	43	43	41
SXI[b]	50	33	8	32	34	50	42	36
AI[c]	21	33	18	9	14	7	15	23
Sex								
Male	55	59	47	23*	55	64	52	51
Female	41	41	37	77	28	36	41	49
Unknown	5	-	16	-	17	-	7	-
Age[d]								
4 - 6	19	28	24	32	22	14	20	27
7 - 9	22	24	23	23	15	21	22	23
10 - 12	17	22	17	23	30	36	18	24
13	30	26	17	23	22	29	24	26
Race								
White	46	39	48	50	72	86	69	49**
Black	45	61	31	41	-	-	19	47
Other	3	-	2	9	-	14	4	4
Unknown	7	-	19	-	17	-	10	-
Income								
≤8,000	38	28	41	18	34	14	32	23
8-24,999	37	43	27	45	35	57	38	45
25-60,000	25	29	32	37	31	29	30	32

[a] SMI = Severely Mentally Impaired
[b] SXI = Severely Multiply Impaired
[c] AI = Autistic Impaired
[d] Population percentages do not equal 100% because children under the age of 4 are not included.

*$p < .05$
**$p < .001$

consisted of didactic material on the population being studied and review and practice with the research protocol. The interviewers were naive to the purpose of the study; however, they were aware that the families were receiving a cash subsidy.

Definition of Terms

This section will present definitions, both conceptual and operational, of the terms used in the study. The federal definition of developmental disabilities is provided first because it is the rubric under which all of the impairments described are subsumed.

Federal Definition of Developmental Disabilities

A developmental disability is a severe, chronic disability attributed to a mental and/or physical impairment, manifested before the person reaches age 22, which is likely to continue indefinitely. It also:

1. Results in substantial functional limitations in three or more of the following areas of major life activity:

    - self care
    - learning
    - mobility
    - self-direction
    - economic sufficiency
    - receptive and expressive language
    - capacity for independent living

2. Reflects the person's need for a combination of individually planned and coordinated care, treatment or other services which are of extended duration.

Impairment Categories

Students are classified as Severely Mentally Impaired (SMI), Severely Multiply Impaired (SXI) or Autistic Impaired (AI) according to criteria established by the Michigan State Board of Education (Michigan State Board of Education, 1983). The state definitions follow.

1. Severely Mentally Impaired:
    a.) Development at a rate of approximately 4½ or more standard deviations below the mean as determined through intellectual assessment;
    b.) Lack of development primarily in the cognitive domain; and
    c.) Impairment of adaptive behaviour.

2. Severely Multiply Impaired:
    a.) Multiple handicaps in the physical and cognitive domains;
    b.) Inability to function within other special education programmes which deal with a single handicap; and
    c.) Development at less than the expected rate for the age group in the cognitive, affective or psychomotor domains.

3. Autistic Impaired:
    a.) Disturbance in the capacity to relate appropriately to people, events, and objects;
    b.) Absence, disorder, or delay of language, speech,, or

meaningful communication;

c.) Unusual or inconsistent response to sensory stimuli in one or more of the following: sight, hearing, touch, pain, balance, smell, taste, and the way the child holds his/her body; and

d.) Insistence on sameness as shown by stereotyped play patterns, repetitive movements, abnormal preoccupation, or resistance to change.

Family

1. Immediate family: For the purposes of ~~this~~ study, immediate family refers to the female primary caregiver, her handicapped child, natural or otherwise, plus the other persons residing in the home who are related by blood, marriage or adoption. The handicapped child's natural father is also considered part of the immediate family, even if he resides outside the family home.

2. Extended family: This term includes those persons the primary caregiver defines as family, beyond members of the immediate family.

Informal Social Support

1. Conceptual definition: "Verbal and/or nonverbal information or advice, tangible aid, or action that is proffered by social intimates or inferred by their presence and has beneficial emotional or behavioral effects on the recipient" (Gottlieb, 1983; p. 28).

2. Operational definition: Actual or perceived assistance which is provided to the primary caregiver in the form of information,

concrete instrumental support or emotional support by family, friends, neighbours, co-workers, or other parents of handicapped children.

Coping

1. Conceptual definition: The continuing ability of the primary caregiver to manage and deal with the social, psychological and financial stresses of raising a severely handicapped child.

2. Operational definition: The degree to which the primary caregiver feels she is dealing with the demands of a handicapped child.

Stress

1. Conceptual definition: The amount of social, psychological and financial strain the family experiences as a result of caring for a severely handicapped child.

2. Operational definition: Stress as an outcome variable contains four dimensions. They include the burden of care, costs related to the care of the handicapped child, family and social pressures and depression in the primary caregiver. Stress as an input includes, the demands of the child due to his or her level of functioning, and life events which contribute to familial stress but are largely unrelated to the handicapped child.

Life Satisfaction

1. Conceptual definition: The degree to which one feels her sccial, psychological and material needs are met.

2. Operational definition: The primary caregiver's satisfaction with her life at this point.

Formal Support

1. Conceptual definition: Support provided to the family or handicapped member which is outside the informal system and is financially reimbursed by the individual receiving the service or a third party payor such as Medicaid, Blue Cross or the state.

2. Operational definition: Direct services, often provided through the school or community agency, by a professional or paraprofessional to the family or handicapped child.

Summary of Definitions

The preceding section described the conceptual and operational definitions for the terms used in this research. For the purposes of clarity and summarization, Table 4.3 outlines the operational definitions of informal social support, coping, stress, life satisfaction and formal support.

Measures

Informal Social Support

1. Carolina Parent Support Scale (CPSS): Social relationships which exist for the primary caregiver were measured by a modified version of the CPSS which was developed by Marie Bristol (1983) and adapted from the Sources of Help Checklist by Bronfenbrenner, Avgar, and Henderson (1977). The instrument asks about possible sources of informal support and the degree to which each source is helpful to the respondent in raising a handicapped child. Although the scale includes items regarding both formal and informal support, only the informal support items were used. Bristol operationally defines informal social

Table 4.3

Operational Definitions of Major Concepts

Measure	Operational Definition
1. Informal Social Support (Three Instruments)[a]	Actual or perceived assistance to the primary caregiver. Can be instrumental, emotional, informational or network.
2. Coping (Coping Scale)	Primary caregiver's perception of her ability to cope with care of the handicapped child.
3. Stress as an Outcome (Impact on Family Scale)[b]	Four Sub-scales: - Burden of Care - Cost of Care - Familial/Social Issues - Depression
Stress Related to Child (Level of Functioning)[c]	Child's ability to communicate, toilet and ambulate. Sexually and physically inappropriate behaviour.
Life Stress (Life Stress Scale)[d]	Common life events, largely unrelated to the handicapped child, which lead to life stress.
4. Life Satisfaction (Life Satisfaction Scale)	Primary caregiver's satisfaction with her life at the current time.
5. Formal Support	Number of services used by the family or handicapped child in the past month.

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[a] Bristol, 1983; Tausig & Epple, 1985;
[b] Stein & Riessman, 1980
[c] Holroyd, 1974
[d] Holmes & Rahe, 1967

support "as those (acts) which do not require exchange of money or formal organization. They include the rating of availability and helpfulness of immediate and extended family, friends, neighbours, and other parents of special children" (p. 1). A Likert response format which ranges in helpfulness from "not at all" to "a great deal" is used with mothers. Respondents can also indicate that the source is "not applicable."

Bristol (1985) reports that she has used the CPSS in four studies of parents with developmentally disabled children, three studies of mothers and one with fathers. In the studies conducted with mothers, perceived adequacy of informal support was significantly related to successful adaptation. For fathers of developmentally disabled children, however, social support did not predict depressive symptoms or stress related to the child. Bristol has not reported on the reliability or validity of the CPSS.

The CPSS was used at both times 1 and 2. At time 1, the same instrument was administered to both married and single women. At time 2, separate versions of the scale were used for married and single women, allowing direct comparisons between husbands and the handicapped child's father regarding degree of helpfulness. Possible scores for each item ranged from 0 (not applicable or not at all helpful) to 4 (a great deal helpful). All items were summed to yield a total support score. At time 1, values ranged from 1 to 28 with a mean of 11.76 and a standard deviation of 5.65. At time 2, values went from 1 to 29 with a mean of 13.93 and a standard deviation of 6.71. The higher mean at time

2 could be accounted for by the fact that single mothers were asked specifically about the helpfulness of the child's father, his parents, and his other relatives.

2. Assistance with Management Scale: This scale was developed by Tausig and Epple (1985) and measures support given to the primary caregiver in the form of information, instrumental help, and emotional support. Also queried is the source of support, its frequency, and how important the assistance was to the respondent. The instrument has content validity in that it measures all three domains of informal social support: informational, instrumental and emotional. No tests of reliability have been conducted according to Tausig. Even with these limitations, I decided to use the scale because, to my knowledge, no other measures there three types of support in one scale have been developed for use with families of handicapped children. The items which comprised the instrumental support measure included, help with: (1) ride to store, bank, etc.; (2) household chores; (3) babysitting for handicapped child; (4) family emergency; (5) housing or space problems; and (6) employment problems. Respondents were asked how often they received assistance with these tasks and items were scored from "never" (0) to "almost always" (3). Scores ranged from 0 to 12 with a mean of 4.03 and a standard deviation of 2.45.

Emotional support was tapped by three questions. Respondents were asked how often they received assistance with: (1) understanding the handicapped child's needs and problems; (2) family problems; and (3) the feeling that the demands of caring for the disabled child are a burden.

Scores ranged from 0 to 7, with a mean of 2.03 and a standard deviation of 1.75.

Finally, informational support was measured by a single item which asks how often the primary caregiver received assistance with information about programmes and services. The range in scores was 0 to 3 with a mean of 1.22 and a standard deviation of .83. All items in the instrument were then tabulated for an overall measure of support. Scores went from 1 to 22, with a mean of 8.09 and a standard deviation of 4.08.

3. Social Network Support: Network support was measured by an instrument which identifies the number of close friends available to the respondent. Specifically, the mother is asked about the people she can confide in, their relationship to her, and whether they are male or female. It was possible for the respondent to name up to four confidants. For each confidant named, the mother received a point. The range in scores was 0 to 4 with a mean of 1.96 and a standard deviation of 1.16.

Summary of Informal Social Support Measures

Three measures of informal social support were included in the questionnaire. The Carolina Parent Support Scale is the only instrument available at time 1 and time 2. However, at time 1, the same support instrument was used for married and single women. At time 2, a separate instrument was administered to married and single mothers, allowing for direct comparisons between these two groups in terms of the perceived helpfulness of husbands and the handicapped child's father. Two additional instruments were introduced at time 2, one measuring instrumental, emotional and informational support, and one measuring the number of network members available to the primary caregiver. Although the instruments measure a different aspect of informal social support, one would expect a correlation between measures. Therefore, the CPSS, management scale and network scale were correlated. Although the correlations between these instruments were moderate, between .35 and .29, they were in the expected directions and statistically significant. Table 4.4 displays the correlation coefficients and the corresponding p-values. Table 4.5 describes the instruments used to measure informal social support by type of support.

Coping

To determine the extent to which mothers felt they were coping, they were asked, on a scale from "poorly" to "excellently," how well they felt they were coping with the demands of their handicapped child. This question is formatted on a Likert Scale with a possible score from 0 to 3. At time 1, the mean was 2.93 with a standard deviation of 1.20. At time 2, the mean score was 2.07, and the standard deviation was .75. In addition to this structured question, respondents were asked an open-ended question at time 1 and time 2 about what helped them cope with the demands of the handicapped child's care. These responses will be analyzed for content.

Table 4.4

Pearson Product-Moment Correlations Between Informal Social Support Measures

	Measure		
Measure	CPSS[a]	Management	Network
CPSS[a]	1.00	.35**	.35**
Management	--	--	.29*
Network	--	--	--

[a] Carolina Parent Support Scale
*$p < .003$
**$p < .001$

Table 4.5

Measures of Informal Social Support by Type of Support

	Measures	Type
1.	Social relationships (Carolina Parent Support Scale)[a] Asks: Do they exist and how helpful are they? *Available at times 1 and 2	-Global measure of perceived support - does not specify type.
2.	Social support (Management Scale)[b] Asks: Do you get help? How important is it? Who provides it?	-Instrumental -Emotional -Information
3.	Social network (Social Network Form) Asks: Do you have people to confide in, and what sex are they?	-Emotional

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[a] Bristol, 1983

[b] Tausig & Epple, 1985

Stress

1. Stress as an outcome variable was measured by the Impact on Family Scale, a 25-item instrument developed by Stein and Riessman (1980) which examines how raising a chronically ill child affects the family. Factor analysis of this instrument by the original authors has identified four issues: (1) "economic burden, or the extent to which the illness changes the economic status of the family, drawing away from other resources; (2) social impact, or the quality and quantity of interaction with those outside the immediate household; (3) familial impact on interaction within the family unit including parental and sibling relationships; and (4) subjective distress, or the strain experienced by the primary caretaker that is directly related to the demands of the illness" (p. 466). In terms of the reliability of the instrument, Stein and Riessman (1980) computed Cronbach's alpha for the four factors and report reliability coefficients for the subscales between .60 and .86 and for the total, .88. All coefficients were felt by the authors to be acceptable for group comparisons, suggesting homogeneity of the item sets.

Although the Impact on Family Scale was designed for use with families having a chronically ill child, it was felt that there were enough similarities between the two populations to warrant use of the instrument with families of developmentally disabled children. Consequently, the wording of items was changed, where appropriate, to refer to "handicapped" children and items felt to be unrelated were dropped altogether. Only 13 of the original 25 items were included in the modified scale and 12 new items were added by the author.

In order to determine whether the modified scale identified similar factors with a population of families with handicapped children, factor analysis was performed. To ascertain whether the instrument measured a single phenomenon or several phenomena, a principle components factor analysis was run. This method revealed that the first factor explained 30% of the variance in the items. Carmines and Zeller (1979) report that researchers should assume that a single phenomenon is being tapped when the first extracted component explains 40% or more of the variance. Therefore, although 30% can be considered high, there is support for the conclusion that more than one phenomenon is measured by the scale. A second factor analysis was performed on the items, but this time a varimax rotation was included with four factors specified to coincide with Stein and Riessman's analysis.

Table 4.6 shows the factor analysis of the Impact on Family Scale by factor loading. The first factor includes items which primarily relate to burden of care issues. For example, the family gives up things, or each day is planned around the child's special needs, are statements indicative of the family's personal costs. Furthermore, foregoing work or school on the part of the primary caregiver, shows the price she must pay when a child with handicaps is part of the family. The second factor explains 8.3% of the variance in items and it concerns the financial impact of caring for a child with disabilities. This, incidently, is the only factor which parallels Stein and Riessman's factor analysis. The third factor has mostly to do with social and family issues, and the fourth factor includes only two items, which together might be construed as a depression score. These two items deal

Table 4.6

Factor Analysis of 25 Impact on Family Items: Matrix Ranked by Factor Loadings (Varimax)

	Factor			
	I	II	III	IV
Because of my child's handicap we find it difficult to take trips or vacations...........	.77	.20	.01	-.09
Our family gives up things because of my child's handicap	.71	.28	.20	.15
I have difficulty getting someone to care for my child when I need to go shopping or on errands.....................	.68	.07	.14	.36
Most of what we do each day is planned around my child's special needs................	.61	.15	.06	.12
I can't take a job outside the home because of my child's condition....................	.58	.17	.24	-.03
It is hard to find a reliable person to take care of my child	.51	.25	.02	.17
I worry about what will happen to my child in the future.....	.47	.10	.00	.23
I don't have much time left over for other family members after caring for my child..........	.46	.39	.29	.12
Our child's handicap does not interfere with out social life	.43	.18	.35	.22
I gave up working for a while because of my child's disability...................	.43	.21	.32	-.29

Table 4.6 (continued)

	Factor			
	I	II	III	IV
My child's handicap has kept me from going to school..........	.41	.37	.41	-.05
I think about not having any more children because of my child's handicap.....................	.29	.17	.04	-.04
Additional income is needed in order to cover our expenses...	.16	.68	-.13	.16
We have to borrow money to help pay for our child's care.......	.07	.63	.04	.07
The cost of my child's care is causing financial problems for the family...................	.21	.61	-.01	.20
I am unable to save much money because of the expense of my child's care..................	.40	.56	-.04	.09
Fatigue is a problem for me...	.23	.49	.12	.08
Time is lost from work due to appointments and care of my handicapped child.............	.28	.45	.15	-.20
Because of my child's disability we are closer as a family.....	-.10	-.22	.62	.08
My child's handicap keeps us from going out to visit friends or relatives.................	.46	.17	.52	.11
Because of my child's handicap we usually don't invite friends to our home..................	.30	.27	.42	.21
My relatives have been understanding and helpful with my child........................	.14	.14	.40	.25

Table 4.6 (continued)

	Factor			
	I	II	III	IV
Learning to manage my child's handicap has made me feel better about myself.................	.02	-.15	.27	-.19
Relatives interfere and think know what's best for my child.	.10	.10	.13	.61
Nobody understands the burden I carry........................	.39	.26	.14	.48

with interference from relatives and the perception of the primary caregiver that no one understands the burden she carries.

It is difficult to make direct comparisons between Stein and Riessman's original scale and the one modified for use in this study, because all the items are not identical. As a reliability check, Cronbach's alpha was computed for the four sub-scales and the total. Table 4.7 shows that coefficients for the sub-scales were between .51 and .86, and for the total it was .89. The total coefficient is high, suggesting good reliability of the instrument.

2. To determine the level of stress attributable to the demands of the handicapped child, the questionnaire included a scale adapted from Holroyd's (1974) Questionnaire on Resources and Stress (QRS). The QRS measures 15 dimensions related to a family's response to a handicapped child. Items were selected from three of the scales: child characteristics, physical incapacitation and social obtrusiveness. Under child characteristics, those items pertaining to communication were included. Regarding physical incapacitation, questions were used which tapped the child's ability to feed, toilet and ambulate. The remaining items dealt with sexually inappropriate and physically abusive behaviours. No scale was used in its entirety, as the objective was to determine a measure of the demands placed on the primary caregiver due to the child's lack of basic skills and inappropriate behaviour. The intent of Holroyd's instrument is to measure stress in families of developmentally disabled children; therefore, scales unrelated to our objective of measuring functional ability were not included.

Table 4.7

Reliability Analysis of Impact on Family Scale, Time 2

Dimension	No. of Items	Alpha Coefficient
Burden of Care	12	.86
Financial	6	.77
Familial/Social	5	.60
Depression	2	.51
Total Score	25	.89

A measure of child's functional level was arrived at by scoring 0 for negative answers and 1 for positive answers. For instance, if the answer to "my handicapped child cannot walk without help" was yes, the value assigned would be 0. This yielded a total score with higher values indicating better ability to function. The mean score at time 1 was 6.71 and the standard deviation 2.64. At time 2 the mean was 7.27 and the standard deviation 2.90. The increase in means between time 1 and time 2 is probably related to maturity in the children.

In order to determine whether items measuring similar functional areas were reliable, Cronbach's alpha was computed for subscales regarding communication, toileting, ambulation and physical abuse. Four questions were analyzed in the area of communication. They included: (1) Is your child able to communicate with others of his or her age group? (2) Is it difficult to communicate with your child because he or she has difficulty understanding what is being said to him or her? (3) Can people understand what your child tries to say? (4) Is your child able to express his or her needs to others? The alpha was .65 indicating that taken together these four items are not a very reliable measure of a handicapped child's ability to communicate. However, all of the items were correlated in the expected direction.

The two questions regarding toileting were: (1) Is your child able to go to the bathroom by him or herself? (2) Does your child use a bedpan or diaper? In this case the alpha was acceptable at .78, suggesting that these questions consistently measure the same phenomenon.

Regarding ambulation, two items were analyzed: (1) Can your child walk without help? (2) Can your child go up or downstairs by him or herself? The alpha was high at .94, indicating good reliability.

I was also interested in whether children who were harmful to others were likely to be harmful to self. Cronbach's alpha was computed for items which asked: (1) Does your child lose control in a way which is harmful to others or destructive of property? (2) Does your child physically harm or abuse him or herself? The alpha was .54, which suggests that children who are physically abusive to self are not necessarily harmful to others.

In summary, the items used to construct this instrument are reliable with respect to toileting and ambulation, but lack an acceptable level of reliability in the functional area of communication. Furthermore, children who abuse themselves will not necessarily turn that aggressiveness on others.

3. Life stress unrelated to the handicapped child was measured by a modified Holmes and Rahe (1967), Stressful Life Events Scale. Added to the scale were three items, two which asked if the handicapped child had entered puberty or changed schools in the past year, and one which asked if the respondent had been robbed or attacked in the past year. Values for these three items were based upon values for similar questions in the scale and the author's expertise on the impact of a handicapped child upon the family. Table 4.8 shows the items used and the values assigned to each life event. The scores ranged from 0 to 314

Table 4.8

Stressful Life Events Rating Scale, Time 2

Rank	Life Event	Value
1	Death of Spouse	100
2	Divorce	73
3	Marital Separation	65
4	Death of Close Family Member	63
5	Robbed or Attacked	53*
6	Personal Injury or Illness	53
7	Marriage	50
8	Fired or Laid-off Work	47
9	Change in Health of Family Member	44
10	Pregnancy	40
11	Handicapped Child Entered Puberty	39*
12	Handicapped Child Started/Changed Schools	30*
13	Child Left Home	29
14	Begin Working Outside the Home	26
15	Change Jobs	20
16	Change Residence	20

*These items were not included in Holmes and Rahe's (1967) Scale but were added by the author. Scores for these items were arrived at by considering similar items included by Holmes and Rahe and the author's knowledge of the impact of a handicapped child on the family.

with a mean of 80.67 and a standard deviation of 69.31. The distribution was skewed to the lower end of the scale, meaning that most people had low or moderate stress scores and a few had extremely high scores. Consequently, the scores for this instrument were not normally distributed, but highly skewed to the lower end of the scale.

Life Satisfaction

Life satisfaction was measured by a question which asked the respondent on a ten point scale how satisfied she is with her life at the present time. Consequently, life satisfaction scores ranged from 0 to 10, with higher scores indicating greater life satisfaction. At time 1, the mean was 6.22 and the standard deviation 2.30. At time 2, the mean value was 6.67 and the standard deviation, 2.23. The difference in life satisfaction between times 1 and 2 was significant at the .05 level (t (88) = 1.95). Using other indicators of satisfaction which were part of the questionnaire, a satisfaction index was constructed. Included in the index were the following three items: (1) Are you satisfied with your present working status? (yes or no) (2) How satisfied are you with the amount of time you get to yourself to do the things you like to do? (1, very dissatisfied to 4, very satisfied) (3) How satisfied are you with the amount of time you were away (for social reasons)? (1, very dissatisfied to 4, very satisfied). The index mean was 5.62 with a standard deviation of 2.11. The correlation coefficient for life satisfaction and the satisfaction index was .42, which has a p value less than .001. This is evidence that the life satisfaction scale has construct validity. No measure of reliability is available.

Formal Support

The primary caregiver was asked about formal services used in the past four weeks. Pertaining to services used, mothers were asked who provided the service, the amount and sources of payment, and whether the service had been used as much as the family wanted. If the family had desired more of the service, the respondent was asked why they had not received it. If the service had not been used, they were asked to indicate a reason. A measure of formal support was arrived at by adding the number of services used in the past four weeks. At time 2, the mean number of services used was 3.94 and the standard deviation, 2.26. Some families did not use any services in the past four weeks and the maximum number of services used was 10.

Summary of Measures

Carmines and Zeller (1979) define construct validity as "the extent to which a particular measure relates to other measures consistent with theoretically derived hypotheses concerning the concepts that are being measured" (p. 23). It can be assumed that coping, life satisfaction and stress, although not the same constructs, are related and therefore a correlation should exist between these measures. In order to test this assumption, Pearson product-moment correlations were computed for combinations of all three constructs. According to Table 4.9, all measures are correlated, in the expected directions, at a significance level of .001 or less, indicating good construct validity.

All of the time 1 instruments can be found in Appendix A and the time 2 instruments are contained in Appendix B. Furthermore, Table 4.10

Table 4.9

Pearson Product-Moment Correlations Between Stress, Life Satisfaction and Coping, Time 2

	Measure		
Measure	Stress	Life Satisfaction	Coping
Stress	--	-.48*	-.32*
Life Satisfaction	--	--	.41*
Coping	--	--	--

*p = .001

Table 4.10

Construct Validity of Coping, Stress and Life Satisfaction Measures

Measure	Corroborating Data
1. Coping (Self Perception)	- Life Satisfaction - Stress
2. Stress (Impact on Family Scale)[a]	- Life Satisfaction - Coping
3. Life Satisfaction (Satisfaction with current life)	- Satisfaction with working status - Satisfaction with time away from child, for self, and away socially - Stress - Coping

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[a] Stein & Riessman, 1980

outlines the corroborating data used to measure the construct validity of coping, stress and life satisfaction. Table 4.11 describes the coding algorithm for the instruments used in the study. Lastly, Table 4.12 gives the descriptive statistics for all of the instruments which will be used in the analysis.

In retrospect, there are some things I would have done differently in designing the research protocol. First, the short form of the Questionnaire on Resources and Stress (QRS) developed by Friedrich, Greenberg and Crnic (1983) could have been used in its entirety instead of selecting items from three sub-scales. There are only 52 items in the short form, reliability and validity have been established, and it has been widely used in the field of developmental disabilities. The QRS could have also served as construct validity for the Impact on Family Scale. Secondly, in adaptation of the Impact on Family Scale for use with handicapped children, it would have been better to preserve the items as much as possible so that the scale could have been more easily compared when used with families having a handicapped child. Changing 12 of the original 25 items made it impossible to determine whether the same factors were identified within the instrument or how families with handicapped children differ from those with chronically ill children. Finally, the time 2 version of the Carolina Parent Support Scale should have been used at both time 1 and time 2. This would have allowed direct comparisons in the level of perceived informal social support between time 1 and time 2.

Table 4.11

Coding Algorithm for Instruments

Indicator	Coding Algorithm	Interpretation
1. Carolina Support Scale, Time 1 and 2	Ranges from 0 to 4 (0 = Not Applicable; 0 = Not At All; 1 = Just a Little; 2 = Some; 3 = Quite a Bit; 4 = A Great Deal)	Higher score, greater perceived informal social support.
2. Frequency of Instrumental, Emotional and Informational Support	Ranges from 0 to 3 (0 = Never; 1 = Sometimes; 2 = Often; 4 = Almost Always)	Higher score, greater frequency of assistance.
3. Importance of Instrumental, Emotional and Informational Support	Ranges from 0 to 3 (0 = Not Very Important; 1 = Somewhat Important; 2 = Important; 3 = Very Important)	Higher score, greater importance of assistance.
4. Social Network Support	Ranges from 0 to 4 (0 = no persons; 1 = 1 persons; 2 = 2 persons; 3 = 3 persons; 4 = 4 persons)	Higher score, greater number of confidants.
5. Coping	Ranges from 0 to 4 (0 = Poorly; 1 = Not Very Well; 2 = Fairly Well; 3 = Very Well; 4 = Excellently)	Higher score, greater ability to cope.
6. Impact on Family (Stress Measure)	Ranges from 0 to 3 (0 = Strongly Agree; 1 = Agree; 2 = Disagree; 3 = Strongly Disagree)	Higher score, greater negative impact and greater stress.

Table 4.11 (continued)

Coding Algorithm for Instruments

Indicator	Coding Algorithm	Interpretation
7. Level of Functioning	Ranges from 0 to 1 (0 = No; 1 = yes)	Higher score, better functioning.
8. Life Stress	Ranges from 20 to 100	Higher score, greater life stress.
9. Life Satisfaction	Ranges from 1 to 10 (1 = Worst Possible Life; 10 = Best Possible Life)	Higher score, greater life satisfaction.
10. Formal Support	Ranges from 0 to 1 (0 = No; 1 = Yes)	Higher score, more Services

Table 4.12

Descriptive Statistics of Instruments, Time 2

Instrument	No. of Items	Mean	S.D.	Minimum	Maximum
CPSS[a]	10	13.93	6.71	1	29
Management	10	8.09	4.08	2	22
Instrumental	6	4.03	2.45	0	12
Emotional	3	2.03	1.75	0	7
Informational	1	1.22	.83	0	3
Social Network	4	1.96	1.16	0	4
Coping	1	2.07	.75	0	3
Impact on Family	25	38.87	10.09	14	67
Level of Functioning	13	7.27	2.90	2	13
Stressful Life Events	16	80.67	69.31	0	314
Life Satisfaction	1	6.67	2.23	1	10
Formal Support	25	3.94	2.26	0	10

[a] Carolina Parent Support Scale

Plan for Analysis

Analysis of the data will be both quantitative and qualitative, with emphasis on quantitative analysis. Descriptive data which show the demographic characteristics of the sample and the functional abilities of the children will be presented first. Next, data which describe the informal social support system available to mothers will be reported. Bivariate analysis, comparing women with high and low levels of informal social support, single with married mothers and those working outside the home with those not, will be discussed. Multivariate linear regression analysis which considers the influence of informal social support on stress and life satisfaction will also be reported. In terms of qualitative analysis, content analysis will be conducted of mother's responses to a question which asked about how they cope with the care their handicapped child requires.

CHAPTER V

RESULTS

Introduction

The purpose of this chapter is to present the results of the analysis of the influence of informal social support on stress and life satisfaction in mothers of children with severe developmental disabilities. Compared will be differences in social support to married as opposed to single mothers, and women working outside the home versus those who are not employed outside the home. Also explored will be the role of the subcategories of informal support, instrumental, emotional, informational, and network, in assisting the primary caregiver to deal with the demands of a severely handicapped youngster. The predictive ability of the theoretical model employed in the study, the Double ABCX Model, will also be analyzed. Qualitative responses will be presented to provide insight to mothers' ways of coping.

The following primary descriptive research question will be explored:

> What is the nature of the informal social support system of the primary caregiver with a severely developmentally disabled child?

In addition, three descriptive research questions which compare women according to level of support and selected demographic variables will be addressed:

1. What are the demographic factors which discriminate mothers who have high levels of informal social support from those who have low levels of support?
2. Do single women differ from married women in their informal social support system?
3. Do mothers who are working outside the home differ from those who are not in their informal social support system?

The primary hypothesis which will be tested is:

> Female primary caregivers who report high informal social support will report lower stress and greater life satisfaction than those women with low informal social support.

With respect to subcategories of informal social support, the following four expectations are also proposed:

1. High Perceived Support - high coping, low stress, high life satisfaction.
2. High Instrumental Support - high, coping, low stress, high life satisfaction.
3. High Emotional Support - high coping, low stress, high life satisfaction.
4. High Informational Support - no significant effect on any measures of coping, stress and life satisfaction.
5. High Network Support - no significant effect on any measures of coping, stress, life satisfaction.

The results will be presented in the following sequence. First, the demographic characteristics of the sample will be presented, along with a description of the functional abilities of the children. Second, data which describe the informal social support system available to this group of ninety female primary caregivers will be presented. Next, compared will be women with high and low levels of informal social support, single mothers with married mothers and those working outside the home with those who are not employed. Multiple linear regression analysis examining the influence of informal social support on coping, stress and life satisfaction will then be reported. Presented lastly will be a qualitative analysis of mothers' responses to an open-ended question about how they cope with the caregiving demands of their handicapped child.

Description of the Sample

Table 5.1 shows that the handicapped children included in the study are either severely mentally impaired (41%), severely multiply impaired (36%) or autistic impaired (23%). Approximately half are male and half female and the children are evenly distributed across the age categories from 4 to 17 years of age. Forty-seven percent of the children are Black, 49% white and 4% Hispanic. Fifty-six percent of the mothers are married and 44% single. Most mothers have a high school education (50%), while 21% have not attained a high school degree and another 29% have at least some college. Four of the primary caregivers are the biological grandmothers of the children and one is a sibling. None of the children is adopted or in a foster home. Approximately half of the families fall above an annual income of $15,000, and the other 50% earn

Table 5.1

Demographic Characteristics of Sample

	Percentage (N=90)
Diagnosis	
Severely Mentally Impaired	41
Severely Multiply Impaired	36
Autistic Impaired	23
Sex of Children	
Male	51
Female	49
Age of Handicapped Child	
4 - 6	27
7 - 9	23
10 - 12	24
13 - 17	26
Race of Children	
Black	47
White	49
Other	4
Marital Status of Mother	
Married	56
Single	44
Educational Level of Mother	
High School	21
High School	50
College	29
Income	
≤$5,000	9
5,001 - 10,000	24
10,001 - 20,000	28
20,001 - 40,000	31
40,001 - 60,000	8
Employment Status of Mother	
Employed Outside the Home	34
Not Employed Outside the Home	66
Employment Status of Father	
Employed	77
Unemployed	23
County of Residence	
Urban	84
Rural	16

an annual income below $15,000. The majority of the fathers are employed (77%) and one third of the mothers are working outside the home. The sample is 84% urban and 16% rural. Analyses presented in the Methodology Chapter showed that the sample is fairly representative of families enrolled in the Family Support Subsidy Program in the four counties included in the study. With respect to the State of Michigan, the sample has significantly more Blacks than the enrolled population. Therefore, caution should be exercised in generalizing the results to the State.

Table 5.2 shows the percentages of yes and no responses to questions regarding the handicapped child's abilities. Most of the children do not toilet independently or speak, and ambulation and physically abusive behaviour is a problem for approximately a third of the sample. The children represent the severe end of the continuum in terms of the developmentally disabled population. Their disabilities are not likely to improve significantly and they therefore present long-term dependency needs to their caregivers.

Primary Descriptive Research Question: What is the nature of the informal social support system of the primary caregiver with a severely developmentally disabled child?

This section will present descriptive data regarding the informal social support system of the primary caregiver. Three dimensions of social support, represented by different instruments, will be reported. Explored first will be the frequency with which instrumental, emotional and informational assistance was received, the importance of this help

Table 5.2

Functional Abilities of Children, Time 2

Function	Responses (N=90) Yes %	 No %
Is ___ able to communicate with others of his/her age group?	13.3	86.7
Can ___ feed him/herself?	68.9	31.1
Is it difficult to communicate with ___ because s/he has difficulty understanding what is being said to him/her?	60.0	40.0
Is ___ able to play by him/herself?	86.7	13.3
Is ___ able to go to the bathroom by him/herself?	38.2	61.8
Does ___ lose control in a way that is harmful to others or destructive of property?	27.0	73.0
Does ___ physically harm or abuse him/herself?	37.8	62.2
Does ___ exhibit sexual behaviour that is difficult to deal with at times?	10.0	90.0
Can people understand what ___ tries to say?	31.1	68.9
Is ___ able to express his/her needs to others?	57.8	42.2
Does ___ have to use a bedpan or diaper?	65.6	34.4
Can ___ walk without help?	66.7	33.3
Can ___ go up or downstairs by him/herself?	61.1	38.9

and the source of help (Management Scale). Described next will be mother's responses to the Carolina Parent Support Scale (CPSS), which measured the perceived helpfulness of possible social support network members. Since the CPSS is available at time 1 and time 2, albeit different versions, scores on this scale will be compared to the extent possible. Finally, the social network of mothers will be described in terms of number and gender of confidants (Social Network Scale).

Mothers of a severely developmentally disabled child appear to take almost full responsibility for the day-to-day care of their handicapped child. Table 5.3 shows that of the 90 mothers interviewed, over 62% said that they never receive help with household chores and approximately 60% reported that they never or only sometimes have babysitting for their handicapped child. With respect to emotional support, almost 57% stated that they never receive help with the feeling that the demands of caring for a handicapped child are a burden. This was true even though they assume a high proportion of the care responsibility.

Although women did not receive much help with daily tasks, the help they did receive was important or very important. For instance, as seen in Table 5.3, of those receiving help with household chores, almost 80% stated that this assistance was important or very important. Similarly, 96% rated help with babysitting for the handicapped child important to very important. This trend held true for all types of assistance queried. The usual source of assistance was family members, regardless of the type of help received (see Table 5.4). The only departure was in

Table 5.3

Percentage of Primary Caregivers Receiving Assistance and Importance of Assistance, Time 2

	How often was assistance received?				If received, how important was this help?			
Assistance	Never %	Sometimes %	Often %	Almost always %	Not very Important %	Somewhat Important %	Important %	Very Important %
Instrumental Support:								
Ride to store, bank, etc.	48.9	33.3	11.1	6.7	6.5	23.9	23.9	45.7
Household chores	62.2	18.9	8.9	10.0	-	20.6	20.6	58.8
Babysitting for handicapped child	11.2	49.4	21.3	18.0	1.3	2.6	28.2	67.9
Family emergency	32.2	48.9	11.1	7.8	-	1.7	11.7	86.7
Financial problems	66.3	25.8	3.4	4.5	-	-	20.0	80.0
Housing or space problems	92.2	6.7	-	1.1	-	14.3	28.6	57.1
Employment problems	91.1	7.8	1.1	-	-	12.5	25.0	62.5
Emotional Support:								
Understanding handicapped child's needs and problems	30.3	41.6	24.7	3.4	-	3.3	27.9	68.9
Family problems	62.9	29.2	7.9	-	3.0	6.1	30.3	60.6
Feeling that the demands of caring for the disabled child are a burden	56.7	31.1	8.9	3.3	2.6	5.3	23.7	68.4
Informational Support:								
Information about programmes/services	18.9	46.7	27.8	6.7	2.9	14.3	32.9	50.0

Table 5.4

Source of Assistance for Those Receiving Help, Time 2

Assistance	Source of help?					
	Family %	Friends %	Co-workers or Neighbours %	Parent Groups %	Community Agency %	Other %
Instrumental Support:						
Ride to store, bank, etc.	67.4	21.7	10.9	-	-	-
Household chores	88.2	5.9	-	-	2.9	2.9
Babysitting for handicapped child	75.0	15.0	7.5	-	2.5	-
Babysitting for other children	78.3	17.4	4.3	-	-	-
Family emergency	83.6	8.2	4.9	-	3.3	-
Financial problems	60.0	6.7	-	-	33.3	-
Housing or space problems	42.9	28.6	-	-	28.6	-
Employment problems	25.0	-	25.0	12.5	25.0	12.5
Emotional Support:						
Understanding handicapped child's needs problems	22.2	12.7	1.6	20.6	27.0	13.9
Family problems	36.4	18.2	-	3.0	30.3	12.1
Feeling that the demands of caring for the disabled child are a burden	30.8	23.1	-	20.5	23.1	2.6
Informational Support:						
Information about programmes/services	-	4.1	4.1	21.9	56.2	9.6

information about services and programmes and help with understanding the handicapped child's needs and problems, where community agencies provided assistance the majority of the time.

While the Management Scale described above measured the actual assistance provided and the source and value of that help, the CPSS measured the primary caregiver's perception of the helpfulness of her social network. Examination of the CPSS by source of help confirms the finding that family members are the most frequent helpers. As seen in Table 5.5, at time 1, husbands or partners were the most important source of assistance and nonhandicapped children the second most cited source. Mother's relatives were found to be more helpful than her husband's relatives, although neither was as important as the spouse and nonhandicapped children. Friends and neighbours did not appear to provide much support to the primary caregiver.

At time 2, separate versions of the CPSS were administered to married and single women. Table 5.6 shows that for married women, husbands were the most helpful, since 62% of mothers stated that their spouses helped a great deal. Again, nonhandicapped children proved to be a great deal of help for 32% of the married mothers. By contrast, almost 75% of single women found the child's father not at all helpful and his relatives were also of very little perceived help to mothers. As shown in Table 5.7, this lack of support was not made up by boyfriends, with 56% of mothers stating either that they did not have a boyfriend or he was not at all helpful. For these primary caregivers, nonhandicapped children were the most important source of support, as

Table 5.5

Level of Perceived Support To Primary Caregivers by Source, Time 1

Source	Degree of Helpfulness[a]				
	N/A[b] or Not At All %	Just A Little %	Some %	Quite A Bit %	A Great Deal %
Husband/Partner	34	6	4	17	39
Ex-husband	96	2	2	-	-
Mother's parents	31	12	16	23	18
Husband's parents	66	12	10	6	7
Mother's other relatives	24	21	29	16	10
Husband's relatives	67	9	18	4	2
Nonhandicapped children	18	12	9	31	30
Friends	33	19	21	16	11
Neighbours	53	20	17	8	2

[a] N = 90
[b] N/A = Not Applicable

Table 5.6

Level of Perceived Support To Married Primary Caregivers by Source, Time 2

	Degree of Helpfulness[a]				
Source	N/A[b] or Not at All %	Just A Little %	Some %	Quite A Bit %	A Great Deal %
Husband	2	4	6	26	62
Mother's parents	36	8	22	24	10
Husband's parents	52	12	16	10	10
Mother's other relatives	34	24	18	20	4
Husband's other relatives	50	16	20	12	2
Parents of handicapped children	56	6	14	14	10
Nonhandicapped children	10	6	18	34	32
Friends	32	18	28	18	4
Neighbours	50	14	24	12	–

[a] N = 50
[b] N/A = Not Applicable

Table 5.7

Level of Perceived Support to Single Primary Caregivers by Source, Time 2

	Degree of Helpfulness[a]				
Source	N/A[b] or Not at All %	Just a Little %	Some %	Quite A Bit %	A Great Deal %
Boyfriend	56.4	5.1	5.1	12.8	20.5
Child's father	74.4	7.7	2.6	10.3	5.1
Mother's parents	28.2	15.4	12.8	20.5	23.1
Parents of child's father	82.1	5.1	5.1	5.1	2.6
Mother's other relatives	25.7	12.8	15.4	28.2	17.9
Other relatives of child's father	92.3	-	2.6	2.6	2.6
Parents of handicapped children	64.1	10.3	12.8	10.3	2.6
Nonhandicapped children	23.1	10.3	2.6	20.5	43.6
Friends	30.8	12.8	20.5	17.9	17.9
Neighbours	51.3	10.3	23.1	7.7	7.7

[a] N = 90

[b] N/A = Not Applicable

43% of mothers reported their other children to be a great deal of help. This was followed by mother's parents who were very helpful for 23% of mothers.

As stated earlier, the CPSS was the only informal social support measure available at times 1 and 2. However, the same instrument was administered to all women at time 1 and separate versions were administered to married and single women at time 2. This limits the reliability of direct comparisons between scores at times 1 and 2; nonetheless, I contrasted the level of perceived support by source. Table 5.8 shows a significant increase at time 2 in support from husbands or boyfriends and ex-husbands or the child's father. This is probably a result of the differences in instruments rather than a true increase. At time 2 the instrument given to single mothers more directly inquired about the helpfulness of the child's father and boyfriend, probably contributing to the higher scores.

To determine whether increases in support from husbands/boyfriends and ex-husbands/child's father were attributable to differences in instruments, I compared married women at times 1 and 2 and single women at both times. There was no increase in support from husbands between times 1 and 2 ($\underline{t}$ (49) = .15, p = .88). However, for single women, support from partner (time 1) or boyfriend (time 2) increased significantly ($\underline{t}$ (38) = 2.39, p = .02) as did support from ex-husband (time 1) or child's father (time 2) ($\underline{t}$ (38) = 2.77, p = .01). Therefore, it can be concluded that increases in perceived helpfulness

Table 5.8

Comparisons in Perceived Support to Primary Caregivers by Source for Time 1 and Time 2

	Time[a]						
	Time 1		Time 2			Values	
Helpfulness of:	Mean	SD	Mean	SD	t	df	p
Husband/boyfriend	3.19	1.78	3.52	1.67	2.11	88	.04
Ex-Husband/child's father	1.15	0.49	1.64	1.25	2.77	38	.01
Mother's parents	2.83	1.52	2.78	1.50	-0.51	88	.61
Husband's/child's father's parents	1.74	1.24	1.82	1.29	0.62	88	.54
Mother's other relatives	2.67	1.28	2.64	1.39	-0.27	88	.79
Husband/child's father's relatives	1.67	1.06	1.65	1.40	-0.17	88	.86
Nonhandicapped children	3.42	1.48	3.63	1.45	1.98	88	.05
Friends	2.54	1.38	2.60	1.36	0.44	88	.66
Neighbours	1.87	1.01	2.03	1.21	1.18	88	.24

[a] Coding was modified to accommodate paired t-test. Values range from 1 to 5.
N = 89

from these sources are accounted for by differences in the instrument at time 1 and time 2.

There was also a significant increase between times 1 and 2 in the helpfulness of nonhandicapped children. This may be a result of two factors. First, during the interim between interviews families received a cash subsidy of $225.00 per month. These extra funds may have been used to compensate siblings for babysitting, or nonhandicapped children may have felt they were benefitting in other indirect ways, rendering them more helpful. A second possible explanation is that siblings will have matured, meaning that some children would be more capable of assisting in the care of the handicapped child. In any case, the increase was small, from a mean of 3.42 to 3.63, and the difference was significant at the .05 level.

To ascertain a measure of social network support, respondents were asked about the number of people with whom they have a close and confiding relationship and the sex of those individuals. Table 5.9 indicates that 60% of the women have at least one or two confidants. Only 9% felt they have no one in which to confide. Table 5.10 shows that of those who have one or two confidants, 65% are female and 35% male. Of those having a third or fourth confidant, approximately 75% are female and 25% male.

Table 5.9

Percentage of Female Primary Caregivers by Number of Confidants, Time 2

No. of Confidants	Percentage Reporting
0	9
1	30
2	30
3	19
4	12

Table 5.10

Sex of Confidants, Time 2

Confidant	Sex of Confidant Male %	 Female %
#1	35	65
#2	35	65
#3	24	76
#4	27	73

Descriptive Research Question #1: What are the demographic factors which discriminate mothers who have high levels of informal social support from those who have low levels of informal social support?

Mothers were dichotomized into two groups by high and low levels of perceived informal social support according to the CPSS. The groups were divided at the median and those with a score of 13 or less were in the low group (N = 45), while those having a score between 14 and 29 were part of the high group (N = 44). Table 5.11 shows that there were no significant differences between women with high and low levels of informal social support on any of the demographic characteristics tested except marital status. Married women were more likely than single women to report high levels of informal social support on the CPSS. This finding will be explored in greater detail in the next subsection. Although the differences were not statistically significant, those in the low informal social support group had less education and lower incomes than those in the high support group. However, this may be expected as marital status is correlated with income and education.

Descriptive Research Question #2: Do single women differ from married women in their informal social support system?

This section will discuss the differences between married and single women in terms of the amount of instrumental, emotional and informational support received, the source of support and the degree to which this help was valued. Differences in the perceived helpfulness of possible network members will be explored and the overall level of perceived support for married and single women will be contrasted.

Table 5.11

Comparative Demographic Characteristics Between Women with Low and High Perceived Informal Social Support, Time 2

	Percentage	
	Low ISS N=45 %	High ISS N=44 %
Diagnosis		
Severely Mentally Impaired	42	41
Severely Multiply Impaired	33	39
Autistic Impaired	25	20
Sex of Children		
Male	44	57
Female	56	43
Age of Handicapped Child		
4 - 6	20	34
7 - 9	25	23
10 - 12	24	23
13 - 17	31	20
Race of Children		
Black	42	43
White	58	57
Marital Status of Mother*		
Married	42	68
Single	58	32
Educational Level of Mother		
High School	27	18
High School	55	41
College	18	41
Income		
$5,000	9	9
5,001 - 10,000	36	14
10,001 - 20,000	31	25
20,001 - 40,000	20	43
40,000 - 60,000	4	9
Employment Status of Mother		
Employed Outside the Home	71	59
Not Employed Outside the Home	29	41

Table 5.11 (continued)

Comparative Demographic Characteristics Between Women with Low and High Perceived Informal Social Support

	Percentage	
	Low ISS N=45 %	High ISS N=44 %
County of Residence		
Urban	87	84
Rural	13	16
Age of Mother		
20 - 30	33	41
31 - 40	42	48
> 40	25	11

Low ISS = CPSS scores between 1 and 13
High ISS = CPSS scores between 14 and 29
*p = .03

Also examined will be changes in perceived social support between time 1 and time 2, and the size and composition of the womens' social networks.

Married and single women were compared to determine differences in the amount of instrumental, emotional and informational social support they received. As seen in Table 5.12, no differences were found in the frequency with which these two groups of women received help with a ride to the store, household chores, babysitting, family emergency or items related to personal feelings. Single women, however, reported more support for family problems (_t_ (87) = 3.97, p .001). They also received help with financial problems more frequently; however, this is confounded by income as no other item varied by income.

When mothers were asked about the importance of the help they received, again the only significant difference was in help with family problems, with single mothers attaching greater importance to this form of assistance (see Table 5.13). For those mothers receiving help, there were no differences in the source of assistance, as both groups of mothers got help mainly from family members.

Turning to an analysis of perceived support as measured by the CPSS, Table 5.14 shows that when each possible source of support was examined at time 1, husbands were perceived to be significantly more helpful than ex-husbands, yet there were no differences between married and single women in the support they saw themselves receiving from mother's relatives, friends or neighbours. When the entire group was considered, nonhandicapped children were seemed to be significantly more

Table 5.12

Differences in Frequency of Assistance Provided to Married and Single Women, Time 2

	Marital Status						
	Married (N=50)		Single (N=40)		Values		
Assistance	Mean	SD	Mean	SD	t	df	p
Instrumental Support:							
Ride to store, bank, etc.	1.60	.86	1.95	.93	-1.85	88	.07
Household chores	1.76	1.10	1.55	.88	0.98	88	.33
Babysitting for handicapped child	2.46	.97	2.46	.85	-0.01	87	.99
Family emergency	1.82	.85	2.10	.87	-1.54	88	.13
Financial problems	1.22	.47	1.75	.95	-3.39	87	.001
Housing or space problems	1.06	.24	1.15	.53	-1.07	88	.29
Employment problems	1.10	.36	1.10	.30	0.00	88	1.00
Emotional Support:							
Understanding handicapped child's needs and problems	1.88	.86	2.18	.78	-1.69	87	.09
Family problems	1.22	.42	1.73	.75	-3.97	87	.001
Feeling that the demands of caring for the disabled child are a burden	1.58	.84	1.60	.74	-0.12	88	.91
Informational Support:							
Information about programmes/services	2.30	.91	2.13	.72	0.99	88	.32

Table 5.13

Differences in Importance of Assistance Provided to Married and Single Women, Time 2

	Marital Status[a]						
	Married (N=50)		Single (N=40)		Values		
Assistance	Mean	SD	Mean	SD	t	df	p
Instrumental Support:							
Ride to store, bank, etc.	3.10	.995	3.08	.997	0.05	44	.96
Household chores	3.43	.870	3.31	.751	0.41	32	.68
Babysitting for handicapped child	3.67	.656	3.59	.551	0.46	76	.64
Family emergency	3.93	.254	3.77	.504	1.62	58	.11
Financial problems	3.80	.422	3.80	.410	0.00	28	1.00
Emotional Support:							
Understanding handicapped child's needs and problems	3.60	.563	3.71	.529	-0.78	59	.45
Family problems	3.00	1.000	3.73	.456	-2.30	12	.04
Feeling that the demands of caring for the disabled child are a burden	3.60	.681	3.56	.784	0.19	36	.85
Informational Support:							
Information about programmes/services	3.23	.891	3.40	.724	-0.88	68	.38

[a] Housing or space problems and employment problems were dropped due to a small number of mothers reporting assistance with these problems.

Table 5.14

Differences in Perceived Support to Married and Single Primary Caregivers by Source, Time 1

	Marital Status						
	Married (N=50)		Single (N=40)		Values		
Helpfulness of:	Mean	SD	Mean	SD	t	df	p
Husband/Ex-husband	2.73	.43	1.39	.66	11.17	65	.001
Mother's parents	2.76	1.53	2.95	1.52	-0.59	88	.56
Mother's other relatives	2.48	1.82	2.88	1.38	-1.46	88	.15
Nonhandicapped children	3.72	1.26	3.08	1.66	2.10	88	.04
Nonhandicapped children[a]	3.75[b]	1.21	3.63[c]	1.38	0.39	76	.70
Friends	2.60	1.35	2.43	1.40	0.59	88	.55
Neighbours	1.90	1.06	1.80	1.16	0.43	88	.67

[a] Includes only those mothers with a nonhandicapped child.
[b] N = 48
[c] N = 30

helpful to married women than single women. However, when those mothers without a nonhandicapped child were dropped from the analysis, there were no significant differences in the helpfulness of nonhandicapped siblings.

At time 2, support from the child's father and his relatives for the single mother were specifically addressed, allowing comparisons on several items between married and single women. Analysis by possible sources of support in Table 5.15 shows that married women received significantly greater support from their husbands, husband's parents and husband's other relatives than single women received from the child's father and his parent's and other relatives.

Again, analysis with all the respondents included indicated a significant difference between married and single women in the level of support from nonhandicapped children at time 2. However, when mothers without a nonhandicapped child were excluded from the analysis, there was no significant difference in the helpfulness of nonhandicapped children to married or single women. Therefore, in single parent families where there is a nonhandicapped sibling, these children were not shown to be of greater assistance than their counterparts in two-parent families at time 1 or 2.

As stated previously, the CPSS used at time 1 did not distinguish well between married and single mothers. With the exception of a reference to the ex-husband, no questions specifically asked about the helpfulness of the child's father and his relatives for the single

Table 5.15

Differences in Perceived Support to Married and Single Primary Caregivers by Source, Time 2

	Marital Status						
	Married (N=49)		Single (N=40)			Values	
Helpfulness of:	Mean	SD	Mean	SD	t	df	p
Husband/child's father	3.49	0.08	0.63	1.23	12.70	64	.001
Mother's parents	1.67	1.44	1.90	1.58	-0.71	87	.48
Husband's/child's father's parents	1.16	1.42	1.40	0.93	2.99	85	.004
Mother's other relatives	1.39	1.26	1.95	1.50	-1.92	87	.06
Husband's/child's father's relatives	1.02	1.18	0.20	0.79	3.91	84	.001
Parents of handicapped children	1.18	1.48	0.75	1.17	1.51	87	.14
Nonhandicapped children	2.76	1.25	4.20	2.78	-3.86	87	.001
Nonhandicapped children[a]	2.79[b]	1.20	3.20[c]	1.13	-1.51	75	.14
Friends	1.47	1.23	1.75	1.52	-0.97	87	.34
Neighbours	1.00	1.12	1.08	1.33	-0.29	87	.77

[a] Includes only those mothers with a nonhandicapped child.
[b] N = 47
[c] N = 30

mother. At time 2 this was rectified and a separate scale constructed for single and married parents. The CPSS scores for each item were summed and analyzed by marital status. As seen in Table 5.16, married women reported significantly more perceived informal social support than single women at time 1 (*t* (88) = 4.31, $p < .001$), while at time 2 the level of support to married women was still greater but not statistically significant, *t* (87) = 1.91, p = .06.

The difference in the instruments probably explains why married women fared better at time 1 than at time 2. In order to determine whether this was the case, I compared married women by mean level of support at time 1 and time 2 and then compared single women in the same fashion. The results show a significant increase for single women at time 2 (*t* (38) = 3.07, p = .004) and no increase for married women (*t* (49) = .36, p = .72). Therefore, it can be concluded that greater perceived informal social support on the part of married women at time 1 is accounted for by the instrument used at time 1.

As noted in the previous section, when the sample was dichotomized into women with low and high levels of informal social support, there were significantly more married women in the high support group. Yet, as seen above, when t-tests were performed, the differences between married and single women did not reach significance. I place more confidence in the t-tests because it is a richer use of the data than analysis by dichotomized groups.

Table 5.16

Differences in Total Perceived Support to Married and Single Primary Caregivers, Time 1 and Time 2

	Marital Status						
	Married		Single		Values		
Time	Mean	SD	Mean	SD	t	df	p
Time 1	14.12	6.04	9.35	3.93	4.31	88	.001
N	(50)		(40)				
Time 2	15.14	6.62	12.45	6.59	1.91	87	.06
N	(49)		(40)				

When married and single women were compared in terms of whether or not they had a confiding relationship, the difference was not significant. Similarly, when the number of confidants in the womens' network was considered, married and single women did not differ in network size. Furthermore, no differences were found with respect to the sex of the confidants of married and single women. This is an interesting finding, since it might be expected that married women would report their husbands as their first confiding relationship. However, this appeared not to be the case as both married and single women identified other women as confidants more frequently than they identified men.

Descriptive Research Question #3: How do mothers who are working outside the home differ from those who are not in the availability of informal social support?

Explored in this section will be the differences in informal social support between women working and not working outside the home. Data comparing the amount of actual assistance received, the source of help and the importance of this help, will be presented. Also compared will be perceived level of support and changes in support, between times 1 and 2. In addition, differences in social network size and composition between these two groups of women will be described.

Mothers were asked about the frequency with which they received assistance with daily tasks, personal feelings and information. The only significant difference in actual assistance to women working and not working outside the home was in babysitting for the handicapped child, with women working outside the home receiving greater help (see Table 5.17). However, working mothers did not receive any more help with daily household chores than their counterparts who were not working outside the home.

When mothers were asked about the importance of the help they received, working mothers thought help with a family emergency was significantly more important than those not working outside the home. Finally, no significant differences were found between working and non-working women in the source of support for the various types of assistance. Overwhelmingly, family members provided the majority of help to both groups of mothers.

As seen in Table 5.18, when perceived level of support was looked at by source at time 1, husbands, husband's other relatives and nonhandicapped children were found to be significantly more helpful to mothers working outside the home than those not working outside the home. Table 5.19 shows that when individual sources of support were examined at time 2, a significant difference was found between the helpfulness of husbands or child's father on behalf of working mothers. Nonhandicapped children were not found to be any more helpful for working mothers at time 2 when the entire group was considered. However, when those women without a nonhandicapped child were dropped, there was a significant difference between the two groups, with women working outside the home perceiving significantly more help from their nonhandicapped children.

Table 5.17

Differences in Frequency of Assistance Provided to Women Working and Not Working Outside the Home, Time 2

	Employment Status						
	Working Outside the Home (N=31)		Not Working Outside the Home (N=59)			Values	
Assistance	Mean	SD	Mean	SD	t	df	p
Instrumental Support:							
Ride to store, bank, etc.	1.61	.80	1.83	.95	-1.09	88	.28
Household chores	1.74	1.10	1.63	.98	0.51	88	.61
Babysitting for handicapped child	2.74	.89	2.31	.90	2.16	87	.03
Family emergency	1.84	.82	2.00	.89	0.84	88	.40
Financial problems	1.42	.81	1.48	.76	-0.37	87	.71
Housing or space problems	1.13	.34	1.09	.43	0.50	88	.62
Emotional Support:							
Understanding handicapped child's needs and problems	2.07	.89	1.98	.81	0.44	87	.66
Family problems	1.33	.61	1.51	.65	-1.22	87	.22
Feeling that the demands of caring for the disabled child are a burden	1.61	.80	1.58	.79	0.21	88	.84
Informational Support:							
Information about programmes/services	2.32	.91	2.17	.79	0.83	88	.41

Table 5.18

Differences in Perceived Support to Women Working and Not Working Outside the Home, Time 1

	Employment Status						
	Working Outside the Home (N=33)		Not Working Outside the Home (N=57)		Values		
Helpfulness of:	Mean	SD	Mean	SD	t	df	p
Husband/Partner	3.82	1.72	2.84	1.72	2.59	88	.01
Ex-husband	1.15	0.51	1.02	0.13	1.89	88	.06
Mother's parents	3.24	1.35	2.61	1.56	1.92	88	.06
Husband's parents	2.03	1.40	1.60	1.12	1.62	88	.11
Mother's other relatives	2.89	1.17	2.53	1.34	1.26	88	.21
Husband's other relatives	2.21	1.29	1.35	0.74	4.02	88	.001
Nonhandicapped children	3.91	1.31	3.16	1.51	2.39	88	.02
Nonhandicapped children[a]	3.35[b]	0.78	2.75[c]	1.29	2.51	72	.01
Friends	2.64	1.25	2.46	1.47	0.59	88	.56
Neighbours	1.79	0.93	1.90	1.19	-0.44	88	.70

[a] Includes only those mothers with a nonhandicapped child.
[b] N = 26
[c] N = 51

Table 5.19

Differences in Perceived Support to Women Working and Not Working Outside the Home, Time 2

	Employment Status						
	Working Outside the Home (N=31)		Not Working Outside the Home (N=58)		Values		
Helpfulness of:	Mean	SD	Mean	SD	t	df	p
Husband/child's father	2.74	1.61	1.91	1.77	2.17	87	.03
Mother's parents	1.84	1.46	1.74	1.53	0.29	87	.77
Husband's/child's father's parents	0.71	1.13	0.88	1.38	-0.59	87	.56
Mother's other relatives	1.61	1.31	1.66	1.45	-0.14	87	.89
Husband's/child's father's relatives	0.71	1.10	0.62	1.11	0.36	87	.72
Parents of handicapped children	1.61	1.46	0.90	1.31	0.87	87	.39
Nonhandicapped children	2.81	1.45	2.54	1.45	0.84	87	.40
Nonhandicapped children[a]	3.35[b]	0.80	2.77[c]	1.28	2.43	73	.02
Friends	1.61	1.28	1.59	1.42	0.09	87	.93
Neighbours	1.16	1.19	0.97	1.23	0.73	87	.47

[a] Includes only those mothers with a nonhandicapped child.
[b] N = 26
[c] N = 53

Although at time 1, women working outside the home reported significantly more informal social support than those not working outside the home according to the CPSS, at time 2 there was no significant difference in the level of support reported by these two groups of women (see Table 5.20). Since observed differences at Time 1 may have been due to a higher proportion of married women in the working group, I computed chi-square by marital and working status. The results indicate that at time 1, the difference in the proportion of married women working was not significantly higher but bordered on significance, X^2 (1, N = 90) = 3.36, p = .07. At time 2, there was clearly no relationship between marital and working status, X^2 (1, N = 90) = 1.03, p = .31. Therefore, the statistically significant difference in support to women working outside the home at time 1 may in part be due to a larger number of married women in that group. In terms of social network, there were no differences between women working and not working outside the home in the number and gender of confidants.

Discussion of Descriptive and Bivariate Analysis

In this sample of ninety mothers of children with severe developmental disabilities, the majority took on the full day-to-day responsibility for the care of their handicapped child. When asked about instrumental, emotional or informational support, most did not receive much assistance in these areas; however, the help they did receive was important to them. Furthermore, mothers' networks lacked multidimensionality, that is, support was usually proffered by immediate family members to the exclusion of help from extended family, friends and neighbours. In terms of network support, 91% of the sample felt

Table 5.20

Differences in Total Perceived Support to Women Working and Not Working Outside the Home, Time 1 and Time 2

	Employment Status						
	Working Outside the Home		Not Working Outside the Home			Values	
Time	Mean	SD	Mean	SD	t	df	p
Time 1 N	14.67 (33)	5.45	10.46 (57)	5.45	3.59	88	.001
Time 2 N	14.59 (31)	5.89	13.60 (58)	7.13	0.63	87	.53

that they had a close friend or confidant and, in most cases, the confidant was another woman.

When mothers were dichotomized into groups with high and low informal social support, there were no significant differences between the two groups on selected demographic variables except marital status. Further analysis using a t-test revealed that although the difference in the mean level of support to married and single mothers bordered on significance, it did not actually reach statistical significance (t (87) = 1.91, p = .06).

Analysis by marital status showed that there were really few differences between married and single women in the informal social support they received and in the degree to which they valued that support. Out of all items queried, single mothers received greater help in only one area, family problems. The most glaring differences between married and single women were on items concerning the perceived helpfulness of husbands versus the child's father. Husbands, husband's parents and husband's other relatives were significantly more helpful to married women than the child's father and his parents and other relatives were to the single mother. It appears that single mothers can expect that the child's father and his family will provide little support to her in caring for a child with severe handicaps. Furthermore, single mothers will probably find that their chances for remarriage are diminished when compared to their counterparts with nonhandicapped children. Consequently, single women often must raise their handicapped children without the support of a husband or the child's father and his family.

The two primary instruments used to measure informal social support were the Carolina Parent Support Scale (CPSS) and the Management Scale. The CPSS measured perceived support and the Management Scale measured the frequency of actual assistance provided. Time 2 analysis showed that married women perceived greater support their husband's and his relatives than single women from the child's father and his relatives, but when actual help with daily tasks was considered, they did not receive any more assistance. Although there is a significant correlation between perceived level of support (CPSS) and overall assistance provided (Management Scale), item by item analysis revealed few differences between these two groups of women in help with daily household and childrearing chores. There are at least two possible explanations for this disparity. The first is that assistance was provided in ways not tapped by the Management Scale. For instance, family members could be helpful to mothers by taking responsibility for tasks unrelated to the care of the handicapped child, thus relieving mothers of burdens in other areas. The second possible explanation is that perceived support is not necessarily based on the actual quantity of help given. There may be important psychological determinants in the perception of informal social support which are not reflected in the level of help one receives on a day-to-day basis. This is an issue which will be explored in greater detail in the multiple linear regression analysis.

Comparisons between women working and not working outside the home, similar to analysis by marital status, revealed few differences between the two groups. The only significant difference in actual assistance to women working and not working outside the home was in babysitting for the handicapped child. Since working outside the home necessitates additional babysitting, it is expected that employed women would receive greater help in this area. Regarding the importance of the help proffered, working mothers attached more significance to help with a family emergency. Again, this is logical in that a working mother may not be able to readily respond to a family emergency and she would therefore find assistance with such a situation beneficial. It was interesting that working mothers did not receive any more help with daily household chores than their counterparts who were not working outside the home. This finding indicates that those women who choose to join the workforce assume the dual role of homemaker and worker.

With respect to perceived level of social support, when each possible source was considered, women working outside the home reported more help from her husband or the child's father and their nonhandicapped children than women not working outside the home. Working women, therefore, felt that they had help from immediate family members more frequently than women who were not working outside the home.

It could be theorized that women employed outside the home are less socially isolated than their counterparts at home. However, when women were compared by the number of confidants they had, non-working women did not differ from working women. Consequently, at least in terms of the number of close friends, women not working outside the home did not experience greater social isolation than those working outside the home.

Comparing the results of this study with the work of other researchers, both commonalities and inconsistencies emerge. I found that mothers' social support networks lacked multidimensionality. That is, support came mostly from family members to the exclusion of support from friends and neighbours. Other researchers have found that when compared to control families, parents with a handicapped child do not differ in the size of their family network but they have significantly fewer friends in their network (Kazak & Marvin, 1984). Although there was not a control group in this study, among the ninety primary caregivers surveyed, family networks were strong and friendship networks were weak. In fact, regarding actual or perceived level of help with the handicapped child, support was proffered mainly from immediate family members rather than extended family, friends or neighbours.

Regarding the relationship between age of the child and social support, Suelzle and Keenan (1981) found that support from family and friends declined significantly over the first 21 years of the handicapped child's life. However, I did not find that level of actual or perceived support was related to age of the child or any other demographic variable. This may be due to the fact that the children in this study represent the severe end of the continuum in terms of disability, whereas those in the Suelzle and Keenan study represented a broader range of disability level. Children with severe disabilities do not gain the degree of independence that children with milder forms of disability attain. Therefore, there is a prolonged need for assistance with severely handicapped children which does not exist to the same extent for less handicapped children.

The impact of having a handicapped sibling upon nonhandicapped children has been widely discussed in the literature. The consensus is that children with a handicapped sibling are not any more likely to manifest emotional problems than children with a nonhandicapped sibling. However, these studies have not measured the degree to which children with a handicapped sibling assume responsibility for daily household tasks or care of the handicapped sibling. This study showed that mothers found their nonhandicapped children to be a very important source of support. In fact, mothers working outside the home perceived significantly greater support from their nonhandicapped children than those not working outside the home. Although beyond the scope of this study, the results indicate that children with a handicapped sibling may take greater responsibility at home than their counterparts with nonhandicapped siblings. Yet, other research indicates that this has not resulted in an increased incidence of emotional difficulties for these children.

The plight of the single-parent with a disabled child has received a fair amount of attention from researchers and practitioners. The results of this study indicate that the only significant difference between married and single mothers is in the perceived helpfulness of the father and his relatives. When actual assistance with daily household tasks was measured, married women did not receive any greater support. While perceived helpfulness from husbands is potentially very important psychologically, we may be overestimating the amount of concrete support married women receive compared to single women. In terms of the day-to-day responsibility for the care of the handicapped child, that job seems to fall to mothers, regardless of marital status.

The fact that husbands provide little assistance with childrearing or household chores to their wives is a phenomenon common to most marriages. In a recent nationwide study, Genevie and Margolies (1987) found that 75% of the women they surveyed felt that their husbands should be more supportive in the day-to-day running of the household. Twenty percent of the sample felt that their husbands gave them so little support that they might as well not be there at all. Therefore, it appears that my results mirror the situation for women in society and may not be related to the presence of a handicapped child.

Summary of Descriptive and Bivariate Analysis

In summary, from the descriptive data and bivariate analysis it can be concluded that mothers with severely handicapped children do not get much help on a day-to-day basis with the care of the handicapped child, but what help they do receive is important to them. Furthermore, help that is proffered comes from immediate family members rather than extended family, friends and neighbours. In addition, the majority of women have a least one close friend in whom they can confide.

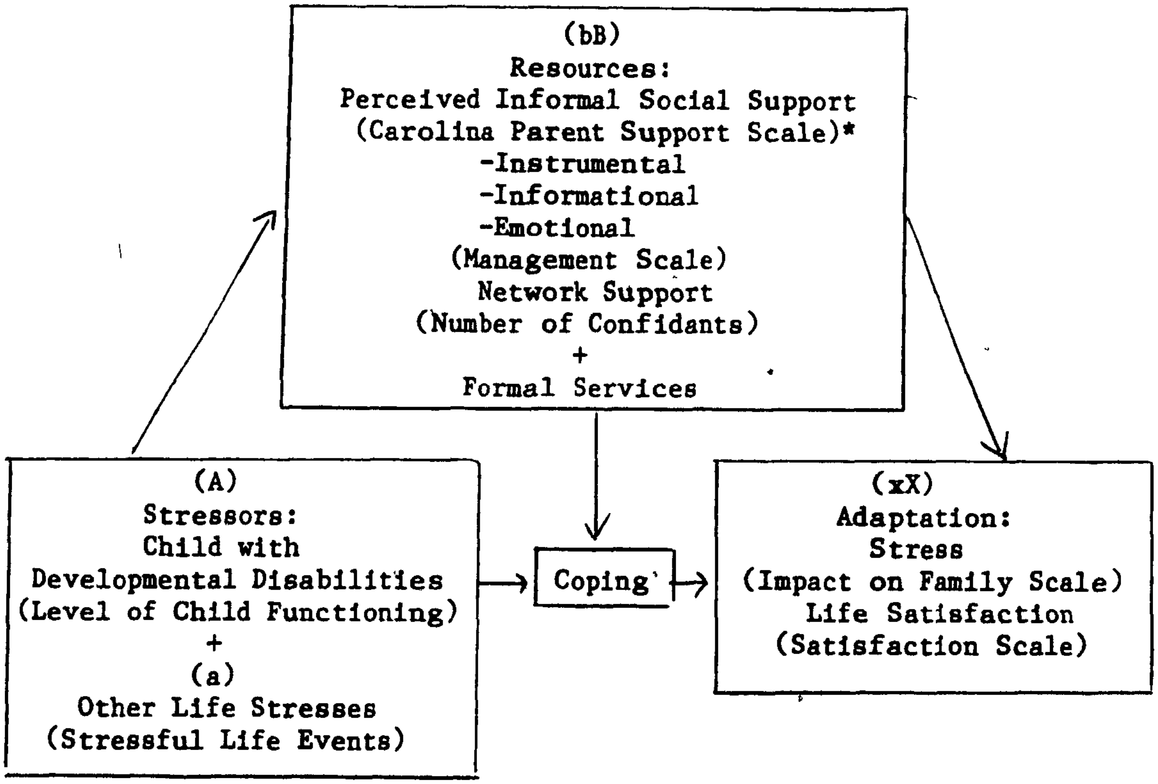
Bivariate analysis of the data showed that single mothers are at risk for low informal social support. This is true because the child's father and his family are not very helpful to the single mother. Women working outside the home, on the other hand, perceived greater assistance from a husband or the child's father and their nonhandicapped children than women not working outside the home. Although married and working women perceived greater assistance from some immediate family members, these groups did not actually receive more assistance with most daily tasks. Therefore, other research may be overstating the degree to which married women are assisted in caring for their children with severe handicaps (Beckman, 1983; Wikler et al., 1984).

Review of the Double ABCX Model and Research Hypotheses and Questions

While the descriptive and bivariate analysis sought to describe and compare the informal social support system of mothers, the purpose of multiple linear regression analysis is to explore the relationships between the independent variables and coping, stress, and life satisfaction. In order to make the multivariate analysis more meaningful, the theoretical model employed, as well as the hypotheses and questions posed, will be reviewed.

The Double ABCX Model (McCubbin & Patterson, 1983b) is a multivariate theoretical framework for explaining family adaptation to stress. The model seeks to identify how stressors are mediated by individual, family and community resources and family coping responses, to produce family adjustment over time. For the purposes of this study,

Figure 5.1. The Double ABCX Model operationalized.



*Instruments in parentheses represent those used to measure each dimension of the model.

adaptation means maternal adaptation as only mothers were interviewed. McCubbin and Patterson's model has been adopted as a framework for this study. Figure 5.1 shows how it has been operationalized.

Stressors

There are two types of stressors which families with a handicapped child experience, one related to the child, and one which can be considered normative, since all families are susceptible to such stresses. The first stressor (A) is determined by the handicapped child's level of functioning. The more disabled the child, the greater the demands placed on the primary caregiver, consequently the greater the stress for the caregiver. This stress also results in chronic stress because the child's condition is not expected to improve. An instrument adapted from the Questionnaire on Resources and Stress (Holroyd, 1974) has been used to measure the child's functional capacity. The second stressor (a) is normative and defined as the other life stresses the family has experienced. This variable is operationalized by the Holmes and Rahe Stressful Life Events Scale (1967). Both of these stress variables are expected to explain maternal adaptation.

Resources

The second step in the model is concerned with resources. Theoretically, resources moderate the degree to which stressors effect maternal adaptation since resources assist mothers in dealing with the demands of caring for a handicapped child. Resources (bB), for the purposes of this research, are defined as informal social support, either perceived, instrumental, informational, emotional or network support, and formal support, or services. (1) Perceived support is a global measure of how helpful mothers view people in their informal network and is operationalized by the Carolina Parent Support Scale (Bristol, 1983). (2) Instrumental support is help with daily tasks. (3) Information about how to care for the handicapped child or information about services available to the family or child is categorized as informational support. (4) Emotional support is that which assists one in expressing and confronting feelings. Instrumental, informational and emotional support are measured by the Management Scale (Tausig & Epple, 1985) which inquiries about support proferred to the mother in each of these areas. (5) Network support consists of the number of people mothers feel they can confide in and is measured by an instrument which asks mothers to name those individuals with whom they have a close and confiding relationship. (6) Formal support relates to the services the family or child is receiving and is measured by summing the number of services received in the past month.

Regarding the types of informal social support, it is hypothesized that perceived, instrumental and emotional support will explain the outcome variables. Informational support and network size are not expected to correlate with any of the dependent variables. Although formal services have received a mixed review in the literature with respect to their ability to reduce family stress, the purpose of the service system is to assist families and therefore a significant, positive relationship between this services and the dependent variables is expected.

Coping

Coping is the third step in the ABCX Model. Conceptually, coping is an outcome of the interaction between resources and perception of the event. No measure of perception of the event has been included in the study because the original intent was to explore the relationship between various types of informal social support and maternal stress. In retrospect, it would have strengthened the research to incorporate a measure of whether or not mothers perceived the presence of the severely disabled child as a catastrophe for the family. However, a measure of mother's perception of their ability to cope was included in the questionnaire. Therefore, it is at least possible to examine the relationship between resources and coping to determine if indeed resources correlate with coping. It is hypothesized that level of coping will be explained by the independent variables in the model. Coping, in turn, is expected to predict the outcome variables.

Adaptation

The outcome of the model, maternal adaptation, is operationalized in three variables, coping, stress and life satisfaction. Coping, which has already been discussed, will be treated as both an independent and dependent variable. This is because it is an outcome of the interaction between resources and perception of the event, in addition to potentially influencing stress and adaptation. Stress relates to the impact upon the mother caring for a handicapped child and is measured by the Impact on Family Scale (Stein & Riessman, 1980). Life satisfaction is measured by an instrument which asks about mothers' satisfaction with their current lives. The dependent variables, coping, stress and life satisfaction, are expected to be explained by the child's functioning, stressful life events, certain types of informal support, and formal support.

Control Variables

A review of the literature on the relationship between caring for a child with developmental disabilities and stress, has uncovered several demographic variables which potentially impinge upon this relationship. Age of the child has been associated with a higher probability of out-of-home placement (Tausig & Epple, 1985). For very severely handicapped children, many of whom do not ambulate or toilet independently, increasing age and consequently size, would be expected to increase stress for the primary caregiver.

Race has also been identified as a factor which may influence the family's response to having a handicapped child (Ramey, Mills, Campbell & O'Brien, 1975). In particular, cultural differences between Black and white families may contribute to variations in both the perception of having a handicapped child and responses to crises.

Income and marital status have also been associated with differences in ability to cope with a disabled child (Schilling, Kirkham, Snow & Schinke, 1966; Beckman, 1983). Both of these variables relate to availability of resources. Low-income families often do not have the material resources to offset the extra costs of caring for a handicapped child, and single parents do not have a spouse to assist in relieving the caregiving responsibilities.

Employment status is another factor which may influence the level of stress experienced by mothers. The literature has been mixed on this subject, with some studies reporting decreased stress for women working outside the home (Bradshaw & Lawton, 1978) and another study reporting wide variations in out-of-home employment be race and income (Breslau, Salkever & Saruch, 1982). It might be theorized that women working outside the home would experience greater stress due to the dual role of primary caregiver and worker, on the other hand, working outside the home could give mothers a needed break from the demands of caring for a handicapped child.

Educational level of the mother, while not consistently identified as an issue in the literature, seems to me to be a potential confounder. Women with higher levels of education may possess skills and attitudes which assist them in navigating a complex system of services on behalf of the handicapped child, Also, education potentially presents women with the knowledge and skills to understand the child's disability and course of habilitation. These attributes could thus lessen stress and enhance coping. On the other hand, women with higher levels of education may have higher expectations of their children than women with lower levels of education and thus experience greater stress when the handicapped child does not perform academically.

To summarize, the following demographic variables have been identified as potential confounders in the Double ABCX Model, age and race of the child, family income, and mother's marital status, employment status and educational level. It is expected that the control variables will have a the same effect across outcome variables. Therefore, subsequent analyses will include these factors as control variables.

Structure of the Analysis

Multiple linear regression analysis will be used to test the relationship between the independent variables enumerated above and the dependent variables, coping, stress and life satisfaction. The analysis will be conducted in a four step process. The purpose of the analysis is first to determine if any of the independent variables in the model explain the variance in coping, stress and life satisfaction. To accomplish this, all of the independent variables in the model, level of child functioning, stressful life events, perceived informal social support and formal services, and the control variables, will be regressed on coping. Second, in order to examine the relationship between coping and the dependent variables, coping will be regressed on stress and life satisfaction. Third, the independent variables in the model will be regressed on stress and life satisfaction. Fourth, moving to an analysis of the relationship between types of support and adaptation, all of the informal social support measures (perceived, instrumental, emotional, informational and network), in addition to the independent variables in the model, will be regressed on coping, stress and life satisfaction.

Limitations of the Operationalized Model

In operationalizing any model, compromises must be made in chosing measures to represent the constructs which make up the model. For instance, a balance must be struck between completeness of the information gathered and reasonableness of the demands placed upon the research subjects. Consequently, some variables in the Double ABCX Model are measured with greater accuracy and depth than others. The stress or variables (Aa) I believe are adequate. They are accepted measures of both level of child functioning and stressful life events.

In terms of informal social support, the global measure of support, or what I have referred to as perceived support, as measured by the Carolina Parent Support Scale, is probably the best we have in the field at this time. The other measures of informal support, instrumental, emotional and informational, are ones in which I have less confidence. Judgements are being made as to the level of support provided to mothers based on a few questions in each area. For instance, instrumental support is measured by asking mothers how frequently they receive help with such tasks as household chores, babysitting, and a ride to the store. Yet, there are many areas in which family members can assist mothers which are not probed by this instrument. Indepth study of mothers' day-to-day lives would provide more complete data on which to determine the actual amount of instrumental, emotional and informational help available to mothers. However, to my knowledge, there are no validated measures of instrumental or informational support. I could have used a separate instrument to measure emotional support, but this would have meant introducing another instrument, thus lengthening the interview. I compromised by using one scale to measure all types of support. The instrument used to measure instrumental, emotional and informational support does have content validity.

The measure of formal services is straightforward and I believe adequate for the purposes of the research. Mothers are asked, from a list of services, to indicate those they or their family have used in the past four weeks. Coping, however, is probably one of the weaker measures. In the model, coping is a product of the interaction between resources and perception of the event. No measure of perception of having a handicapped child is available. Coping is represented by one item which asks mothers how well they feel they are coping with the care of the handicapped child on a scale from one to five. There is little variance in this measure, as most mothers consider themselves to be coping well.

The other measures of adaptation, life satisfaction and stress, are strong measures. Life satisfaction is still only one item which asks mothers how satisfied they are with their current life on a scale of one to ten, but it is highly correlated with other satisfaction measures in the questionnaire. Stress, or impact on the family scale, is the most reliable instrument measuring outcome. It includes 25 items, tapping three dimensions of family stress.

In summary, compromises have been made in operationalizing the Double ABCX Model. Some measures are better proxies of the variables they are meant to represent in the model than others. The Double ABCX Model has not been empirically tested, with the exception of Bristol's (1984) work. This is probably due in part to the complexity of model. It is especially difficult to test the model using a survey design, as I have, because of the amount of information needed. Bristol used a clinical population which means that she had more data at hand, but she sacrificed her ability to generalize the results due to sampling bias. Despite its limitations, the contribution this research makes is in adding to our knowledge of how efficacious the model is as a framework for social workers attempting to understand the relationship between family stress and adaptation.

Primary Hypothesis: Female primary caregivers who report high informal social support will also report higher coping, lower stress and greater life satisfaction than those with low informal social support.

In order to determine whether informal social support promoted coping, I regressed level of child functioning, stressful life events, informal social support and formal services on coping, while controlling race and age of the child, family income, and mothers' marital and employment status and education. As reported in Table 5.21, the entire model explained 25% of mothers' ability to cope (F (10,78) = 2.55, $p <$ .01). Only perceived informal social support, as measured by the Carolina Parent Support Scale (CPSS), significantly predicted coping ($p <$ .002). None of the other independent variables, nor the control variables, correlated with coping.

Next, coping was regressed on stress and life satisfaction, excluding the independent variables mentioned above, but including the control variables. As shown in Tables 5.22 and 5.23, coping was a significant predictor of both stress and life satisfaction. The model explained 19% of the variance in stress (F (7,81) = 2.78, $p <$.01) and 17% of the variance in life satisfaction (F (7,81) = 2.38, $p <$ .03). Of

Table 5.21

Multiple Regression Analysis of Selected Variables on Coping, Time 2

Results for Model: N = 89 $F(10,78) = 2.55$, $p < .01$ $R^2 = .25$

Variables	Mean	b	t	Sig t
Level of Child Functioning	7.27	.038	1.16	.25
Stressful Life Events	80.67	.001	.77	.44
Carolina Parent Support Scale	13.93	.040	3.30	.002
Formal Services	3.94	.042	1.14	.26
Coping	2.92			

Control Variables:
- Race
- Age of Child
- Income
- Marital Status
- Working Status of Mother
- Education of Mother

Table 5.22

Multiple Regression Analysis of Coping on Stress, Time 2

Results for Model: N = 90 $F(7.81) = 2.78$, $p < .01$ $R^2 = .19$

Variables	Mean	b	t	Sig t
Coping	2.07	-5.01	-3.57	.001
Stress	38.87			

Control Variables:
- Race
- Age of Child
- Income
- Marital Status
- Working Status of Mother
- Education of Mother

Table 5.23

Multiple Regression Analysis of Coping on Life Satisfaction, Time 2

Results for Model: $N = 90$ $F(7,81) = 2.38$, $p < .03$ $R^2 = .17$

Variables	Mean	b	t	Sig t
Coping	2.07	1.19	3.81	.001
Life Satisfaction	6.67			

Control Variables:
- Race
- Age of Child
- Income
- Marital Status
- Working Status of Mother
- Education of Mother

the control variables, only mothers' employment status predicted stress, with women working outside the home experiencing significantly lower stress than their counterparts who were not working ($t = 2.19$, $p < .04$). None of the control variables significantly correlated with life satisfaction.

Finally, level of child functioning, stressful life events, informal social support and formal services were regressed on stress and life satisfaction, using the same control variables as in the previous equations. With respect to stress, the entire model accounted for 23% of the variance in stress ($F\ (10,78) = 2.38$, $p < .02$). Between the independent and control variables, only perceived informal social support (CPSS) was a significant predictor of stress ($p < .001$, see Table 5.24). As shown in Table 5.25, the same equation only explained 7% of the variance in life satisfaction, and none of the independent or control variables proved to be significant predictors ($F\ (10,78) = .59$, $p < .81$).

In summary, as hypothesized, perceived informal social support significantly predicted coping and, coping in turn was a predictor of both stress and life satisfaction. Perceived informal support was also associated directly with reduced stress, but had no impact on life satisfaction. Employment status was the only control variable to explain stress, with mothers working outside the home experiencing less stress than those not working outside the home. None of the independent variables, level of child functioning, stressful life events and formal services, nor the control variables, was significantly related to life

Table 5.24

Multiple Regression Analysis of Selected Variables on Stress, Time 2

Results for Model:	N = 89	F (10,78) = 2.38, $p < .02$	$R^2 = .23$

Variables	Mean	b	t	Sig t
Level of Child Functioning	7.27	-.004	-.01	.99
Stressful Life Events	80.67	.001	.08	.94
Carolina Parent Support Scale	13.93	-.652	-3.93	.001
Formal Services	3.94	.729	1.47	.12
Stress	38.87			

Control Variables:
- Race
- Age of Child
- Income
- Marital Status
- Working Status of Mother
- Education of Mother

Table 5.25

Multiple Regression Analysis of Selected Variables on Life Satisfaction, Time 2

Results for Model:	N = 89	F (10,78) = .59, $p < .81$	$R^2 = .07$

Variables	Mean	b	t	Sig t
Level of Child Functioning	7.27	-.070	-.66	.52
Stressful Life Events	80.67	-.003	-.72	.48
Carolina Parent Support Scale	13.93	-.062	-1.55	.13
Formal Services	3.94	.072	.60	.55
Life Satisfaction	6.67			

Control Variables:
- Race
- Age of Child
- Income
- Marital Status
- Working Status of Mother
- Education of Mother

satisfaction. (See Appendix C for Tables reporting the level of significance for control variables included in all multiple regression analyses.)

Expectations Regarding the Influence of Types of Informal Social Support on Coping:

1. High perceived support - high coping
2. High instrumental support - high coping
3. High emotional support - high coping
4. High informational support - no effect
5. High network support - no effect

To examine the influence of the different categories of informal social support, these measures were regressed on coping. According to Table 5.26, the entire equation explained 35% of the variance in coping (F (14,74) = 2.82, $p < .002$). The only support measure which predicted positive coping was perceived support (CPSS) ($t = 3.91$, $p < .001$). Emotional support, however, was associated with lessened ability to cope ($t = -2.94$, $p < .004$). Therefore, perceived informal social support was significantly correlated with positive coping, emotional support was associated with lessened ability to cope, and instrumental, informational and network support did not predict coping. None of the control variables were correlated with coping.

Table 5.26

Multiple Regression Analysis of Informal Social Support Measures on Coping, Time 2

Results for Model:	$N = 89$	$F(14,74) = 2.82$, $p < .002$	$R^2 = .35$

Variables	Mean	b	t	Sig t
Carolina Parent Support Scale	13.93	.049	3.91	.001
Instrumental Support	4.03	.050	1.34	.15
Emotional Support	2.03	-.155	-2.94	.004
Informational Support	1.22	.134	1.47	.15
Network Support	1.96	-.020	-0.27	.79
Coping	2.07			

Control Variables:
- Race
- Age of Child
- Income
- Marital Status
- Working Status of Mother
- Education of Mother
- Level of Child Functioning
- Stressful Life Events
- Formal Services

Expectations Regarding the Influence of Types of Informal Social Support on Stress:

1. High perceived support - low stress
2. High instrumental support - low stress
3. High emotional support - low stress
4. High informational support - no effect
5. High network support - no effect

When all measures of informal social support were regressed on stress, the model explained 31% of the variance (F (14,74) = 2.34, $p < .01$), and none of the control variables were significant predictors of stress (see Table 5.27). Again, only perceived informal social support (CPSS) predicted reduced stress ($t = -4.01$, $p < .001$), and emotional support proved to significantly increase the probability that mothers will experience stress related to the care of the handicapped child ($t = 2.30$, $p < .02$).

Expectations Regarding the Influence of Types of Informal Social Support on Life Satisfaction:

1. High perceived support = high life satisfaction
2. High instrumental support = high life satisfaction
3. High emotional support = high life satisfaction
4. High informational support = no effect
5. High network support = no effect

I used the same method as that employed to measure the effect of the various types of informal social support on coping and stress to

Table 5.27

Multiple Regression Analysis of Informal Social Support Measures on Stress, Time 2

Results for Model: N = 89 F (14,74) = 2.34, $p < .01$ $R^2 = .31$

Variables	Mean	b	t	Sig t
Carolina Parent Support Scale	13.93	-.693	-4.01	.001
Instrumental Support	4.03	.771	1.48	.14
Emotional Support	2.03	1.740	2.38	.02
Informational Support	1.22	.754	.60	.55
Network Support	1.96	-1.340	-1.33	.19
Stress	38.87			

Control Variables:
- Race
- Age of Child
- Income
- Marital Status
- Working Status of Mother
- Education of Mother
- Level of Child Functioning
- Stressful Life Events
- Formal Services

determine the relationship between the same variables and life satisfaction. The equation explained 18% of the variance in life satisfaction, which did not reach significance (F (14,74) = 1.19, p .30, see Table 5.28). However, unlike the previous regression analysis of life satisfaction, in this equation, perceived informal social support (CPSS) significantly predicted life satisfaction. This was not true when all of the independent variables in the equation were entered with the exception of the subcategories of informal support. Consequently, adding the types of support produced a significant, positive relationship between perceived support and life satisfaction. Consistent with the other regression analyses, emotional support was significantly correlated with diminished life satisfaction (t = -3.13, p .003). None of the other support or control variables predicted satisfaction.

Discussion of Multiple Linear Regression Analysis

Multiple regression analysis revealed that coping, as expected, predicted both mothers' stress and life satisfaction. Furthermore, perceived informal social support (CPSS) was the only independent variable in the model which significantly explained the variance in coping and stress. When the types of informal social support were entered into the equation, only then did perceived support significantly correlate with life satisfaction. Emotional support consistently predicted the dependent variables, however, in the wrong direction. Emotional support was associated with increased stress and decreased coping and life satisfaction.

Table 5.28

Multiple Regression Analysis of Informal Social Support Measures on Life Satisfaction, Time 2

Results for Model: N = 89 F (14,74) = 1.19, $p < .30$ $R^2 = .18$

Variables	Mean	b	t	Sig t
Carolina Parent Support Scale	13.93	.090	2.21	.03
Instrumental Support	4.03	.133	1.08	.28
Emotional Support	2.03	-.544	-3.13	.003
Informational Support	1.22	.078	.26	.80
Network Support	1.96	.138	.54	.59
Life Satisfaction	6.67			

Control Variables:
- Race
- Age of Child
- Income
- Marital Status
- Working Status of Mother
- Education of Mother
- Level of Child Functioning
- Stressful Life Events
- Formal Services

In an attempt to explain the unexpected finding that greater emotional support led to decreased ability to cope, it is instructive to review the wording of the items included in the emotional support index. Mothers were asked how often they received help with (1) understanding the handicapped child's needs and problems; (2) family problems; (3) feeling that the demands of caring for the disabled child are a burden. Apparently, these items are measuring the degree to which mothers are having difficulty coping. For mothers not experiencing problems with coping, they would be expected to answer "never" when asked how often they receive help with the emotional demands of their handicapped children. It was my erroneous assumption that all mothers will feel burdened by the caregiving demands of a handicapped child. Consequently, I have developed an index which taps emotional problems, not emotional support.

To further explore the impact that emotional problems have on the relationship between perceived informal support and life satisfaction, I dichotomized the sample into those with high and low emotional problems. I then correlated perceived support and life satisfaction for both groups of women. I did this because controlling for emotional problems produced a significant relationship between informal social support and life satisfaction. Therefore, it was clear that there was a difference in the correlation between informal social support and life satisfaction for women based on the level of emotional problems. The results showed that for those mothers with few emotional problems, there was a positive, significant relationship between perceived support and life satisfaction ($N = 56$, $\underline{t} = 2.16$, $\underline{p} < .04$). Mothers in the high emotional problems group did not experience any greater life satisfaction with increasing amounts of informal support (N = 34, t = -.84, p .41). Therefore, informal support enhances life satisfaction only in mothers who are not already experiencing emotional problems.

Since perceived informal social support is a global measure of support and it is consistently correlated with the dependent variables, it may be masking a significant relationship between the other types of support and the dependent variables. To test this possibility, I ran the regression equations, excluding perceived support, while including the other subcategories of support. Although emotional support continued to correlate with the dependent variables, instrumental, informational, and network support did not predict coping, stress or life satisfaction when perceived support was removed from the equation.

In summary, perceived informal social support was the only independent variable associated with increased coping ability, reduced stress, and enhanced life satisfaction. Further analysis showed that when emotional support, a proxy for emotional problems, was controlled, only then did perceived support significantly predict life satisfaction. Emotional problems was significantly linked with decreased coping and life satisfaction, and increased stress. Working status was the only control variable which explained any of the independent variables. Women working outside the home experienced significantly less stress than their counterparts at home. None of the other control variables, race and age of child, total family income, marital status, and education of mother, were correlated with the dependent variables.

In order to test whether there was an interaction between informal social support and the control variables, I conducted further analyses. For each control variable, I created an interaction variable which allows for the possibility that informal social support has a different effect on the dependent variables by demographic characteristic (see Appendix D, Table 5.29b). For instance, for race I created a new Carolina Parent Support variable, RCPSS, (Race Carolina Parent Support Scale) which includes the CPSS values for Black families only. I then regressed RCPSS, CPSS, all of the other support measures and all of the control variables on coping, stress and life satisfaction.

Table 5.30b (Appendix D) reveals that, in most cases, the effect of the CPSS on coping, stress and life satisfaction is not modulated by the interaction between any of the control variables and the CPSS. There are three exceptions. Marital status and employment modulate the effect of the relationship between informal social support and coping, and income modifies the correlation between support and life satisfaction. In the cases of marital and employment status, entering the new CPSS variable resulted in a correlation which was not significant when previously there had been a significant relationship between informal social support and coping. Income, on the other hand, modulated the effect of informal social support on life satisfaction in the other direction. Where there had not previously been a significant relationship, adding the new CPSS variable produced a significant correlation between support and life satisfaction.

In the following section, I will attempt to explain why none of the independent variables, other than perceived informal social support, was significantly correlated with any of the dependent variables. Each independent variable will be considered separately.

(A) Stressor: Level of child functioning. All of the children in the sample are on the severe end of the disability continuum. Had the sample included nonhandicapped or mildly handicapped children, it is more likely that this variable would have explained more of the variance in the dependent variables. The literature supports this contention, as stress and out-of-home placement have been linked with the degree of dependency upon the primary caregiver which the child presents (Eyman et al., 1972; Tausig & Epple, 1985). The majority of the children in this study are quite dependent in that most do not toilet independently or speak.

(a) Pile-up stressors: Stressful life events. This variable is a little more difficult to explain since one might expect that stressful life events and the stress of raising a handicapped child, ability to cope with the child, and life satisfaction would be logically related. Two possible explanations are offered. First, looking at the responses to the stressful events scale, 19 or 21% of the sample reported no stressful events in the past year. Furthermore, the distribution for the remaining 71 respondents was highly skewed to the lower end of the scale. In order to test the hypothesis that the effects are limited to those with high stressful life events, I created a new variable in which those mothers with a stressful life event score below the median were assigned a value of 0 (N = 47) and those above the median (N = 43) maintained their actual score. I then regressed stressful life events, the new stressful life events variable, the other independent variables (level of child functioning, informal support and services), plus the control variables, on coping, stress and life satisfaction. Again, the stressful life events variable did not predict coping ($\underline{t}$ = .90, $\underline{p}$. < 37), stress ($\underline{t}$ = .85, $\underline{p}$ < .40), or life satisfaction ($\underline{t}$ = -.09, $\underline{p}$ < .92), indicating that there is not a differential impact upon the dependent variables based upon lower or higher stressful life events.

Another, possibly more plausible explanation for the fact that stressful life events did not explain any of the dependent variables, is that the stressful event alone is less important than how the event is perceived and the informal and formal supports one possesses to deal with the event. Although support related to the handicapped child was controlled, no data on both informal and formal support for other life problems were gathered. Consequently, the focus of this study, caring for a handicapped child, may have excluded other information pertinent to dealing with stress unrelated to the child.

(b) Resources: Formal services. This finding is of little surprise since the mean number of services used was 3.91 and most of these were provided directly to the child, not the family. Speech, occupational and physical therapy and medical services were most frequently mentioned by families. Traditional family support services, such as respite care, training in how to deal with the child, or counselling, were used by only a few families in the past year.

(b) Resources: Informal social support. Multiple regression analysis of the types of informal social support showed that perceived support predicted coping, stress and life satisfaction while instrumental, informational and network support were not correlated with any of the dependent variables. Although informational and network support were not expected to correlate with any of the dependent variables, it was a surprise to discover that emotional support was a significant predictor of all the dependent variables, however in the wrong direction. As explained earlier, this is a result of an emotional support index which actually measured emotional problems. The next section of the discussion will elaborate findings concerning the subcategories of informal social support and their relationship to the dependent variables.

Perceived versus instrumental support. My finding that perceived support (CPSS) had an impact on coping and stress but the actual support provided to mothers did not, deserves explanation. There are at least two possible reasons for this discrepancy, both of which were mentioned in the discussion of the bivariate analysis. The first is that family members may be helpful to mothers in ways not tapped by the instrumental support measure. Qualitative research which examines the day-to-day environment and activities of the family would answer this question.

The second possible explanation is that the perception of support may be more important than the act of providing assistance. In thinking about the role of perception of help versus quantity of help, the satisfaction measures may shed some light on this subject. Mothers were asked about the amount of time they had away from the child for things they like to do, for social reasons, and for time with their spouse. They were then asked about their satisfaction with time away. Pearson product-moment correlations between time away and satisfaction time away did not reveal a significant relationship between these two variables. It might be concluded from these findings that perception of the adequacy of a variable is more important to one's feeling of life satisfaction than the amount of that variable provided. Generalizing this concept to the relationship between informal social support and stress, the amount of support proffered may be less important in relieving the experience of stress related to the child with developmental disabilities than the perception of that help.

Many factors come into play in evaluating the adequacy of informal social support. Cultural, social and psychological influences are potentially important determinants of mothers' beliefs regarding appropriate roles and behaviours of social support network members. Expectations about the amount and type of assistance which should be extended are shaped by these beliefs. Theoretically, then, the disparity between expectations regarding help and the actual amount of assistance offered, contributes to one's perception about the adequacy of support. Employing this logic, the fact that level of perceived informal social support predicted stress, which actual help did not, becomes understandable. The important issue is not the objective amount of help received, but how closely expectations about support and amount of support available are matched.

Network support. Network support was measured by the number of persons mothers felt they were able to confide in. Although House and Kahn (1985) state that it is important to establish the fact that a network actually exists, other researchers have found that it is not the number of network members but the quality of the relationships which is important (Kazak & Marvin, 1984). My finding that the number of supportive people did not explain any of the dependent variables, while perception of the level of support from family, friends and neighbours did, corroborates prior research.

Perceived support and its relationship to life satisfaction. Perceived informal social support did not significantly correlate with life satisfaction until emotional problems was entered in the equation. Therefore, when mothers' emotional problems was controlled, there was a significant relationship between level of perceived support and life satisfaction. Further analysis revealed that the positive benefits of perceived support are felt only when mothers have few emotional problems.

Another curious finding was that perceived informal social support explained stress but not life satisfaction. It is obvious that stress and life satisfaction are different constructs. Examination of the stress instrument used in the research protocol reveals that the items relate directly to the presence of a handicapped child. For instance, queried are issues such as the impact of the child's care requirements upon the family's ability to save money, take vacations or have social outings. Life satisfaction, however, is a more general concept which has to do with overall satisfaction with one's life. Such issues as satisfaction with one's working status, educational level, place of residence and social life come into play in evaluating life satisfaction.

Considering the work of others, Crnic et al.'s (1983) research seems to contradict my findings. They found that support from a partner or spouse and community support were highly significant predictors of general life satisfaction. Measured by Crnic et al., were both presence or absence of these types of support and satisfaction with the situation. Although both availability and satisfaction with support predicted general life satisfaction, only satisfaction with intimate support had a significant effect on satisfaction with parenting. This finding indicates that satisfaction with support is an important consideration in whether or not one is satisfied with other aspects of one's life. Of course, research of this nature is plagued with questions of reciprocal causation. It is never clear whether satisfaction with support causes life satisfaction and satisfaction with parenting, or vice versa. It can only be said with certainty that there is a significant relationship between the two variables.

Bristol (1984) is the only other researcher to test the ability of the Double ABCX Model to explain family adaptation. In her study of families having autistic or autistic like children, she found that perceived informal social support predicted family adaptation, marital adjustment and maternal depression. Severity of the handicap and formal services were not correlated with any of the above dependent variables.

Where her results differ from my own is with respect to stressful life events. She found that other life stresses explained all of the dependent variables. Bristol's measure of other life stresses included a sum of the Holmes and Rahe (1967) instrument, which I also used, and the Limits on Family Opportunity Scale of the Questionnaire on Resources and Stress (Holroyd, 1974). She does not report separate analyses for the two instruments. Therefore, I have no way of knowing whether the Holmes and Rahe scale alone explained the variance in the outcome variables. It is interesting to note that the Limits on Family Opportunity Scale is an instrument concerned with the impact of having a handicapped child. I speculated earlier that stressful life events in my research did not correlate with the dependent variables because it was related to generic life experiences, whereas the other variables were focused on support and outcomes specific to dealing with a handicapped child. It is possible that Bristol uncovered the same phenomenon, but it is masked by summing the two instruments. This is an area which deserves further study.

My finding that women working outside the home experience less stress than those not working outside the home, is consistent with Bradshaw and Lawton's (1978) research. They found that mothers who were able to do paid work were less depressed than those who did not do paid work. I think, however, that this issue needs to be explored in further depth. Since employment status was the only control variable which correlated with an outcome variable, and it was only correlated with stress, this difference may have occurred due to chance.

Qualitative Analysis of Coping Strategies

The study does not specifically ask about the ways in which mothers cope with the care of a severely handicapped child, but I think some of the qualitative data mothers shared with us during the interviews provides depth and humaneness to the research. It gives insight into some specific responses mothers had to their situation with their children. Mothers were asked in an open ended format, "Please tell me a little bit more about how well you feel you are coping (with the care demands of your handicapped child)." The responses tended to cluster in five different categories: child related reasons; general acceptance; support of family; religion; and those having difficulty coping. I will give examples of responses indicative of each category.

Child Related Reasons

The greatest number of responses had to do with some aspect of the child. Many mothers, not unlike mothers of nonhandicapped children, identify positive qualities in their child and the love they have for the child as the reasons why they are able to cope. An example is the following statement, "I am able to understand him quite well and it's the love I have for him that makes me understand him." Another mother stated about her son, "He's happy and he smiles all the time... I enjoy taking care of him, maybe it's because I love him." One mother spoke of the emotional ups and downs when she said, "It's very hard, I get depressed, then he does something I'm proud of and I get out of it."

General Acceptance

Several mothers expressed general acceptance of the child and the situation with which they are confronted. In speaking of her daughter, a mother related: "I deal with whatever she offers; I accept what we can and cannot do; I look for the best instance out of the worst." Another mother echoed others when she said, "We go from day-to-day and do what has to be done." One mother stated it plainly: "She's my child and has to be taken care of; I just have to take care of her; I don't know what else to say."

Support of Family

Informal social support was also mentioned by several mothers. The following response reflects the importance of help from family for mothers working outside the home. "I think I'm coping very well but, the reason is family support. My mother and father are both retired, so if I'm at work and she gets sick they can go pick her up." Another mother talked about support form other parents of handicapped children. "Parents' meetings are a great help. Being able to talk and share is one of the best things available." Someone else summed up the importance of the marital relationships when she said, "My husband is my right arm and the two of us can handle any problems."

Religion

Some mothers drew strength from their belief and trust in God. For instance, one mother told us, "God only gives you what you can handle." Another said, "I do it with the Lord's help." Still another stated:

"When I get down I look up in my mind and then go on; the spiritual part of my life keeps me going."

Difficulty Coping

Most mothers felt they were coping well, but some were having a difficult time as in the case of this mother. "I have lots of resentment. Why should I take what society gives? Why was I stuck with a kid with handicaps?" A few mothers spoke of the impact upon other family members. "I wish I could do better so I could do more for her and still have time for the kids." There were some mothers who exhibited severe stress, such as the mother who said: "I feel his problems are all my fault, so I deserve what I get; I'm worried about what will happen to Michael when I die; one women and two kids isn't a family."

Summary of Qualitative Analysis

Generally, mothers felt they were coping well with the demands of their handicapped child. Although I have broken down the responses into five categories, many interviewees actually mentioned two or three of the categories in their statement, demonstrating the need for them to garner strength in several ways. Mothers spoke frequently of the frustration they experience in addition to be the coping strategies they employ. The responses often revealed the difficult behaviours such as head banging and temper tantrums of the children. I was reminded that parents must live with the disappointment of their child's severe limitations. As one mother said: "It hurts to see her that way; I look forward to her tugging on me, or the day she can call me momma."

Notably absent from these qualitative data are references to support from friends or formal services. Consistent with the quantitative data, mothers primarily receive support from immediate family members and, lacking that, no other source seems to fill the gap.

CHAPTER VI

CONCLUSIONS AND RECOMMENDATIONS

Introduction

In this chapter I will conclude with a review and analysis of the results of my research on mothers of handicapped children and make recommendations for social policy and direct interventions with families. The proposed recommendations are intended to help social workers, policy makers and others concerned with families who have a developmentally disabled child to understand the role of informal social support in assisting the primary caregiver and to guide them in the design and implementation of family support services. I will also review the Double ABCX Model as a framework for social work practice, and explore the implications of the state bias towards family care of vulnerable members upon mothers of handicapped children, in light of the research findings. Finally, I will discuss the limitations of this study and future research directions.

Review of the Major Research Findings

The intent of this study is to provide descriptive information about the types of informal social support available to mothers of children with developmental disabilities and to examine the relationship between informal support and coping, stress and life satisfaction. The types of support studied were perceived, instrumental, informational, emotional and network support. There were two primary support instruments utilized, the Carolina Parent Support Scale which measures perceived support from family, friends and neighbours, and the Management Scale, which measures actual support provided in the form of concrete assistance, information and emotional support. The theoretical model employed is the Double ABCX Model, developed by McCubbin and Patterson (1983b).

Descriptive and bivariate analysis revealed that mothers of children with severe developmental disabilities are primarily responsible for the day-to-day care of their children. However, the help they do receive is important to them. Assistance proffered to mothers comes mostly from immediate family members, such as husbands and nonhandicapped children, rather than extended family, friends or neighbours. One of the more revealing findings of the study is that although married and working women perceive greater support from some family members, when help with daily tasks was measured, these women did not actually receive any greater assistance.

Applying the Double ABCX Model of Family Functioning, it was theorized that informal social support would enhance coping, which in turn would moderate stress and promote life satisfaction. Multivariate analysis showed that perceived informal social support was associated with better ability to cope and lower levels of stress. The influence of informal social support on life satisfaction was less certain. Ability to cope was significantly correlated with decreased stress and increased life satisfaction.

None of the various types of informal support (instrumental, informational or network) explained coping, stress or life satisfaction. Emotional support appears to be a proxy for emotional problems, and so it was associated with higher stress and lower coping and life satisfaction. None of the other independent variables included in the model (severity of handicap, formal support or life stress) explained the variance in the dependent variables.

The Efficacy of Informal Social Support as a Policy Option

Policy makers and programme planners have a number of options in terms of how services are organized for families of handicapped children. However, there are limited resources which force difficult decisions among competing models of service delivery. Therefore, it is essential to know the efficacy of increasing amounts of specific types of support to families. In this section, I will examine the relative importance of informal social support in reducing stress and enhancing coping and life satisfaction.

From a policy point of view, it is important to determine how large the increase must be in informal social support before appreciable changes are seen in coping, stress and life satisfaction. Even though support is significantly correlated with coping and stress, the amount of support needed to produce notable changes in the lives of mothers may not be realistically achieved. To evaluate the magnitude of the effect, one must examine the regression coefficients (b) associated with the various informal social support measures. The coefficient is a measure of the amount of change in the dependent variable for a one unit increase in the independent variable.

Table 6.1 provides the data necessary to evaluate (1) the change in the dependent variables for every one, two, or three unit increase in the Carolina Parent Support Scale (CPSS) (see Panel B); (2) the number of units of CPSS necessary to bring an individual two standard deviations from the mean to the mean level of the dependent variables (Panel C); and (3) the number of units of CPSS necessary to bring a mother in the 80th percentile of stress, and 20th percentile of coping, to the mean on both measures (Panel C).[1] Examining the magnitude of change for increasing amounts of informal social support illustrates the expected impact as each unit of support is added. Looking at the amount of support needed to bring individuals from two standard deviations from the mean and the 80th or 20th percentiles, shows how much support is needed to bring extreme cases to the mean.

Life satisfaction is not included in the analysis of the efficacy of informal social support because for every unit increase in support, mothers' satisfaction decreased by .06 ($\underline{M}$ = 6.67; Range = 1 to 10; S.D. = 2.23). Thus, the correlation was not in the expected direction,

Table 6.1. The Efficacy of Increasing Amounts of Informal Social Support

Panel A

Dependent Variables	Mean	CPSS b	Coping b
Stress	38.87	-.652	-5.01
Life Satisfaction	6.67	-.062	1.19
Coping	2.07	.040	—

Panel B

	Amount of Change	
Unit Increase[2]	Stress	Coping
1 Unit Increase in CPSS	- .65	.040
2 Unit Increase in CPSS	-1.30	.080
3 Unit Increase in CPSS	-1.96	.120

Panel C

	Number of Units of CPSS Needed to Reach Mean[3]
Stress: 2 S.D. above Mean = 59.05	30.95
Stress: 80th percentile = 46.00	11.41
Coping: 2 S.D. below Mean = .57	37.50
Coping: 20th percentile = 2.00	23.00

however this did not reach significance. Consequently, I have excluded life satisfaction from the results.

Consider the impact of informal social support on the stress levels of mothers with a handicapped child. Although the correlation between informal social support and stress is significant, looking at the coefficient, it is striking how great the increases in social support must be before appreciable changes are seen in level of stress. For instance, as seen in Panel B, a one unit increase in social support only results in a .65 decrease in stress, while a three unit increase in social support means a 1.96 drop in stress. In this case, the stress mean (_M_) is 38.87, the range in actual stress scores is 14 to 67, and the standard deviation (S.D.) in stress is 10.69. (In subsequent discussion I will only use abbreviations to report the mean, range and standard deviation of each dependent variable.) Furthermore, to bring an individual from the 80th percentile on the stress scale to the mean would require 10.17 units of informal social support.

The relative importance of a unit of informal social support is brought into focus by examining the CPSS. The CPSS asks mothers to report, on a 1 to 5 scale ranging from "not at all" to "a great deal," how helpful possible network members are to her in the care of the handicapped child. Consequently, a unit increase of support means that one member has increased support along a continuum from 1 to 5. For instance, if a husband went from being "not at all supportive," to "a great deal of help," that would represent an increase equal to 4 units of support and a 2.6 point decrease in stress.

Coping was also significantly correlated with informal social support. For every unit increase in support, mothers' ability to cope increased by .04 (M = 2.07; Range = 0 to 3; S.D. = .75) (see Panel B). Furthermore, a three unit increase in support means a .12 increase in maternal coping. As reported in Panel C, 37.50 units of support are needed to bring a mother two standard deviations below the mean in coping to the mean level, and 23 units of support are required to move a mother in the 20th percentile to the coping mean. Mothers were asked on a four point scale from "poorly" to "excellently," how well they felt they were able to cope with the care of their handicapped child. To put this in perspective, it would take 25 units of informal social support to bring a mother who is coping "fairly well" to the next level, which is coping "very well." Or, looking at it from another angle, if a husband went from being "not at all supportive" to "a great deal of help," it would represent a .16 increase in coping.

The prospect of helping mothers of handicapped children reduce their stress and improve their coping by increasing informal social support, looks pretty dismal given my findings. However, suppose my results are misleading and the actual effects are really two, three or even four times greater than the regressions coefficients indicate. In order to analyze the sensitivity of the results to such larger effects, I have calculated the change in the coping and stress resulting from the coefficients being two, three and four times greater.

Table 6.2 shows that even if the regression coefficients were much larger, the improvements in maternal life satisfaction and coping would

Table 6.2. The Impact Given Regression Coefficients that were Two, Three or Four Times Larger than Those Reported

Panel A

	Amount of Change in Stress (M=38.87)		
Unit Increase	(bx2)	(bx3)	(bx4)
1 Unit Increase in CPSS	-1.30	-1.96	-2.61
2 Unit Increase in CPSS	-2.60	-3.92	-5.22
3 Unit Increase in CPSS	-3.90	-5.88	-7.83

Panel B

	Amount of Change in Coping (M=2.07)		
Unit Increase	(bx2)	(bx3)	(bx4)
1 Unit Increase in CPSS	.080	.120	.160
2 Unit Increase in CPSS	.160	.240	.320
3 Unit Increase in CPSS	.240	.360	.480

not be impressive. For instance, if the regression coefficient for the relationship between informal support and coping was actually two times larger, it would mean a .08 increase in coping and even at four times larger, the improvement in coping with three units of support would only be .48 (see Panel C).

Focusing on stress, although still a modest impact, if the regressions coefficient for stress were actually twice as large and support increased by three units, maternal stress would drop by 3.90 points (see Panel A). Furthermore, if the coefficient was four times as large and three units of support were added, stress would decrease by 7.83 points. Considering that all people will experience some stress, it is not a realistic goal to expect that stress will be reduced to zero. Therefore, a four point decrease in stress may mean a real difference in the lives of mothers.

In research of this nature, it is difficult to determine the exact meaning of decreasing amounts of stress to mothers. Since stress is largely a subjective experience, the impact may vary among mothers. One way that I have dealt with this is by examining the issue from a relative perspective. For instance, considering how much support is necessary to move mothers in the 80th percentile or the second standard deviation, to the mean, provides a context within which to view the amount of informal social support it would take to help mothers on the extreme end of the continuum. Still, as social scientists, we must live with these limitations due to the current state of knowledge.

Another policy option for supporting families of handicapped children is the provision of a cash subsidy. Since this research was part of a larger study of the impact of a cash subsidy totaling $225.00 per month to families, it is possible to compare the benefits of informal social support and monetary support. After receiving the subsidy for approximately one year, mothers experienced a 20 percent drop in mean level of stress from 48.50 to 38.87, a significant increase in life satisfaction from 6.3 to 6.7, and coping was unchanged (Meyers & Marcenko, 1986). By contrast, it would take 14.77 additional units of informal support to achieve the same results in stress.

Clearly, receipt of the money was associated with a dramatic reduction in maternal stress level. An item-by-item analysis showed a significant decrease in stress on items related directly to financial stress such as: "the cost of my child's care is causing financial problems for the family;" or, "I am unable to save much money because of the expense of my child's handicaps."

In terms of life satisfaction, receipt of the subsidy was associated with greater satisfaction, where social support was negatively, although not significantly correlated with satisfaction. Coping, however, was not influenced by money but was improved with increasing amounts of social support. One caveat which must be mentioned is that this was the first year of the subsidy and what we may be seeing is a honeymoon effect which could be modulated in subsequent years of the programme. Therefore, longitudinal data are necessary to evaluate the effects of the programme long-term. If the positive impact of the subsidy proved to diminish over time, policy makers would have to decide if the short-term benefits were substantial enough to warrant continuation of the programme or if the negative impact of withdrawing the subsidy outweighed the benefits to families.

Consequently, as a policy option, at least initially, money has a more positive impact than informal social support. However, in terms of stress, the relief was felt around financial issues, indicating that this approach alone will not meet all of a family's needs. More data are required to determine the relative effect of various types of family support.

Possible Explanations for the Results

There is a central question which must be addressed if social policy is to be informed by these findings. Does this research represent the true relationship between informal social support for mothers of handicapped children; or are there measurement or methodological issues which limit generalizations from this research? There are several possible explanations for the weak performance of the Double ABCX Model generally, and informal social support specifically.

First, informal social support may not be as effective against chronic stress as it is in cases of acute, time-limited stress. As crises arise, available informal support may prove to be more beneficial than it is for the day-to-day chronic stress of raising a child with handicaps. Longitudinal research is required to illuminate the role informal social support plays as crises are introduced and resolved.

Cross-sectional data, such as those provided here, are insufficient to measure the strength of social support during times of acute stress.

A second possible explanation for the weak results is that informal social support has been oversold as a mechanism for reducing stress. Although support has some impact on maternal stress, it alone cannot overcome the stress associated with caring for a handicapped child. Furthermore, there are limitations to how many network members there are and how much each member can increase his or her support. Therefore, even if there had been a stronger correlation between support and stress, there are practical constraints on the amount of support mothers have at their disposal. This point will be discussed in greater depth in the intervention section of this chapter.

Another possibility which must be examined is that the Double ABCX Model may not be adequate to explain coping, stress or life satisfaction in mothers of handicapped children. Wikler (1986) has conducted a comprehensive review of the family research in developmental disabilities, using the ABCX Model as an organizing framework. She concludes that we are a long way from testing the validity of the model as a theoretical framework for explaining family adaptation to stress. She recommends that researchers (1) operationalize family resources in the form of validated instruments and put the instruments in general use; (2) develop a clear idea of what constitutes successful family functioning; and (3) examine family adaptation over time. At this point, it is premature to judge the usefulness of the Double ABCX Model for assessing families' reactions to the stress of raising a handicapped child. In defense of the ABCX Model, it appears to have all of the components professionals in the field would expect to explain family adaptation. Additional research, incorporating Wikler's recommendations, is needed to confirm or reject the Double ABCX as a theoretical model appropriate for this population.

It is curious to me that more researchers in the developmental disabilities field have not chosen to test the Double ABCX Model in its entirety. This is true even though McCubbin and Patterson published their conceptualization of the model in 1983, and before that, Hill published his original ABCX framework in 1958. My presumption about why others have not taken up the banner is that the total model is too unwieldy for practical application in a research project. First, not counting control variables, there are at least six independent variables which should be included in the model. These are, severity of the handicap, pile-up stressors, informal and formal resources, coping and meaning of the event. Second, many of the variables are complex and abstract, making them difficult to measure. For instance, how does one measure the meaning of the presence of a handicapped child? What aspect of "meaning" should be measured, and from whose perspective? Third, in terms of methodology, given the number and complexity of the variables to be considered, the research protocol generally requires face-to-face interviews with families, for usually an hour or longer in duration. Finally, in order to conduct a multiple regression analysis, the sample size must be sufficiently large to support the number of independent variables included in the equation. Using ten subjects for each independent variable as a ballpark figure, the ideal sample size for most research of this type necessitates upwards of 100 subjects. Then once the data are collected, the variables are generally abstract making interpretation of the results for application in social work practice difficult.

I have attempted to deal with the issues I have raised regarding the Double ABCX Model in the following manner. First, all of the independent variables generally accepted as part of the model were included with the exception of "meaning of the event." This is probably the most difficult variable in the model to capture because of uncertainty about what aspect of "meaning" to measure. Bristol used mother's self blame and the extent to which mothers defined the handicap as a family catastrophe to operationalize the concept. Only definition as a family catastrophe significantly explained the variance in one of the three dependent variables, family adaptation. Therefore, my exclusion of this variable may not have altered the results significantly. Second, with respect to sample size, the number of subjects I had was sufficiently large for the analysis, but this was in part possible because I conducted this research as part of another study. Finally, regarding my concern about application of the results to social work practice, it will become evident later in this chapter that I have dealt with this issue by bringing together the multivariate analysis, descriptive and qualitative data and my own practical knowledge gained from associations with families of handicapped children, to guide recommendations regarding social work interventions.

It is my contention that research into the validity of the Double ABCX Model is conceptually complex, costly and time-consuming to conduct and difficult to interpret once completed. It may not be that the model is wrong or poorly conceived, but I think that we are not likely to see much research using the entire model due to the issues I have raised. In-depth, qualitative research with a small sample of families may be a more appropriate avenue for future studies. However, generalizations are limited with this approach. In short, I expect that much of the research with families will continue to be focused on a few variables at a time and will probably not embrace the full scope of factors which constitute the Double ABCX Model. Finally, I have discussed the ways in which I have attempted to deal with the above issues.

In summary, several possible explanations have been offered for the weak results of this research. They include: differences in the effectiveness of informal support for acute and chronic stress; the possibility that too much confidence has been placed in social support as a way to reduce stress; and difficulties with the application of the Double ABCX Model. Wikler has suggested further research, conducted over time, employing a clear definition of family function and using commonly accepted, validated instruments. Only then will we be able to assess the validity of the model with families of handicapped children. In my estimation, the Double ABCX in its entirety will probably not be the focus of much research in the future.

The Findings of this Research Compared to Previous Research

A review of the literature contained in Chapter III revealed that there was limited research on the role of informal social support in moderating stress for mothers of developmentally disabled children. Marie Bristol is the only researcher who has tested the Double ABCX Model with this population. Although she utilized the Carolina Parent Support Scale, severity of the handicap, pile-up stressors and formal support, as I did, she also included measures of family cohesion, externalization of blame, the definition of the handicap as a family crisis and patterns of coping. Her outcome variables were different from my own and consisted of general family adaptation, maternal depression and marital adjustment.

In Bristol's conceptualization, the model explained 55% of the variance in family adaptation ($p = .0001$), 33% of the variance in maternal depression ($p = .04$), and 53% of the variance in marital adjustment ($p = .01$). The model as I constructed it explained 23% and 7%, respectively, of the variance in stress and life satisfaction. Regarding informal social support, Bristol found that perceived support was significantly correlated with all three dependent variables. My findings indicated that informal support was associated with coping and stress, but not life satisfaction. Both Bristol and I found that severity of the handicap and formal support were not related to any of the dependent variables. I cannot compare the magnitude of change in the dependent variables with increasing amounts of the independent variables because Bristol did not report means for her dependent variables.

Recognizing the limitations of comparisons between my research and Bristol's, it appears that Bristol had much stronger results. Our research differs in that she incorporated a number of variables which were not part of my model. In addition, she did not include any control variables. This was true despite the fact that there were wide ranges in subjects' ages, social class and marital status. These factors may account, at least in part, for the disparity in our findings. On the basis of these two studies, it is premature to assess the strength of the Double ABCX Model. Further research is required to determine the validity of the model as a theoretical framework for understanding how families adapt to caring for a handicapped child. As stated earlier, there needs to be agreement regarding appropriate measures for the various components of the model and greater consistency in application of these measures (Wikler, 1986).

Turning to the research of others in the field of developmental disabilities, again it is difficult to draw specific comparisons between the findings of my research and theirs due to differences in methodology, variables measured, instruments used, and often the focus of the research. Generally, research into the informal social support systems of families of children with developmental disabilities has been descriptive and has not analyzed the relationship between support and adaptation. For instance, Suelzle and Keenan (1981) studied the level of support to the family over the life cycle of the handicapped child using a mail questionnaire. Kazak and Marvin (1984) used a control group to determine differences between families with and without a handicapped child in terms of familys' social networks. Although each of these studies contributes to our understanding of informal social support, comparisons between these data and my research are impeded due to differences in design, methodology and measures.

Still, a couple of researchers have examined the relationship between informal social support and various outcome measure. One such study is the work of Dunst et al. (1986), who analyzed the impact of parental satisfaction with support upon adaptation in mothers and fathers of handicapped children. The only dependent variable they used which approximates my was parental well-being. The results showed that satisfaction with support was the only main effect independent measure associated with well-being. The researchers report R^2 and change in R^2 for each variable added to the equation, but not the regression coefficients (b). Therefore, I cannot compare their results with my analysis of the efficacy of increasing amounts of social support reported on earlier in this chapter. Similarly, Crnic et al. (1983) examined the relationship of stress and social support to adaptation in mothers of premature and full-term infants. They found that intimate and community support significantly predicted general life satisfaction. Again, they reported the R^2 and not regressions coefficients, making it impossible for me to compare my analysis of efficacy with their work.

Generally, informal social support, regardless of how it is measured, has proven to be associated with positive outcomes for families. However, considering correlations alone is misleading because it does not provide the data necessary to analyze the amount of social support necessary to making meaningful changes in the lives of mothers with handicapped children.

To facilitate knowledge building in the area of family stress, it would behoove researchers to examine the change in dependent variables for every unit increase in social support so that we can better understand the potential impact of programmes designed to increase informal support to families. Furthermore, researchers should operationalize similar variables and utilize common instruments. The lack of agreement among social scientists regarding the variables to be measured and instruments to be used, probably reflects the recentness of serious attention to this field of study. In keeping with Wikler's (1986) recommendations, greater continuity among studies would move our understanding of family stress farther along.

Implications for Social Work Practice

Accepting that the Double ABCX Model generally, and informal social support specifically, did not prove very useful in explaining the variance in coping, stress and life satisfaction in mothers of children with developmental disabilities, it is still possible to utilize these data in tandem with the descriptive and qualitative data to inform social work practice. In this section, I will bring together all of the results, with the work of other writers in the field of developmental disabilities, to suggest implications for interventions at the policy and programme level and in direct practice.

Implications for Policy and Programmes

Research indicates that families of children with developmental disabilities prefer to care for them at home (Hauber, Bruininks, Hill, Larkin & White, 1982). Given this fact, there are two systems through which support can be provided to families with a disabled member. The first is internal to the family and includes informal social support, their own monetary resources and assets, and the physical and psychological preparedness of the individual family members to meet the demands of home care. The second is external to the family and consists of the service delivery system designed to support families. Although good effectiveness data are not available, it is generally agreed among professionals that in families opting for home care, programmes of family support based on their needs should be available. Services should include, but not be limited to, respite care, homemaker services, cash subsidies, training in how to care for the handicapped child and counselling. However, in the event that the family is unable to care for their handicapped child at home, even with a full range of support services, residential options should be available.

The current debate in the developmental disabilities field, vis-a-vis family support, is around the role the state should play versus that which should be the responsibility of the family. In terms of the state's commitment to provide support services to families, Moroney (1986) contends that state resources are allocated primarily to substitute for family care instead of to support families. He points to greater expenditures for out-of-home care of handicapped children than for services to families providing care. Furthermore, he observes that the state often gets involved with families only after they are unable or unwilling to provide care. Instead of a crisis oriented model, he supports the concept of shared responsibility which implies providing services to the family when they are needed and to substitute for the family only when necessary.

There is mounting evidence for the argument that the state is not sharing in the care of handicapped children. For instance, although there has been an increase in the number and amount of family support services available throughout the State of Michigan (Herman, 1984), in the sample of families interviewed for this study, few families actually received those services (Marcenko & Meyers, 1985). One might argue that if the services are available but not used, they are obviously not needed. However, looking at respite care as an example, only 11% of the sample had used respite care in the past year. Yet when we asked mothers what services they needed but were not getting, one of the more frequent responses was babysitting for the handicapped child. Clearly other factors act as barriers to receiving this service. These barriers may be social, psychological, financial, geographical or cultural. Also, information about services may not be well disseminated, or they may be delivered in a way which makes them unusable by families. I am reminded of one single mother who said that she needed respite care for her six year old non-ambulatory son in the last month of her recent pregnancy because she could not lift him alone. However, the respite care agency told her that she was not eligible for the service until she delivered her baby. Ferreting out the various reasons families do not receive services is not possible from this study, given the available data, but further examination of this issue could provide valuable information to policy makers and programme planners.

On the family side of the equation, if the state is not providing support services, then all of the responsibility for care of children with handicaps rests with families. Furthermore, based on my findings, most of the day-to-day care is actually performed by mothers. As stated earlier, one of the primary internal resources available to families is informal social support. Even though my results indicate that there is a weak relationship between informal support and stress, the alternative is to disregard the importance of informal support to mothers and to allow the family system as it currently operates to persist. I contend that this is unfair to women and will lead to a perpetuation of this situation. Therefore, I think that it is important to look for ways to provide mothers with more informal support in order to more fairly distribute care of the handicapped child among the informal network members.

Another factor which is likely to compound the problems associated with mothers as primary caregivers, is the increasing participation of women in the labour force. It is projected that by the year 2000, women will make up 47.5 percent of the labour force, compared to 42.5 percent in 1980. Furthermore, most women are employed out of economic necessity, so that working mothers of handicapped children are often not in a position to choose between being full-time homemaker and working outside the home (U.S. Department of Labor, 1984). This is particularly troublesome since I found that even women who work outside the home the are still mainly responsible for the care of the handicapped child.

So far, I have established three factors which should be taken into account when planning family support policies and programmes. They are: (1) as it stands now, services most often replace families instead of support them; (2) women are the primary caregivers for their handicapped children, even if they work outside the home; and (3) in the next ten years we are likely to see greater feminization of the workplace. I have also put forth several values which I believe should underlie family policies and programmes. They are: (1) it is unjust for women to both mainly care for their severly handicapped children and to work outside the home; (2) the state has some responsibility to assist in the care of handicapped children; and (3) in most cases, family care of handicapped children is preferred over institutional care.

The most pressing question facing the family support field is how to design effective services, while at the same time capitalizing on the family's own resources. The role of family support policies and programmes should be to relieve families of some of the burden of caring for their children with handicaps. There are two resource systems available to achieve that goal, the family system and the formal service system. Programmes should therefore maximize the family's informal system and augment the family system with formal services. This implies flexibility in the type and amount of services provided since each family will present its own unique set of circumstances. The formal system, as it now operates, is not reaching many families. It is our task as professionals to formulate an effective service delivery system and to conduct ongoing programme evaluation to assure maximum benefit to families. At this point in the development of family support services, we have very little effectiveness data. Furthermore, little is known about the barriers families experience in accessing the services which are available.

The findings of my study and the experiences of others in the field can inform policy and programme development. For instance, given my finding that informal social support relieves stress and promotes coping, while formal services did not have an effect on any of the outcome variables, it would behoove us to find ways to augment the informal system rather than replace it. When services are rigid in their criteria for admission, and highly structured in their delivery, they do not mesh with families' informal systems of support, which are highly individualized and flexible.

I also found that nonhandicapped siblings are very helpful to mothers in the care of the handicapped child. Programmes which recognize the contributions of siblings could prove efficacious to the entire family. An example might be the family friend model of respite care, which has been tried in some communities. This model allows a friend of the family or a family member, such as a sibling, to be reimbursed for providing babysitting services. Other models which similarly bolster the informal network could be tried and evaluated against more traditional approaches.

Looking to the advice of other experts in the field, Moroney (1986) suggests a new approach by professionals towards service delivery. He encourages professionals to ask caregivers what services or resources would enable them to continue as caregivers, and then provide them. In this model, the job of the professional is to translate family requests into services offered within community agencies. He states that there is no evidence to support the contention that families would make unreasonable demands. On the contrary, similar programmes in England have resulted in positive outcomes for families, with few families actually making excessive demands. On the strength of this and other research, social policies and programmes meant to address the needs of families with handicapped children should capitalize on and promote the informal social support of families. Instead of substituting for family care, ways should be devised to provide services that augment the family system. In order to achieve this goal, there must be a loosening of the boundaries between informal and formal social supports.

It is instructive to speculate about why family support services are designed to replace as oppose to complement the family. One reason may be that it is easier to design and monitor services where the control resides with the professionals rather than the family. For instance, cash subsidies provided directly to families with handicapped children, to be used at their own discretion for the special needs of the family, is a policy option which has proved efficacious for families (Meyers & Marcenko, 1986). Yet, such a liberal approach to family support has not been taken by any state other than Michigan. Some states do provide financial relief to families of handicapped children, but only on a limited and specific basis (Bates, 1985).

As we begin to design family support services, I recommend that we actively engage families in the process. If families had a meaningful voice in how the service system was fashioned, the result would be services which are both relevant to different family needs and provided in a manner which does not pose as many barriers. The caution here is that we do not add another burden to families by involving them in programme planning. Understandably, some families will have neither the energy nor the desire to participate. However, there is ample evidence from the advocacy movement that many parents are both willing and committed to improving services. One need only look at organizations such as the Association for Retarded Citizens and United Cerebral Palsy to witness the strength of parent advocacy.

In summary, systemic interventions must look for innovative ways to capitalize on the strengths of families and provide services when they are needed. Informal social support is a moderator of maternal stress which should be promoted and augmented with formal services where necessary. Greater flexibility within the service system and a larger role for families in molding services would result in services which address the unique needs of families.

Direct Practice Implications

The social work practitioner working with a family who has a child with severe developmental disabilities typically has two foci, the child and the family unit. The goal for the child is to assist the young person in reaching his or her maximum functional capacity and to do it in the most normalized and least restrictive environment[3] possible. In our society, for children, the most normal living situation is the biological family, hence our concern with helping families to care for their member with a developmental disability. The goal for the family is to help the family maintain its developmentally disabled member at home while at the same time allowing for a high quality of life for the other family members. "High quality of life" can be measured by several dimensions such as life satisfaction, stress or ability of members to pursue their own goals. Stress and life satisfaction were the variables examined in this research.

In this section, I will concentrate on social work interventions which are directed at providing support to families, rather than on services for the handicapped child. Consistent with the previous section, some interventions are intended to bolster informal social support, while others are aimed at augmenting the family system with formal resources. I will also examine the way in which family support services are organized to determine the potential impact of this factor on families.

Families of children with severe developmental disabilities will require supports from multiple sources across the life cycle of the child. The role that social workers typically assume with families of handicapped children is one of case manager. A recent publication of the American National Association of Social Workers (1987), states that "case management has been uniquely a social work role for more than 100 years" (p. 1). Moxley (1987) defines case management as "a designated person or team who organizes, coordinates, and sustains a network of formal and informal supports and activities that are designed to optimize the functioning and well-being of people with multiple needs" (p. 13). This is an essential function since it brings together formal as well as informal resources for the purpose of optimizing individual and family functioning. Moxley points out that with deinstitutionalization and community care has come a system of fragmented, decentralized services which may frustrate and discourage the consumer. Effective case management can help families capitalize on support available to address their unique needs.

The effectiveness of case management has been proven with persons who have chronic mental illness and the elderly. In several demonstration projects with the elderly, case management has been shown to be an effective tool for diverting them from costly institutional care. The success of these demonstrations led to the incorporation of case management as a benefit under the Older Americans Act (Moxley, 1986). Within the field of developmental disabilities, case management has gained intuitive appeal. Given its popularity, there is an absence of empirical studies focusing on the use of case management with developmentally disabled children and their families. Thus, my recommendation is not to institutionalize case management at this time, but to conduct further research on its effectiveness with this population.

Social workers operating within the case management role can be guided in their interventions with families by the findings of this study. For instance, I found that women do not receive much concrete assistance with the care of the handicapped child, but the concrete help they do receive is important to them. Two daily concrete tasks appear particularly problematic; help with household chores and babysitting for the handicapped child. Almost a third of the sample reported that they never got help with household chores. However, of those receiving help, 80% found it to be "important" to "very important" to them. Similarly, over 60% of the women never or only sometimes got help with babysitting for the handicapped child, but of those who did get help, 96% stated that it was "important" to "very important." Based on these findings, if women received additional help just in these two common tasks, it could prove of great assistance to them. However, my results do not indicate that this help significantly reduces maternal stress. Therefore, although mothers state that concrete assistance is important to them, the impact is not felt in the area of stress. The positive outcome for mothers may be in ways not explored by this study.

The study results further indicate that fathers are not often involved in babysitting for the handicapped child. Although not part of this study, it has been my experience that fathers are seldom responsible for other child care related activities such as making appointments, taking children for appointments, or arranging respite care. Social workers can perpetuate this situation or encourage full family participation by their interaction with families. For instance, are agency hours convenient for working fathers to attend meetings regarding the child? Do social workers attempt to communicate with both parents, or do they only call mothers with information? Do social workers assume that mothers will take responsibility for child care activities and therefore interact with families in ways which communicate this message? Social workers, as members of this society, are subject to the same biases as all other members. Therefore, they must be consciously aware of how their behaviour impedes or encourages participation of the entire family, and especially fathers, in the care of the child with developmental disabilities.

An unexpected finding of my study was that perceived informal social support was significantly correlated with life satisfaction for mothers with few emotional problems. However, for mothers experiencing greater emotional difficulties, increasing amounts of informal support did not lead to improved life satisfaction. Therefore, mothers with emotional difficulties require help which goes beyond informal support if they are expected to feel more satisfied with their current life situation. Social workers should be alerted that this group of women is at-risk and make them the target of social work interventions.

In order to address the inequities in responsibility for the handicapped child, social work intervention should be family focused. Interventions aimed at the handicapped child or the mother alone will have little impact on the distribution of labour within the family. Since the results showed that most of the help which is proffered comes from husbands or nonhandicapped children, social work practice should incorporate these and other individuals who are important to the family system into their work with the family.

Despite my recommendation to increase informal social support to mothers, I realize that we as a profession lack the technology to produce predictably the desired changes in level of social support. Because families are active participants in the process, to a large degree the success or failure of our interventions relies on the willingness of families to change. This is further complicated by the fact that a family consists of individuals, each with his or her own needs and priorities. Consequently, the family must be viewed as a unique system which brings with it a particular set of values and life circumstances. For instance, an intervention goal may be to increase support from the father and nonhandicapped siblings, but the success of that goal is dictated by the actions of these family members. Even if they agree to the goal, implementation, and consequently outcome, rests in their hands. Additionally, social support differs from many concrete services such as respite care because it is much more abstract and its adequacy is evaluated based on perception rather than a set of objective criterion. Therefore, it is difficult to quantitatively assess both the amount of support provided and the impact. Nevertheless, social workers must be diligent in their attempts to evaluate the efficacy of their interventions with families and work to improve their direct practice strategies.

It could be argued that since informal social support moderated stress linked to the care of a handicapped child and formal services did not, that formal services should be withdrawn in favour of the informal system. However, this tactic is not advisable, since few family support services were actually used by families. Consequently, it is not known how services tailored to the needs of families will moderate stress associated with the caregiving demands of the child. If families had access to services they found useful and appropriate, the correlation between stress and formal support may have been stronger. It is the job of the social worker, in the case management role, to provide families with information about services so that they are able to make informed choices. The social worker should also identify barriers which the family may experience in accessing services and work to resolve those barriers.

Turning to a community organization perspective, social workers are responsive to the many subgroups within the population who are discriminated against in various ways. Women caring for vulnerable family members constitute such a group because they take on the majority of the day-to-day care of their handicapped children, without compensation. Therefore, a crucial role for social workers is to organize women for the purposes of supporting each other, gaining an awareness of their common issues, and working to affect change within the service system and the family. Women are providing a valuable service by caring for their handicapped children, a service which goes largely unrecognized and unpaid. Changes which benefit women are not likely to occur within the service system or the family without action on the part of women. Individually they have little influence, but together they may have the power to bring about recognition of the their contribution to the state and family. In turn, this will potentially create greater options for mothers and their families. Options might include: a full continuum of support services; compensation to mothers for care provided in the home; or a more equitable division of labour within the family. Social workers, due to their contacts with a large number of mothers, are able to help women organize, give them information about how the service system works and teach them the skills necessary to bring about desired change.

Historically, in the United States and Canada, parents have organized to demand services and protect the civil rights of their disabled children. Examples of parent groups include The Association for Retarded Citizens, The Society for Autistic Citizens and United Cerebral Palsy. All have been influential in exerting pressure upon the service system and policy makers to respond to the needs of their children. Families should be provided with information about parent groups and encouraged to form liaisons with other families. These relationships are helpful as both a source of informal social support and as a vehicle for social change. Leonard (1975) calls this process "group conscientization" because it develops critical consciousness and can contribute to social change.

Many social service agencies organize family support groups. It must be recognized that agency-based parent groups are not the optimal site for groups which are change oriented. A potential conflict of interest exists for the agency since parents may conclude that the agency should alter the type of services or manner in which services are offered. Agencies, therefore, have a vested interest in the outcomes of parent groups and this may work at cross-purposes with the needs of families. Furthermore, if families are dependent upon the agency for other services such as health care or education for their children, they may fear that their efforts will have a negative impact on the quality of service provided to their children. Parent groups which are not based in the organization where services are provided should therefore be encouraged and supported by social workers.

In summary, social workers play a key role in case management for families and they must be aware of available community services, and work to breakdown any barriers families experience in accessing services. Furthermore, direct interventions with families of handicapped children should include the whole family and not just mothers. Social service agencies can promote or impede full family participation by arranging their hours to accommodate working parents, especially fathers and school-age siblings, and by being conscious of incorporating all family members in the service plan. Another crucial role for social work is to organize mothers for the purposes of supporting each other and making changes within the family and service system which benefit them. Finally, social workers can help families advocate for better conditions for themselves and their handicapped children by encouraging them to join established parent groups.

The Double ABCX Model as a Framework for Social Work Practice

The theoretical model used in this study, the Double ABCX, is based on systems theory. It was pointed out in Chapter III that the Double

ABCX Model is multivariate, easily applied longitudinally and understandable to the cadre of professionals involved with families and children with developmental disabilities. Furthermore, it recognizes positive, as well as poor adaptation to the presence of a handicapped family member. It was also argued that systems theory is inherently conservative because it perpetuates the status quo by accepting society's institutions in their present form. Therefore, interventions using a systems framework are aimed at making systems work better rather than devising alternatives to those systems. Recognizing these strengths and limitations with respect to the Double ABCX Model, I will discuss the implications of the model for social work practice.

Multivariate analysis revealed that coping and perceived informal social support significantly moderated stress. Interventions based on these results should therefore be aimed at helping families to cope better and to build a strong system of social support. Programmes would, consequently, be focused on change within families. There is a plethora social work literature which supports this approach. For instance, in a recent article by Whittaker, Schinke and Gilchrist (1986) they suggest an ecological paradigm for child, youth and family services which promotes teaching life skills and facilitating social support. In their words this means: "(1) building more supportive, nurturant environments for clients through various forms of environmental helping that are designed to increase social support and (2) improving client's competence in dealing with both proximate and distal environments through the teaching of specific life skills" (p. 492). For families with a handicapped child this would entail helping them build networks of social support and teaching them the skills necessary to care for their handicapped member. These interventions are based on the premise that greater support and life skills will result in better adaptation.

The social worker who employs this strategy does not take into account the influence of public attitudes, policy and programmes on children and families. Interventions which analyze the family on a case-by-case basis do not see the common struggles and problems families face. Change is therefore directed at the individual family system as opposed to the social system which may be contributing to family problems. Taking this analysis one step further, mothers who are having difficulty coping would be encouraged to develop informal social support systems and gain competencies to deal with the care of her handicapped child. Individually-oriented interventions are thus focused on modifying mother's behaviours, not on recognizing the common hardships mothers endure.

While there is merit to analyzing the unique situation each family presents, the danger social workers face is in not seeing issues which are common across families. These generic issues need solutions on a policy level, not on an individual basis. In fact, many of the problems identified by families of children with developmental disabilities can be generalized to other family constellations. It could even be said that all families with children have common issues about which they will be concerned. A case in point is day care. Most families with children will at some time need day care or babysitting services. State policies and programmes designed to address these common needs reflect the degree of commitment the state has to supporting families.

The Double ABCX Model as a theoretical framework has particular application for social workers operating as case managers. In this role, social workers examine the constellation of resources and limitations each family presents and develops a plan to assist families. The Double ABCX provides a model for performing this function which results in a plan that is understandable to families and the cadre of professionals working with them. Where the model falls short is in identifying systemic issues which may contribute to family difficulties.

The model also helps us assess a family's response to caring for a child with developmental disabilities and the relationship between stressors, resources perception, and coping and family adaptation. Wikler (1986) points out that the shift from institutional to family care of persons with developmental disabilities assumes that family care is better. However, this presumption is based on little concrete data. To the extent that researchers utilize the model, in conjunction with reliable measures, we can begin to build a data base upon which can inform public policy and programmes.

Implications of the Findings for Mothers of Handicapped Children

In the past 10 to 15 years there has been a change in public policy regarding the most appropriate venue of care for children with handicaps. Previously, parents were encouraged by professionals and the lack of community services to place their child in an institutional setting. Now parents are not only discouraged from placing their child, but the lack of available community placements may make it almost impossible to take a child out of the family home. In reality, few options exist for parents who desire out-of-home placement.

Although the state policy of family care for severely developmentally disabled children has ramifications for the entire family, it holds particular significance for mothers. Given this policy direction, one of the most important findings of this study is that women take on the major responsibility as caregiver for their child with severe developmental disabilities. The results show that they receive little assistance in the necessary day-to-day home and child care activities related to the handicapped child. This was true whether they were married or single, working outside the home or not. Consequently, not unlike their counterparts with nonhandicapped children, mothers of handicapped children assume most of the responsibility for the care of their children.

It seems unlikely that women will receive more assistance from the informal system, under the current conditions. There is no reason to believe that family, friends and neighbours will provide greater support, and assume greater responsibility for the care of the handicapped child. Unless there is a dramatic change in the perception of family roles, no impetus exists for a transfer of responsibility from mother to other family members. Consequently, home care of severely developmentally disabled children will result in women taking on the major caregiving responsibility, regardless of marital or employment status. With a shift from community and institutional care to family care, the state essentially transfers responsibility to the mother.

Also of relevance to this study is children's policies vis-a-vis policies for women. Miller (1987) points out that recent policies meant to improve women's work lives are in conflict with those developed for children. It has already been established that policies for children support family care. These policies assume that families, and primarily women, will take responsibility for the care of dependent children. Policies for women, on the other hand, have promoted and supported their labour force participation. In the United States this trend can be seen in legislation such as the Equal Opportunity Act, the Pregnancy Disability Act, and the Retirement Equity Act of 1984. As a result of these two policy directions, women are put in the often unrealistic position of being full-time mother and worker.

Future Research Directions

Future research which builds on the findings of this study is suggested both by the limitations of this work and the questions it raises. First, there is a need for more studies of the informal social support system of families with a handicapped child compared to those families with only nonhandicapped children. Introducing a matched control group of mothers with nonhandicapped children would provide important comparative data. It is not known, based on this study, whether the structure of the informal social support system reported by this group of mothers with severely handicapped children is typical or different from that of all mothers of young and adolescent children.

For instance, I found that these mother's social networks lacked multidimensionality. This may be an indication of social isolation which is peculiar to mothers of handicapped children or it may be true of mothers with children in the age range described here. Other control groups should also include families with less severely handicapped children and children with emotional problems to determine variations related to type and severity of the disabling condition.

In addition to the use of control groups, longitudinal research is needed to help us understand how families cope with the care of severely handicapped children across the life cycle. Data which describe how the informal social support system changes quantitatively and qualitatively could be used to plan formal services for the purpose of augmenting the informal system. Wikler (1986b) has done some interesting work around the issue of normative developmental crises which exist for families of children with developmental disabilities. Her research is predicated on the work of others who have found that families with nonhandicapped children typically experience predictable developmental crises. Longitudinal research with families having handicapped children would both document crisis points and reveal the way in which informal social support changes or does not change to accommodate these crises.

A further limitation of my research is that it does not establish causation. It can only be said that there is a relationship between perceived informal social support and maternal stress. Consequently, interventions based on the study results require ongoing evaluation to determine whether or not they are efficacious. Prospective research which establishes a baseline of mothers' psychological, physiological and social characteristics and follows a cohort over time to observe how social support assists those experiencing stress would begin to address the issue of causation.

My research shares a problem common to most studies of families in that it only reports the experiences and perceptions of mothers. Subsequent studies should focus on all family members, and particularly fathers. A review of the literature turned up a plethora of studies on mothers, a sizeable body of research on siblings, but almost no studies of fathers. This is a neglected area which should receive the attention of researchers.

The finding that perceived informal social support may be more important than the acutal support received raises questions for me about how support is actually proffered on a day-to-day basis. Additional research is needed to qualitatively assess the manner in which mothers are provided and accept instrumental, emotional and informational support. The Management Scale which was used to tap these support dimensions revealed that little help was received by mothers, but assistance offered was very important to them. A qualitative study of how mothers manage with the support of others would be useful not only for the data it would generate but also as a guide in the development of a reliable and valid instrument to measure various types of informal social support.

An issue which continues to surface throughout this and other research is families' lack of formal service utilization. Data regarding the social, psychological, financial, geographical and cultural barriers families experience in accessing services would, therefore, make a significant contribution to the field.

Finally, the finding that coping moderated stress and enhanced life satisfaction points to another promising area of research. There are at least two avenues which could be explored in greater detail. The first area is the relationship between coping and informal social support. Certain types of coping styles may correlate with high or low informal social support. I identified five coping strategies: (1) child related reasons; (2) general acceptance; (3) support of family; (4) religion; and (5) those having difficulty coping. Certain coping styles or combination of styles may correlate with level of informal social support. Second is the relationship between coping styles and adaptation. As various coping styles may be related to level of informal support, they may also correlate with adaptation. Further in-depth study of the relationship between coping style and adaptation would provide useful data to the practitioner.

Subsequent areas of research have been suggested based on the limitations of my research and the questions it raised. Future studies should provide reliable comparative data between families with and without handicapped children and they should qualitatively explore the psychological, social, cultural and environmental aspects of informal social support, coping and adaptation.

FOOTNOTES

[1] The amount of change was calculated by multiplying the number of unit increase in the CPSS by the regression coefficient (b).

[2] The number of units of CPSS needed to reach the mean was calculated by using the following formula: $(x - \underline{M})/b$, where x is equal to two standard deviations above the mean or percentile.

[3] Least restrictive environment means that services for persons with disabilities must be provided under the least confining and most normalized and integrated circumstances consistent with their needs.

References

Agosta, J. M. & Bradley, V. J. (Eds.) (1985). Family care for persons with developmental disabilities: A growing commitment. Boston, MA: Human Services Research Institute.

Bachrach, L. L. (1981). Deinstitutionalization: Development and theoretical perspective. In I. D. Rutman (Ed.), Planning community services for deinstitutionalization: A review of principles, methods and applications, (pp. 5-22). Rockville: Project Share.

Bates, M. V. (1985). State Family Support/Cash Subsidy Programs. Wisconsin Council on Developmental Disabilities.

Baumeister, A. (1970). The American residential institution: Its history and character. In A. Baumeister & E. Butterfield (Eds.), Residential facilities for the mentally retarded. Chicago: Aldine Publishing.

Beckman, P. J. (1983). Influence of selected child characteristics on stress in families of handicapped infants. American Journal on Mental Deficiency. 88, 150-156.

Blacher, J. (1984). A dynamic perspective on the impact of a severely handicapped child on the family. In J. Blacher (Ed.), Severely handicapped young children and their families. (pp. 7-28). Orlando: Academic Press, Inc.

Boggs, E. M. & Henny, R. L. (1979). A Numerical and functional description of the developmentally disabled population in the United States by major life activities as defined in the Developmental Disabilities Assistance and Bill of Rights Act as Amended in P. L. 95-602. Philadelphia, PA: EMC Institute.

Bradley, V. J. (1984, October). Enhancing the family's role in the care of persons with developmental disabilities. Overview prepared for Conference of the National Association of Developmental Disabilities Councils, (pp. 1-13). Oakland, CA.

Bradshaw, J. & Lawton, D. (1978). Tracing the cause of stress in families with handicapped children. British Journal of Social Work 8, 182-191.

Breslau, N., Salkever, D. & Saruch, K. S. (1982). Women's labor force activity and responsibilities for disabled dependents: A study of families with disabled children. Journal of Health and Social Behavior. 23, 169-183.

Bristol, M. M. (1983). Carolina Parent Support Scale. Unpublished manuscript, University of North Carolina at Chapel Hill, the Frank Porter Graham Child Development Center.

Bristol, M. M. & Schopler, E. (1984). Coping and stress in families of autistic adolescents. E. Schopler & G. Mesiliou (Eds.), Families of autistic children. (pp. 251-278). New York: Plenum Press.

Bristol, M. M. (1984, October). Families of developmentally disabled children: Healthy adaptation and the double ABCX model. Paper presented at the Family Systems and Health Pre-Conference Workshop, National Council on Family Relations, San Francisco, CA.

Bristol, M. M. (1985, April). A series of studies of social support, stress, and adaptation in families of developmentally disabled children. Paper presented a meeting of the Society for Research in Child Development, Toronto, Ont.

Bronfenbrenner, U., Avgar, A. & Henderson C. (1977). An analysis of family stresses and supports. Unpublished manuscript, Cornell University.

Brown, D. R. & Gary, L. E. (1985). Social support network differential among married and nonmarried black females. Psychology of Women Quarterly. 9, 229-241.

Brownell, A. & Shumaker, S. A. (1985). Where do we go from here? The policy implications of social support. Journal of Social Issues. 41, 111-121.

Burrell, G. & Morgan, G. (1979). Sociological paradigms and organizational analysis. London: Heinemann.

Carmines, E. G. & Zeller, R. A. (1979). Reliability and validity assessment. Sage University Paper Series on Quantitative Applications in the Social Sciences, series no. 07-001. Beverly Hills and London: Sage Publications.

Cassel, J. (1976). The contribution of the social environment to host resistance. American Journal of Epidemiology. 104, 107-123.

Cloward, R. A. & Piven, F. F. (1975). Notes toward a radical social work. In R. Bailey & M. Brake (Eds.), Radical social work (pp. VII-XLVIII). New York: Pantheon Books.

Cobb, S. (1976). Social support as a moderator of life stress. Psychosomatic Medicine. 38, 300-314.

Cohen, S. & Syme, S. L. (1985). Issues in the study and application of social support. In S. Cohen and S. L. Syme (Eds.), Social support and health. (pp. 3-22). New York: Academic Press.

Conroy, J. W. & Bradley, V. J. (1985). Pennhurst Longitudinal Study: A report of five years of research and analysis. Philadelphia: Temple University Developmental Disabilities Center. Boston: Human Services Institute.

Crnic, K. A., Greenberg, M. T., Ragozin, A. S., Robinson, N. M., & Basham, R. B. (1983). Effects of stress and social support on mothers and premature and full-term infants. *Child Development*. *54*, 209-217.

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

Cummings, S. T., Bayley, H. T. & Rie, H. E. (1966). Effects of the child's deficiency on the mother: A study of mothers of mentally retarded, chronically ill and neurotic children. *American Journal of Orthopsychiatry*. *36*, 595-608.

Davis, M. & MacKay, D. (1973). Mentally subnormal children and their families. *The Lancet*. *2*, 974-975.

Deutsch, M. & Brown, B. (1964). Social influences on negro-white intelligence differences. *Journal of Social Issues*. *20*, 23-35.

Dohrenwend, B. S. & Dohrenwend, B. P. (1974). Overview and prospects for research on stressful life events. In B. S. Dohrenwend & B. P. Dohrenwend (Eds.), *Stressful life events: Their nature and effects*. (pp. 313-331). New York: John Wiley & Sons.

Dooley, D. (1985). Causal inference in the study of social support. In S. Cohen and S. L. Syme, (Eds.), *Social support and health*. (pp. 109-125). New York: Academic Press.

Dorner, S. (1975). The relationship of physical handicap to stress in families with an adolescent with spina bifida. *Developmental Medicine and Child Neurology*. *17*, 765-776.

Drover, G. & Shragge, E. (1977). General systems theory and social work education: A critique. *Canadian Journal of Social Work Education*. *3*, 29-39.

Dunst, C. J., Trivette, C. M. & Cross, A. H. (1986). Mediating influences of social support: Personal, family, and child outcomes. *American Journal of Mental Deficiency*. *90*, 403-417.

Eheart, B. K. & Ciccone, J. (1982) Special needs of low-income mothers of developmentally delayed children. *American Journal of Mental Deficiency*. *87*, 26-33.

Erickson, G. (1976). The concept of personal network in clinical practice. *Family Process*. *14*, 487-498.

Eyman, R. K., O'Connor, G., Tarjan, G. & Justice, R. S. (1972). Factors determining residential placement of mentally retarded children. *American Journal of Mental Deficiency*. *76*, 692-698.

Farber, B., Jenne, W. C. & Toigo, R. (1960). Family crisis and the decision to institutionalize the retarded child. Council for Exceptional Children, Research Monograph, (1, Series A). (pp. 1-66).

Farber, B. (1968). Mental retardation: Its social context and social consequences. New York: Houghton Mifflin Company.

Finch, J. (1984). Community care: Developing non-sexist alternatives. Critical Social Policy. 9, 6-17.

Fowle, C. M. (1968). The effect of the severely mentally retarded child on his family. American Journal of Mental Deficiency. 73, 468-473.

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

Gath, A. (1972). The mental health of siblings of congenitally abnormal children. Journal of Child Psychology and Psychiatry. 13, 211-218.

Gayton, F. G., Friedman, S. B., Tavormina, J. F., & Tucker, F. (1977). Children with cystic fibrosis: Psychological test findings of patients, siblings, and parents. Pediatrics. 59, 888-894.

Genevie, L. & Margolies, E. (1987). The motherhood report. New York: Macmillan Publishing Company.

German, M. L. & Maisto, A. A. (1982). The relationship of perceived family support system to the institutional placement of mentally retarded children. Education and Training of the Mentally Retarded. 17, 17-23.

Goldstein H. (1975). Some critical observations on the relevance of social systems theory for social work practice. Canadian Journal of Social Work Education. 1, 13-23.

Gortmaker, S. & Sappenfield, W. (1984). Chronic childhood disorders: Prevalence and impact. Pediatrics Clinic of North America. 31, 3-18.

Gottlieb, B. H. (1981). Social networks and social support in community mental health. In B. H. Gottlieb (Ed.), Social networks and social support. (pp. 11-42). Beverly Hills: Sage Publications.

Gottlieb, B. H. (1983). Social support strategies: Guidelines for mental health practice. Beverly Hills: Sage Publications.

Gouldner, A. W. (1970). The coming crisis of western sociology. New York: Basic Books.

Hauber, F. A., Bruininks, R. H., Hill, B. K., Larkin, K.C. & White, C. C. (1982). National census of residential facilities: Fiscal year 1982. Minneapolis: University of Minnesota, Department of Educational Psychology.

Herman, S. E. (1984). Baseline study on family support services in the State of Michigan. Research and Evaluation Division: Michigan Department of Mental Health.

Hill, R. (1958). Social stresses on the family, generic features of families under stress. Social Casework. 39, 139-150.

Hirsch, B. J. (1979). Psychological dimensions of social networks: A multimethod analysis. American Journal of Community Psychology. 7, 263-277.

Hirsch, B. J. (1980). Natural support systems and coping with major life changes. American Journal of Community Psychology. 8, 159-172.

Hobbs, M. T. (1964). A comparison of institutionalized and non-institutionalized mentally retarded. American Journal of Mental Deficiency. 69, 206-210.

Hollis, F. (1972). Casework: A psychosocial therapy (rev. ed.). New York: Random House.

Holmes, T. H. & Rahe, R. H. (1967). The social readjustment scale. Journal of Psychosomatic Research. 11, 213-218.

Holroyd, J. (1974). The questionnaire on resources and stress: An instrument to measure family response to a handicapped family member. Journal of Community Psychology. 2, 92-94.

Holt, K. S. (1958). The influence of a retarded child upon family limitation. Journal of Mental Deficiency Research, 2, 28-36.

House, F. S. & Kahn, R. L. (1985). Measures and concepts of social support. In S. Cohen and S. L. Syme (Eds.), Social support and health. (pp. 83-108). New York: Academic Press.

Jaslow, R. I., Kime, W. L. & Green, M. F. (1966). Criteria for admission to institutions for the mentally retarded. Mental Retardation. 4, 2-5.

Johnston, W. B. & Packer A. E. (1987). Workforce 2000: Work and workers for the twenty-first century. Indiana: Hudson Institute.

Kazak, A. E. & Marvin R. S. (1984). Differences, difficulties and adaptaion: Stress and social networks in families with a handicapped child. Family Relations. 33, 67-77.

Kessler, R. C. (1983). Methodological issues in the study of psychosocial stress. In H. B. Kaplan (Ed.), Psychosocial stress: Trends in theory and research. (pp. 207-341). New York: Academic Press.

Korn, S. I., Chess, S. & Fernandez, P. (1978). The impact of children's physical handicaps on marital quality and family interaction. In R. M. Lerner and Y. B. Spanier (Eds.), Child influence on marital and family interaction: A life span perspective. (pp. 299-326). New York: Academic Press.

Leonard, P. (1975). Towards a paradigm for radical practice. In R. Bailey and M. Brake (Eds.), Radical social work. (pp. 46-61). New York: Pantheon Books.

Lewis-Beck, M. S. (1985). Applied regression: An introduction. Sage University Paper series on Quantitative Applications in the Social Sciences, 80-5821. Beverly Hills and London: Sage Publications.

Marcenko, M. O. & Meyers, J. C. (1985, May). Families who care for their developmentally disabled children at home: The relationship of income to purchases and needs. Paper presented at the meeting of the American Association on Mental Deficiency Annual Meeting, Philadelphia, PA.

McAllister, R. J., Butler, E. W. & Lei, T. J. (1973). Patterns of social interaction among families of behaviorally retarded children. Journal of Marriage and the Family. 35, 93-100.

McCubbin, H. I. & Patterson, J. M. (1983a). Family transitions: Adaptation to stress. In. H. I. McCubbin & C. R. Figley (Eds.), Coping with normative transitions: Vol. 1 (pp. 5-25). New York: Brunner/Mazel.

McCubbin, H. I. & Patterson, J. M. (1983b). The family stress process: The double ABCX model of adjustment and adaptation. In H. McCubbin, M. Sussman & J. Patterson (Eds.), Social stress and the family: Advances and developments in family stress theory and research. (pp. 7-37). New York: The Haworth Press.

McLanahan, S. S., Wedemeyer, N. V. & Adelberg, T. (1981). Network structure, social support, and psychological well-being in the single-parent family. Journal of Marriage and the Family. 43, 601-612.

Mercer, J. R. (1966). Patterns of family crisis related to reacceptance of the retardate. American Journal of Mental Deficiency 71, 19-32.

Meyers, J. C. & Marcenko, M. O. (1986). An evaluation of Michigan's Family Support Subsidy Program: Coping with the cost. Wayne State University.

Michigan Department of Mental Health. (1983). [Admissions of children (0-17) to regional centers for the developmentally disabled]. Unpublished raw data.

Miller, D. C. (1987). Children's policy and women's policy: Congruence or conflict? *Social Work*. *32*, 289-292.

Moroney, R. M. (1983). Allocation of resources for family care. In L. Wikler & M. P. Keenan (Eds.), *Developmental disabilities no longer a private tragedy*. (pp. 208-218). Silver Spring, MD: National Association of Social Workers and American Association on Mental Deficiency.

Moroney, R. M. (1986). *Shared responsibility, families and social policy*. New York: Aldine Publishing.

Moxley, D. P. (1987). *The practice of case management in human services*. Manuscript submitted for publication.

Murphy, M. A. (1982). The family with a handicapped child: A review of the literature. *Developmental and Behavioral Pediatrics*. *2*, 73-82.

National Association of Social Workers. (1987). *Case management in health, education and human service settings*. Silver Spring, MD.

Neter, J., Wasserman, W. & Kutner, M. H. (1983). *Applied linear regression models*. Homewood, IL.: Richard D. Irwin, Inc.

Nihira, K., Meyers, C. E. & Mink, I. (1980). Home environment, family adjustment and the development of mentally retarded children. *Applied Research in Mental Retardation*. *1*, 5-24.

Nuckolls, K. B., Cassel, J. & Kaplan, B. H. (1972). Psychosocial assets, life crisis and the prognosis of pregnancy. *American Journal of Epidemiology*. *95*, 431-441.

Olshansky, S. (1962). Chronic sorrow: A response to having a mentally defective child. *Social Casework*. *43*, 190-193.

Ott, L., Larson, R. F. & Mendenhall, W. (1983). *Statistics: A tool for the social sciences*. Boston, MA: Duxbury Press.

Ramey, C. T., Mills, P., Campbell, F. A. & O'Brian, C. (1975). Infants' home environments: A comparison of high-risk families and families from the general population. *American Journal of Mental Deficiency*. *80*, 40-42.

Richards, I. D. G. & McIntosh, H. T. (1973). Spina bifida survivors and their parents: A study of problems and services. *Developmental Medicine and Child Neurology*. *15*, 292-304.

Roos, S. (1975). The future of residential services for the mentally retarded in the United States: A delphi study. Unpublished manuscript.

Rothman, D. J. (1978). The state as parent: Social policy in the progressive era. In W. Gaylin, I. Glasser, S. Marcus, & D. Rothman (Eds.). Doing good: The limits of benevolence (pp. 67-96). New York: Pantheon Books.

Schaefer, C., Coyne, J. C. & Lazarus, R. S. (1981). The health related functions of social support. Journal of Behavioral Medicine. 4, 381-406.

Schilling, R. F., Kirkham, M. A., Snow, W. H. & Schinke, S. P. (1986). Single mothers with handicapped children: Different from their married counterparts? Family Relations. 35, 69-77.

Schonell, F. J. & Watts, B. H. (1956). A first survey of the effects of a subnormal child on the family unit. American Journal of Mental Deficiency. 61, 210-219.

Selye, H. (1956). The stress of life. New York: McGraw-Hill.

Sherman, B. R. & Cocozza, J. J. (1984). Stress in families of the developmentally disabled: A literature review of factors affecting the decision to seek out-of-home placements. Family Relations 33, 95-103.

Sosa, R., Kennell, J., Klaus, M., Robertson, S. & Urrutia, J. (1980). The effect of a supportive companion on perinatal problems, length of labor, and mother-infant interaction. The New England Journal of Medicine. 11, 597-600.

Stabenow, D. (1983). The Family Support Subsidy Act: Questions and answers on P.A. 240 of 1983 (H.B. 4448). Lansing, MI.

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

Suelzle, J. & Keenan, V. (1981). Changes in family support networks over the life cycles of mentally retarded persons. American Journal of Mental Deficiency. 86, 267-274.

Tallman, I. (1965). Spousal role differentiation and the socialization of severely retarded children. Journal of Marriage and the Family. 27, 37-42.

Tausig, M. (1985). Factors in family placement decision-making for disabled individuals. American Journal of Mental Deficiency. 89, 352-361.

Tausig, M. & Epple, W. A. (1985). The placement process: Individual, family, and service factors. New York State Office of Mental Retardation and Developmental Disabilities.

Tew, B. J., Payne, H. & Laurence, K. M. (1974). Must a family with a handicapped child be a handicapped family? Developmental Medicine and Child Neurology. 16, 95-98.

Tew, B. J. & Laurence, K. M. (1975). Some sources of stress found in mothers of spina bifida children. British Journal of Preventive and Social Medicine. 29, 27-30.

Tizard, J. & Gard, J. (1961). The mentally handicapped and their families. Oxford: Oxford University Press.

Turnbull III, R. H., Ellis, J. W., Boggs, E. M., Brooks, P. O. & Biklen, D. P. (1981). The least restrictive alternative: Principles and practices. R. H. Turnbull, III (Ed.). Washington, D.C.: American Association on Mental Deficiency.

U.S. Bureau of the Census (1983). Country and city data book. Washington, DC: U.S. Government Printing Office.

U.S. Department of Labor. (1984). Facts on women workers. Washington, D.C.: U.S. Government Printing Office.

Von Bertalanffy, L. (1968). General system theory: A critical review. In W. Buckley (Ed.), Modern systems research for the behavioral scientist: A sourcebook. (pp. 11-30). Chicago: Aldine.

Waisbren, S. E. (1980). Parents' reactions after the birth of a developmentally disabled child. American Journal of Mental Deficiency. 84, 345-351.

Weinraub, M. & Wolf B. M. (1983). Effects of stress and social supports on mother-child interaction in single- and two-parent families. Child Development. 54, 1297-1311.

Whittaker, J. K., Schinke, S. P. & Gilchrist, L. D. (1986). The ecological paradigm in child, youth and family services: Implications for policy and practice. Social Service Review. 37, 483-503.

Wikler, L. & Hanusa, D. (1980, May). The impact of respite care on stress in families of developmentally disabled. Paper presented at American Association on Mental Deficiency. San Francisco, CA.

Wikler, L., Haack, J. & Intagliata, J. (1984). Bearing the burden alone? Helping divorced mothers of children with developmental disabilities. Family Therapy Collections. 11, 44-62.

Wilker, L. M. (1986a). Periodic stress of families of older mentally retarded children: An exploratory study. American Journal of Mental Deficiency. 90, 703-706.

Wikler, L. M. (1986b). Family stress theory and research on families of children with mental retardation. In J. Gallagher & P.M. Vietz (Eds.), Families of handicapped persons, research, programs and policy issues. (pp. 167-195). Maryland: Brookes Publishing.

Zimmerman, S. L. (1984). The mental retardation family subsidy program: Its effects on families with a mentally handicapped child. Family Relations. 33, 105-118.

APPENDIX A

TIME 1 QUESTIONNAIRE

1984

00. EXACT TIME NOW: ____________________

A1. I'd like to start by learning about you and your family. Let's start with your child who is handicapped. What is the child's name?

FILL IN NAME IN CHART ON NEXT PAGE (BELOW) - ON LINE 1

A2. Tell me the names of any other children in your family, including foster, step, or adopted children, starting with the oldest, down to the youngest.

FILL IN, IN DESCENDING ORDER IN CHART BELOW
FOR EACH CHILD LISTED, ASK A3 - A10

A3. Is ______ your natural child or is s/he a step, foster, or adopted child?

CODE AS FOLLOWS:

1. Natural → GO TO A5
2. Step → ASK A4
3. Foster → ASK A4
4. Adopted → ASK A4
5. Adopted-Step → ASK A4

A4. How long has ________ been living with you?

A5. (IF NOT OBVIOUS ASK:) Is _______ a male (boy) or female (girl)?

A6. What is ________'s birthdate?

FOR INDEX CHILD ONLY ASK:

ALL OTHERS → GO TO A8.

A7. What is __________'s racial/ethnic background?

1. BLACK
2. WHITE
3. HISPANIC
4. AMERICAN INDIAN
5. ASIAN, PACIFIC ISLANDER
6. OTHER (SPECIFY:)

IF OTHER CHILDREN, RETURN TO A1. IF NOT, GO TO A11

FOR OTHER THAN INDEX CHILD ASK:

A8. Is _________ living with you?

1. YES → GO TO A10
2. NO → ASK A9

A9. Where is ________ living?

A10. Does _________ have any special mental or physical problem or condition, or a long-term health problem?

1. YES
2. NO → GO TO A11

A10a. Could you briefly describe the problem.

X = INDEX CHILD

		A3	A4	A5	A6	A7	A8	A9	A10
Child's Name	X	Relationship to R	How Long	Sex M (1) F (2)	Birthdate MO/DAY/YR	Race	Home Y N (1) (2)	Location	Handicap of Child Other than Index
1)	X				/ /		Y N	▨	▨
2)	▨				/ /	▨	Y N		
3)	▨				/ /	▨	Y N		
4)	▨				/ /	▨	Y N		
5)	▨				/ /	▨	Y N		
6)	▨				/ /	▨	Y N		
7)	▨				/ /	▨	Y N		
8)	▨				/ /	▨	Y N		

Now I'd like to ask you a few questions about yourself.

A11. What is your birthdate? _____/_____/_____ month day year

A12. (RB, P. 1) Which of these describes your marital status? Are you:

1. MARRIED
2. SEPARATED
3. DIVORCED
4. WIDOWED
5. NEVER MARRIED
6. DIVORCED AND REMARRIED
7. WIDOWED AND REMARRIED
8. UNMARRIED LIVING W/ PARTNER

A12a. How long have you been married? _______ years

(IF NOT OBVIOUS, ASK:)

A12b. Is this your first marriage?

1. YES
2. NO → GO TO A12c

A12c. When did your previous marriage end? _______ year

A12d. When were you (divorced, separated, widowed)? _______ year

Now I'd like to know about the other people living in your home who have no other regular home. I don't need their names, just their ages and their relationship to you. These are people other than the children we've already talked about.

LIST EACH PERSON ON THE GRID BELOW AND ASK A13-A16 FOR EACH.

A13. What is _______'s relationship to you?

A14. (IF NOT OBVIOUS ASK:) Is ______ male or female?

A15. How old is _________?

A16. Is __________ financially dependent upon you?

A13 RELATIONSHIP TO R	A14 M (1)	 F (2)	A15 AGE	A16 FINANCIALLY DEPENDENT 1	 2
1.	M	F		Y	N
2.	M	F		Y	N
3.	M	F		Y	N
4.	M	F		Y	N

SECTION B

CHILD CHARACTERISTICS

B1. Now I'd like to learn more about _______. Is s/he severely mentally impaired, severely multiply impaired, or autistic?

1. SEVERELY MENTALLY IMPAIRED
2. SEVERELY MULTIPLY IMPAIRED
3. AUTISTIC IMPAIRED

B2. (RB, P. 2) Does _____ suffer from any of these other impairments or ongoing health problems?

	YES (1)	NO (2)	COMMENT (3)
a. Hard of hearing?			
b. Deaf?			
c. Visually handicapped?			
d. Blind?			
e. Downs syndrome?			
f. Cerebral Palsy?			
g. Seizure disorders?			
h. Physical handicap? (specify)			
i. Chronic pneumonia?			
j. Asthma?			
k. Diabetes?			
l. Hydrocephalus			
m. Microcephalus			
n. Obesity?			
o. Muscular dystrophy?			

	YES (1)	NO (2)	COMMENT (3)
p. Sickle cell?			
q. Speech deficit?			
r. Spina bifida?			
s. Cleft lip or palate?			
t. PKU ?			
u. Chronic ear problems?			
v. Chronic bronchitis?			
w. Chronic influenza?			
x. Hepatitis B?			
y. Skin diseases? (specify)			
z. Severe emotional prob.?			
aa. Heart Impairment?			
bb. Arthritis?			
cc. Cystic fibrosis?			
dd. Tay-sachs?			
ee. Hyperactivity?			
ff. Severe allergies ? (specify)			

B3. Does ____ have any other impairments or ongoing health problems?

1. YES → GO TO B4

2. NO → GO TO B5

B4. What other impairments or health problems does ____ have?

____

____

____

B5. In your own words, briefly describe ____'s physical or medical condition.

____

____

____

____

B6. How old was ____ when you first suspected that s/he had a handicap or problem?

B6a. AGE OF CHILD IN MONTHS (OR YEARS IF >2 YEARS OLD) ____________________

B6b. Can you tell me more about what you noticed?

____

____

____

B7. How old was ____ when a professional told you that s/he had a handicapping condition?

B7a. AGE OF CHILD IN MONTHS (OR YEARS IF >2 YEARS OLD) ____________________

B7b. What were you told?

____

____

____

B8. Do you have health insurance which covers ____?

1. YES ↓

2. NO → GO TO B9

B8a. What is the name of the insurance?________________________

B8b. How is the coverage provided?

1. HUSBAND'S EMPLOYMENT

2. WIFE'S EMPLOYMENT

3. PRIVATE INSURANCE

4. OTHER, SPECIFY________________________

GO TO B10

B9. Can you tell me why you do not have health insurance for ____?

____

____

____

B10. Now I'd like to know a little about what ____ can and cannot do.

LEVEL OF CHILD FUNCTIONING

	YES (1)	NO (2)
a. Is ____ able to communicate with others of (his/her) age group?		
b. Can ____ feed (him/herself)?		
c. Is it difficult to communicate with ____ because s/he has difficulty understanding what is being said to (him/her)?		
d. Is ____ able to play by (him/herself)?		

	YES (1)	NO (2)
e. Is ____ able to go to the bathroom by (him/herself)?		
f. Does ____ lose control in a way that is harmful to others or destructive of property?		
g. Does ____ physically harm or abuse (him/herself)?		
h. Does ____ exhibit sexual behavior that is difficult to deal with at times?		
i. Can people understand what ____ tries to say?		
j. Is ____ able to express (his/her) needs to others?		
k. Does ____ have to use a bedpan or diaper?		
l. Can ____ walk without help?		
m. Can ____ go up or downstairs by (him/herself)?		

SECTION C

IMPACT ON FAMILY

Caring for a child with handicaps affects families in different ways. I am going to read some statements that people have made about how their family was affected. For each statement, please tell me how much, at the present time, you would agree or disagree with the following statements. (RB, P. 4)

	STRONGLY AGREE (1)	AGREE (2)	DISAGREE (3)	STRONGLY DISAGREE (4)
a. The cost of my child's care is causing financial problems for the family..........	1	2	3	4
b. Time is lost from work due to appointments and care of my handicapped child......................	1	2	3	4
c. Additional income is needed in order to cover our expenses..................	1	2	3	4
d. We have to borrow money to help pay for our child's care.	1	2	3	4
e. I am unable to save much money because of the expense of my child's care.................	1	2	3	4
f. I gave up working for a while because of my child's disability..................	1	2	3	4
g. I can't take a job outside the home because of my child's condition....................	1	2	3	4
h. My child's handicap has kept me from going to school.......	1	2	3	4
i. Because of my child's handicap we find it difficult to take trips or vacations...........	1	2	3	4

	STRONGLY AGREE (1)	AGREE (2)	DISAGREE (3)	STRONGLY DISAGREE (4)
j. It is hard to find a reliable person to take care of my child..................	1	2	3	4
k. I have difficulty getting someone to care for my child when I need to go shopping or on errands................	1	2	3	4
l. My child's handicap keeps us from going out to visit friends or relatives.........	1	2	3	4
m. Because of my child's handicap we usually don't invite friends to our home..........	1	2	3	4
n. Our child's handicap does not interfere with our social life	1	2	3	4
o. Most of what we do each day is planned around my child's special needs................	1	2	3	4
p. Because of my child's disability we are closer as a family......................	1	2	3	4
q. My relatives have been understanding and helpful with my child................	1	2	3	4
r. Relatives interfere and think they know what's best for my child............	1	2	3	4
s. I think about not having any more children because of my child's handicap.......	1	2	3	4
t. I don't have much time left over for other family members after caring for my child.....................	1	2	3	4

	STRONGLY AGREE (1)	AGREE (2)	DISAGREE (3)	STRONGLY DISAGREE (4)
u. Our family gives up things because of my child's handicap	1	2	3	4
v. Fatigue is a problem for me......................	1	2	3	4
w. Nobody understands the burden I carry................	1	2	3	4
x. Learning to manage my child's handicap has made me feel better about myself..........	1	2	3	4
y. I worry about what will happen to my child in the future......................	1	2	3	4
z. (ASK IF R IS MARRIED OR LIVES WITH A PARTNER) My (husband/ partner and I discuss my child's problems together.....................	1	2	3	4

SECTION D

FAMILY SUPPORT

Now I'd like to ask you some questions about what it is like for you to raise and care for ____.

D1. Does ____ attend a school program?

1. YES   2. NO → GO TO D2

D1a. During what hours? ______________________________

D1b. During what months? ______________________________

GO TO D3

D2. Why doesn't ____ attend a school program?

____

____

____

D3. How old was ____ (in years) when s/he first enrolled in the public school program?

AGE IN YEARS: ______________________________

D4. (RB, P. 5) How much time do you get for yourself each day to do the things you like to do? Do not count time working sleeping or in school.

1. NONE OR LESS THAN 1/2 HR.
2. BETWEEN 1/2 AND 1 HR.
3. 1 TO 3 HOURS
4. 3 TO 5 HOURS
5. MORE THAN 5 HOURS

D5. (RB, P. 6) How satisfied are you with the amount of time you get to yourself to do the things you like to do?

1. VERY DISSATISFIED
2. SOMEWHAT DISSATISFIED
3. SOMEWHAT SATISFIED
4. VERY SATISFIED

D6. (RB, P. 7) About how much time were you away from your child in the past two weeks for social reasons, for example, going to the movies or visiting friends?

1. NONE OR LESS THAN 1 HOUR
2. BETWEEN 1 AND 3 HOURS
3. 4 TO 9 HOURS
4. 10 TO 25 HOURS
5. MORE THAN 25 HOURS

D7. (RB, P. 8) How satisfied are you with the amount of time you were away?

1. VERY DISSATISFIED
2. SOMEWHAT DISSATISFIED
3. SOMEWHAT SATISFIED
4. VERY SATISFIED

IF R IS MARRIED OR IN A RELATIONSHIP, ASK: D8 - D9
IF NOT → GO TO D10

D8. In the past month how many times have you and your (spouse/partner) been out together without the (child/ren)?

1. NONE AT ALL	2. ONLY ONCE	3. BETWEEN 2 AND 4 TIMES	4. MORE THAN 5 TIMES

D9. (RB, P. 9) How satisfied are you with the amount of time you spend together without the children?

1. VERY DISSATISFIED	2. SOMEWHAT DISSATISFIED	3. SOMEWHAT SATISFIED	4. VERY SATISFIED

CAROLINA PARENT SUPPORT SCALE

I am going to read a list of people or services which may or may not be helpful to you as the parent of a child with special needs. Think about how helpful each of them is in making your job as the parent of a special child easier. They may help you in any way. For example, they may help take care of ____. They may give you useful information or services. They may just give you understanding and support. For each item, please tell me how helpful the person or service is by indicating Not At All, A Little, Some, Quite a Bit, or A Great Deal. (RB, P. 9) (N/A=NOT APPLICABLE)

D18. How helpful (is/are) your:	N/A (1)	NOT AT ALL (2)	JUST A LITTLE (3)	SOME (4)	QUITE A BIT (5)	A GREAT DEAL (6)
a. (Husband/Partner)?						
b. Ex-Husband?						
c. Parents?						
d. Husband's parents?						
e. Other relatives?						
f. Husband's relatives?						
g. Children?						
h. Friends?						
i. Neighbors?						

PURCHASES - YEAR

Now I'd like to ask you about any major items you may have purchased for your child or to assist you in caring for ______ during the past year - (since [June/July] of 1983).

(ASK ALL APPROPRIATE QUESTIONS FOR EACH ITEM ON FACING PAGE)

E14. Have you purchased _____ at any time during the past year (since [June/July] of 1983)?

1. YES

2. NO → GO TO E17

E15. (RB, P.14) How was it paid for (Who paid for it)? (SOURCE CODE)

IF 1 (REGULAR FAMILY INCOME) ASK E16 ALL OTHER'S PROCEED TO NEXT ITEM ON LIST

E16. Approximately how much did it cost you to purchase ______ ? (ROUND TO NEAREST DOLLAR)

PROCEED TO NEXT ITEM

SOURCE CODE

1. Regular family income
2. Relatives paid for it
3. Friends or neighbors
4. Private insurance
5. Medicaid
6. Crippled children's
7. School
8. Charity
9. Community agency
10. SSI - if they can pinpoint as separate from family income
11. Other (Specify ________)
12. Don't know

E17. (RB, P.15) What was the reason you did not purchase this item during the past year?

REASON CODE A

1. I or my child didn't need
2. Needed but couldn't afford
3. Needed but not available
4. Needed but didn't have time to get
5. Other (Specify____)

GO TO NEXT ITEM ON LIST

PURCHASES	E10 FOUR WEEKS	E11 SRCE	E12 AMOUNT	E13 WHY NOT
ak. Extra insurance related to child	1. Y 2. N	☐	$ ______	☐
al. Special walking aids—wheelchair, braces, crutches	1. Y 2. N	☐	$ ______	☐
am. Pads, harnesses	1. Y 2. N	☐	$ ______	☐
an. Adaptive equipment for child	1. Y 2. N	☐	$ ______	☐
ao. Communication aids - typewriter, special board	1. Y 2. N	☐	$ ______	☐
ap. Special food preparation equipment	1. Y 2. N	☐	$ ______	☐
aq. Adaptation or remodeling of home	1. Y 2. N	☐	$ ______	☐
ar. Special vehicle to transport child	1. Y 2. N	☐	$ ______	☐
as. Equipment or utensils to use when taking care of ______	1. Y 2. N	☐	$ ______	☐
at. Eyeglasses or hearing aid	1. Y 2. N	☐	$ ______	☐
au. Family vacation	1. Y 2. N	☐	$ ______	☐
av. Other (Specify_____)	3. Y 4. N	☐	$ ______	☐

E18. Are there other things that I have not mentioned which you need but have not purchased?

1. YES   2. NO   GO TO E21

E19. What are they?

(LIST BELOW)

a.____

b.____

c.____

E20. Why haven't you bought (or done) these things?

____

____

____

E21. Of all the items we have mentioned, which are the ones you need most that you do not have?

a.____

b.____

c.____

E22. Thinking about the approximately $2700 you can receive from the Family Support Subsidy, which is about $225.00 per month, how do you think you might use the money? I understand that how you <u>actually</u> use the money once you have it might be very different from how you <u>think</u> you might use it now, but I am just wondering what you <u>think</u> you might do with the extra money.

____

____

____

____

PURCHASES - MONTH

Now I'd like to ask you about any items you may have purchased for your child or to assist you in caring for _______ during the past four weeks.

ASK ALL APPROPRIATE QUESTIONS FOR EACH ITEM ON FACING PAGE

E10. Have you purchased _____ at any time during the past 4 weeks?

1. YES

2. NO → GO TO E13

E11. (RB, P.14) How was it paid for (Who paid for it)?

IF 1 (REGULAR FAMILY INCOME) ASK E12

ALL OTHER'S PROCEED TO NEXT ITEM ON LIST

E12. Approximately how much did it cost you to purchase _______ during the past 4 weeks? (ROUND TO NEAREST DOLLAR)

PROCEED TO NEXT ITEM ON LIST ON FACING PAGE AND RETURN TO E10

SOURCE CODE

1. Regular family income
2. Relatives paid for it
3. Friends or neighbors
4. Private insurance
5. Medicaid
6. Crippled children's
7. School
8. Charity
9. Community agency
10. SSI - if they can pinpoint as separate from family income
11. Other (Specify _______)
12. Don't know

E13. (RB, P.15) What was the reason you did not purchase this item during the last 4 weeks?

1. Didn't need
2. Needed but couldn't afford
3. Needed but not available
4. Needed but not enough time to get
5. Other (Specify_____)

GO TO NEXT ITEM ON LIST

		E10	E11	E12	E13
	PURCHASES	FOUR WEEKS	SRCE	COST (ROUND TO $)	WHY NOT
ab.	Prescription medications	1. Y 2. N	☐	$ ________	☐
ac.	Over-the-counter medicines	1. Y 2. N	☐	$ ________	☐
ad.	Special toys, learning aids, games	1. Y 2. N	☐	$ ________	☐
ae.	Educational materials-for school	1. Y 2. N	☐	$ ________	☐
af.	Replaced household items, broken due to child's behavior	1. Y 2. N	☐	$ ________	☐
ag.	Special clothing	1. Y 2. N	☐	$ ________	☐
ah.	Diapers, rubber pants	1. Y 2. N	☐	$ ________	☐
ai.	Special foods	1. Y 2. N	☐	$ ________	☐
aj.	Other (Specify ______)	1. Y 2. N	☐	$ ________	☐

SECTION E

SERVICES

A child such as ____ often requires a number of special services. I would like to talk with you about the special service needs of your child during the past four weeks.

FOR EACH ITEM ON THE FACING PAGE, ASK ALL APPROPRIATE QUESTIONS RELATED TO THAT ITEM

E1. Have you used _____ at any time during the past four weeks?

IF NO, ASK E2 IF YES → SKIP TO E3

E2. (RB, P.10) Looking at this list of possible reasons, can you tell me which answer best describes why you didn't use this service in the past month?

REASON CODE A
1. I (or my child) didn't need it
2. We needed it but couldn't afford it
3. We needed it but as far as I knew it was not available
4. We needed it but didn't have time to get it
5. Other (spec.__)

RETURN TO E1 AND ASK APPROPRIATE QUESTIONS FOR NEXT ITEM ON FACING PAGE

E3. How many times (on how many separate occasions) did you use this service during the four weeks?

E4. For how many hours all together (total) did you use this service during the four weeks?

E5. (RB, P.10) From this list of possible providers, can you tell me who provided the service?

PROVIDERS

1. Family member (SPECIFY WHICH ONE)	5. School
2. Neighbor	6. Person or private provider other than above paid for service (Private nurse, paid sitter)
3. Friend	
4. Community agency	7. Other (Specify ______)

E6. (RB, P.11) Using the choices on this list, can you tell me how this service was paid for. For instance, did you pay for it yourself, was it paid for by someone outside the family, or was it covered by a community agency at no cost to you?

SOURCE CODE

1. From regular family income	5. Medicaid
2. Relative paid	6. Crippled children's
3. Friend/neighbor	7. Other (Specify)
4. Community agency	8. Don't Know

IF 1 (REGULAR FAMILY INCOME) → ASK E7 IF ANSWER IS 2-8 → SKIP TO E8
TURN THE PAGE FOR E7 AND REMAINING QUESTIONS FOR THIS ITEM

SERVICES	E1 USED	E2 WHY NOT	E3 TIMES	E4 HOURS	E5 PROVIDER	E6 SOURCE
a. Regular babysitters to care for child in your home	1. Y 2. N	☐	☐	☐	☐	☐
b. Emergency sitter to care for child in your home	1. Y 2. N	☐	☐	☐	☐	☐
c. Regular respite care for the child in-home (day overnight, extended)	1. Y 2. N	☐	☐	☐	☐	☐
d. Regular respite care for the child out of home (day, night, extended)	1. Y 2. N	☐	☐	☐	☐	☐
e. Emergency respite care for the child out of the home	1. Y 2. N	☐	☐	☐	☐	☐
f. Care for the nondisabled children while meeting the needs of _____	1. Y 2. N	☐	☐	☐	☐	☐

E7. Approximately how much did the service cost you (your family) in the past 4 weeks? (What did you spend on this?)

E8. Were you able to use this service as much as you would have liked or thought you needed?

IF NO: ASK E9

IF YES, RETURN TO PRECEDING PAGE AND START OVER WITH E1 FOR NEXT ITEM

E9. (RB, P.11) From this list of possible reasons, can you tell me the reason you did not get as much of this service as you wanted or needed?

REASON CODE B

1. Couldn't afford more
2. There wasn't as much available as I needed
3. Other (Specify ______)

SERVICES	E7 AMOUNT	E8 MORE	E9 WHY NOT
a. Regular babysitters to care for child in your home	$ _______	1. Y 2. N	☐
b. Emergency sitter to care for child in your home	$ _______	1. Y 2. N	☐
c. Regular respite care for the child in your home (day, overnight, extend)	$ _______	1. Y 2. N	☐
d. Regular respite care for the child out of home	$ _______	1. Y 2. N	☐
e. Emergency respite care for the child out of the home	$ _______	1. Y 2. N	☐
f. Care for the nondisabled children while meeting the needs of _____	$ _______	1. Y 2. N	☐

Let me ask you about some other kinds of services.

CONTINUE AS BEFORE -ASKING ALL APPROPRIATE QUESTIONS RELATED TO EACH ITEM ON THE FACING PAGE

E1. Have you used _____ at any time during the past four weeks?

IF NO, ASK E2 IF YES SKIP TO E3

E2. (RB, P.12) Again, from the list of possible reasons, can you tell me which answer best describes why you didn't use this service in the past month?

REASON CODE A

1. I (or my child) didn't need it
2. We needed it but couldn't afford it
3. We needed it but as far as I knew it was not available
4. We needed it but didn't have time to get it
5. Other (Specify _______)

RETURN TO E1 AND CONTINUE WITH THE NEXT ITEM ON FACING PAGE

E5. (RB, P.12) From the list of possible providers, can you tell me who provided the service?

PROVIDERS

1. Family member (SPECIFY WHICH ONE)
2. Neighbor
3. Friend
4. Community agency
5. School
6. Person or private provider other than above paid for service (Private nurse, paid sitter)
7. Other (Specify ______)

E6. (RB, P.13) Using the choices on the list, can you tell me how this service was paid for?

SOURCE CODE

1. From regular family income
2. Relative paid
3. Friend/neighbor
4. Community agency
5. Private insurance (Blue Cross/Blue Shield)
6. Medicaid
7. Crippled children's
8. School
9. Other (Specify_____)
10. Don't Know

IF 1 (REGULAR FAMILY INCOME) ASK E7

IF ANSWER IS 2-9 → SKIP TO E8

E7. Approximately how much did the service cost you (your family) in the past 4 weeks? (What did you spend on this?)

E8. Were you able to use this service as much as you would have liked or thought you needed?

IF NO: ASK E9 IF YES: → RETURN TO E1 AND BEGIN WITH NEXT ITEM

E9. (RB, P.13) From the list of possible reasons, can you tell me the reason you did not get as much of this service as you wanted or needed?

REASON CODE B

1. Couldn't afford more
2. There wasn't as much available as I needed
3. Other (Specify _____)

RETURN TO E1, AND BEGIN WITH NEXT ITEM

Let me ask you about some other kinds of services.

CONTINUE AS BEFORE -ASKING ALL APPROPRIATE QUESTIONS RELATED TO EACH ITEM ON THE FACING PAGE

E1. Have you used _____ at any time during the past four weeks?

IF NO, ASK E2 IF YES SKIP TO E3

E2. (RB, P.12) Again, from the list of possible reasons, can you tell me which answer best describes why you didn't use this service in the past month?

REASON CODE A

1. I (or my child) didn't need it
2. We needed it but couldn't afford it
3. We needed it but as far as I knew it was not available
4. We needed it but didn't have time to get it
5. Other (Specify _______)

RETURN TO E1 AND CONTINUE WITH THE NEXT ITEM ON FACING PAGE

E5. (RB, P.12) From the list of possible providers, can you tell me who provided the service?

PROVIDERS

1. Family member (SPECIFY WHICH ONE)
2. Neighbor
3. Friend
4. Community agency
5. School
6. Person or private provider other than above paid for service (Private nurse, paid sitter)
7. Other (Specify _______)

E6. (RB, P.13) Using the choices on the list, can you tell me how this service was paid for?

SOURCE CODE

1. From regular family income
2. Relative paid
3. Friend/neighbor
4. Community agency
5. Private insurance (Blue Cross/Blue Shield)
6. Medicaid
7. Crippled children's
8. School
9. Other (Specify______)
10. Don't Know

IF 1 (REGULAR FAMILY INCOME) ASK E7

IF ANSWER IS 2-9 → SKIP TO E8

E7. Approximately how much did the service cost you (your family) in the past 4 weeks? (What did you spend on this?)

E8. Were you able to use this service as much as you would have liked or thought you needed?

IF NO: ASK E9 IF YES: → RETURN TO E1 AND BEGIN WITH NEXT ITEM

E9. (RB, P.13) From the list of possible reasons, can you tell me the reason you did not get as much of this service as you wanted or needed?

REASON CODE B

1. Couldn't afford more
2. There wasn't as much available as I needed
3. Other (Specify ______)

RETURN TO E1, AND BEGIN WITH NEXT ITEM

SERVICES	E1 USED	E2 WHY NOT	E5 PROVIDER	E6 SOURCE	E7 AMOUNT	E8 MORE	E9 WHY NOT
g. Health care - medical doctors, specialists - in-town	1. Y 2. N	☐	☐	☐	$ ____	1. Y 2. N	☐
h. Health care - medical doctors, specialists-out-of-town	1. Y 2. N	☐	☐	☐	$ ____	1. Y 2. N	☐
i. Dentist &/or orthodontist	1. Y 2. N	☐	☐	☐	$ ____	1. Y 2. N	☐
j. Speech therapy	1. Y 2. N	☐	☐	☐	$ ____	1. Y 2. N	☐
k. Physical therapy	1. Y 2. N	☐	☐	☐	$ ____	1. Y 2. N	☐
l. Optomotrist, podiatrist, optician, orthotist	1. Y 2. N	☐	☐	☐	$ ____	1. Y 2. N	☐
m. Occupational therapy	1. Y 2. N	☐	☐	☐	$ ____	1. Y 2. N	☐
n. Counseling, therapy __marital (Check wh/) __family __individual (for whom) ____________	1. Y 2. N	☐	☐	☐	$ ____	1. Y 2. N	☐
o. Other nonmedical diagnostic evaluations	1. Y 2. N	☐	☐	☐	$ ____	1. Y 2. N	☐
p. Training in how to care for the child	1. Y 2. N	☐	☐	☐	$ ____	1. Y 2. N	☐
q. Training in how to train ____ to feed, toilet, care for self	1. Y 2. N	☐	☐	☐	$ ____	1. Y 2. N	☐

E14. We have just finished talking about the services you used during the past four weeks. Were there any services that you can recall using during the past year that were a major expense for you; for instance, major medical expenses or summer camp last year, anything at all?

1. YES → ASK E15

2. NO → GO TO E16

E15. (LIST EACH SERVICE AND ASK:)

Approximately how much did it cost you?

SERVICE COST

a.____

b.____

c.____

E16. Of the services I have mentioned, which are most important to you in caring for your handicapped child at home? That is, which are the ones you couldn't live without?

a.____

b.____

c.____

E17. Given your situation, which 3 services do you think you need most that you are not getting at the present time?

a.____

b.____

c.____

SERVICES	E1 USED	E2 WHY NOT	E5 PROV-IDER	E6 SOURCE	E7 AMOUNT	E8 MORE	E9 WHY NOT
r. Homemaker to help with household chores - cooking, cleaning, laundry	1. Y 2. N	☐	☐	☐	$ ____	1. Y 2. N	☐
s. Aid to help with personal or medical care of child	1. Y 2. N	☐	☐	☐	$ ____	1. Y 2. N	☐
t. Life-planning for child-planning for his/her future needs	1. Y 2. N	☐	☐	☐	$ ____	1. Y 2. N	☐
u. Life-estate planning - for care of child after parents can't	1. Y 2. N	☐	☐	☐	$ ____	1. Y 2. N	☐
v. Legal services related to the child	1. Y 2. N	☐	☐	☐	$ ____	1. Y 2. N	☐
w. Recreation program	1. Y 2. N	☐	☐	☐	$ ____	1. Y 2. N	☐
x. Summer camp (ASK ONLY IF AFTER JULY 1 AND CHILD NOT IN SCHOOL)	1. Y 2. N	☐	☐	☐	$ ____	1. Y 2. N	☐
y. Transportation service	1. Y 2. N	☐	☐	☐	$ ____	1. Y 2. N	☐
z. Laundry, dry-cleaning, diaper service	1. Y 2. N	☐	☐	☐	$ ____	1. Y 2. N	☐
aa. Anything else you can think of that we haven't covered (Specify) ____	1. Y 2. N	☐	☐	☐	$ ____	1. Y 2. N	☐
ab. ____	1. Y 2. N	☐	☐	☐	$ ____	1. Y 2. N	☐

SECTION F

STRESSFUL LIFE EVENTS

F1. Have you or any member of your immediate family experienced any of the following during the past year (since last June/July)?

		YES (1)	NO (2)
a.	Divorce?		
b.	Separation/Break-up of a Relationship? →		
c.	Marriage/New Live-in Relationship?		
d.	Gave Birth or Adopted a Child? →		
e.	Pregnancy?		
f.	Purchased or Built a Home? →		
g.	Death of an Immediate Family Member?		
h.	Lost or Quit a a Job? →		
i.	Stopped Working for an Extended Period?		
j.	Family Moved to a New Home? →		
k.	A Serious Illness or Injury?		
l.	Hospitalization? →		
m.	Difficulty with the Law?		
n.	A Member Dropped Out or was Suspended from School?		
F1o.	Did your handicapped child enter (puberty/start menses)?		
F1p.	Did your handicapped child (start/change) school(s)?		

F2. Have any other major life events occurred to you or any member of your immediate family in the past year (since last June/July)?

1. YES
2. NO → IF NO, GO TO F3

F2a. What were those events?

____

____

____

F3. (FOR ANY EVENTS R HAS IDENTIFIED ASK) Can you tell me a little about these events and their impact on you and your family?

1. ____

2. ____

3. ____

4. ____

5. ____

SECTION H

LIFE SATISFACTION AND COPING

(RB, P. 18) Here is a picture of a ladder. Suppose we say that at the top of the ladder (Number 10) the rung represents the best possible life for you and the bottom (Number 1) represents the worst possible life for you.

H1. Where would you put yourself on the ladder at the present stage of your life in terms of how satisfied or dissatisfied you are with your own personal life?

1 2 3 4 5 6 7 8 9 10

H2. Where would you say you were one year ago?

1 2 3 4 5 6 7 8 9 10

H3. Where would you say you are likely to be 12 months from now?

1 2 3 4 5 6 7 8 9 10

H4. (RB, P. 19) How well do you feel you are able to cope with ____ and the care that s/he requires?

1. EXCELLENTLY
2. VERY WELL
3. FAIRLY WELL
4. NOT VERY WELL
5. POORLY

H4a. Please tell me a little more about how well you feel you are coping.

INTERVIEWER CHECKPOINT:
IF THERE ARE OTHER CHILDREN IN THE HOME ASK: H5

IF NOT → GO TO H6

H5. (RB, P. 20) To what extent do any of your other children have trouble coping with ____?

1. NONE
2. A LITTLE
3. SOME
4. MUCH
5. A GREAT DEAL

(UNLESS ANSWER IS "NONE" ASK: H5a)

H5a. Would you tell me about it? Which (child/ren)?

INTERVIEWER CHECKPOINT:
IF R IS MARRIED OR PREVIOUSLY MARRIED, ASK: H6

IF NOT → GO TO H7

H6. (RB, P. 20) Would you say that ____ has had an influence on your marriage?

1. NONE
2. A LITTLE
3. SOME
4. MUCH
5. A GREAT DEAL

(UNLESS ANSWER IS "NONE" ASK: H6a)

H6a. Please tell me in what ways.

____

____

____

____

____

H7. Thinking back over ____'s life, what were the most difficult times caring for (him/her)?

____

____

____

____

____

____

SECTION I

DEMOGRAPHIC DATA

INTERVIEWER CHECKPOINT:
FOR THIS SECTION USE CURRENT HUSBAND AS REFERENCE IF R IS REMARRIED

I1. Now I need to know about your educational background. What was the highest grade of school or year of college you completed?

GRADE OF SCHOOL													COLLEGE				
00	01	02	03	04	05	06	07	08	09	10	11	12	13	14	15	16	17

I2. (IF CURRENTLY OR PREVIOUSLY MARRIED, ASK) What was the highest grade of school or year of college your husband completed?

GRADE OF SCHOOL													COLLEGE				
00	01	02	03	04	05	06	07	08	09	10	11	12	13	14	15	16	17

I3. What diplomas, certificates or degrees do you have?

1. HIGH SCHOOL
2. GED
3. ASSOCIATE
4. BACHELOR
5. GRADUATE
6. OTHER, (SPECIFY)____________________

I4. (IF CURRENTLY OR PREVIOUSLY MARRIED, ASK) What diplomas, certificates or degrees does your (husband/former husband) have?

1. HIGH SCHOOL
2. GED
3. ASSOCIATE
4. BACHELOR
5. GRADUATE
6. OTHER, SPECIFY____________________

I5. I'd like to move now to your work history. Are you currently employed outside the home or do you perform any services in the home for which you receive payment? (i.e., babysitting)

1. YES

2. NO → GO TO I6

I5a. How many hours per week?____________________

I5b. What kind of work do you do?____________________

I5c. How old was (disabled child) when you returned to work?

AGE OF CHILD IN YEARS:____________________

I5d. (IF NOT OBVIOUS, ASK) Is this work performed in your home or at another work setting?

1. IN HOME

2. ANOTHER SETTING

I6. Which of these terms best describes your current situation? Are you temporarily laid off, unemployed, disabled, retired, a student or homemaker?

1. TEMPORARILY LAID OFF

2. UNEMPLOYED

3. DISABLED

4. RETIRED

5. STUDENT

6. HOMEMAKER

7. OTHER, SPECIFY____________________

I6a. What type of work did you do on your last job?

____

I6b. When did you leave your last job?____________________
YEAR

INTERVIEWER CHECKPOINT:
IF CURRENTLY OR PREVIOUSLY MARRIED, ASK I7 - I8 ☐

ALL OTHERS GO TO I9 →

I7. Is your (husband/former husband) currently employed?

1. YES
2. NO → GO TO I8

I7a. How many hours per week?____________________

I7b. What kind of work does he do?____________________

I8. Which term best describes his current situation? Is he temporarily laid off, unemployed, disabled, retired or a student?

1. TEMPORARILY LAID OFF
2. UNEMPLOYED
3. DISABLED
4. RETIRED
5. STUDENT
6. OTHER, SPECIFY____________________

I8a. What type of work did he do on his last job?

____

I8b. When did he leave his last job?____________________
YEAR

I9. Have you or your husband or any other person (i.e. friend or relative) quit work to care for your child?

1. YES

2. NO → GO TO I10

I9a. Who was it?

1. WIFE

2. HUSBAND

3. OTHER, (SPECIFY)____________________

I9b. (IF OTHER, ASK) What were the circumstances?

____

____

____

I10. Have your child's special needs affected your job or career?

1. YES

2. NO → GO TO CHECKPOINT BELOW

I10a. In what way has your job been affected?

____

____

____

____

<u>INTERVIEWER CHECKPOINT</u>:
IF CURRENTLY OR PREVIOUSLY MARRIED, ASK I11

ALL OTHERS GO TO I12

I11. Have your child's special needs affected your husband's (former spouse's) career or job?

1. YES
2. NO → GO TO I12

I11a. In what way has his career or job been affected?

____

____

____

____

I12. Have your personal or professional goals changed in any way due to ____'s handicap?

1. YES
2. NO → GO TO CHECKPOINT BELOW

I10a. In what ways have your goals changed?

____

____

____

____

INTERVIEWER CHECKPOINT:
IF CURRENTLY OR PREVIOUSLY MARRIED, ASK A13

ALL OTHERS GO TO I14

I13. Have your (husband's/former husband's) personal or professional goals changed in any way due to ____'s handicap?

1. YES

2. NO → GO TO I14

I13a. In what ways have his goals changed?

____

____

____

____

I14. Are you satisfied with your present working status?

1. NO, NOT SATISFIED WITH PRESENT STATUS → GO TO I14a

2. YES, SATISFIED WITH PRESENT STATUS → GO TO I15

I14a. How would you like it to be different?

____

____

____

____

I15. (RB, P. 21) Please tell me all sources of your family income for 1983.

Did you receive money from:

	YES (1)	NO (2)
a. Wages or salary? →		
b. Supplemental security income (SSI)?		
c. Social Security? →		
d. Aid to families with dependent children (ADC)?		
e. Food stamps? →		
f. Other public assistance or welfare?		
g. Unemployment compensation? →		
h. Workman's compensation? →		
i. Veteran's payments? →		
j. Alimony? →		
k. Child support? →		
l. Interest and dividends?		
m. Other regular contributions from persons not living in the home?		
n. Other regular contribution from persons living in the home?		
o. Other? SPECIFY ______		

I16. (RB, P. 22) Taking into consideration all sources of income, what was your total (family) income before taxes in 1983. Just tell me the number on the page.

1. Under 3,000
2. 3,001-5,000
3. 5,001-8,000
4. 8,001-10,000
5. 10,001-15,000
6. 15,001-20,000
7. 20,001-25,000
8. 25,001-30,000
9. 30,001-40,000
10. 40,001-50,000
11. 50,001-60,000

I17. (RB, P. 23) Overall, how would you describe your financial state this year as compared to last year?

1. A GREAT DEAL WORSE
2. WORSE
3. NO CHANGE
4. SOMEWHAT BETTER

I18. What is your religious preference?

1. PROTESTANT
2. ROMAN CATHOLIC
3. JEWISH
4. NONE
5. OTHER, SPECIFY________________________________

I19. How would your rate your physical health?

1. EXCELLENT
2. GOOD
3. FAIR
4. POOR

IF MARRIED OR PREVIOUSLY MARRIED, ASK: I20

IF NOT GO TO I21

I20. How would you rate your (husband's/former husband's) physical health?

1. EXCELLENT 2. GOOD 3. FAIR 4. POOR

I21. Are there anythings I have not asked about regarding the care of _____ and what it has meant to you and your family that you think it would be important for me to know?

____

____

____

____

____

These are all the questions we have for now. Thank you very much for taking the time and effort to discuss what it is like to raise _____. You have provided a great deal of helpful information. I believe that this information will be extremely valuable not only to those of us involved with the project, but also to other parents in similar situations.

01. EXACT TIME NOW:____________________

DON'T FORGET TO MENTION THAT WE WILL BE ASKING FOR A SECOND INTERVIEW IN ABOUT ONE YEAR. PLEASE GIVE R $5.00 AND HAVE HER SIGN A RECEIPT.

APPENDIX B

TIME 2 QUESTIONNAIRE

1985

00. **EXACT TIME NOW:** ____________________

A1. I would like to start by finding out if there have been any major changes in your life in the past year. Have any children been added to your household either through birth, adoption, marriage or some other arrangement?

1. YES | 2. NO → GO TO A4 ☐

A2. How many children have been added to your household? ____________

A3. What were the circumstances?

1. BIRTH | 2. ADOPTION | 3. MARRIAGE | 4. FOSTER-CARE

5. OTHER ____________________________ ☐

A4. Have any children left your household in the past year?

1. YES | 2. NO → GO TO A6 ☐

A5. What were the circumstances?

1. LEFT TO LIVE INDEPENDENTLY | 2. DEATH | 3. LEFT TO LIVE WITH FATHER

4. OTHER ____________________________________ ☐

A6. Has your marital status changed in the past year?

1. YES | 2. NO → GO TO SECTION B ☐

☐ A7. (RB, P. 1) Which of these describes your new marital status? Are you:

☐ 1. MARRIED ☐ 2. SEPARATED ☐ 3. DIVORCED ☐ 4. WIDOWED

☐☐ A8. When did this occur? ______/______ MONTH YEAR

SECTION B

CHILD CHARACTERISTICS

B1. Now I'd like to learn more about ______. Is s/he severely mentally impaired, severely multiply impaired, or autistic?

1. SEVERELY MENTALLY IMPAIRED | 2. SEVERELY MULTIPLY IMPAIRED | 3. AUTISTIC IMPAIRED ☐

B2. Have any new medical problems of ______ been diagnosed in the past year?

1. YES ↓ GO TO B3 | 2. NO → GO TO B4 ☐

B3. What medical problems have been diagnosed? ☐☐

1. ____________________

2. ____________________

B4. Do you have health insurance which covers ____?

1. YES ↓ | 2. NO → GO TO B5 ☐

B4a. Which of these do you have? ☐

1. PRIVATE | 2. MEDICAID | 3. CRIPPLED CHILDREN'S

4. OTHER, SPECIFY ____________________

GO TO B6

B5. Can you tell me why you do not have health insurance for ____?

1. COULDN'T AFFORD

2. OTHER, SPECIFY____

B6. Now I'd like to know a little about what ____ can and cannot do.

LEVEL OF CHILD FUNCTIONING

		YES (1)	NO (2)
☐			
☐	a. Is ____ able to communicate with others of his/her age group?		
☐	b. Can ____ feed him/herself?		
☐	c. Is it difficult to communicate with ____ because s/he has difficulty understanding what is being said to him/her?		
☐	d. Is ____ able to play by him/herself?		
☐	e. Is ____ able to go to the bathroom by him/herself?		
☐	f. Does ____ lose control in a way that is harmful to others or destructive of property?		
☐	g. Does ____ physically harm or abuse him/herself?		
☐	h. Does ____ exhibit sexual behavior that is difficult to deal with at times?		
☐	i. Can people understand what ____ tries to say?		
☐	j. Is ____ able to express his/her needs to others?		
☐	k. Does ____ have to use a bedpan or diaper?		
☐	l. Can ____ walk without help?		
☐	m. Can ____ go up or downstairs by him/herself?		

SECTION C

IMPACT ON FAMILY

Caring for a child with handicaps affects families in different ways. I am going to read some statements that people have made about how their family was affected. For each statement, please tell me how much, at the present time, you would agree or disagree with the following statements. (RB, P. 2)

	STRONGLY AGREE (1)	AGREE (2)	DISAGREE (3)	STRONGLY DISAGREE (4)
a. The cost of my child's care is causing financial problems for the family	1	2	3	4
b. Time is lost from work due to appointments and care of my handicapped child	1	2	3	4
c. Additional income is needed in order to cover our expenses	1	2	3	4
d. We have to borrow money to help pay for our child's care.	1	2	3	4
e. I am unable to save much money because of the expense of my child's care	1	2	3	4
f. I gave up working for a while because of my child's disability	1	2	3	4
g. I can't take a job outside the home because of my child's condition	1	2	3	4
h. My child's handicap has kept me from going to school	1	2	3	4
i. Because of my child's handicap we find it difficult to take trips or vacations	1	2	3	4

		STRONGLY AGREE (1)	AGREE (2)	DISAGREE (3)	STRONGLY DISAGREE (4)
j.	It is hard to find a reliable person to take care of my child	1	2	3	4
k.	I have difficulty getting someone to care for my child when I need to go shopping or on errands	1	2	3	4
l.	My child's handicap keeps us from going out to visit friends or relatives	1	2	3	4
m.	Because of my child's handicap we usually don't invite friends to our home	1	2	3	4
n.	Our child's handicap does not interfere with our social life	1	2	3	4
o.	Most of what we do each day is planned around my child's special needs	1	2	3	4
p.	Because of my child's disability we are closer as a family	1	2	3	4
q.	My relatives have been understanding and helpful with my child	1	2	3	4
r.	Relatives interfere and think they know what's best for my child	1	2	3	4
s.	I think about not having anymore children because of my child's handicap	1	2	3	4
t.	I don't have much time left over for other family members after caring for my child	1	2	3	4

	STRONGLY AGREE (1)	AGREE (2)	DISAGREE (3)	STRONGLY DISAGREE (4)	
u. Our family gives up things because of my child's handicap	.1	2	3	4	☐
v. Fatigue is a problem for me........................	.1	2	3	4	☐
w. Nobody understands the burden I carry................	.1	2	3	4	☐
x. Learning to manage my child's handicap has made me feel better about myself...........	.1	2	3	4	☐
y. I worry about what will happen to my child in the future.......................	.1	2	3	4	☐

SECTION D

FAMILY SUPPORT

Now I'd like to ask you some questions about what it is like for you to raise and care for ____.

D1. Does ____ attend a school program?

1. YES   2. NO → GO TO D3   ☐

D2. Does ____ attend school during the summer?

1. YES   2. NO   ☐

D3. Why doesn't ____ attend a school program?

____

____

____

D4. (RB, P. 3) How much time do you get for yourself each day to do the things you like to do? Do not count time working sleeping or in school.

1. NONE OR LESS THAN 1/2 HR.
2. BETWEEN 1/2 AND 1 HR.
3. 1 TO 3 HOURS
4. 3 TO 5 HOURS
5. MORE THAN 5 HOURS

D5. (RB, P. 4) How satisfied are you with the amount of time your get to yourself to do the things you like to do?

☐

1. VERY DISSATISFIED
2. SOMEWHAT DISSATISFIED
3. SOMEWHAT SATISFIED
4. VERY SATISFIED

D6. (RB, P. 5) About how much time were you away from your child in the past two weeks for social reasons, for example, going to the movies or visiting friends?

☐

1. NONE OR LESS THAN 1 HOUR
2. BETWEEN 1 AND 3 HOURS
3. 4 TO 9 HOURS
4. 10 TO 25 HOURS
5. MORE THAN 25 HOURS

D7. (RB, P. 4) How satisfied are you with the amount of time you were away?

☐

1. VERY DISSATISFIED
2. SOMEWHAT DISSATISFIED
3. SOMEWHAT SATISFIED
4. VERY SATISFIED

IF R IS MARRIED OR IN A RELATIONSHIP, ASK: D8 - D9

IF NOT → GO TO D10

D8. (RB, P. 6) In the past month how many times have you and your (spouse/partner)
been out together without the (child/ren)?

☐

1. NONE AT ALL
2. ONLY ONCE
3. BETWEEN 2 AND 4 TIMES
4. MORE THAN 5 TIMES

D9. (RB, P. 4) How satisfied are you with the amount of time you spend together without the children?

1. VERY DISSATISFIED	2. SOMEWHAT DISSATISFIED	3. SOMEWHAT SATISFIED	4. VERY SATISFIED	☐

D10. Do you belong to any clubs, organizations, or church groups?

1. YES	2. NO	→ GO TO NEXT CHECKPOINT	☐

D10a. Please tell me what they are. (LIST BELOW)

D10b. Are you active or inactive in each?

	ACTIVE	INACTIVE		
1.________________	_____	_____	☐	☐
2.________________	_____	_____	☐	☐
3.________________	_____	_____	☐	☐

IF CURRENTLY MARRIED, ASK: D11
IF NOT → GO TO D12

D11. Does your husband belong to any clubs, organizations, or church groups?

1. YES	2. NO	→ GO TO D12	☐

D11a. What are they? (LIST BELOW)

D11b. Is he active or inactive in each?

	ACTIVE	INACTIVE		
1.________________	_____	_____	☐	☐
2.________________	_____	_____	☐	☐
3.________________	_____	_____	☐	☐

CAROLINA PARENT SUPPORT SCALE

I am going to read a list of people or services which may or may not be helpful to you as the parent of a child with special needs. Think about how helpful each of them is in making your job as the parent of a special child easier. They may help you in any way. For example, they may help take care of ____. They may give you useful information or services. They may just give you understanding and support. For each item, please tell me how helpful the person or service is by indicating Not At All, A Little, Some, Quite a Bit, or A Great Deal. (RB, P. 7)
(N/A=NOT APPLICABLE)

IF MARRIED ASK D16/IF SINGLE, ASK D17

D16. How helpful (is/are):	N/A (1)	NOT AT ALL (2)	JUST A LITTLE (3)	SOME (4)	QUITE A BIT (5)	A GREAT DEAL (6)	
a. Your husband?							☐
b. Your parents?							☐
c. Your husband's parents?							☐
d. Your other relatives?							☐
e. Your husband's other relatives?							☐
f. Other parents of handicapped children							☐
g. Your own children?							☐
h. Friends?							☐
i. Neighbors?							☐

D17. How helpful (is/are):	N/A (1)	NOT AT ALL (2)	JUST A LITTLE (3)	SOME (4)	QUITE A BIT (5)	A GREAT DEAL (6)	
a. Your boyfriend							☐
b. Child's father							☐
c. Your parents							☐
d. Parents of child's fathers							☐
e. Your other relatives							☐
f. Other relatives of child's father							☐
g. Other parents of handicapped children							☐
h. Your children							☐
i. Friends							☐
j. Neighbors							☐

MANAGEMENT SCALE

Below is a list of activities or situations in which some families may need assistance. Please tell me how often you have actually received such assistance and how importan such help was to you.

	D18. (RB, P.8) How often was assistance received?				D19. (RB, P.9) (If received,) how important was this help?			
	(1) Never	(2) Some-times	(3) Often	(4) Almost Always	(1) Not Very Impor-tant	(2) Some-what Impor-tant	(3) Impor-tant	(4) Very Impor tant
Ride to store, bank, etc....................								
Household chores.......								
Babysitting for handicapped child...........								
Babysitting for other children...............								
Family emergency.......								
Understanding handicapped child's needs and problems...............								
Family problems........								
Information about programs/services.........								
Financial problems.....								
Housing or space problems................								
Feeling that the demands of caring for the disabled child are a burden.								
Employment problems.....								

MANAGEMENT SCALE

D20. (RB, P. 10) For the same activities or situations as in the previous question, please tell me which person or group was your main source of support for help you received.

(CHECK ONE ONLY)	Indicate the main source of help for each area in which you actually received help. (LEAVE BLANK IF NOT APPLICABLE) (CHECK ONE ONLY)					
	(1) Family	(2) Friends	(3) Co-workers or Neighbors	(4) Parent Groups	(5) Community Agency	
a. Ride to store, bank, etc.						☐
b. Household chores						☐
c. Babysitting for handicapped child						☐
d. Babysitting for other children						☐
e. Family emergency						☐
f. Understanding handicapped child's needs and problems						☐
g. Family problems						☐
h. Information about programs/services						☐
i. Financial problems						☐
j. Housing or space problems						☐
k. Feeling that the demands of caring for the disabled child are a burden						☐
l. Employment problems						☐

SECTION E

SERVICES AND PURCHASES

A child such as ______________________ often requires a number of special services. I would like to talk with you about the special service needs of your child during the past four weeks.

Let's start out talking about childcare.

E1. Have you left your child in someone else's care (apart from the time he/she is in school) at any time during the past four weeks?

1. YES

2. NO GO TO E2

☐

E2. (RB, P. 12) Looking at the list of possible reasons, can you tell me which answer best describes why you didn't use any childcare?

(CHECK APPROPRIATE RESPONSE)

☐

____ 1. I (or my child) didn't need it.
____ 2. We needed it but couldn't afford it.
____ 3. We needed it but there is no one available who can take care of a child like mine.
____ 4. Other (specify) ____.

E3. There are several kinds of childcare one might have a need for. Can you tell me if you used any of the following during the past 4 weeks:

			YES	NO
☐	a.	babysitting at your home	______	______
☐	b.	babysitting at someone else's home	______	______
☐	c.	respite care - provided as a community service, either in your home, or out-of-the home.	______	______
☐	d.	Care for __________'s brothers/sisters while meeting special needs of this child.	______	______

FOR ANY ITEMS IN E3 (A-D) ANSWERED YES, ASK E4 - E7:
IF NONE ARE ANSWERED YES, GO ON TO E8.

Let me ask you about some other kinds of services.
(CONTINUE AS BEFORE -ASKING ALL APPROPRIATE QUESTIONS RELATED TO EACH ITEM ON THE FACING PAGE)

E10. Have you used _______ at any time during the past four weeks?

IF NO, ➧ ASK E11 IF YES ➧SKIP TO E12

E11. (RB, P. 15) Again, from the list of possible reasons, can you tell me which answer best describes why you didn't use this service in the past month?

REASON CODE A

1. I (or my child) didn't need it
2. We needed it but couldn't afford it
3. We needed it but as far as I knew it was not available
4. We needed it but didn't have time to get it
5. Other (Specify _______________)

RETURN TO E10 AND CONTINUE WITH THE NEXT ITEM ON FACING PAGE

E12. (RB, P. 16) From the list of possible providers, can you tell me who provided the service?

PROVIDERS

1. Family member (SPECIFY WHICH ONE)
2. Neighbor
3. Friend
4. Community agency
5. School
6. Person or private provider other than above paid for service (Private nurse, paid sitter)
7. Other (Specify _________________)

E13. Approximately how much did the service cost you (your family) in the past 4 weeks, that is, how much did you spend out of your own pocket for this service?

E14. Were you able to use this service as much as you would have liked or thought you needed?

IF NO: ➧ASK E15 IF YES: RETURN TO E10 AND BEGIN WITH NEXT ITEM

E15. (RB, P. 17) From the list of possible reasons, can you tell me the reason you did not get as much of this service as you wanted or needed?

REASON CODE B

1. Couldn't afford more
2. There wasn't as much available as I needed
3. Other (Specify _______________)

RETURN TO E10 AND GO ON WITH NEXT ITEM

E4. On how many separate occasions during the past 4 weeks did you use this type of childcare (a-d)?

E5. For how many hours all together (total) did you make use of (a-d) during the past 4 weeks:

E6. (RB, P. 15) From this list of possible providers, can you tell me who the provider of the childcare was?

PROVIDERS

1. Family member (SPECIFY WHICH ONE)
2. Neighbor
3. Friend
4. Community Agency
5. Person or private provider other than above paid for service (Paid sitter)
6. Other (Specify_________)

E7. Approximately how much did you spend on this form of childcare in the past 4 weeks?

DIDN'T USE	USED:	E4 TIMES	E5 HOURS	E6 PROVIDER	E7 COST
a.					
b.					
c.					
d.					

E8. Have you used respite care services at any time during the past year?

1. YES　　　2. NO　　　☐

E9. (IF NO) (RB, P.14) Looking at the list of possible reasons, can you tell me which answer best describes why you didn't use any respite care?

(CHECK APPROPRIATE RESPONSE)

___ 1. I (or my child) didn't need it.
___ 2. We needed it but couldn't afford it.
___ 3. We needed it but I didn't know it was available.
___ 4. Other (specify) ______________________________.

☐

SERVICES	E10 USED	E11 WHY NOT	E12 PROVIDER	E13 AMOUNT	E14 MORE	E15 WHY NOT
a. Health care - medical doctors, specialists - in-town	1. Y 2. N	☐	☐	$ ______	1. Y 2. N	☐
b. Health care - medical doctors, specialists-out-of-town	1. Y 2. N	☐	☐	$ ______	1. Y 2. N	☐
c. Dentist &/or orthodontist	1. Y 2. N	☐	☐	$ ______	1. Y 2. N	☐
d. Speech therapy	1. Y 2. N	☐	☐	$ ______	1. Y 2. N	☐
e. Physical therapy	1. Y 2. N	☐	☐	$ ______	1. Y 2. N	☐
f. Optomotrist, podiatrist, optician, orthotist	1. Y 2. N	☐	☐	$ ______	1. Y 2. N	☐
g. Occupational therapy	1. Y 2. N	☐	☐	$ ______	1. Y 2. N	☐
h. Counseling, therapy __marital (Check wh/) __family __individual (for whom) ______________	1. Y 2. N	☐	☐	$ ______	1. Y 2. N	☐
i. Other nonmedical diagnostic evaluations	1. Y 2. N	☐	☐	$ ______	1. Y 2. N	☐
j. Training in how to care for the child	1. Y 2. N	☐	☐	$ ______	1. Y 2. N	☐
k. Training in how to train ____ to feed, toilet, care for self	1. Y 2. N	☐	☐	$ ______	1. Y 2. N	☐

Let me ask you about some other kinds of services.
(CONTINUE AS BEFORE -ASKING ALL APPROPRIATE QUESTIONS RELATED TO EACH ITEM ON THE FACING PAGE)

E10. Have you used _______ at any time during the past four weeks?

IF NO, → ASK E11 IF YES → SKIP TO E12

E11. (RB, P. 15) Again, from the list of possible reasons, can you tell me which answer best describes why you didn't use this service in the past month?

REASON CODE A

1. I (or my child) didn't need it
2. We needed it but couldn't afford it
3. We needed it but as far as I knew it was not available
4. We needed it but didn't have time to get it
5. Other (Specify _______________)

RETURN TO E10 AND CONTINUE WITH THE NEXT ITEM ON FACING PAGE

E12. (RB, P. 16) From the list of possible providers, can you tell me who provided the service?

PROVIDERS

1. Family member (SPECIFY WHICH ONE)
2. Neighbor
3. Friend
4. Community agency
5. School
6. Person or private provider other than above paid for service (Private nurse, paid sitter)
7. Other (Specify _________________)

E13. Approximately how much did the service cost you (your family) in the past 4 weeks, that is, how much did you spend out of your own pocket for this service?

E14. Were you able to use this service as much as you would have liked or thought you needed?

IF NO: → ASK E15 IF YES: RETURN TO E10 AND BEGIN WITH NEXT ITEM

E15. (RB, P. 17) From the list of possible reasons, can you tell me the reason you did not get as much of this service as you wanted or needed?

REASON CODE B

1. Couldn't afford more
2. There wasn't as much available as I needed
3. Other (Specify _______________)

RETURN TO E10 AND GO ON WITH NEXT ITEM

SERVICES	E10 USED	E11 WHY NOT	E12 PROVIDER	E13 AMOUNT	E14 MORE	E15 WHY NOT
l. Homemaker to help with household chores - cooking, cleaning, laundry	1. Y 2. N	☐	☐	$ ______	1. Y 2. N	☐
m. Aide to help with personal or medical care of child	1. Y 2. N	☐	☐	$ ______	1. Y 2. N	☐
n. Life-planning for child: planning for his/her future needs	1. Y 2. N	☐	☐	$ ______	1. Y 2. N	☐
o. Life-estate planning - for care of child after parents no longer can	1. Y 2. N	☐	☐	$ ______	1. Y 2. N	☐
p. Legal services related to the child	1. Y 2. N	☐	☐	$ ______	1. Y 2. N	☐
q. Recreation program	1. Y 2. N	☐	☐	$ ______	1. Y 2. N	☐
r. Summer camp (ASK ONLY IF CHILD IS OUT OF SCHOOL FOR THE YEAR)	1. Y 2. N	☐	☐	$ ______	1. Y 2. N	☐
s. Transportation service (OTHER THAN SCHOOL BUS)	1. Y 2. N	☐	☐	$ ______	1. Y 2. N	☐
t. Laundry, dry-cleaning, diaper service	1. Y 2. N	☐	☐	$ ______	1. Y 2. N	☐
u. Anything else you can think of that we haven't covered (Specify) ______	1. Y 2. N	☐	☐	$ ______	1. Y 2. N	☐

E16. We have just finished talking about the services you used during the past four weeks. Were there any services that you can recall using during the past year that were a major expense for you; for instance, major medical expenses or summer camp last year, anything at all?

☐ 1. YES → ASK E17 ☐ 2. NO → GO TO E18

E17. (LIST EACH SERVICE AND ASK:)

Approximately how much did it cost you?

	SERVICE	COST
a.	____________	____________
b.	____________	____________
c.	____________	____________

E18. Of the services I have mentioned, which are most important to you in caring for your handicapped child at home? That is, which are the ones you couldn't live without?

a. ____________

b. ____________

c. ____________

E19. Given your situation, which 3 services do you think you need most that you are not getting at the present time?

a. ____________

b. ____________

c. ____________

SECTION F

STRESSFUL LIFE EVENTS

F1. Please tell me which of these events have happened to you in the past year? (Since last June/July)

(Did you...)	YES (1)	NO (2)	N/A (3)	
a. Get married?				☐
b. Get separated from spouse?				☐
c. Get divorced?				☐
d. Have a child?				☐
e. Lose spouse through death?				☐
f. Lose close family member through death?				☐
g. Did a child leave home?				☐
h. Did you change place of residence?				☐
i. Change jobs?				☐
j. Begin working outside the home?				☐
k. Did your spouse begin working outside the home?				☐
l. Did your spouse stop working outside the home?				☐
m. Did you get fired or laid off from a job?				☐
n. Did you quit a job?				☐
o. Were you robbed or attacked?				☐
p. Have a serious personal injury or illnes?				☐
q. Have a serious illness or injury of immediate family member?				☐
r. Handicapped Child Entered Puberty/Started Menses?				☐
s. Handicapped Child Started/Changed School(s)?				☐

F2. Have any other major life events occurred to you in the past year? (Since last June/July)

☐ 1. YES 2. NO → IF NO, GO TO SECTION G

F2a. What were those events?

☐ ______________________________

☐ ______________________________

☐ ______________________________

LIFE SATISFACTION AND COPING

(RB, P. 20) Here is a picture of a ladder. Suppose we say that at the top of the ladder (Number 10) the rung represents the best possible life for you and the bottom (Number 1) represents the worst possible life for you.

H1. Where would you put yourself on the ladder at the present stage of your life in terms of how satisfied or dissatisfied you are with your own personal life?

1	2	3	4	5	6	7	8	9	10

H2. Where would you say you were one year ago?

1	2	3	4	5	6	7	8	9	10

H3. Where would you say you are likely to be 12 months from now?

1	2	3	4	5	6	7	8	9	10

H4. (RB, P. 21) How well do you feel you are able to cope with ____ and the care that s/he requires?

1. EXCELLENTLY	2. VERY WELL	3. FAIRLY WELL	4. NOT VERY WELL	5. POORLY

H4a. Please tell me, what helps you to cope with the demands of ____'s care?

INTERVIEWER CHECKPOINT:
IF THERE ARE OTHER CHILDREN IN THE HOME ASK: H5

IF NOT ——→ GO TO H6

H5. (RB, P. 22) To what extent do any of your other children have trouble coping with ____?

1. NONE
2. A LITTLE
3. SOME
4. MUCH
5. A GREAT DEAL

(UNLESS ANSWER IS "NONE" ASK: H5a)

H5a. Would you tell me about it? Which (child/ren)?

INTERVIEWER CHECKPOINT:
IF R IS MARRIED OR PREVIOUSLY MARRIED, ASK: H6

IF NOT → GO TO H7

H6. (RB, P. 23) Would you say that _____ has had an influence on your marriage?

1. NONE	2. A LITTLE	3. SOME	4. MUCH	5. A GREAT DEAL

(UNLESS ANSWER IS "NONE" ASK: H6a)

H6a. Please tell me in what ways.

____

____

____

____

____

SECTION I

DEMOGRAPHIC DATA

I1. In the past year have you completed an additional year of schooling?

1. YES

2. NO → GO TO I3

I2. What is the highest grade of school or year of college you have completed?

GRADE OF SCHOOL													COLLEGE				
00	01	02	03	04	05	06	07	08	09	10	11	12	13	14	15	16	17+

I3. Have you obtained any diplomas, certificates or degrees in the past year?

1. YES

2. NO → GO TO I5

I4. What have you obtained?______________________________

I5. I'd like to move now to your present work situation. Are you currently employed outside the home or do you perform any services in the home for which you receive payment? (i.e., babysitting)

1. YES

2. NO → GO TO I6

☐☐ I5a. How many hours per week?______________________________

☐☐ I5b. What kind of work do you do?______________________________

I6. Which of these terms best describes your current situation? Are you temporarily laid off, unemployed, disabled, retired, a student, or homemaker?

1. TEMPORARILY LAID OFF
2. UNEMPLOYED
3. DISABLED
4. RETIRED
5. STUDENT
6. HOMEMAKER
7. OTHER, SPECIFY________________________

☐

INTERVIEWER CHECKPOINT:
IF CURRENTLY OR PREVIOUSLY MARRIED, ASK I7 - I8

ALL OTHERS GO TO I9: ⟶

I7. Is your your (husband/former husband) currently employed?

1. YES
2. NO ⟶ GO TO I8

☐

I7a. How many hours per week?________________________ ☐

I7b. What kind of work does he do?________________________ ☐

I8. Which term best describes his current situation? Is he temporarily laid off, unemployed, disabled, retired, or a student?

1. TEMPORARILY LAID OFF
2. UNEMPLOYED
3. DISABLED
4. RETIRED
5. STUDENT
6. OTHER, SPECIFY________________________

☐

I9. Have you or your husband or any other person (i.e. friend or relative) quit work in the past year to care for your child?

1. YES

2. NO → GO TO I10

I9a. Who was it?

1. WIFE

2. HUSBAND

3. OTHER, SPECIFY ____________________

I9b. IF OTHER, ASK: What were the circumstances?

____

____

____

I10. Are you satisfied with your present working status?

1. NO, NOT SATISFIED WITH PRESENT STATUS GO TO I10a

2. YES, SATISFIED WITH PRESENT STATUS → GO TO I11

I10a. How would you like it to be different?

____

____

____

____

111. **Please tell me all sources of your family income for 1984.**

Did you receive money from:

		YES (1)	**NO** (2)	
a.	**Wages or salary**			☐
b.	**Supplemental security income (SSI)**			☐
c.	**Social Security**			☐
d.	**Aid to families with dependent children (ADC)**			☐
e.	**Food stamps**			☐
f.	**Other public assistance or welfare**			☐
g.	**Unemployment compensation**			☐
h.	**Workman's compensation**			☐
i.	**Veteran's payments**			☐
j.	**Alimony**			☐
k.	**Child support**			☐
l.	**Interest and dividends**			☐
m.	**Other regular contributions from persons not living in the home**			☐
n.	**Other regular contribution from persons living in the home**			☐
o.	**OTHER, SPECIFY** ________________			☐

I12. (RB, P.26) Taking into consideration all sources of income, what ~~was~~ your total (family) income before taxes in 1984? Just tell me the number on the page.

1. Under 3,000	2. 3,001-5,000	3. 5,001-8,000
4. 8,001-10,000	5. 10,001-15,000	6. 15,001-20,000
7. 20,001-25,000	8. 25,001-30,000	9. 30,001-40,000
10. 40,001-50,000	11. 50,001-60,000	

I13. (RB, P. 27) Overall, how would you describe your financial state this year as compared to last year?

1. A GREAT DEAL WORSE	2. WORSE	3. NO CHANGE	4. SOMEWHAT BETTER

I14. How would your rate your physcial health?

1. EXCELLENT	2. GOOD	3. FAIR	4. POOR

IF MARRIED, ASK I15 →

IF NOT → GO TO I16

I15. How would you rate your husband's physcial health?

1. EXCELLENT	2. GOOD	3. FAIR	4. POOR

APPENDIX C

CONTROL VARIABLES

Table 5.21b

Multiple Regression Analysis of Selected Variables on Coping

Control Variables	Mean	b	t	Sig t
Race	-	.19	1.10	.27
Age of Child	8.39	-.04	-1.71	.09
Income	5.71	.06	1.42	.16
Marital Status	-	-.17	-.78	.44
Working Status of Mother	-	.03	.14	.89
Education of Mother	3.10	-.02	-.24	.81

Table 5.22b

Multiple Regression Analysis of Coping on Stress, Time 2

Control Variables	Mean	b	t	Sig t
Race	-	-1.94	- .89	.38
Age of Child	8.39	.47	1.71	.09
Income	5.71	.06	.10	.92
Marital Status	-	2.60	.87	.39
Working Status of Mother	-	5.10	2.19	.04
Education of Mother	3.10	2.22	1.73	.09

Table 5.23b

Multiple Regression Analysis of Coping on Life Satisfaction, Time 2

Control Variables	Mean	b	t	Sig t
Race	-	.19	.39	.70
Age of Child	8.39	.01	.22	.83
Income	5.71	- .01	- .06	.95
Marital Status	1.45	.13	.20	.85
Working Status of Mother	-	- .09	- .17	.87
Education of Mother	3.10	.28	.99	.32

Table 5.24b

Multiple Regression Analysis of Selected Variables on Stress

Control Variables	Mean	b	t	Sig t
Race	-	2.68	1.55	.25
Age of Child	8.39	.11	.36	.72
Income	5.71	.27	.43	.67
Marital Status	-	.29	.10	.93
Working Status of Mother	-	-3.99	- .01	.99
Education of Mother	3.10	2.17	1.62	.11

Table 5.25b

Multiple Regression Analysis of Selected Variables on Life Satisfaction

Control Variables	Mean	b	t	Sig t
Race	-	- .51	- .91	.37
Age of Child	8.39	.04	.57	.57
Income	5.71	- .08	- .51	.61
Marital Status	-	.08	.11	.91
Working Status of Mother	-	.11	.18	.86
Education of Mother	3.10	- .29	- .91	.36

Table 5.26b

Multiple Regression Analysis of Informal Social Support Measures on Coping

Control Variables	Mean	b	t	Sig t
Race	-	.18	1.09	.28
Age of Child	8.39	- .03	-1.10	.29
Income	5.71	.06	1.29	.20
Marital Status	-	- .38	-1.67	.10
Working Status of Mother	-	.05	.29	.77
Education of Mother	3.10	- .04	- .46	.65

Table 5.27b

Multiple Regression Analysis of Informal Social Support Measures on Stress

Control Variables	Mean	b	t	Sig t
Race	-	2.27	.99	.33
Age of Child	8.39	.29	.90	.37
Income	5.71	.01	.02	.98
Marital Status	-	-2.48	- .79	.43
Working Status of Mother	-	-3.72	-1.53	.13
Education of Mother	3.10	2.04	1.56	.12

Table 5.28b

Multiple Regression Analysis of Informal Social Support Measures on Life Satisfaction

Control Variables	Mean	b	t	Sig t
Race	-	- .42	- .77	.44
Age of Child	8.39	- .02	- .23	.82
Income	5.71	- .02	- .14	.89
Marital Status	-	.87	1.16	.25
Working Status of Mother	-	.07	.12	.91
Education of Mother	3.10	- .28	- .89	.38

APPENDIX D

INTERACTION TERMS AND ANALYSIS

Table 5.29b

Definitions of Interaction Terms

Abbreviation	Definition of Abbreviation
CPSS	Carolina Parent Support Scale
RCPSS	Carolina Parent Support Scale values for Black families.
ACPSS	Carolina Parent Support Scale values for children less than 9 years old.
ICPSS	Carolina Parent Support Scale values for families with incomes of $15,000 per year and under.
MCPSS	Carolina Parent Support Scale values for women who are married.
EMCPSS	Carolina Parent Support Scale values for women who are employed outside the home.
EDCPSS	Carolina Parent Support Scale values for women who have education beyond high school.

Table 5.30b

Multiple Regression Analysis of Interaction Between Informal Social Support and Control Variables

	RCPSS			CPSS			Race		
Dependent Variables	b	t	sig t	b	t	sig t	b	t	sig t
Coping	-.01	-.36	.72	.05	3.15	.002	- .07	- .18	.86
Stress	.22	.71	.48	- .80	-3.46	.001	- .82	- .17	.87
Satisfaction	.08	1.12	.27	.05	.91	.37	-1.57	-1.35	.18

	ACPSS			CPSS			Age		
Dependent Variables	b	t	sig t	b	t	sig t	b	t	sig t
Coping	-.04	-1.96	.05	.07	4.25	.001	- .35	-.98	.33
Stress	.35	1.12	.27	- .10	-3.68	.001	.01	1.30	.20
Satisfaction	-.02	- .28	.78	.11	1.80	.08	- .14	- .11	.91

Table 5.30b (continued)

	ICPSS			CPSS			Income		
Dependent Variables	b	t	sig t	b	t	sig t	b	t	sig t
Coping	- .02	- .74	.47	.06	3.20	.002	- .28	- .76	.45
Stress	.46	1.49	.14	- .94	-3.91	.001	9.45	1.88	.06
Satisfaction	- .11	-1.54	.13	.15	2.64	.01	-2.06	-1.72	.09

	MCPS			CPSS			Marital Status		
Dependent Variables	b	t	sig t	b	t	sig t	b	t	sig t
Coping	.03	1.41	.16	.03	1.87	.07	.80	2.15	.04
Stress	.42	1.35	.18	.47	1.99	.05	-7.91	-1.55	.13
Satisfaction	.09	1.22	.23	.04	.76	.45	2.04	1.68	.10

Table 5.30b (continued)

Dependent Variables	EMCPSS			CPSS			Employment		
	b	t	sig t	b	t	sig t	b	t	sig t
Coping	.05	2.38	.02	.06	.17	.87	.77	2.00	.05
Stress	- .01	- .04	.97	-.68	-2.11	.04	-3.93	- .71	.48
Satisfaction	- .02	- .25	.80	.09	.96	.34	.36	.28	.78

Dependent Variables	EDCPSS			CPSS			Education		
	b	t	sig t	b	t	sig t	b	t	sig t
Coping	- .05	-1.99	.05	.06	4.44	.001	.82	1.96	.05
Stress	.14	.35	.73	- .69	-3.55	.001	- .08	- .30	.77
Satisfaction	.04	.42	.68	.08	1.70	.09	- .45	- .32	.75