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**AN INVESTIGATION OF BURDEN AND RESPITE EXPERIENCED  
BY FAMILIES OF DISABLED CHILDREN ENROLLED IN  
CHILDREN'S SPECIAL SERVICES SUMMER PROGRAM**

by

**WENDY E. MACDONALD, M.A., A.R.C.T.**

**A Thesis Submitted to the Faculty of Graduate Studies  
in Partial Fulfilment of the Requirements for the Degree of  
MASTER OF SOCIAL WORK**

**Faculty of Social Work**

**University of Manitoba**

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**WENDY E. MacDONALD 1997 (c)**

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## **Abstract**

Children's Special Services provides an out of home respite service for children with developmental disabilities in the City of Winnipeg. The present study explores the characteristics of the burden of care experienced by the families of handicapped children who attended the program. A secondary purpose of the study is to explore the relationship between burden and the children's attendance at the program. Parents' and workers' assessments of the impact of the program on the families' lives as well as the parents' expression of consumer satisfaction with the program enabled an appraisal of whether camp attendance provided respite from burden.

The study findings challenge the prevalent assumption that burden is related to age, gender, type and severity of disability and level of overall child problem behaviour. Furthermore, burden was not found to be related to parental characteristics such as age, level of education, family income, or type of parental employment.

This study found a relationship between employed mothers and a lower level of burden, a lower level of child problem behaviour and a positive sense of renewal and nurturance expressed by the parents due to the impact of the program. Mother's employment was not related to family income, type or level of disability, or age of the child.

In order to explore the relationships that have emerged in this study, future research should include information regarding whether mothers are employed full-time or part-time; furthermore, the additional social supports available to mothers, in

addition to the camp program, should be described. The nature and quality of the marital dyad could also be assessed. Other variables which could be investigated in future research are the psychological strengths of the parents, as well as information about the family's typology. Future research could also include a pre-respite as well as a post-respite measure of burden; furthermore, future research could be directed at longitudinal studies with a larger population of families in order to evaluate the intervention effect of a summer camp program on perceived level of burden.

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## **Chapter One**

### **INTRODUCTION**

The primary purpose of the present study is to explore of the characteristics of the burden of care experienced by the families of handicapped children who attended the Children's Special Services Summer Program. This program provides an out of home respite and recreational service for children with developmental disabilities in the City of Winnipeg. Thus, these children are provided with an opportunity to participate in an enriching program of summer activities; concomitant with this opportunity, parents are provided with a break from the burden of care. In recognition of this latter opportunity, a secondary purpose of the present study is to explore the relationship between burden and the children's attendance at the program. In order to define and assess the nature of this relationship, parents' and workers' assessments of the impact of the program on the lives of these families, as well as their expression of consumer satisfaction with the program enabled an appraisal of whether camp attendance provided respite from burden.

The present study evolved as an adjunct of an initial evaluative plan which was devised to assess parent's consumer satisfaction with the summer program. This initial study context provided a concomitant opportunity for a post-respite evaluation of burden. Because there was no opportunity provided for *both* a pre-respite and post-respite evaluation of the characteristics of burden, the present study is essentially exploratory in nature. Nevertheless, an exploration of burden is the theme and to this end burden is examined in terms of the

relationship between burden and child, parent and family variables, as well as burden and the impact of the summer program, and burden and consumer satisfaction with the program. The secondary issue, the exploration of the effect, if any, of the summer camp on burden was explored to further delineate the great complexity of the phenomenon of burden.

The present study describes the results of the exploration of burden and of the relationship between burden and respite. Chapter Two of this study includes a review of the literature concerned with burden, and the factors related to respite from burden. Chapter Three of this study is a review of the methodology used in the study as well as the results. The study design is described as well as the procedures involved in developing and implementing the study. This chapter outlines each step in the research project, including the initial development of the study design, the construction of the questionnaire, the design and development of the scales used in the study, the collection of data, and the subsequent analysis of the data. This chapter also includes a presentation of the study findings, including the correlational data regarding burden and child, parent and family variables, as well as burden and the impact of the summer program, and burden with relation to parents' consumer satisfaction. Chapter Four of the study is a discussion of the significance of the study findings, particularly with relation to the literature review of relevant research concerning burden and respite. The study concludes with a final consideration of the knowledge of burden which has been gleaned from this research, and a final suggestion for areas of further research into the phenomenon of burden.

## Chapter Two

### **LITERATURE REVIEW OF THE CHARACTERISTICS OF THE BURDEN BORNE BY FAMILIES WITH A DISABLED CHILD**

Burden! The connotations of the term are onerous and forbidding, particularly when used to describe the experience of a family with a handicapped child. The birth of any child can have a profound impact on the family. The addition of a new family member can cause a disruption to the existing family routine as well as present a strain on the family's financial and other support systems. The birth of a handicapped child is, perhaps, every parent's worst anticipated fear; and, the effect on the family system, i.e., the "burden" of the ongoing care of a handicapped child can strain the family's physical, emotional and financial equilibrium.

The ability to cope effectively with the ongoing needs of a handicapped child is dependent upon the resilience and resourcefulness of the members of each individual family system; however, researchers have suggested that some families never adjust fully to the caregiving requirements of the child due to the ongoing stress that accompanies rearing the child at home (e.g., Flynt & Wood, 1989; Olshansky, 1962, Wikler, 1981). For example, Wikler (1981) refers to the sense of "disappointments over time and of the chronic sorrow" (p.287). Other researchers maintain that the cause of the "grief" at the birth of the handicapped child is the

perceived loss of the fantasized normal child (Parks, 1977; Emde & Brown, 1978). Still, other researchers (Flynt, Wood and Scott, 1992) refer to the "chronic stressors that exist across the life-cycle in families of children with mental retardation" (p.235).

Furthermore, it is only in recent years that conceptions of family functioning have been taken seriously by those professionals who work with families with a chronically disabled child. In some families, the singular focus on the disabled individual has, as its potential, major drawback, neglect of other family members. For example, in some instances, the nonaffected family members may be coping poorly. A concentrated focus on the disabled family member can be shortsighted in that doing so neglects the dynamic nature of family functioning (Seligman & Darling, 1989). It is likely that a deficiency in one family member will affect the entire system (and, will in turn reverberate to affect the disabled family member); thus, the family may be forced to reconceptualize how it plans to continue functioning effectively in the present and in the future. The unique demands placed on the family system by a disabled member have been summed up by Fewell (1986) who states that:

When a family has a disabled child, all the actors in this support network must adapt to the extended needs of the disabled member. The adaptations family members make are often significant, and individual destinies may be determined by the experience. Family adaptations change as the child matures; the stress at various periods may affect family members differently, for much depends on the familial and environmental contributions to the dynamic interactions of adaptation at a given point and time. (in Seligman & Darling, 1989, p.23)

The purpose of this chapter is to provide an overview of the literature which examines the characteristics of the supposed burden of a handicapped child on the family system, and the potential relief from burden, (i.e., respite), and concomitant improvement in quality of life



provided by various types of support systems. Although a review of the literature concerned with burden reveals a considerable degree of overlap and interaction between and among the variables involved, this paper will categorize and then consider representative samples from the burden literature from the standpoint of the following areas:

- (i) Stress experienced by families with disabled children.
- (ii) Coping Strategies of families with disabled children, (with a particular emphasis on family support in rehabilitation).
- (iii) Respite Care Use by families with disabled children.
- (iv) Parental vs. Professional Views of the needs of families with disabled children.
- (v) Empowerment of families with disabled children.

The first variable to be considered is the characteristics of the stress apparently experienced by families with a disabled member.

Hill (1949) described a stress model that is often cited in the family stress literature (e.g., McCubbin & Patterson, 1983). This model has been designated as the ABCX family crises model and is organized as follows: A (the stressor event) interacts with B (the family's crisis-meeting resources) which interacts with C (the definition the family makes of the event) to produce X (the crisis).

A more recent area of family stress theory highlights the complex role which certain family typologies play in buffering the impact of stressful life events (e.g., the birth of the disabled child) and in facilitating family adaptation following a crisis situation. For example, McCubbin &

McCubbin (1989) introduced the Typology Model of Family Adjustment and Adaptation. This model describes families at two related but discernible phases in their response to life changes and catastrophes. The first phase is the adjustment phase and the second is the adaptation phase. The model is based on a definition of the Family Type which suggests the profile of family functioning. According to these researchers, a family's "type" is a set of basic attributes about the family system which explains how that particular family system typically operates and/or behaves. These are predictable and discernible patterns of family behavior. Some examples of different family "type" are those that have been labelled as balanced, regenerative, resilient, rhythmic. For example, **balanced** families respond supportively to normal life transitions, and in the face of severe chronic illness, balanced families indicate more positive health outcomes for the chronically disabled child; the "regenerative" families (i.e., those with strengths of family hardiness and coherence) are better able to manage hardships and to promote other family strengths of bonding, flexibility, as well as marital and family satisfaction (McCubbin, Thompson, Pimer, & McCubbin, 1988.)

The Typology Model of Family Adjustment and Adaptation emphasizes that in crises situations, it is critical that professionals appraise the established pattern or typology of family functioning, because once the family "type" is understood, it can be improved upon and the family unit will be in a better position to manage its own recovery and adaptation to stressful and crisis situations (McCubbin & McCubbin, 1989 in Figley, 1989, p 9-11).

The parenting stress experienced in families who have a child with a disability is an area receiving considerable attention, and the research recognizes that parents of disabled children do

report high levels of stress (Scott, Sexton & Wood, 1986, Beckman, 1983; Boyce et al., 1991; Farber, 1959, Hanson & Hanline, 1990; Holroyd & McArthur, 1976), and higher levels of stress than do parents of children without disabilities in matched-group comparative studies (Dyson & Fewell, 1989; Kazak & Marvin, 1984). Although it appears that greater stress is present in those families with disabled children, studies thus far have not agreed on whether the cause of the stress is related to parental/family factors and /or to child factors. For example, in two comparative studies, one found that parental/family stress (i.e., the impact of parenting a disabled child on aspects of the parent's life such as - physical health, spousal relationship, relationships with others). was not different from matched-control groups (Dyson & Fewell, 1989). The other study found differences in parental/family stress among the groups (Kazak & Marvin, 1984). In both studies, child related stress (i.e., stress resulting from the parent's perception of what the disabled child brings to the parent-child relationship) was higher than in the matched-control group.

According to Beckman (1991), increased stress does not always lead to dysfunction in families. In order to explore this factor, Beckman investigated the variability in family experiences of stress. He found significant differences between fathers and mothers on the parent domain of the Parent Stress Index, with the mothers reporting more stress than did the fathers; those parents of children with disabilities reported more caregiving requirements and stress in all domains. In this particular study, stress was negatively associated with informal support for both parents and positively associated with increased caregiving requirements for mothers (p.585-6).

The parenting stress research, in general, is not clear on the influence of different types of disabilities or ages of children on parental stress. Birenbaum (1971) reported that the increased age of a severely or profoundly handicapped child is related to marital problems and tensions with spouse. Gallagher et al., (1983) have reviewed the stress literature and point out that stress often appears to increase with the age of the handicapped child, and is also based on the daily caregiving demands of the child. Zucman (1982) has also observed that as the disabled child gets older, the parents may experience increased social isolation. As the age of the child increases, the handicapped child can become more difficult to manage and the differences between the child and his or her peers can become more noticeable. These researchers (i.e., Gallagher et al., 1983; Zucman, 1982) have also pointed out that significant differences have been found in family stress based on the diagnostic category of the child. Holroyd and McArthur (1976) investigated this area of family stress and contrasted the amount of stress reported by parents of children with autism, children with Down's Syndrome, and children who were patients in an outpatient psychiatric clinic. They found that the families revealed different patterns of parental responses and that families of autistic children reported the most overall stress. Fewell and Gelb (1983) have emphasized that each disability type is characterized by a different "type" of stress.

Two more recent studies have found that the severity/type of disability, but not child age, have an impact on reported stress levels (Boyce et al., 1991; Hanson & Hanline, 1990). Boyce et al. (1991) obtained child and family stress data on the Parenting Stress Index (Abidin, 1990) from 479 families who had young children with disabilities. The variables that explained most of the parent-related stress variance were family resources, family life events, family cohesion,

family support, child ethnicity, and gender of child. Together, these variables explained 30% of the variance. For child-related stress, the best explanatory variables were severity/type of disability, family cohesion, family life events, mother's age, presence of a sibling with disabilities, and family resources. However, all the variables in the model explained only 19% of the variance in child-related stress. While these results are important in furthering an understanding of stress, they also demonstrate that the research findings are not always clear with regard to the causes of stress.

As previously noted, stress as a concept is difficult to assess because doing so involves not only the actual occurrence of events but, also the individuals' perceptions of these events. For example, Boyce and Barnett (1991) have demonstrated that more time spent in daily activities (a potential source of stress) for parents of a child with disabilities did not result in decreased satisfaction with the child (a possible result of more stress). With an awareness of this finding, Innocenti, Huh and Boyce (1992) warn, therefore, that items typically used to assess stress may not be valid for populations with disabilities. That is, these typical items may only be describing characteristics common to the population under study and may not be sensitive to the expected concomitant changes (e.g., less satisfaction with parenting, disturbed family relations, parent depression, etc.) that are indicators of possible stress. These researchers state, nonetheless, that "currently available instruments can still be used to measure stress and to facilitate intervention efforts" (p.425). However, they emphasize that "family measurement is not a well-developed area especially in dealing with nontypical populations." They also conclude there is "a continued need for the development of tests that accurately reflect the phenomena

being assessed (construct validity) for nontypical populations" (p.424-25).

Wikler (1986) has explored the "subjective" factor and has stressed that the subjective factor is elusive, because it is situated within the subjective realm of each family member...its inaccessibility to the researcher may account for the lack of attention it has been given in studies" (p. 186-188).

That is, according to Wikler, a single numerical value cannot indicate with absolute accuracy the extremely complex web of beliefs, attitudes, and morals that make up each individual's perception of the stressor. Such a number would only reflect one person's perspective and would not necessarily reveal the collective experience of the stressor within the family group. Each family copes with the stress in a different manner which is reflective of their "type". The details of a family's perception of the stressor, as individuals and as a group probably account for the differences in outcomes; that is, the family's perception of the stressor (i.e., the disabled child) may make the difference between families who decide to care for their child at home and those who choose, for example, to place their child in an institution or in foster care. And, it is important to realize that some research has also highlighted the parent and family's capacity for a *successful* adjustment to a disabled child (e.g., Widerstrom and Dudley-Marling, 1986; Saddler, Hillman and Benjamin, 1992).

Although no one would dispute the highly stressful effects on both mothers and fathers of learning that their child has a disability, some research has focused on understanding the similarities and differences between mothers and fathers in their perceptions of and responses to the experience of parenting a child with special needs. In the U.S.A., recent federal legislation

has added new incentives for the development of more precise knowledge about differences between families with and without a child with disabilities and about similarities and differences among family members of children with disabilities. PL 99 - 457, the 1986 Amendments to the Education for all Handicapped Children Act, mandates that early intervention programs for children with known or probable disabilities between the ages of birth and 3 years develop Individualized Family Service Plans. Programs are now responsible for evaluating the needs of the family as a whole, rather than focusing exclusively on those of the child in isolation from his or her most central environment (Krauss & Jacobs 1990). Given this family centred focus, it will be necessary for program developers to realize that the traditional nuclear family is comprised of four subsystems (i.e., marital, parental, sibling, extra familial), and to consider also the needs of both parents (as well as the siblings and other involved family members) as part of service planning (Krauss, 1993).

With regard to considering the needs of both parents, Krauss (1993) evaluated both the similarities and differences in child-related and parenting stress between mothers and fathers of 121 toddlers with disabilities. Krauss pointed out that "although the empirical literature is not extensive, there is some evidence that mothers and fathers have different perspectives on their experiences" (p.394). In the Krauss (1993) study, mothers and fathers reported similar levels of parenting-related stress overall, but had scores that are considered to be well below those which are clinically significant (Abidin, 1983). There were, however, revealing differences with respect to specific dimensions of parenting stress. Notably, these mothers reported more difficulty than did fathers in adjusting to the personal aspects of parenting and parenthood (parental health,

restrictions in role, and relations with spouse). However, there were no differences between parents in some of the more commonly investigated aspects of parenting a child with disabilities, such as social isolation, depression, or sense of competence. These findings are in contrast with those reported by Bristol et al. (1988), and Beckman (1991), who found mothers of children with disabilities to have higher depression scores than did fathers. However, the Krauss (1993) study utilized comparatively young children, a factor which may account for these findings because other research suggests higher levels of parental stress and depression associated with older children (e.g., Bristol & Schopler, 1984). Thus, it appears that further research is needed to clarify the onset of and durability of significant differences between mothers and fathers in such a central issue as parenting stress.

The Krauss (1993) study also reported that, in contrast to the patterns of similarity between mothers and fathers with respect to parenting stress, fathers reported more stress related to their child's temperament (e.g., child's mood and adaptability) and their relationship to the child (such as feelings of attachment and of being reinforced by the child). These findings are consistent with those reported by Beckman (1991), who found differences with respect to feelings of attachment between mothers and fathers. Thus, there is evidence that fathers of young children with disabilities experience trouble in the formation of emotional attachment to their children; additional research is needed in order to clarify its causes.

Furthermore, the Krauss (1993) study reinforces Wikler's (1986) observation in suggesting that the most powerful correlates and predictors of stress for both mothers and fathers were aspects either of the parents themselves (e.g., their appraisal of professionals' control



over their child's development), of their perceptions of the family environment (e.g., its adaptability and cohesion), or of their social support networks ( e.g., perceived helpfulness of networks). Moreover, the weight of these factors in the Krauss study differed between mothers and fathers.

Specifically, parenting stress among fathers was much more sensitive to the effects of the family environment. Twenty-six percent of the variance in paternal parenting stress scores was explained by the fathers' perceptions of the adaptability and cohesion within their families, compared to 10% of the variance in maternal parenting stress scores. One interesting and potentially significant factor was the finding that helpfulness of social support contributed an additional 3% of the variance to maternal parenting stress scores, whereas social support was not a significant contributor for fathers. Krauss (1993) suggests that mothers are more affected by their social support networks than are fathers. Fathers may turn inward, towards their families, whereas mothers turn outward, towards their social support networks, in the face of a "crisis" regarding their child's development. The benefits derived from these spheres clearly differ between mothers and fathers. Thus, it would seem that for early intervention professionals, greater awareness of the "agents" of assistance for parents - both mothers and fathers - of children served in their programs is critical to the development of responsive and effective service plans. (p.400-403).

Two major trends are evident from the growing body of stress research. Traditional investigators have envisioned that stressors result inevitably in pathology, whereas stress - resistance researchers have emphasized the capacity of individuals to remain healthy when

stressors occur, the latter premise suggests the adaptive value of effective coping strategies. In order to investigate these trends, the second variable to be considered in this paper is the characteristics of the coping strategies developed by families with disabled children.

Interest in the range of familial coping strategies in rehabilitation has been evident for at least 30 years. Wright (1960) stressed that parents are crucial figures in the eventual psychological fate of their children. According to this author, "Their most important contribution is family support, conveying to children in behavior and words that they are loved, respected and wanted" (p. 288). Saflios-Rothschild (1970) described studies in which family ties (i.e., marital status and numbers of dependents) were shown to be related to rate of recovery, resumption of family role, and rehabilitation (Deutch & Goldston, 1960; Gibson & Ludwig, 1968). She also examined studies that suggest that overprotective family ties can hinder rehabilitation (Litman, 1966).

Family norms and available resources (e.g. social support) influence health behavior and, as such can be viewed as "coping" behavior. Folkman and Lazarus (1985) stress that coping is a complex process and that the essence of stress, coping and subsequent adaptation is change. That is, the emotions experienced by the family members of a handicapped child may be characterized by flux. At first, family members may feel anxious, angry, or guilty, and then loving and joyful. The sequence of feelings reflects that changing meaning or significance of what is happening, as the encounter unfolds for the family. Coping behavior may involve initial avoidance or denial-like strategies to ward off the significance of an event; but coping may then involve a decision to deal head-on with a problem. Or, the family might cope by avoiding

contact with others, but a little later may seek emotional support from a friend. Indeed, stress implies a disturbed person-environment relationship that coping behavior is meant to change (p.149-150).

Medical sociologists Litman (1974) and Freidson (1960) have observed that a family's adjustment to and ability to cope with a member's chronic illness or disability have a significant impact on that member's motivation for recovery and rehabilitation. Furthermore, DiMatteo and DiNicola (1982) describe family support as a link in the intention-behavior chain, enhancing compliance with medical treatment, prescribed exercise, diet and fitness programs, home dialysis, use of orthotic appliances, and other preventive and rehabilitative regimens. In general, these researchers stress that overall family functioning, especially communication, role patterns, and problem solving are important mediators of adjustment for persons with long-term mental illness and substance abuse disorders.

In recent years, conceptual articles concerning family participation in rehabilitation have grown. As the numbers have increased, so has the consensus on the importance of family involvement in the rehabilitation process (Cook & Ferritor, 1985; Dew, Phillips, & Reiss, 1989; Gonzalez, Steinglass, & Reiss, 1987; Herbert, 1989; Kerosky, 1984).

The process of acquiring and allocating resources for meeting the demands inherent in the rehabilitation process is a critical aspect of family adjustment. Researchers realize that resources, both human and material, are limited. Resources must be allocated among multiple goals to meet the needs of the family and its members. For example, according to McCubbin and McCubbin (1989) the family should be seen as a resource exchange network, and these

researchers use their Typology Model to describe coping strategies as facilitating the exchange (p.24). In the context of the Typology Model, coping behavior is a specific effort (covert or overt) by which an individual (or a group of individuals such as the family) attempts to reduce a demand on the family system. Specific coping behaviors can be grouped together into patterns, such as coping behavior directed at "maintaining family integration and cooperation"; this latter behavior is one of the coping patterns that has emerged as important for families who have a chronically ill child. When coping is viewed in the context of multiple family demands (i.e., the pileup), it is useful to view coping as a generalized response rather than as situation specific. Family coping can be viewed as coordinated problem-solving behavior of the whole family system.

McCubbin and McCubbin (1989) state that "the function of coping is to maintain or restore the balance between demands and resources" (p.25). They identify four ways this function can be accomplished within the family system:

- (I) coping can involve direct action to reduce the number and/or intensity of demands.
- (ii) coping can involve direct action to acquire additional resources not already available to the family.
- (iii) coping can involve management of the tension associated with ongoing strains associated with stress.
- (iv) coping can involve appraisal to change the meaning of a situation to make it more manageable. This strategy for coping

interacts very directly with what has been labelled "perceptions"

in the Typology Model, (and in the research by Wikler, 1986).

Coping may be directed at changing the individual's or family's view of demands placed by the stressors such as reducing role strain by lowering performance expectations; or, it may be directed at resources (e.g., seeing oneself or the family as capable and competent). Maintaining an optimistic outlook and an acceptance that this is the best the family can do under the circumstances are other appraisal coping strategies (McCubbin & McCubbin, 1989 p.24-25). Some researchers have evaluated families' use of utilitarian resources as a coping strategy. For example, Friedrich, Wiltner and Cohen (1985) operationalized, in their research study, such family resources as family income and parental education. They found that more highly educated individuals have higher incomes and greater utilitarian resources (which can be viewed as coping resources) then might be enjoyed by less educated, less well-off families.

There are a number of factors that have provoked a renewed interest in the critical role played by families in the rehabilitation process. Independent living, advocacy, and empowerment movements encourage interdependence and partnerships between professionals and consumers, families, and significant others. Recent health care crises brought about by AIDS, Alzheimer's disease, cocaine babies, (addicted) traumatic brain and spinal cord injuries, and an aging population functionally limited because of chronic illness have refocused attention on implications of the impact of disability on both individuals and families or significant others (Jennings, Callahan, & Caplan, 1988).

Social support is related to health and perceived quality of life (Sarason, Sarason, &

Pierce, 1990), and can be viewed as a coping mechanism. Longitudinal and retrospective field studies and laboratory experiments with both animals and people offer evidence that supportive social relationships can promote human health and well-being, reduce exposure to stress, and buffer the impact of stress or other hazards on health (Berkman & Syme, 1979; Cassell, 1976; House, 1981). To be truly effective, the social support received must match the individual's perceived need for it. Furthermore, social support can include the family as a source of support (Seligman & Darling, 1989 p.18).

A family's coping strategies are important factors that can influence an individual's adjustment to disability. For example, the four studies about to be considered emphasize the interdependent nature of this adjustment process and demonstrate that family support can have a direct bearing on the behavior of persons (albeit adults in these particular studies) with blindness, spinal cord injuries, and cardiac impairments.

Morrison (1982) and Schulz (1980) found that an individual's adjustment to loss of sight is closely related to the attitudes, behaviors and perceptions of his or her family. Similar findings were reported by Vargo (1983), who investigated spousal adaptation to men with spinal cord injuries. Vargo noted the lack of attention to nondisabled family members during medical rehabilitation. Problems observed in spouses included feelings of emotional isolation, helplessness and frustration, depression, worry and disturbed sleep, financial problems, and feelings of being trapped by the situation. Vargo reported that the impact of the presence of an adequate, functional support system was the single most influential and important factor in the adjustment of wives. Early interaction with partners of persons with spinal cord injuries was

deemed an essential factor in rehabilitation counselling.

Requesting information about an illness and its treatment is a coping strategy used frequently by family members with both disabled children and adults. For example, Burgess et al. (1987) conducted a study in which this form of coping strategy was found to be a major influence in rehabilitation. Findings revealed that when families were provided with relevant information and support from medical staff, the patients with cardiac disease were significantly less stressed and less dependent during the rehabilitation period. Studies about family support in developmental disabilities suggest the importance of parental adjustment to the disabled child. For example, Bristol, Schopler, and McConnaughey (1984) report that a single parent may be more likely to be the head of a family with children with disabilities. However, although Kazak & Marvin, (1984) have noted a higher stress level in families with a disabled child, they did not find significant differences in divorce rate or marital satisfaction.

Other research has suggested that single parents of disabled children may not provide sufficient environmental stimulation and may resort to institutionalization of the disabled family member (Appel & Tisdall, 1988). Bristol (1987) referred to the need for longitudinal studies in order to develop clear pictures of family adaptation to disabled children. Furthermore, this researcher pointed to the need to investigate whether single parents of nondisabled children are more or less likely to receive support in the form of child care assistance.

Parents of children with disabilities have reported severe symptoms of anxiety and depression because of taxed financial resources, the requirements of physical care, and social isolation. For example, Rosenberg (1977) and Rabkin and Streuning (1976) found that lower

class families experience more stress, and hence more "burden" than do more affluent families. Reisinger, Ora and Frangia (1976) reported that the ability of parents to adapt to a "change agent" role with their handicapped child is related to socioeconomic class. Singer, Irvin, Irvin, Hawkins, and Cooley (1989) evaluated the role of social support services in alleviating parental depressions and anxiety. A group of 49 parents of children with moderate to severe disabilities, ages 3 to 14 years, from an urban area were randomly assigned to intensive or less intensive support interventions. Those in the former group received case management and respite care services plus assistance from community volunteers as well as 16 weekly classes in coping skills. Four types of measures were used in evaluation of the benefits of support services—descriptive, outcome, process, and social validation. Mothers who received a combination of services in coping strategies (i.e., behavioral parent training and stress management training) showed less anxiety and depression. These benefits continued to be evident at a 1-year follow-up.

According to Holahan and Moos (1990) in an investigation of effective coping skills, exposure to stress may result in maladaptive outcomes and negative affect, but the exposure can also broaden a person's perspective on life, and in particular, may encourage resilience in the development of new coping skills and thus may lead eventually to positive psychosocial growth. Resilience has been conceptualized as developing from an effective confrontation with stressful experiences through adaptive emotional and behavioral coping.

Although the stress literature has reported parents' negative responses and maladaptive behaviors (Burden & Thomas, 1986), other studies of resources and coping behaviors have suggested a the family's capacity for successful adjustment and growth (Darling, 1988; Rodger,



1987; Trivette, Dunst, Deal, Hamer & Propst, 1990; Widerstrom & Dudley-Marling, 1986). Margalit and Ankonina (1991) investigated the role of stress-resistance resources that predict healthy outcomes among parents with disabled children, with a focus on identifying factors that predict positive and negative affect. Affect has often been related in the literature to stressful events and has been investigated as a single measure characterized by depressive moods, and anxiety (Clark & Watson, 1988). Research highlighting the 2-factor construct of positive and negative affect has demonstrated that negative affect is equally important for understanding mental health and well-being in general (Clark & Watson, 1988), and the way we process and interpret social episodes or encounters in particular (Forgas, Bower & Krantz, 1984).

Positive affect as a coping strategy is an exciting concept in that it reflects the extent to which a person feels a "zest for life." More than simply not becoming distressed, positive affect requires an active and enthusiastic involvement in day-to-day living. High positive affect is defined by words such as "excited", "strong" and "elated", expressing energy and pleasurable engagement, whereas high negative affect represents the extent to which a person feels upset or unpleasantly aroused, distressed, nervous, guilty or tense (Clark & Watson, 1988, Diener & Emmons, 1984).

Separate assessments of positive and negative affect reveal different reactions to pleasant and unpleasant events. For example, positive affect can be related to the occurrence of pleasant events, while negative affect can be associated with physical complaints, health problems and anxiety (Clark & Watson, 1988). Mood states have been found to bias peoples' perceptions by selectively influencing what they learn about others and by distorting interpretations and

association (Forgas & Bower, 1987). Margalit & Ankonina (1991) reported that parents of disabled children have higher levels of negative (distressed) affect, adopted more avoidant coping strategies, and differed in their familial interrelations and the opportunities for personal growth available to them in their families. The discrepancies between the fathers' and mothers' scores in avoidant coping and in the family climate areas of personal growth were greater among the parents of disabled children than among the control parents. A positive affect was closely related to more favorable interpersonal impressions and had a pronounced positive effect on perception, judgement and memory.

Coping may be defined as the behaviors and cognitions which an individual uses in order to evaluate and buffer the effects of raising a disabled child (Folkman & Lazarus, 1985). Individual coping style has been conceptualized by Moor, Cronkite, Billings, and Finney (1987) to include active coping methods (i.e. approach coping, information seeking and problem solving) as well as avoidance coping (i.e. efforts to deny, minimize, or escape the stressful situation). Holohan and Moos (1985; 1987) also have shown that more active coping strategies are related to adaptation, whereas avoidance coping strategies are related to psychological distress. Holahan and Moos (1985), found that among individuals experiencing a high level of stressors, those who adapted to stressors without experiencing physical or emotional distress were less likely to rely on avoidant coping responses.

According to these researchers (Holohan & Moos, 1990), "the family environment constitutes one of the primary social resources mediating stress and is linked to adaptive coping functioning in stressful situations" (p.291). Research on family climate has shown that families

characterized by supportive relationships and a greater emphasis on personal growth report fewer complaints of emotional distress among the family members. Research which has examined strengths of families with disabled children has found that adaptive functioning is closely related to marital bonding. Parents' coping efforts have been found to be more effective if their respective strategies are either parallel or complementary (Schilling, Schenke & Kirkham, 1985).

Friedrich (1979) has also acknowledged that a key element in an effective family response to a handicapped member appears to be the functioning of the parental subsystem. Marital satisfaction seems to be a predictor of positive family coping with the stressors associated with family care of a disabled child (Friedrich, 1979). There has been evidence that families with positive adjustment during the early years of a handicapped child do tend to contain highly cohesive marital partners (Trute & Hauch, 1988). Trute's research (1990) aimed at examining directly the importance of marital adjustment as a key predictor of family functioning in households containing young, disabled children. Trute found that overall family functioning has little to do with specific characteristics of a disabled child during the first years that a disabled child is in the family. The child's sex, level of disability, and temperament attributes do not appear to be directly related to family adjustment. In Trute's study, families containing disabled children are not found to be any more distressed or disorganized than other families. Trute concludes that the strengthening of the parental subsystem should be the primary concern of those professionals who wish to assist the family to maintain a stable home for their disabled child or children. The cohesiveness and closeness of the couple should be recognized as a coping

resource and as a key element in family adjustment (Trute, 1990).

Researchers have long recognized that measurement of both the coping resources and the stress experienced by families with disabled children is a difficult task. The Questionnaire on Resources and Stress (QRS, Holroyd, 1974) was originally designed to answer this need, but the length and psychometric weaknesses of this instrument have interfered with more widespread usage. With an awareness of the shortcomings of this instrument (i.e., the QRS), Friedrich, Greenberg, and Crnic (1983) collected and item analyzed data from 289 QRS; 52 items emerged as most reliable, forming a short form of the QRS. These items were then factor analyzed, and four distinct factors were found: Parent and Family Problems, Pessimism, Child Characteristics, and Physical Incapacitation. The correlation between the total scores of the QRS and the shortened form was .997.

The coping resources of parents with disabled children were also examined by Friedrich, Wilturner and Cohen (1985). The four broad dimensions of coping resources assessed were utilitarian resources, energy/morale, general and specific beliefs, and social support. The dimensions were related to a measure of the adequacy of parental coping ( i.e., Questionnaire on Resources and Stress -- (Friedrich Factor 1) -- Parent and Family Problems). A measure of marital satisfaction again was a significant predictor of the overall ability of the parents to cope with the stress of care of the disabled child (its importance was underscored in the follow-up analyses where it was the single best predictor of change in the quality of outcome over time). Other significant variables were maternal depression, and the quality of the family social climate. Child variables, such as behavior problems and medical problems were also related to greater

parent/family problems. This study is important for developing an awareness of the complexity and interrelatedness of the variables being measured. Furthermore, these researchers stressed that the relation between a child with a behavior problem and a depressed mother in an unhappy marriage is clearly multidirectional; this study's findings underscore the importance of the individual's ability to cope, particularly by means of support from spouse, and a supportive family context.

Social support has a demonstrated buffering effect (Johnson & Sarason, (1978); i.e., high stress families with high social support cope better than do similarly stressed families with low social support, and low-stress families do equally well with or without peer social support. The relationship is interactive in that better copers presumably have more social support, and more social support facilitates coping. That is, mothers who are depressed and who do not feel support in their marriage or from their friends are going to be less able to reinforce appropriate behavior in their disabled children, than are mothers who are not depressed and who are involved in several supportive relationships. Acting-out children are definitely going to affect their mothers' sense of overall well-being and make it harder for mothers to invest emotional energy in the marriage and family. Thus, it is apparent that child and parental variables interact in a multiple, correlated fashion. Significantly, it also suggests that "simple" interventions that target only one of the coping resources, or the child's behavior may not be as effective as interventions having multiple foci.

In a study referred to previously, in this discussion, Trute and Hauch (1988) examined the social support network attributes of families who had coped well with the birth of a

developmentally disabled child. As survey data from this study were reviewed, recurring "coping" themes in the successful families' human networks emerged. The size of these human networks tended to be small. This finding was consistent with previous research which argues that home care of a disabled child involves at least some degree of social isolation on the part of the principal caregivers. In this study (i.e., Trute and Hauch) successful families' networks were not only typically small, but also were abundant in support provision. Mothers' mean total network density was high, not an unusual finding in families providing sole care for handicapped children. The second, identifying feature of successful families in this study was unusually high spousal boundary density in both total and family networks. This study finding indicates that the parents tended to maintain largely mutual contacts and shared relationships with others. The researchers interpret this finding as reflecting a high level of cohesion in the spousal sub-system and a commitment among parents, in the successfully adjusted families, to function as a team both in instrumental tasks and social relationships. As a result of this finding, the study concludes with the caution that the target of care must extend beyond the child, the parental system, and even the family unit, to include the social environment in which the family system is embedded.

It has been found that mothers and fathers do show differences in the amount and type of stress they experience. Research has been directed at examining help-seeking preferences (i.e., the coping behavior) of parents of disabled children. Nadler, Lewinstein and Rahav (1991) investigated differences in help seeking behavior in an equal number of fathers and mothers (n=25) of mentally retarded children. These researchers point out that help seeking has implications for the person's ego. That is, the reluctance to seek help has often been viewed as

an attempt to avoid the self-threat associated with the admission of inferiority and dependency that may be implied by a request for help (Gross & McMullen, 1983). A key determinant of the help-seeking behavior is the degree to which the need for help reflects an ego-central deficiency. In the same way that physical handicap constitutes a personal disability, mental retardation of a child may give rise to a sense of deficiency for the parent (Wolfensberger & Menoloscina, 1970). Still, some parents may have a higher level of acceptance of physical disability than do other parents. These parents would regard their families as "normal" units that participate in regular family activities and have a retarded child. For families who have not accepted their child's retardation, the child's disability is at the centre of the family's "self-concept." For these families, the child's disability is central to their identity. Thus, the disabled child's retardation is not equally central for all families and appears to be dependent on the parents' acceptance of the child's retardation.

Nadler, Lewinstein and Rahav (1991) have developed an Acceptance of Retardation Scale on which parents' scores are related to their expressed willingness to seek help. The research findings portray a complex set of interrelated variables. A separate examination of mothers and fathers' responses revealed intriguing differences. For fathers, a positive relation between self-help and seeking outside help indicates that those individuals who prefer helping themselves also show a high level of willingness to seek outside help. An opposite finding was obtained for mothers. Mothers who show high willingness to help themselves prefer not to approach external sources of help. These differences may reflect different meanings attached by mothers and fathers to needing help in this particular context.

Because caring for the child is often the mothers's responsibility, the difficulties in this domain may be more central to her self-concept. Because of the apparent greater self-threat, mothers prefer to solve the problems on their own rather than seek outside help more than did fathers. The more fathers were willing to attempt self-help to solve the problem, the more they were also willing to approach external sources of help. For them, seeking help seemed to be no different from other coping efforts such as self-help, and was not associated with ego consideration which often inhibit the seeking of help. Thus, fathers seemed willing to seek help from an "instrumental" perspective, whereas mothers adopted an "ego" perspective. Consequently, help-seeking for mothers is affected by ego considerations. Help seeking is attempted only when coping by relying on self is seen as inadequate. The patterns in the data in this study suggest that the ego relevant orientation (i.e., viewing the seeking of help as bearing negatively on one's view of oneself) is characteristic of mothers, whereas the instrumental orientation (i.e., viewing the seeking of external assistance as a coping behavior that does not reflect negatively on one's view of self as an able person) is characteristic of fathers. The relatively greater ego-centrality of child-related problems for mothers is offered as the reason for these different orientations, suggesting that it is possible that in domains that are defined as more ego-central for fathers (e.g., financial problems), the opposite pattern will be observed.

Adaptive familial coping strategies have been evaluated in the research of Beavers, Hampson, Hulgus and Beavers (1986). In their study, a complex set of interrelated variables emerged which highlighted the contrasts between higher and lower functioning families. For example, the most adaptive qualities of families with handicapped children were high levels of



conflict resolution, congruent mythology, and individual responsibility. Given the pervasive uncertainty about the disabled child (what he or she is capable of, how and how much can we as a family be helped), the capable family uses more than one approach. The perceived "set-apartness" of these families seems to increase their awareness of how they function. Family members were more conscious of how they interact and scored high on "responsibility" items, a finding which suggests that when one family member is disabled, the other family members are clear about goals and responsibilities.

This study also emphasizes the necessity for a cohesive, effective parental coalition. For example, in the high functioning families, (with and without disabled children) the coalition was equal in power; in the adequate, midrange and least capable families, one parent tended to be more capable and more involved with the handicapped child than the other parent. The degree to which the family is organized around the handicapped child emerged as a measure of family adaptation. Families who acknowledge the extra needs and the "differentness" of the disabled member, while giving other family members' needs and views equal weight, were the most competent; and in these families (i.e., the "competent" families) there appeared to be a more conscious awareness of, and effort to balance the special needs of the handicapped child with other family concerns. A related observation was that the availability of outside supports and activities helped families to adapt. Higher functioning families respected different views and were able to use more than one approach. With a strong cohesive parental coalition, they were able to select and develop areas of strength, to capitalize on the individual responsibilities of family members, and to experience collective pride in being a good family for the disabled

member.

Coping strategies have also been explored by Sloper, Knussen, Turner and Cunningham (1991). The Ways of Coping Questionnaire (Folkman & Lazarus, 1985) was adapted in order to measure the ways in which parents coped with problems concerning the children with Down's syndrome. Responses from mothers and fathers were pooled and five factors were obtained and designated as: (1) practical coping, (2) wishful thinking; (3) stoicism; (4) seeking emotional social support and, (5) passive acceptance. The findings suggest that coping strategies have an impact on mothers' reactions to potential stressors, and that research should include measurement of coping strategies in any studies of family functioning.

Some researchers have investigated the role of mothers' employment as a coping device for mothers of disabled children. For example, Baruch, Biener and Barnett (1987) argue that evidence is now accumulating that the data do not support the view that employed women will necessarily experience an increase in stress-related illness. In fact, they stress that studies comparing the physical or mental health of employed versus nonemployed women find employed women to be advantaged. Similarly, Gottlieb's (1997) research found that "generally" multiple roles have been associated with greater well-being for mothers of disabled children. Barnett (1982) also found that multiple roles may predict a greater sense of competence, overall effectiveness and well-being for women, if the roles are balanced, without role conflict or role overload. Wikler (1986) referred to the "buffering" effect of certain variables which have been identified as instrumental in mediating stress; mothers' employment could be viewed as a family resource and, as such, could be viewed as a "coping" strategy for mothers in order to deal with

stress. Sloper et al. (1991) researched the coping strategies of families with disabled children and point out that mothers' employment represents "a social resource for mothers, giving mothers...roles and interests outside the family, with a concomitant greater independence" (p.669). That is, mothers' employment, as an effective coping strategy, may be related to higher satisfaction with life.

The third variable to be considered in this review is the use of respite care by families of handicapped children. Due to the perceived burden experienced by at least some families with children who are handicapped, the use and availability of respite services are often identified as priorities (Cohen, 1982; McGee, Smith, & Kenney, 1982; Seltzer & Krauss, 1984; Intagliata, 1986, Upshur, 1982). Respite care has been defined as the provision of temporary relief of burden to the families of developmentally disabled children living at home (Upshur, 1982). Respite service in general and respite care in particular are both viewed as important sources of social support for families parenting a child with a disability.

Respite care is seen as one of a variety of community programs and services that could become part of individualized treatment plans for disabled children and adults. Where families with normal children may have a range of babysitting and day care options in most communities, the behavioral and medical problems of the developmentally disabled child, prevent families from being able to leave them at all (Upshur, 1978, Intagliata, 1986). The mental and physical burden for a family in order to provide constant care for a disabled person, sometimes for an entire lifetime, continues to be a major factor in support of maintaining traditional institutional settings (Townsend & Flanagan, 1976).

Studies have been conducted to identify the merits of different program models for providing respite care services. For example, Upshur (1982) evaluated ten different models for providing respite care, one of which was a summer campership program. The program allowed disabled children daytime or overnight camp experiences. The study indicated that families require, and respite care programs can provide for a range of needs, from simple relief from burden time, to help in a family emergency. It also pointed out that although one might assume that the demand for respite services could become overwhelming once families become aware of the service, agencies have reported an apparent reluctance on the part of the parents to leave their disabled children with strangers. Families also expressed a sense of guilt for using the service for relief, for vacations or personal needs, rather than only in extreme emergencies.

With a view to considering the apparent ambivalence of some families who would be considered candidates for respite care, Salisbury (1990) examined characteristics of users and nonusers of respite care. Salisbury states that although proponents of respite care suggest that the service will be heavily used by families, and that the service is capable of reducing stress, improving family relationships, reducing social isolation, improving individual well-being, and reducing the likelihood of out-of-home placement (Intagliata, 1986), evidence to support all of the foregoing assumptions is lacking. For example, Intagliata (1986) analyzed available outcome research on respite care and concluded that the results of available studies are generally weak, their designs flawed, and their treatment of important issues inadequate (p.284). Cohen (1982) suggests that although respite care is often requested by parents, and in the eyes of professionals, is a necessary resource for families, it is apparent that the issue is very complex and that a number

of individual, child, family and contextual variables will play key roles in determining the extent to which parents will actually use the service.

The research of Salisbury (1990) is notable because in this study despite financial subsidies, competently trained providers, high need and an expressed interest, only 30% of the mothers in the study actually used the service. That is, there was a marked discrepancy between professed level of interest and actual utilization. Salisbury pointed out that a direct link between agency staff, provider and parent at some point in the intake process is necessary in order to enhance service utilization. Obviously then, any study of the value of a particular respite service for relief of burden should consider the many potential variables which are related to actual service utilization.

In a study of the effects of respite care on mothers of school-age children with severe disabilities, Botuck and Winsberg (1991) acknowledged the contradictions in the literature regarding the value of respite care for reducing burden, and conducted a study in which the immediate and short-term effects of a preplanned, 10-day overnight respite on 14 mothers were evaluated. In this particular study, changes in maternal mood, well-being and activity patterns were measured before, during and after respite. Their findings indicate that during respite, mothers experienced increased feelings of well being and less depressed mood. Accompanying changes in activity patterns were also found. After respite, the increased feelings of well-being continued and there was a strong tendency for mothers to be less depressed. Thus, in this study the beneficial consequences of respite persisted for at least 3 to 4 days after the disabled child's return. Cohen (1982) suggested that providing respite allows "a revitalization to occur and

inspires a fresh outlook for the continued care of the dependent member" (p.10).

Parents have often expressed an interest in normalization for their disabled children (as described by Wolfensberger, 1972); Galloway and Chandler (1979) have emphasized that the best and most effective respite services should be integrated, continuous and normalized. They have argued that integrated respite services will influence how the handicapped child will be perceived by others.

The fourth variable to be considered in this review is parental versus professional views of the needs of families with a handicapped child. Researchers have often conceptualized the experience of the birth of a handicapped child into a family system from a very negative perspective. In this perspective, parents are seen as suffering "chronic sorrow" (Olshansky, 1962; Wikler, Wasow, & Hatfield, 1981) and as facing ongoing child care circumstances which have been described as "grim and almost unbearably complex" (Berger & Foster, 1976). This negative perspective focuses on the deficits associated with family member responses to the disabled child and corroborates the prevailing view maintained by professional caregivers (e.g., Longo & Bond, 1984). Marital discord and family instability are often seen as "inevitable consequences" of having a developmentally disabled child. Although this negative stereotype is widely held by human service professionals serving disabled children and their families, research evidence to reinforce the negative viewpoint is inconclusive (Darling, 1979; Kazak, 1986).

In an attempt to present a model for counselling families of young handicapped children, Sloper and Turner (1991) argue that the process that parents go through following the birth of a handicapped child is akin to bereavement following loss. They warn that professionals in a wide

range of disciplines should be sensitive to the grief that parents are experiencing. These authors draw on Le Poidevin's theory of adjustment to loss to structure their own theories and to devise a checklist to assist other professionals. These researchers counsel that adjustment to having a handicapped child should involve the approaches used in bereavement counselling in order that parents work through the pain of their loss.

In conjunction with this view of the supposed negative impact of the handicapped child on the family, it is interesting to review the research of Sloper and Turner (1991). One of the purposes of their study was to examine both parents' and paediatricians' views of the prevalence of needs for help in a number of different areas related to child and family functioning.

Paediatricians estimated the percentage of families who would need help in each area; parents also described their own needs. When the estimates were compared, it was found that paediatricians tended to overestimate the negative impact of the child on the family and the parents' needs for help in teaching the child. The results of this study have a number of implications for practice. Professionals' potentially negative views of the impact of the disabled child on the family and of parents' coping abilities may, in some instances, impede the process of communication between parents and professionals and the provision of services appropriate to parental need. They conclude that in such situations, the important elements of the parent-professional partnership, such as the acknowledgement of the parents' expert knowledge of their own child and current life situation and their right to select appropriate services, are less likely to be observed. Thus, in some cases professional contacts may exacerbate rather than moderate stress.

The sources of differences between parents and professionals and the ensuing misunderstandings are discussed by Darling (1988). Such sources include professionals' lack of informal contact with children with disabilities; the socialization of professionals in a society which views disability as stigma; the medical model of training and practice which emphasizes curing; and the tradition of professional dominance in which the professional assumes power and control in the relationship with the client.

The continued existence of differences in views between parents and professionals is discussed in research by Nelson, Ruch, Jackson, Bloom and Part (1992). This exploratory study examined the family environment of ten families, each with a physically disabled adolescent, and at least one non-disabled adolescent. Family members completed the Moos Family Environment Scale (FES) and discussed with the interviewer their experiences as a family. Blind and independent rating on the FES by social workers involved in the study provided a comparison with the families' self ratings. Family ratings on the FES gave no indication of distress, but showed slightly higher than average emphasis on cohesion and achievement orientation. The social work ratings, in contrast, indicated elevated levels of conflict, and control. The study warns of the danger of assuming the prevalent negative and dysfunctional view of families with disabled children and adolescents. Families who see no problems in their internal environment and who value their sense of cohesion will not readily accept interventions which focus on changing the family dynamics.

Finally, one cannot assume that professionals have a right to intervene in families simply because those families have a disabled child. One parent has written:



No one ever seemed to examine professionals' reactions ... *parents* are turned into patients and are endlessly analyzed, scrutinized, and finally packaged into neat stages as if they were one-celled animals going through mitosis .... Although parents and people with disabilities do have obligations and responsibilities, they must not be victimized by their status. (Pieper in Darling & Darling, 1982, p.viii)

Parents must be active participants in determining what kinds of help they need and how much help is needed.

In addition to the forgoing admonition that parents of disabled children must not be victimized by their status, therapeutic interventions with families of disabled children should consider the response to the child by the other siblings in the family. Wilson, Blacher and Baker (1989) studied 24 children, ages 9 to 13, with regard to life with their younger disabled siblings who had severe handicaps. In contrast to the prevailing negative stereotypical view of life with a disabled family member, this study presented a multi-faceted view of family life with a younger disabled sibling. Although the children did not gloss over the hardships engendered by their brother or sister's disability, for the most part positive responses predominated. Pleasure in their ability to amuse and care for the sibling and a strong sense of family solidarity were common themes. These positive findings are consistent with comparisons of sibling dyads that have suggested that children are "kinder" in their interactions with a brother or sister who has a disability than with another sibling (Wilson, Blacher and Baker, 1989). As a group, the siblings described a high level of day-to-day involvement with the handicapped child, accompanied by feelings of responsibility for his or her welfare. There was a striking consistency in their

familiarity with the child's schooling, respite care and home management.

Characteristics of the sibling with handicaps did little to explain the variance among the respondents in this study. One factor, the degree of similarity between the sibling and the child with handicaps, appeared to have an impact opposite to that predicted by some authorities. Kaplan (1977) cited fear of being like the child with handicaps as central to the sibling experience; however, almost none of these siblings admitted to concerns about being like their brother or sister. Children who were the same sex and relatively close in age to the child with mental retardation reported more positive impact. In light of their siblings' pervasive cognitive and physical disabilities, establishing a sense of connectedness might have been a more salient task than differentiation. The children's overall success in this endeavour, with or without the apparently facilitative effects of shared gender and close age spacing, is perhaps the most impressive finding in this study.

In keeping with a more positive view of family experience with a handicapped child, the fifth and final variable to be reviewed is the Empowered Family (EFM) Model, which has been designed for families with a disabled member, and which adopts a positive approach meant to enable families to become empowered, not dependent. It is opposed to therapeutic strategies involving professionals who paternalistically intervene to "rescue" the family and impart skills, knowledge and resources to the family (McCallion & Toseland, 1993). The inevitable byproduct of such paternalistic interventions is that the family surrenders control and autonomy to the professional, an act which reinforces feelings of helplessness, hopelessness, and alienation. The family is thus not prepared to deal with subsequent stressful events. However, many families

with disabled children are not hopeless and helpless, and such surrender of personal authority and autonomy is unnecessary. The EFM is a short-term intervention using a five-step framework involving: (i) understanding the family's experience; (ii) developing a collaborative alliance between family and practitioner; (iii) choosing a specific problem to address; (iv) developing a plan of action; (v) improving coping skills for the future. This model uses a positive and helping orientation that enables and empowers rather than assists families; families make decisions based upon their own values and skills for identifying natural supports to remedy problem situations.

The complexity of the issues involved in assessing the nature and characteristics of the burden borne by families with disabled children should be apparent from the foregoing literature review. This review began by considering the types of stressors experienced by families with disabled children, while simultaneously acknowledging that for many families, the care of a disabled child is not, in fact, considered to be a "stressor". Furthermore, the complex role which certain family typologies can play in buffering the potential stress due to the negative impact of the birth of a disabled child was also considered because once the family "type" is defined and understood, the family unit will be in a better position to manage its own recovery and adaptation to stressful and crisis situations. However, the stress research has also found that increased stress does not always lead to dysfunction in families; furthermore, two major trends in the body of stress research have become evident. That is, while traditional investigators have assumed that stressors inevitably result in pathology, stress resistance researchers now emphasize the resilience and capacity of individuals to remain healthy in spite of the onset of stressors. The adaptive value of effective familial coping strategies in order to deal with stress was also considered. For

example, family resources (e.g., social support) can be viewed as "coping" behavior, and familial coping can in turn, be viewed as coordinated problem-solving behavior engaged in by the whole family system; a review of the literature suggests that all of the family's coping strategies are important factors that can influence an individual's adjustment to disability. The literature review of the quality and type of respite care used by families of handicapped children emphasizes the apparent ambivalence of some families who would be considered likely candidates for respite care and suggests the many potential variables which must be related to actual service utilization. That is, there are numerous contradictions in the literature regarding the value of respite care for reducing burden. Furthermore, there are also contradictions in the literature regarding parental versus professional views of the *needs* of families with a handicapped child. For example, families who perceive no problems in their internal family environment and who value their sense of cohesion will *not* readily accept interventions which focus on changing the family dynamics.

This literature review has also considered a more positive view of family experiences with a handicapped child in investigating the Empowered Family Model (EFM) a model which adopts a positive approach by which families are enabled to become empowered, rather than dependent. A significant portion of the literature is now focused on the need to promote a positive attitude toward life with a disabled family member. The literature review has also revealed that a child's disability has a potential impact on all members of the family system; these family members, in turn, play the most important role in shaping the disabled child's future. In review then, childhood disability as a source of potential burden for the family system has been considered from the perspectives of current stress research; coping strategies for dealing with stress; the use

of respite care by families of disabled children; the dichotomy between parental and professional views of the needs of families with disabled children and, finally, from the standpoint of the most positive approach to life with a disabled child which is embodied in the empowerment of families with disabled children in order to alleviate any potential experience of burden.

In the following study, the nature and characteristics of burden and the concomitant use of respite care to relieve burden are explored in a population of families with disabled children in attendance at Children's Special Services Summer Program in Winnipeg, Manitoba.

## Chapter Three

### **METHOD AND RESULTS**

#### **The Project**

The project was a collaborative effort between the University of Manitoba and Children's Special Services of the Manitoba Department of Family Services. At the beginning of the project, representatives from both groups formed an evaluation consultation team. The team included representation from Children's Special Services, the Respite Coordinator, a Family Services Worker, and the Program Director, Mr. Richard Asselin. Other members of the consultation team were advisor Dr. B. Trute, and fellow M.S.W. student Nora Cristall.

The initial objective of the team was to develop a study plan to evaluate the Children's Special Services Summer Program; the Burden Study was developed as an adjunct to this initial study plan. The team assisted the two social work students in the questionnaire construction and plan for study implementation.

#### **Subjects: Selecting the Families**

At the outset of the project, and after several meetings with the members of a consultation team, Children's Special Services provided a complete list of the 1994 summer program participants (n=226). The following probability sampling strategy was followed in order to make a random selection of subjects:

(I) To achieve a homogeneous population, the first step was to exclude the preschool

children from the sampling frame ( $n=11$ ).

(ii) To establish the elements that would constitute the survey population from which the analysis would ultimately proceed, it was decided to create a stratified sample, and sample to group size, (i.e., a sampling ratio of 1:4), with a 25% representation of children, ages six to twelve years, and a 25% representation of children, ages thirteen to seventeen years. It was also decided that the age category would be established using the age of the child as of August 1, 1994.

(iii) To create each stratum of the sampling frame, the names of the eligible children were selected by means of a random numbers table. Of the eligible group of 136 children ages 6 to 12 years, 34 children made up this stratum of the study sample; of the eligible group of 68 children ages 13 to 17 years, 17 children made up this stratum of the study sample. Fifty-one children were thus selected to become the study sample. Subsequent to this initial selection procedure, the sample was reduced further because one family could not be located, and eight families were excluded because they had participated in individualized summer program activities; furthermore, eight families then declined to participate in the study so that the final number of subjects who completed questionnaires was thirty-four. Given that the eligible sample was  $n=42$ , the above sample represents 81% of the total eligible sample.

### **Creating the Sample of Workers**

After the formation of an evaluation consultation team, the Respite Coordinator provided the team with a list of the 1994 summer program participants. After the study

sample was selected, the MSW students were both provided with the names of the specific Family Services workers whose caseloads included those families who were to be included in the study. Each Family Services worker was responsible for several families from the study sample. After the initial seven organizational meetings of the consultation team, there was ongoing contact with Family Services regarding the study; furthermore, each of the two MSW students was in contact with the individual Family Services workers who were responsible for the study families.

### **PROCEDURE FOR DATA COLLECTION**

After final approval from the Human Subjects Committee, Family Services Workers were provided with a list of children in the study sample. The workers sent out the letter introducing the study (Appendix 3) to families on their caseloads. The workers then contacted the families by telephone for verbal consent to provide their names to the study interviewers. Once verbal consent was given, the families' names and phone numbers were provided and families were contacted to make arrangements to have parents sign the Letter of Consent (Appendix 4), and to drop off the Parent Survey Questionnaires (Appendix 5). The questionnaires were left with the families for seven days. The consultation team agreed that the MSW students would distribute the questionnaires by dropping them off and then picking them up at the individual family homes.

A pilot involving three families was then launched. These parents provided complete information and expressed their impressions that the questionnaire was easy to understand and they were able to complete the questions without difficulty and without an



interviewer's assistance. The three sets of parents stated that the distribution, drop off and pick up was convenient. Following this pilot, the decision was made to follow this method of questionnaire distribution. The drop off and pick up was preferred to a mail out as it was hoped that return rates would be higher.

Contacting the parents by telephone at least twice, and visiting the house on two occasions gave interviewers an opportunity to discuss the questionnaire with the parents and to provide information to the parents about the project. The questionnaires were distributed to 35 families over a nine week period (one family did not complete the questionnaire). Many Family Services workers were re-contacted regarding the names of their families, as some workers were on vacation and had not sent the Letter of Consent out. The contact with the workers was staggered over the initial five week period. Thus, most parents were contacted by the interviewer within a few days of receiving the letter and discussing the project with their Family Services workers. Parents were very cooperative and provided detailed answers to the open-ended questions and completed most of the closed ended items.

Once parents agree to participate in the study, their Family Services workers were interviewed using the Family Services Worker Questionnaire (Appendix 6). The interviews took approximately thirty minutes and included questions about the specific family's experience, as well as general questions about the worker's satisfaction with the summer program. A structured survey interview (Babbie, 1989) was conducted with the worker involved with each family.

Two of the 11 workers were away on maternity leave and one worker had left her

position. Eight workers were interviewed and questionnaires were completed on 28 of the 35 children. This was a 100% response rate of the available workers for each family in the study sample. The two workers on maternity leave were contacted by telephone and they answered the open-ended questions about the program. Their responses were recorded and were incorporated into the evaluation summary.

**(a) Child Information:**

The average age of the children in the study was twelve years. Table 1 (Appendix 1) presents a summary of the age frequencies, mean age, and standard deviation of the study participants. The figures summarized on Table 1 indicate that 56% of the summer program participants were age 12 years or less; 44% of the sample were 13 years of age or more. These groups will be considered as two separate cohorts for program analysis.

The Summer Program Questionnaire required that respondents indicate the disability which describes the child most accurately. Sixty-five percent of the respondents indicated that their child's primary disability was Developmental Delay. Table 2 (Appendix 1) presents a breakdown of the different types of disabilities that characterize the children in this study.

With regard to the number of child disabilities, some parents indicated that their child has more than one disability. Table 3 (Appendix 1) presents the frequencies for the numbers of disabilities as recorded by the parents of the summer camp children. It appears from Table 3 that although 41.2% of the children are afflicted with only one disability, 59% of the children report two or more, (i.e., multiple), disabilities.

The frequencies of male and female children in the study sample are presented in Table 4 (Appendix 1) with the figures indicating a slightly larger number of males than female children. Furthermore, this figure replicates the frequencies of male and female children with disabilities in Winnipeg.

Children in the summer program attended camp in a time frame ranging from one week to eight weeks maximum as shown in Table 5 (Appendix 1). The frequencies summarized on Table 5 indicate that the time stay for children in the program can be divided into two categories: 47% attended camp for three weeks or less, whereas 53% attended camp for four weeks or more.

Parents indicated whether or not they were able to enroll their child in the program they had desired. Table 6 (Appendix 1) presents parents' responses to this query. The frequencies indicate that the majority of parents and children attended the camp of their choice. That is, it appears from the data that 88.2% of the summer camp children attended the camp of their choice while only 3% (i.e., only one family) did not attend the camp of choice.

There was a variety of camps available and Table 7 (Appendix 1) presents the frequencies for the childrens' camp attendance at each one of the available programs.

Parents responded to the query "what type of program was preferable for your child -- segregated or integrated?" Table 8 (Appendix 1) presents the frequencies response to the query, and the figures indicate that 88% of the children attended integrated camps; only a few children (i.e. 13%) attended a segregated program that only accepts children with disabilities.

When Family Services workers responded to the query regarding whether the summer program type, i.e., segregated or integrated, was a factor in the selection of a summer program for the child, the results that emerged (presented in Table 9, Appendix 1) suggest that the segregated or integrated nature of the program was an important factor in program selection. That is, 79.2% of the Family Services workers stated that the degree of integration or segregation was a significant factor in program selection.

Furthermore, when the Family Services workers were asked to identify the importance of certain specific beneficial factors of the program in their assessment of families' need for a summer recreational activity for their children, their responses, on a four point Likert scale, ranged from not important to very important. The mean scores for the responses related to the identified benefits of the program are presented in rank order in Table 10 (Appendix 1).

**Note:** Because the subject pool was reduced when the data from the Parent Survey Questionnaires and the Family Services Workers' Questionnaires were combined, Tables 8, 9, 10 present figures based on the reduced subject pool, i.e.,  $n=24$ .

#### **(b) Parent Information**

The fathers who were involved in this study ranged in age from 25 to 67 years, with a mean age of 39 years (S.D. = 5.75,  $n=34$ ); the mothers who were involved in the study ranged in age from 25 to 66 years, with a mean age of 41 years (S.D. = 8.40,  $n=34$ ).

**Employment Status:**

Of the fathers in the study who responded to the query regarding their employment status, 79% indicated they are employed, while 21% responded that they are unemployed; Table 11 (Appendix 2) presents the employment status of the fathers.

In contrast to the reported employment status of the fathers, Table 12 (Appendix 2) shows that of the mothers of children in the study who did respond to the query regarding employment status, 61.3% reported they are employed, while 39% indicated they are unemployed.

Although data are not available regarding whether employed mothers in the study work full-time or part-time, a perusal of the questionnaires reveals that most of the mothers who reported that they are "unemployed", also described their occupations as "homemaker", a response which suggests that the stereotype of "homemaking" as a "non-job or a non-activity" persists, at least within the population of this study. Of the nine mothers who reported that they were unemployed, seven said that they are full-time homemakers.

**Education Level:**

Of the fathers who responded to the query regarding their level of education, 57% reported education levels in descending order from community college, to high school, to partial high school completion. Furthermore, 17.6% reported completing one university degree, while 6% reported completing more than one university degree. The breakdown in father's education level is presented in Table 13 (Appendix 2).

Of the mothers in the study who responded to the query regarding their level of education, 71% reported education levels in descending order from community college, to high school, to partial high school completion. The remainder of the sample who responded (n=34, i.e., 29%) reported educational levels of partial to a completed university degree; none of the mothers in this sample reported having more than one university degree. This latter finding is in contrast to the fathers' sample in which 6% reported more than one degree. Table 14 (Appendix 2) presents the Mothers' Educational Level.

#### **Parents' Occupation:**

The occupational status of the fathers ranged from "retired" to "professional"; of the fathers who responded to the query regarding occupation, (n=24), 33.3% described themselves as "professional"; the remaining 66.6% of the sample categorized themselves, in descending order as skilled craftsmen, service workers, labourers, or retired. Table 15 (Appendix 2) presents the frequencies and percentages for fathers' occupation, while Table 16 (Appendix 2) presents data for the mothers.

Of the mothers who responded to the query regarding occupation, 25% described themselves as "professionals"; the remainder of the respondents, i.e., 75%, described their occupations, in descending order from "skilled craftsman", to service worker, to labourer, to clerical worker, to homemaker. Of this latter occupational breakdown, 25% of those individuals who responded to the query reported themselves as "homemakers".

**Family Income:**

Parents were asked to indicate the level of the family income, in a range from under \$10,000. to over \$100,000. The level of yearly family income reported most often (i.e. 26.7%) by those who responded to the query was \$40,000 to \$50,000. Table 17 (Appendix 2) presents income level as reported by the parents in the study.

**Number of Children in Study Families:**

On the average, there were three children in each study family. Table 18 (Appendix 2) presents the frequencies of number of children in the study families. Of those parents who responded to the question regarding number of children, 91% of the sample reported having two or more children; 6.5% of the sample reported five or more children, while 3.2% reported families with seven or more children.

**Birth Order:**

The parents who responded to the query regarding birth order of the disabled child provided the information which is presented in Table 19 (Appendix 2). One third of the sample were first born children.

## **Questionnaire Construction**

A Parent Survey Questionnaire (Appendix 5) and a Family Services Worker Questionnaire (Appendix 6) were formulated after a literature review and a subsequent presentation and review of the items by the consultation team. Several themes related to the degree of Burden borne by families with disabled children, and factors influencing respite from Burden, emerged from the literature and were structured into both Likert and open-ended questions. The representatives from Children's Special Services responded to, and provided feedback about these items related to both **Burden** and **Respite**. The consultation team agreed that the method of data collection and analyses would be survey research (Babbie, 1989).

### **The Parent Survey Questionnaire**

The Parent Survey Questionnaire (Appendix 5) included items that required that mothers and fathers evaluate different aspects of the program and describe the disability and behaviour of their child. The questions in the survey evaluated the following factors:

- specific aspects of the program
- reasons for participation in the program
- factors in selection of a camp
- resources available to families
- a Behaviour Problem Checklist
- questions evaluating level of disability



- items evaluating degree of Burden experienced by parents
- items describing socioeconomic status of families in the study
- open ended questions regarding the program

### **Family Services Workers Questionnaire**

The Family Services Workers Questionnaire (Appendix 6) included items requiring that the workers evaluate different aspects of the summer program attended by each child in the survey sample. Specifically, the questionnaire evaluated the following factors:

- reasons for referral of each family to the program
- factors in camp selection
- parent/caregiver burden items
- open-ended questions regarding the program

## **SCALE CREATION**

The scales which were created from the Parent Survey Questionnaire to measure the degree of Burden and Respite were constructed as follows:

### **(I) The Burden Scale**

The Burden Scale was comprised of the following six variables:

- **Time** demands created in looking after the needs of the disabled child
- **Disruptions** to "normal" family routines due to care required by disabled child
- **Financial costs** assumed by the family due to care of disabled child

- **Chronic stress** in family as a consequence of care for disabled child.
- **Reduction in time** parents can spend with friends as a result of care for disabled child
- **Tension with spouse** due to burden of care for disabled child.

Following the choice of potential items for the Burden Scale, (i.e., the original scale consisted of seven variables, one of which was deleted in order to achieve a desired alpha level of 0.80), the reliability coefficient for the final six item Burden Scale is .86; standardized item alpha = .86.

#### **(ii) Disability Scale**

A four item Disability Scale was used to measure the extent and nature of the child's disability. Developed by Trute (1990), the scale can be used as a cumulative score to describe the extent of the child's disability in terms of overall mental and physical functioning.

The components of the Disability Scale are as follows:

- To what extent will the child's disability affect his/her mental or intellectual development?
- To what extent will the child's disability affect physical development?
- To what extent will ongoing specialized medical attention be required?
- How much assistance will this child require over the years to perform everyday activities like eating, bathing, toileting?

The Disability Scale has an alpha of .70 when applied to this study sample.

### **(iii) Behaviour Problem Index Scale**

The Behaviour Problem Index (BPI) (Achenbach & Edelbrock, 1981) was used to develop a Behaviour Problems Index Scale consisting in its final form of 13 items to describe characteristics of the child's behaviour. The index includes both common and serious behaviour problems (Aschenbach & Edelbrock, 1981). The items on the index, as well as the cumulative index score can be explored separately. The BPI is a reliable measure of behaviour patterns and has been used widely in studies of child emotional adjustments.

The 13 scale items are as follows:

- Has sudden changes in mood or feelings
- Is high strung, tense or nervous
- Cheats or tells lies
- Is too fearful or anxious
- Has difficulty concentrating
- Bullies, or is cruel or mean to others
- Is disobedient at home
- Is disobedient at school
- Has trouble getting along with other children
- Is not liked by other children
- Is restless or overly active
- Is stubborn, sullen, or irritable
- Has difficulty getting mind off certain things ... has obsessions

When the reliability analysis for the above 13 item scale employed in this study was calculated, the alpha was .88.

#### **(iv) Impact of the Summer Program Scale**

The final version of the Impact of the Summer Program Scale includes 7 items which were also drawn from the Parent Survey Questionnaire. The items are as follows:

- Program had positive effect on whole family
- Program relieved strain the child places on you
- Program allowed time to socialize with friends and relatives
- Program provided time for rest and sleep
- Program provided more time for yourself
- Program allowed child to meet non-family members
- Program improved family harmony

When the reliability analysis for the above 7 item scale is calculated in this study, the resulting alpha is .85.

#### **(v) The Consumer Satisfaction Scale**

The Consumer Satisfaction Scale was composed from the Parent Survey Questionnaire and, in the final version includes the following 7 items:

- If a friend in need of similar summer activity for disabled child, would you recommend the program?
- If you were to use a summer program again, would you use this program?

- Was program staff knowledgeable about special needs of disabled children?
- Did program provide suitable recreational activities for your child?
- How would you rate overall quality of program?
- Did Summer Program introduce you to new recreational resources for you and family?
- Were you satisfied with communications between summer program staff and yourselves?

The reliability analysis for the 7 item Consumer Satisfaction Scale in this study yielded an alpha of .88.

#### **Description of Scale Derived from the Family Services Workers Questionnaires**

One scale was formulated based on the data from the Family Services Workers Questionnaires, and it is as follows.

##### **(I) The Workers' Evaluation of the Summer Program Scale.**

This scale is made up of the following four items:

- If you were to seek this kind of service again, would you use the same program?
- Were the program staff knowledgeable about the special needs of disabled children?
- Do you think the program staff had the necessary skills to work with disabled children?
- Was the program able to adapt the recreational activities to allow this child optimal participation?

When the reliability analysis for the above four item scale was conducted, the resulting alpha was .83.

## RESULTS

### I (a) Burden and Child Characteristics

A review of the relationship (Pearson correlation) between the Burden Scale and Child Characteristics reveals the following findings, presented in Table 20.

Table 20

#### Burden and Child Characteristics

	Child Behaviour Problem Index	Child Disability Level	Age of Child	Gender of Child	Number of Disabilities
Burden	-.3306 (24) P=.115	.1206 (31) P=.518	.2174 (31) P=.240	.0933 (31) P=.617	.2801 (31) P=.127

The figures reflect that none of the specific child characteristics show a significant relationship with Burden.

### (b) Burden and Child Behaviour Problem Index

Although Burden does not correlate with the overall level of Child Behaviour problem (measured by the Behaviour Problem Scale), an examination of individual items from the Behaviour Problem Scale reveals several significant negative correlations between Burden and the following specific behaviours:

- Child is easily confused and seems in a fog;  $r = -.42$ ,  $p = .036$ .
- Child is sullen, stubborn, irritable;  $r = -.50$ ,  $p = .010$ .

The above are Pearson correlation coefficients with 2-tailed significance.

#### © Burden and Parent Characteristics

The Pearson correlations between Burden and Parent Characteristics reveal that the only significant relationship was that between Burden and the mothers' employment. The figures present an inverse relationship between Burden and mothers' employment, a finding which suggests a significant relationship between Burden and Mother's employment status. Table 21 presents the relationship between Burden and Parent Characteristics.

Table 21

**Burden and Parent Characteristics**

	Mother's Age	Father's Age	Father's Education	Mother's Education	Father Employed	Mother Employed
Burden	.1910 (31) P=.303	.0173 (31) P=.926	-.0222 (27) P=.913	.1219 (28) P=.537	-.2425 (27) P=.223	-.4167 (28) P=.027

In order to clarify the foregoing finding, two groups of mothers were then compared:

- (1) employed mothers (either part-time or full-time)
- (2) unemployed mothers

Independent t-tests were performed using mothers' employment status as the independent variable and Burden as the dependent variables. The results are presented in the following Table 22 which follows:

Table 22

**Parental Burden by Mother's Employment Status**

Variable	Number of cases	Mean	SD
BURDEN			
NO	10	18.5000	4.170
YES	18	14.6111	4.245

Mean Difference = 3.8889



Table 23

**t-test for Parental Burden by Mother's Employment Status**

Variations	t-value	df	2-Tail Sig
Equal	2.34	26	.027

A significant difference between the two groups was found. Employed mothers perceive their disabled children to be less burdensome than do unemployed mothers. The Pearson correlation between Mother's Employment (part-time and / or full time) and Child Disability reveals no significant relationship between these two variables; however, the Pearson correlation between Mother's Employment (part-time or full-time) and the level of Child Problem Behaviour reveals a moderate relationship between these two variables. Table 24 indicates the relationship between Mothers' Employment and Child Disability level, and Mothers' Employment and Child Problem Behaviour. The findings suggest that employed mothers reported their children as having a lower level of behaviour problems.

Table 24

**Mothers' Employment, Child Behaviour Problem,  
and Child Disability Level**

	Child Behaviour Problem	Child Disability Level
Mothers' Employment	.5102	-.24
	(23)	(30)
	Sig. = .013	p = .211

The Pearson correlation between Mothers' Employment and the Impact of the Summer Program on the family reveals a significant relation between these two variables; employed mothers reported a higher positive impact of the summer program on the family. However, no significant relationship emerged between Mothers' Employment and Consumer Satisfaction with the summer program. Table 25 presents these findings:

Table 25

**Mothers' Employment, the Impact of the Summer Program and Consumer Satisfaction with the Summer Program**

Variable	Impact of the Summer ...	Consumer Satisfaction with Summer Program
Mothers' Employment	.4785 (31) P=.006	-.0071 (29) P=.971

**(d) Burden and Family Characteristics**

Burden and Family Characteristics, i.e., gross income and number of children in the family) were not significantly related. Table 26 presents these findings.

Table 26

**Burden and Family Characteristics**

	Gross Income	# of Children
Burden	.1164	-.1342
	(26)	(28)
	P= .571	P= .496

**II. Burden and the Impact of the Summer Program**

There is an inverse moderate relationship between scores on the Burden Scale and the overall impact of the summer program on the child and his/her family as measured by the Impact Scale ( $r = -.5404$ ,  $n = 31$ ,  $p = .002$ ). Furthermore, Burden is significantly related to several individual items from the Impact Scale which relate directly to either household or child circumstances. The significant correlations are presented in Table 27.

Table 27

**Burden and the Impact of the Summer Program**

	Program Provided a Relief from Strain due to Child Care	Program Allowed Parents Time to Socialize	Program Provided Time for Rest/Sleep	Program Provided More Time for Self	Program Improved Family Harmony
Burden	-.5132 (31) P=.013	-.4045 (31) P=.024	-.5137 (31) P=.003	-.5187 (31) P=.004	-.3534 (31) P=.043

However, moving away from personal and household circumstances results in a loss of significant relationships between the Impact Scale and the Burden Scale. Those individual items from the Impact Scale that did not result in a significant relationship with Burden are presented in Table 28 which follows.

Table 28

**Burden and the Impact of the Summer Program**

	Summer Camp had Positive Effect on Entire Family	Program Allowed Child to Meet More Non-Family Members
<b>Burden</b>	-.1866 (31) P=.315	-.2233 (31) P=.227

**III (a) The Impact of the Summer Program and Parent Consumer Satisfaction**

When the relationship between the overall Impact of the Summer Program Scale and the Consumer Satisfaction Scale is examined, the inverse relationship is moderate and significant ( $r=-.3479$ ,  $n=32$ ,  $p < .05$ ).

When parents completed the Survey Questionnaire, they responded to several open-ended questions; those responses are relevant to an interpretation of the above finding of a significant relationship between Consumer Satisfaction and the Impact of the Summer Program. The parents' responses are summarized as follows:

(a) Parents responses to the query, "What were your reasons for using the summer program?" are summarized as follows:

- Socialization for child - social skills - interaction (54.5%);
- Activity for child - recreation (48.5%);
- Respite for family (24.2%).

(b) Parents responses to the query, "Was the summer program staff supportive and helpful to your child", are summarized as follows:

Caring (40%); Supportive (40%); Communication was good, Encourage independence, Well educated, Not Well trained (each 20%).

(c) Parents' responses to the query, "Could you identify what you liked the most, and what you liked the least about the summer program, are summarized as follows:

Activities (30.0%); Communications (16.7%); Recreation available (16.7%); Socializing (13.3%); Staff was helpful (13.3%).

(d) Parents' responses to the query, "Did the program have a positive or negative impact on you and your family, are summarized in Table 29:

Table 29

**Program had Positive Impact**

	Positive Impact
Made child happy - child enjoyed it	50.0%
Respite - gave me (us) a break	34.6%
Activities - gave child something to do	19.2%
Time with other children	15.4%
Social interaction for child	15.4%

(f) Parents responses to the query, "If the program was not available, what would be the implications for your family and your child?", are summarized as follows on Table 30:

Table 30

**What are Implications If Program not Available**

More stress - tension	42.4%
Bored child	33.3%
Child care needed	15.2%
Child would have less interaction with other children	15.2%
Would not benefit child - less stimulation	12.1%
Child would be involved in less activities	12.1%

(f) Parents responses to the query, "What did you like the least about the summer program?", are summarized as follows on Table 31:

Table 31

**Parents Liked Least About Summer Program**

Transportation	15.0%
Poorly trained staff	15.0%
Not enough time - did not last long enough	15.0%
Loose structure	10.0%

(g) Parents responses to the query, "Why did you choose this program?", are summarized as follows on Table 32:

Table 32

**Reason Why Parents Chose Program**

Like activities offered	38.7%
Recommended - suggested by social worker - teacher	22.6%
Socialization for child/social interaction	22.6%
Close to home - drop off - pickup site close	19.4%
Geared to child's needs - include special needs	16.1%

**The Impact of the Summer Program and Child Behaviour Problem Index**

The moderate relationship between the Impact of the Summer Program and the overall level of Child Behaviour Problem is significant ( $r = .4027$ ,  $n = 25$ ,  $p = .046$ ); parents with children with lower levels of behaviour problems rated the summer program as having a higher impact on their family life. *[NOTE: A high score on the Behaviour Problem Index refers to a lower level of child problem behaviour.]*

Furthermore, there are significant relationships between several individual items from the Impact of the Summer Program Scale, and the overall Child Problem Behaviour score. That is, parents with children with *higher* levels of behaviour problems reported that the summer program has *less* of an impact on family life. The relationship between Child Problem Behaviour and the three variables from the Impact of the Summer Program Scale is summarized in the following Table 33:



Table 33

**Impact of Summer Program and Child Behaviour Index**

	Program Provided Time for Socializing with Friends	Program Provided Time for Rest and Sleep	Program Provided More Time for Yourself
Child Behaviour Problem	.5044 (25) P=.010	.5094 (25) P=.009	.5098 (25) P=.009

**Family Services Workers' Evaluation of Program and Parent Consumer Satisfaction**

When the Workers' Evaluation of the Summer Program is correlated with Parent Consumer Satisfaction, a strong significant relationship is found. Table 34 presents this finding:

Table 34

**Family Services Workers' Evaluation of Program and Parent Consumer Satisfaction**

	Parent Consumer Satisfaction (Spearman)
Workers' Evaluation of the Summer Program	-.7792 (22) p<.001

That is, the Family Services Workers appraisal of the quality of the program corroborates the parents' assessment of the quality of the summer program.

### **Comparison of Two Age Cohorts of Children: Pre-Teens and Teens**

Two strata of children involved in summer programs were compared:

- (1) younger children, ages 6 to 12 years of age,
- (2) older children, ages 13 to 17 years of age.

The results are presented in the following Tables 35 to 37 below:

Table 35

#### **Parental Burden by Age Cohorts of Child**

Variable	Number of cases	Mean	SD
younger	12	16.0833	2.712
older	13	15.7692	2.948

t-value = .28; df=23; 2-Tail Sig. = .785

When the two age cohorts were compared using age as the independent variable and burden as the dependent variable, there were no significant differences in level of burden between the two groups.

Table 36

**Parental Consumer Satisfaction by Age Cohorts of Child**

Variable	Number of cases	Mean	SD
younger	15	22.6667	4.254
older	17	22.6471	4.030

t-value=.01; df=30; 2-Tail Sig. =.989

Again, when the two age cohorts were compared, there were no significant differences in level of consumer satisfaction between the two groups.

Table 37

**Impact of Summer Program by Age Cohorts of Child**

Variable	Number of cases	Mean	SD
younger	16	15.3125	4.316
older	18	13.2778	4.184

T-value= 1.39; df=32; 2-Tail Sig. =.173

When the two age cohorts were compared, there were no significant differences in the impact of summer program between the two groups.

## Chapter Four

### DISCUSSION

The purpose of the present study was two-fold: the study explored the characteristics of the burden of care experienced by the families of handicapped children who attended the Children's Special Services Summer Program; in order to define the nature of the burden experienced by caregivers, the study investigated the relationship between burden and demographic variables such as child, parent and family characteristics that can be related to burden. A secondary purpose of the study was to explore the relationship between burden and the children's attendance at the summer camp program. The parents' assessments of the impact of the program on their lives, and their expression of consumer satisfaction with the program enabled an appraisal of whether camp attendance provided respite from burden for the caregivers.

#### **Burden and Child Characteristics**

Our study's finding was that burden of care for the disabled child is not related to any of the specific child characteristics explored (with the exception of two individual behaviours from the Behaviour Problem Index); that is, the logic that burden may be related to age, gender, number of disabilities, level of child disability, and overall level of child problem behaviour was not upheld in the present study. Although this finding is not consistent with some previous research findings, a review of the literature highlights the complexity of age as a child characteristic related to parental burden.

An extensive literature has accumulated that links parental stress to child

characteristics, and one dimension that appears to be related to parental stress is the age of the handicapped child. The exact nature of the relationship between the child's age and parental stress must be complex due to the potential interaction between age and other variables such as type of disability, severity of disability and the characteristics of the members of the family system. Thus, child age should be conceptualized as one piece of a larger puzzle made up of many interlocking components.

For example, Bristol (1987) pointed out that as the child's age increases, the handicapped child can become more difficult to manage, and the differences between the child and his/her peers become more noticeable. Zucman (1982) referred to the social isolation due to the child's disability which may increase as the child gets older. Seligman and Darling (1989) note that "as a handicapped child approaches critical transition periods, parents may experience renewed anxiety or sadness" (p. 20).

The concept of "critical periods" is important because as the handicapped child moves from one developmental level to the next, the period of transition may be stressful for the caregivers. Wikler (1986) suggests that transition periods in the life cycle of the family with a handicapped child may be associated with more parental stress than other periods. Wikler examined parental stress during two transition periods of children with mental retardation: the onset of adolescence (ages 11 to 15 years) and the onset of adulthood (ages 20 to 21 years). Family stress levels were assessed once, and then two years later. Parents did report higher levels of stress associated with the child's disability during the two periods of transition; however, stress levels subsided during the intervening ages 16-19 years, time period. These findings were reported for the initial assessment and

the later assessment.

In our study, the initial finding that age does not correlate with burden was reinforced by the subsequent independent t-test in which the two age groups were compared using burden as a dependent variable. In our study sample the children were divided into two age groups (ages 6-12 years, ages 13-17 years); considering the research findings summarized above, one might speculate that in our study, the second age group (i.e., the older children ages 13 to 18 years) might be a source of burden for the caregivers due to the special problems associated with the transition to adolescence, i.e., the possibility of a lack of peer acceptance, for example, due to the presence of disability. Furthermore, a perusal of the individual components of the Burden Scale suggests that the care giving needs of the older handicapped child may have a particular impact on the time demands, the financial costs of care, and the chronic stress on the family due to ongoing child care which one can assume has been of greater duration for the older cohort than for the younger cohort of children. However, the expectation of a significant relationship between burden and age is not reflected in our findings.

Our study finding of no relationship between burden and gender, number of child disabilities, or overall level of disability is puzzling. A literature review reveals that research to date is equivocal regarding the nature of the relationship between child characteristics such as gender, severity of the child's disability and parent functioning. Intuitively, one might expect that severity of disability will have a profound impact on burden because of the potential for the ongoing dependency of the child, the obvious need for increased attention to care for the child's needs, the possibility of frequent medical

contacts, and, of course, the intimidating possibility (for some parents, at least!) of lifelong care. This "expectation" for a significant relationship between burden and disability level can be derived from some literature sources which have reported that burden is directly related to the type and severity of child disability.

In our study, 59% of the children are reported as having two or more (i.e., multiple) disabilities. Furthermore, our study sample includes a range of different types of disabilities including, for example, Developmental Delay - 64.7%; Down's Syndrome - 14.7%; Autism - 17.6%; and Attention Deficit - 11.8%. There is a possibility of overlap between the categories; for example, Attention Deficit often characterizes autistic children (Blacher, 1984) and Down's Syndrome children are sometimes characterized with hearing loss (e.g., 2.9% of our sample), and or vision loss (e.g., 5.9% of our sample). The disability level of the children in the present sample was ascertained by means of the disability scale in order to conceptualize disability level on a continuum from mild - to - moderate - to - severe; Some researchers, for example, Fewell and Gelb (1983) advocate doing so; at the same time, they also emphasize that each level of disability is characterized by a different "type" of stress.

Seligman and Darling (1984) warn that "labelling" children according to disability level categories can be somewhat arbitrary (p. 98), but, for the purpose of this discussion, it appears that our study sample may include representatives from each category. In the "mild" category, parental burden may be enhanced by the "borderline" nature of the child's disability. Fewell and Gelb (1983) have pointed out that children labelled as mildly retarded occupy a position astride the "normal" category and the "disabled" category.

Their "marginality" may, in some cases, suggest a possible ambiguity inherent in the parent's acceptance of the child's disability, and their expectations for the child's level of social functioning. For example, parental stress may derive from parental anxiety over their inability to predict what the child will do in any situation. Children in the moderate to severe categories (as would surely include some of the children in the present study) can also exacerbate stress experienced by the parents, and by the entire family system. The disruption to family routine and social life due to the demands of caring for a severely disabled child has been reported by Blacher (1984), Beckman (1983) and Friedrich et al. (1985); Seligman and Darling (1989) summarize the difference between the mildly handicapped child and the severely handicapped child as due to the "burdensome, unrelenting chronicity of care" and the ongoing "burden of multiple needs" (p. 102-3).

Furthermore, Birenbaum (1971) reports that the increased age of a severely or profoundly handicapped child (especially a male over 9 years of age) is related to marital problems and tensions with spouse. Holroyd and McArthur (1976) found significant differences in parental stress related to the diagnostic category of the child. In their study, they found that parents of children with Autism and Down's Syndrome reported different patterns of parental responses; parents with autistic children reported the most stress. The diagnosis of Autism (found in 17.6% of our study sample) has been investigated by Bristol and Schopler (1984) who point out that "there may be a characteristic pattern of stress associated with parenting an autistic child ... the stress ... is both similar to and different from that experienced by families of children with other types of handicapping conditions" (p. 105). Bristol (1987) reported finding that mothers of older autistic children, both boys



and girls (n=20; 9.5-19 years), reported significantly more parental coping problems and negative effects on family integration than did mothers of younger children (n=20; 4-9 years) (in Bristol and Schopler, 1984, p. 131). Blacher stated that the two major reasons for the greater stress in the older group were "parental realization of the permanency of the child's handicap and a greater lack of activities and services for older autistic children" (p. 105). Thus, the research on Autism seems to suggest that the unique nature of the disability causes more stresses for families than do other types of handicapping conditions.

However, in our study, the independent t-test using Burden as the dependent variable and the two groups of children (categorized as Autistic versus non-Autistic) as independent variables yielded no significant finding of a potential impact of the Autism factor. Furthermore, the partial correlation of burden with Autism which is controlled by age revealed no significant finding.

Still, in spite of the foregoing research findings, our study finding of no relationship between burden and level of disability and number of disabilities and burden must be interpreted.

Trute (1995) has pointed out that for some parents, providing care at home for a handicapped child "will not be perceived as a particularly threatening or challenging circumstance, but as a natural occurrence in the life of the family which is met by smooth accommodation and seen as requiring modest adjustment within the family setting" (p. 1225). Trute's observation can be considered in conjunction with Wikler's research on the elusive "subjective factor" (see page 9 of this study) which may offer a means of interpreting our study's findings. Wikler defines the subjective factor as the "hugely

complex web of beliefs, attitudes, morals ..." that make up the individual's perception of the stressor (i.e., the handicapped child). Wikler warns that responses to the stress of caring for a handicapped child can vary greatly from family to family, even as the objective character of the stressor and the extent of the parental and family resources are kept constant. Margalit and Antonina (1991) point out that stress resistance researchers have emphasized people's capacity to remain healthy when stressors occur, demonstrating the adaptive value of effective coping strategies. Other researchers have highlighted the parent and family's capacity for successful adjustment to the disabled child (Widerstrom and Dudley-Marling, 1986; Saddler, Hillman and Benjamin, 1992).

In interpreting the present study's findings, one can only surmise that a positive attitude toward (i.e. perception of) the supposed "stressor" (i.e., the handicapped child) may have been of some influence in our study finding of no relationship between burden and child disability level. This finding was corroborated in the partial correlation of burden with disability and controlled by age which revealed no significant relationship. As one contemplates the fact that our study sample includes older children with multiple handicaps, some of whom are autistic, then the study finding suggests that the relationship between burden and disability level is not simple and direct, but multifaceted.

Thus, it would appear to be difficult to conclude with any certainty how the type of disability will affect the family because factors other than severity of the handicap may play an important role in determining family adaptation. The importance of exploring and defining the factors, other than severity of disability, has been done in the research of Kazak and Marvin (1984); these researchers explored family strengths and found on the

one hand, that the presence of the handicapped child may sometimes strengthen a marital relationship, and that despite the presence of high levels of stress associated with severity of disability and type of disability, the families were found to have successful strategies for coping with the child's disability. Furthermore, Trute (1988) explored families that had adapted well to the birth of a child with developmental disabilities in order to study what made these families strong. Trute's finding was that positive adaption is unrelated to the degree of the child's disability. A clearly defined picture of the characteristics of the parents and of the marital relationship and the family system in conjunction with the demand characteristics of the child's disability is needed in order to evaluate with any precision the relationship between burden and level of disability.

Although our study found no relationship between burden and overall child problem behaviour, a moderate relationship was found between burden and two individual child problem behaviours from the Behaviour Problems Scale:

(I) the child is easily confused and seen to be in a fog; (ii) the child is stubborn, sullen, or irritable. Either one of the foregoing behaviour patterns could be associated with Autism, Down's Syndrome, Attention Deficit, or Developmental Delay, all of which disabilities were found in the sample.

The finding of no relationship between burden and overall child behaviour problem score is somewhat difficult to interpret. On the one hand, as previously noted, our study sample does include a percentage of children designated as autistic; furthermore, if one allows for the overlap in the sample between different disability types, and includes attention deficit (11.8 %) with those children diagnosed as autistic, one would expect that

behavioural problems linked to autism, for example, would have, at the very least a mild to moderate relationship to burden. For example, the behavioural manifestations of Autism have been investigated by researchers, especially Bristol and Schopler (1984). In an extensive review of the research on Autism, they report that the stress which can be related to the behaviour of the autistic child affects most aspects of family life. These researchers point out that "it does appear that the particular nature of autism is more stressful than other types of handicapping conditions" (p. 103). Furthermore, Holroyd and McArthur (1976) found greater stress reported by families of autistic children; in their study, the comparative scale scores suggest that mothers of autistic children reported greater stress than mothers of Down's Syndrome children in areas specifically related to child's behaviour. For example, autistic children were reported to have more difficult behaviour management problems than the Down's Syndrome children. Bristol and Schopler (1984) point out that because of the "normal" appearance of some autistic children, their behavioural patterns may generate ambiguity with regard to the community's response to the child, and this ambiguity may, in turn, contribute to increased family stress. For example, bizarre behavioural patterns exhibited in public by an autistic child who appears to be normal may engender a negative public response that can increase the stress on the families of the autistic child. Lemanek, Stone and Fishel (1993) investigated whether child and parent behaviour differ as a function of the child's disability. They found autistic children demonstrated behavioural differences from the mentally retarded group in being less compliant.

Because an awareness of the degree of child behavioural problem can assist in

picturing the demand characteristics of the child's disability (and hence, the burden of child care), and because a percentage of our study group were autistic, one might expect that child behaviour would be related to burden of care. Still, this relationship was not found. However, our study lacks specific information on family factors such as resources and/or social support that may have an impact on parents' ability to cope with stress related to behavioural problems.

Sloper et al. (1991) have emphasized that although some of the research in the field of disability has focussed on the behavioural characteristics of the disabled child as a source of stress, the relationship between interrelated risk factors such as low developmental level, care and supervisory demands, and child behaviour problems, has not been sufficiently investigated.

### **Burden and Parent and Family Characteristics**

When the relationship between burden and several selected characteristics of the parents and of the family was evaluated, several unexpected findings emerged. Burden was *not* found to be related to the ages of either parent, to the level of education of either parent, or to the employment status of the *father*; however, a significant relationship did emerge between burden and the mother's employment status.

The finding that burden and parental age were not related was somewhat surprising when one considers the ages of the parents in our study sample; the mean age of fathers in the sample was 39 years, with 74% of the fathers ages 35 years or older, and 6 fathers

aged 65 years. The mean age of mothers in the study sample was 41 years, with 79% of the mothers ages 35 years or older, and 2 mothers aged 65 years! Thus, it seems appropriate to designate our sample as "middle-aged". In reflecting further on the age characteristics of our study sample, one might expect that the demands often placed on parents of disabled children due to, for example, the time requirements of care, the potential financial burden, and the potential for disruptions to the normal family routine might wear any parents down, but especially older parents. Indeed, some literature findings support this assumption. For example, Seligman and Darling (1989) point out that the "chronicity of care that families with a disabled child anticipate ... can be experienced as a dark cloud that will continue to engulf the family for years to come and family members can see little relief when they look into the future" (p. 88). Furthermore, Seligman and Meyerson (1982) state that "... living with a handicapped child over many years can take its toll psychologically, physically, and financially" (p. 103). Sherman and Coccozza (1984) investigated factors which influence the decision made by families to institutionalize their disabled child and found the importance of such variables as the parental age and parental health status, for as the disabled children became adolescents and young adults, their aging parents may be unable to meet their needs adequately. Allen (1972) found that older parents tend to seek out of home placements to assure that their disabled adult children receive appropriate long term care. And, with reference once more to Autism (diagnosed 17.6% of our study sample), researchers have identified maternal age as associated with higher levels of reported stress in families of autistic children, for example, Bristol (1979) reported that older parents and also parents of older children

report more stress.

In order to account for our study finding of no relationship between Burden and parental age, it is probably wise to evaluate this result in conjunction with the concomitant finding of no relationship between burden and the parental levels of education and family income.

On the one hand, one might assume that older, better educated parents would have better jobs with higher income levels, and thus, enjoy access to better support systems that might, in turn, alleviate the chronic burden of care. This assumption has some support in the research findings of Friedrich, Wiltner and Cohen (1985) who examined the coping strategies of families with handicapped children. They evaluated utilitarian resources which were operationalized in their research study as family income and parental education; they found that better educated individuals have higher incomes and greater utilitarian resources (which can be viewed as coping resources) than might be enjoyed by a less educated, less well-off sample. However, their study sample was not heterogeneous, but was almost exclusively middle class and above parents who were generally well educated. However, following this line of thinking, our study sample can be examined from the standpoint of utilitarian resources such as parental education and income. Our sample is also not heterogeneous because it is weighted towards parents with lower education and non-professional occupational status, and income levels (e.g., only 17.6% of the study fathers reported having attained one university degree; 23.5% of the study fathers reported professional status occupation; 20.6% of study mothers reported professional status occupations). However, our study sample did report that 58.7% of the sample earn less

than \$50, 000 per annum. Thus, because our study sample could be described as of lower to middle socioeconomic status, one might expect that reported burden would be related to parental education, parental occupation and family income level.

In keeping with the research findings of Rosenberg (1977) and Rabkin and Streuning (1976), one might expect that lower class families experience more stress, and hence, more burden than do more affluent families. In a similar vein, Reisinger, Ora and Frangia (1976) reported that the ability of parents to adapt to a "change agent" role with their handicapped child is related to socioeconomic class. Gallagher, Beckman and Cross (1983) report that "available evidence suggests that lower class families react less energetically, enthusiastically and efficiently to intervention programming than do middle-class families of the handicapped" (p. 13). Korn, Chess, and Fernandez (1978) reported in a longitudinal study of families with disabled children that midrange occupations were associated with higher levels of family distress. In their study, fathers in the highest and lowest occupational categories were the least distressed, whereas a higher percentage of men in clerical and sales positions were in high distress families. Thus, in order to interpret the findings of our present study, further speculation about the significance of the relationship between the foregoing variables is probably not helpful without now considering the additional finding that burden is significantly related to mothers' employment.

In our study sample, 35% of the mothers reported that they are unemployed, while 56% reported that they are employed. And, it was the employed mothers in our sample who appear to perceive their disabled children as less burdensome. Our data are



incomplete with respect to two important factors. Information on family income exclusive of mothers' earnings was not gathered from the sample of families; furthermore, information on whether the study mothers were employed full-time or part-time was not gathered. Nevertheless, we do know that 71% of study mothers reported educational levels in descending order from community college (29.4%) to complete high school (24%), to partial high school (12%); only 8.8% of the sample reported some university education. Furthermore, only 20.6% of the study mothers reported their occupation as "professional" positions. The remainder of the sample designated their occupations as labourer (12%), clerical (12%), service worker (12%), skilled craftsmen (6%). From this available information, it appears that the study mothers were engaged in occupations with rather limited earning potential. In the absence of more specific information, it is impossible to assess with any degree of accuracy how "fulfilling" the above occupations may have been for the study mothers. However, it does appear that the employed mothers who were engaged in the above occupations did, somehow, respond "differently" than did the unemployed mothers with regard to the burden of care for their disabled children.

To account for this finding, one can begin with a review of the general research concerned with the stressfulness of multiple roles for women in the work place. For example, Baruch, Biener and Barnett (1987) in their investigation of work-related stress found that research has tended to focus on males and to neglect gender as a variable. Often, findings from studies of men are incorrectly generalized to women. The failure to "build women in" to conceptual models has impaired our understanding of work role stressors. For example, the home has traditionally been viewed as a stress-free sanctuary,

whereas workplace stress has been overemphasized and seen as particularly dangerous for women. However, as Baruch et al. point out, evidence is now accumulating that the data do not show an increase in stress-related illness in employed women. Indeed, they point out that studies comparing the physical or mental health of employed versus nonemployed women typically find employed women to be advantaged. Such findings call into question the assumption that the home should be viewed as a buffer against the stress of the workplace for women.

When the "supposed" additional stressor of the burden of care for a disabled child is added to the employed mothers' responsibilities, one might predict that the multiple role pressure would be difficult (i.e., burdensome) for some mothers. Gottlieb (1997) investigated the impact of employed status and a nonspousal partner on the overall well-being of single mothers of children with developmental disabilities. This researcher found that generally multiple roles were associated with greater well-being for the mothers. Although Gottlieb's research differs from our study in that it concentrated on a population of single mothers, the research is instructive nevertheless in furthering an understanding of the significance of employment status for women. Gottlieb examined current theories regarding women's multiple roles. For example, one such theory is concerned with the scarcity hypothesis (Goode, 1960) which states that too many roles drain limited available energy; however, the enhancement hypothesis (Marks, 1977) focuses on the net positive gain (e.g., self-esteem, recognition, and money) associated with having simultaneous roles.

Some researchers have stated that the quality of the mother's roles may be just as

important as the number of roles assumed by the mothers. For example, McBride (1990) pointed out that certain factors, such as poverty conditions and the extra caregiving demands which accompany caring for children with disabilities or with behaviour problems may increase the stress experienced by women with multiple roles. On the other hand, some literature findings have suggested that multiple roles may predict greater sense of well-being for women, if the roles are balanced, without role conflict or role overload (Barnett, 1982).

In the presence of limited specific information about our study sample with regard to the psychological strengths of the parents, the quality of the marital relationship, the mothers' need for self-esteem and recognition and/or the mothers' need for money, one can only speculate about the interaction between burden and mothers' employment.

Perhaps it is possible to interpret our study finding from the standpoint of what Wikler (1986) has referred to as the "buffering" effect of certain variables which have been identified as instrumental in mediating stress. That is, mothers' employment could be viewed as a "family resource", and, as such, could be viewed as a "coping" strategy for mothers to deal with stress, (assuming that the disabled child is perceived as a stressor in the family). For example, Sloper, Knussen, Turner and Cunningham (1991), in their research on coping strategies of families with disabled children, point out that employment outside the home represents "a social resource for mothers, giving mothers a broader access to social relationships, and roles and interests outside the family, with a concomitant greater independence" (p. 669). Effective coping strategies, according to Sloper et al., appear to be related to higher satisfaction with life. It is interesting that these positive

results that evidently can emanate from mothers' employment are also related to components or individual items which make up our Burden Scale.

Furthermore, according to Justice, O'Connor and Warren (1971), the higher a family's social class, the greater are the family's financial resources and the more resources are available to the family to negotiate the service delivery system. Middle-class families with disabled children are more likely to be able to utilize the available community services than are lower class families. It may be possible that our study mothers found that the added financial advantage associated with employment somehow decreased the burden of care. Our additional study finding that mothers' employment was related to the level of child problem behaviour can be viewed as a reflection of, and an extension of the foregoing discussion. That is, there is a significant correlation between employed mothers and a lower level of perceived child problem behaviour.

While no single explanation can account for this finding, there is, nonetheless, a suggestion of interconnections between the variables in our study considered so far. That is, it is already known that employed mothers in our study reported lower levels of burden, and, that burden is not related to overall level of a parent's perception of their child's behavioral functioning. Furthermore, our study has found a relationship between employed mothers and a lower level of perceived child problem behaviour. There was no significant relationship between mothers' employment and the disability level of the child, the age of the child, or, the family income. So, a pattern of relationships seems to emerge which emphasizes the relation of maternal employment to lower levels of both burden and perceptions of child behaviour and adjustment. It may be that one finding reflects, and

reinforces the other. That is, if employed mothers in our study perceive that their disabled children are less burdensome and have fewer concomitant problem behaviours, they may feel less constrained to remain in the home in order to provide full-time care for their disabled children. However, they also may be less centrally focused on their child as the major element in their daily lives and therefore may not be as vigilant about their child's behaviour.

Some recent research has focussed on exploring, in part the role of mothers' employment and child problem behaviour in families with disabled children. For example, Sloper, Knudsen, Turner and Cunningham (1991) have explored factors related to stress and satisfaction with life in mothers of Down's Syndrome children. Unlike our study, in their study, both the severity of the child's disability and the degree of child behaviour problems were related to maternal functioning. Their study findings indicated that mothers who were likely to be most able to cope with child behaviour problems without added stress and risk to their own health (i.e., the mothers) were those who had good adjustment to the child and, who were employed. These researchers theorize that mothers with positive attitudes towards their children value them regardless of any behaviour problems and are able to view the problem behaviours as less central to their relationship with the child. This may or may not be true of mothers in our study sample; our study did not measure parental personality type, affect and/or attitude toward the child. However, Sloper et al. did demonstrate in their research that mothers' employment was a factor in moderating and buffering the effects of child behaviour problems on mothers' reports of stress, as well as being related to mothers' satisfaction with life. Thus, Sloper et al.

suggest that mothers' employment may be an important resource factor and that support service to mothers to enable them to go out to work may be beneficial.

With regard to the finding of our study, it is not possible to assume a cause and effect relationship between variables; that is, one cannot state that study mothers are employed because their children are less burdensome or because the children engage in lower levels of problem behaviour. Rather, it would appear that our study mothers probably work, at least in part, due to financial considerations (although there was *not* a significant correlation in our study between family income and mothers' employment). But, it is nonetheless possible that the child characteristics of problem behaviour and concomitant level of burden may facilitate the ease with which our study mothers went out to work. On the other hand, one can speculate that our study mothers may also work to escape housework and child care. Concomitant with this speculation is the possibility that mothers' employment may enhance mothers' overall sense of well-being. This latter interpretation seems plausible in light of the next study finding to be considered in this discussion -- that of the significant relationship between mothers' employment and the impact of the summer program. In our study, employed mothers reported a positive relationship between mothers' employment and the impact of the summer program.

An interpretation of this significant relationship between mothers' employment and the impact of the summer program should probably begin with a consideration of the individual items on the Impact Scale. Of the seven items on the Impact Scale, six items relate to specific aspects of the summer program that enabled personal self-renewal (it is of interest to note that the study families indicated that 77% of the questionnaires had been

completed by the mothers). For example, on the Impact Scale, parents indicated whether the program had a positive effect on the whole family, relieved the strain the child places on parents, allowed time for parents to socialize, provided time for parents to rest and sleep, provided more time for selves, and improved family harmony. The positive correlation between mothers' employment and the Impact Scale items is an interesting finding because it suggests the value of the summer program to the parents, especially to employed mothers.

The relationship may suggest that employed mothers found that the stress of the multiple roles they assume means that the necessity for personal self-renewal is even more critical for them. One cannot assume that the non-employed study mothers did *not* need personal renewal, but, for our study mothers, the opportunity for self-renewal seems to be linked to, and derived from, the impact of the program. As Kandel, Davies and Raveis (1985) have pointed out, for employed women in particular, role overload, stemming from a combination of distinct roles, may be stressful for some employed mothers, particularly for employed mothers with disabled children. According to Barnett and Baruch (1985) this role burden can have a negative impact on women's physical and psychological health. Although it has been acknowledged on the one hand that mothers' employment can have a positive impact on mothers' psychological well-being, there is, nonetheless, the possibility of stress and strain due to the combined roles of occupational, marital, household, and parenting for the mothers in our study population. There is a possibility of an interactive effect, a build up of stress that is probably at work among these variables, that could contribute to the stress load borne by the study mothers.

Another suggestion to account for this significant relationship is that perhaps if employment is viewed as a family resource, and thus, as a "coping" strategy, then the relationship between mothers' employment and the impact of the program suggests that the program not only enhances the well-being of the mothers, but in doing so also contributes to their sense of empowerment. That is, these mothers are "empowered" now to turn inward to acknowledge and tend to their own personal needs. Our study sample mothers appear to be employed in jobs that combine high levels of demands with little *autonomy*; such jobs may be low-level and low-paying ones. Although these types of jobs may be typical of our study fathers as well as the study mothers, according to Baruch et al. (1987) it is women who are more likely to find themselves restricted to low-level, low-paying jobs by social factors such as discrimination. If one views the availability of the summer program as an additional "coping" strategy available to employed mothers, it is possible that the positive impact of the program may enable mothers to become renewed and more effective, and thus more empowered. Access to the program, especially a program with a positive significant impact on mothers' personal well being may have the effect of empowering these women in their ability to care for a disabled child as well as help support their families financially.

### **Burden and the Impact of the Summer Program**

With the finding that Burden is related not only to the overall impact of the summer program, but also to several individual items from the Impact Scale, there is an interesting constellation of variables to ponder. For example, Mothers' employment is correlated with



lower levels of Burden, and lower levels of perceived child problem behaviour, and with the positive impact of the summer program; furthermore, Burden is related to the impact of the summer program -- but, as the level of burden increases, the impact of the summer program diminishes.

An examination of constituents of the Burden and the Impact of the Summer Program Scale indicates that many of the items are very closely related. For example, one item on the Burden scale related to the time demands involved in looking after the needs of the disabled child, and it can be matched with comparable items on the Impact Scale: for example -- the program provided more time for self; program provided time for rest and sleep; program provided time to socialize with friends and relatives. Thus, there is considerable overlap between the items on both scales. Thus, the correlation between the two scales might be expected because as the child care becomes more "burdensome", the impact of the program -- especially a program of such short duration as the summer camp program (47% attended camp for 3 weeks or less; 53% attended camp for 4 to 8 weeks) might be expected to diminish. The overall Burden score was also related to 5 of 7 individual items from the Impact Scale; in each case the relationship was an inverse one, with the impact of the individual item from the Impact Scale diminishing as the Burden Scale score rose.

The findings from this constellation of interrelated variables offers a limited means for evaluating the summer program as a source of *respite* for the parents. The importance of respite care services has been studied by Intagliata (1986) who cautions that "although respite care services are believed to provide crucial support to both individuals with

developmental disabilities and their families, the evaluation data that could substantiate the beneficial impact of respite care and be used to justify its continued existence are extremely limited both in amount and sophistication" (p. 263). Still, the significant correlations that have appeared in our study data offer evidence that might demonstrate the effectiveness of the summer program. That is, these relationships provide a means of understanding *how* the summer program may have had an impact on the family.

The relationship between the Burden Scale and the Impact Scale offers an evaluation of the family's perception of the quality of respite care offered. The Burden Scale does provide a measure of family stress which may have been experienced due to care for the disabled child. The obvious shortcoming with our study is that the initial level of stress (i.e., pre-respite stress level) is not available, and it is unknown whether the initial level of burden was relatively low anyway. If the study families had an initial high level of burden, then it is probably unrealistic, given the short duration of the summer program to expect that it would have had a powerful enough intervention effect to reduce the burden level significantly. This would be particularly true in families whose sources of stress are multiple and include factors that are independent of the level of burden associated with caring for the disabled child. Obviously, the relationship between the measurement of burden and the degree of truly beneficial impact from the summer program is very complex.

Furthermore, our measurement of stress (i.e. burden) was done at one point in time, *after* the respite had been used for a specified period. Thus, it is a retrospective, subjective measure. These concerns are raised here, because it may not be realistic to

expect a substantial change in family response to the burden of care after a duration ranging from 1 to a maximum 8 weeks participation in the summer camp program.

### **The Impact of the Summer Program and Parent Consumer Satisfaction**

The additional finding that the impact of the program is related to parent consumer satisfaction lends credibility to the foregoing discussion regarding the apparent beneficial impact of the program on the family. Not only was the impact of the program related to the overall Consumer Satisfaction Scale, the latter scale was also related to two specific individual items from the Impact Scale -- (i) the Summer Program had a Positive Effect on the Family, and (ii) the Summer Program improved Family Function.

While the individual components of the Impact Scale are related to personal renewal, the items that make up the Consumer Satisfaction Scale are related to the specific utilitarian aspects of the program, i.e., scale items that indicate *how* the program may have been of value to the family and to the disabled child. In addition to considering the components of the Consumer Satisfaction Scale, one can also review the parents' responses to the series of open-ended questions about the value of the summer program. Parents' responses to these questions reinforce the finding that the summer camp was a positive source of respite for the parents. For example, several items required that parents describe staff *attitude*, and some of the highly positive percentage responses referred to the staff as "caring, concerned, understanding, supportive, responsible" -- 46%; staff had "good attitude" (36.1%). When one considers the foregoing responses in conjunction with

questions that tapped parents' responses to the summer program as having a positive or negative impact on the family, the connection between the parents' positive views of the camp staff and the positive overall impact of the program offer further credibility for the program. For example, 50% of the parents described the camp program as having had a positive impact on the child in that it "made the child happy -- the child enjoyed it"; and 35% of the parents responded that "the camp gave us a break"; 56% of the parents indicated that they wanted "socialization for the child -- social skills and interaction with other children"; a total of 76% of the parents described that the implications for them if the program was not available would be "more stress-tension" and a "bored child".

The foregoing findings offer a clue as to the parents' perception of the *quality* of the respite offered by the program. As Upshur (1982) has pointed out, the families' perception of the quality of respite care offered by any program influences the degree to which families actually make use of respite care services available, with services perceived as higher quality being utilized more frequently. According to Intagliata (1986), one of the factors likely to influence the perception of quality is the training and experience of respite care workers. Furthermore, Cohen (1982) found that behavioural characteristics that differentiated significantly between respite care workers who had been rated at the top versus the bottom of the group by their supervisors included "dependability, consideration, cooperation, supportive communication with clients, client assistance skills" -- as can be seen, many of these qualities also describe the characteristics of our summer program staff.

Parents in our study sample had expressed a desire to have their children enrolled in integrated programs (i.e. 88% of the parents expressed a preference for an integrated

program while 79% of the Family Service workers stated that the degree of integration was a significant factor in program selection). One could speculate about a possible connection between the parents' expressed desire for integration and the principle of normalization. For example, Galloway and Chandler (1979) stated that according to the principle of normalization (as described by Wolfensberger, 1972), services to handicapped children must be integrated, continuous and normalized to provide the best respite service. They argue that integration will influence how the handicapped child will be perceived by others. Salisbury (1986) has stated that strategies for integrating children with moderate and severe disabilities into normal child care settings must be refined. Those researchers also pointed out that there are different opinions about what expectations are reasonable for providers of respite care. On the one hand, some parents are so grateful that their child has something to do, and somewhere to go, that they are rather nonjudgemental about the content and quality of the services rendered. This is particularly true for parents of older developmentally disabled children. On the other hand, parents of younger handicapped children have more stringent expectations of the appropriateness of what is offered and the relationship of this material to their child's development. Salisbury stressed that the most frequently voiced concern is that related to the capabilities of the provider to meet the needs of their child appropriately. Although our study data do not differentiate between parents' statements of consumer satisfaction for younger versus older children, the responses do, nonetheless, express in a general sense, positive evaluations of the quality of service provided by the program staff.

## **Family Service Workers' Evaluation of Summer Program and Parent Consumer Satisfaction**

Further credibility regarding the value of the summer program can be derived from the responses of the Family Services Workers when they were asked to evaluate different aspects of the summer program. There is a strong, significant correlation between the workers' evaluation of the program and parents' consumer satisfaction. Parents and Family Service Workers appear to be in clear agreement regarding their satisfaction with the quality of the summer programs. Furthermore, a review of the items on the Family Services Worker Questionnaire that were identified by the workers as very important aspects of summer programs reinforces the foregoing finding regarding the quality of the programs. The highest mean responses (on a four point scale, i.e., those of 3.00 and above) highlight specific aspects of the program that were particularly valuable; these responses are as follows:

- program provided recreation for the child
- program provided socialization for the child
- program improved child quality of life
- program content was suited to the child
- program met the needs of the family
- program alleviated the stress of parenting
- program improved the family's quality of life
- overall quality of program was high

This constellation of items suggests the multidimensional aspect of the program and

its contribution to both the family and the child's quality of life.

When one decomposes the Consumer Satisfaction Scale and the Worker Evaluation Scale, it is quite evident that the scale items are clearly related, and that both scales tap parents' and service workers' experiences of such specific aspects of the program as, for example, staff skill and expertise, effectiveness of communication with parents, and suitability of program resources. Thus, although our study sample was quite small ( $n=24$ ) nonetheless, the foregoing findings do seem to reflect a genuine positive pattern of parental experience with the program; however, a pre-post program study with a larger sample might allow for more generalization of study findings. It appears nevertheless that although causality cannot be inferred, one could assume (cautiously) that the summer program reviewed in this study, as a form of family support, did assist study families' adjustment to the child's disability.

Still, the picture is far from clear. For example, the age of the study children (who were divided into two age cohorts) did *not* relate to parental burden, to consumer satisfaction, or to the impact of the program. Furthermore, overall consumer satisfaction did not relate to parental burden, a finding which suggests that parents with different levels of burden did not differ in their levels of satisfaction with the summer program.

The foregoing discussion of the findings from our study indicates the obvious complexity of the relationship between the variables examined; the possibility for interaction between the different variables seems endless. The disabled children all live and function within a context; in our study, the contexts were -- the family and the summer camp. In our study, the child was part of a family system of interacting units, and a social

system consisting of parents, family service workers and camp staff. Our study should make the dynamic interrelationship between the variables at work here obvious. We would need to exercise caution in drawing conclusions from our data. However, given that the traditional view has emphasized a chronic burden of care imposed upon families due to the presence of a disabled child, our findings do suggest the possibility of some relief from burden attributable to the summer camp program.



## Chapter Five

### CONCLUSION

The results of this investigation of the characteristics of burden and the relationship of burden and respite are both tentative and tantalizing -- tantalizing in the seeming myriad of suggestions for future research that emanate from the findings of this exploratory study.

The characteristics of burden that can be inferred, at least tentatively, from our study's findings challenge the assumption that burden is, of necessity, related to age, gender, type and severity of disability, and level of overall child problem behaviour. Furthermore, based on the results of this study one cannot assume that burden is related to parent characteristics such as parental age, level of education, level of family income, or type of parental employment. One of the most intriguing findings of our study was that of a relationship between employed mothers and several variables examined in the study. That is, mother's employment seemed to emerge as a noteworthy "thread" in the tapestry of interconnecting variables in this study. The findings are intriguing because employed mothers were related to a lower level of burden, a lower level of child problem behaviour, and to a positive sense of renewal and nurturance expressed by the parents due to the impact of the summer program. Conversely, and as if to "confound" one's expectations, mother's employment was not related to family income, type or level of disability, or age of the child. To delineate the relationships that have emerged so far in this study, future research should include information regarding family income exclusive of mothers' earnings from employment; furthermore, information should be included regarding whether the mothers are employed full-time or part-time. In conjunction with this

information, the additional social supports that may be available to the mothers, in addition to the camp program, should be described. Mothers' attitudes toward their occupations, and information about how "fulfilling" the mothers find their employment can provide valuable insights into an interpretation of the role of mothers' employment in the lives of families with a disabled child.

Concomitant with information about the social support available to employed mothers, the nature and quality of the marital dyad should be carefully assessed in future research, as current research findings point to the importance of the spousal relationship as a source of support and solace for both employed and unemployed mothers of disabled children. Other variables that may interact with mothers employment and which could be investigated in future research are the psychological strengths of the parents, the mothers' need for self-esteem and recognition, and the mothers' need for money. Furthermore, information on how long our study mothers have been employed is lacking. Thus there may be a "circularity" at work in the interpretation of our study findings because one cannot be certain whether mothers are employed because the burden of child care is perceived to be low, or whether employed mothers work to escape the burden of care and, as a result of being absent from the home perceive that their child care burden is low. Obviously, our study findings would be more generalizable if a pre-respite, and then a post-respite measure of burden had been possible. Future research should include both the "pre" and "post" respite burden measures.

Future research could also include information about the family's typology, i.e., their set of basic attributes which characterize and explain how the family system behaves, and hence their ability to cope with a stressor. Such information about family typology would

provide a clue to interpreting and predicting the health outcome for the disabled child within the family's "system".

The importance of the camp program as a source of respite for our study parents can be inferred from the findings. A further unifying "thread" in our tapestry of interrelated study variables was the focus by both parents and Family Services Workers on the camp program as a valuable source of integrated summer activity for this population of disabled children. Again, the obvious shortcoming of our study is that the initial pre-respite burden level was not available; furthermore, information regarding whether the initial burden level was relatively low anyway, prior to respite was also not available. Given the short duration of the summer program in this study, future research should be directed at longitudinal studies with a larger population of families in order to evaluate the intervention effect of the program on level of burden. Our study's retrospective measurement strategy limits the generalizability of our findings. However, at the same time, the findings point to both parents' concerns for appropriate activity for their children, along with parents' expressed satisfaction with the quality of the program and with the training and experience of the program staff. A suggestion for future research may be to differentiate between parents' statements of consumer satisfaction for a younger cohort versus an older cohort of children.

One could ponder whether the parents' focus on the desire for summer activities for their disabled children reflects a desire for "normalcy"; future research could tap the attitudes, hopes, dreams, aspirations of parents for their children's future. Perhaps the most valuable contribution of the present study is that the findings permit one to speculate that perhaps our study families did not perceive their disabled children to have a negative influence, and

pathological impact on their respective family systems. Perhaps one could conclude that within the context of our study population, our findings suggest a “redefinition” of the role of the disabled child within their family systems - a redefinition which implies that within these family systems, these children are not considered to be a burden!

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**Appendix 1**  
**Child Information**

**Appendix 1**

Table 1

**Age of Summer Program Participants**

Age of Child	Frequency	Percent
6	2	5.9
7	3	8.8
8	3	8.8
9	3	8.8
10	2	5.9
11	3	8.8
12	3	8.8
13	2	5.9
14	3	8.8
15	3	8.8
16	5	14.7
17	1	2.9
18	1	2.9
Total	34	100.0

Mean 12.8    Standard deviation 3.540

Table 2

**Disability of Child**

Developmental Delay..	64.7%
Cerebral Palsy.....	8.8%
Hearing Loss.....	2.9%
Vision Loss.....	5.9%
Autism.....	17.6%
Physical Disability.....	20.6%
Downs Syndrome.....	14.7%
Rett Syndrome.....	2.9%
Attention Deficit.....	11.8%
Lesch-Nyhan Syndrome	2.9%
Other.....	2.9%
Total cases	100%

**Table 3**  
**Number of Disabilities**

Number of Disabilities	Frequency	Percent
1	14	41.2
2	7	20.6
3	8	23.5
4	2	5.9
5	2	5.9
6	1	2.9
<b>Total</b>	<b>34</b>	<b>100.0</b>
	34	100.0

Mean = 2.235      Standard Deviation = 1.37199

**Table 4**  
**Sex of children in Summer Program**

Sex of Child	Frequency	Percent
Boy	20	58.8
Girl	14	41.2
<b>Total</b>	<b>34</b>	<b>100.0</b>

Table 5

**Length of Program Attendance**

<b>Time Length</b>	<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>
one week	3	8.8	9.4
two weeks	10	29.4	31.3
three weeks	2	5.9	6.3
four weeks	6	17.6	18.8
five weeks	2	5.9	6.3
six weeks	4	11.8	12.5
seven weeks	1	2.9	3.1
eight weeks	4	11.8	12.5
Total	32	94.1	100.0
missing	2	5.9	
Total	2	5.9	
	34	100.0	

Table 6

**Child Attended Camp Program Requested**

Attended Program Requested	Frequency	Percent	Valid Percent
Yes	30	88.2	96.8
No	1	2.9	3.2
Total	31	91.2	100.0
Missing	3	8.8	
	34	100.0	



Table 7

**Summer Camp Program Attended**

	Summer camp	Frequency	Percent	Valid Percent
	Y Camp Manitou	7	20.6	21.9
	City of Winnipeg	2	5.9	6.3
	City of Winnipeg adapted	1	2.9	3.1
	Holiday Adventures	2	5.9	6.3
	North YMCA	5	14.7	15.6
	St. Amant	1	2.9	3.1
	Camp Arnes	2	5.9	6.3
	Mini University	2	5.9	6.3
	Kimberly YMCA	1	2.9	3.1
	Unicity	1	2.9	3.1
	Fun and Fitness	1	2.9	3.1
	St. Boniface University	1	2.9	3.1
	Day Camp			
	R.E.A.C.H.	1	2.9	3.1
	YMCA on Fermor	3	8.8	9.4
	Bernie Wolfe School	1	2.9	3.1
	DK name	1	2.9	3.1
	Total	32	94.1	100.0
	NS	2	5.9	
Missing	Total	2	5.9	
Total		34	100.0	

Table 8

**Preferred Program Type**

Program	Frequency	Percent
Segregated	3	12.5
Integrated	21	87.5

Table 9

**Program Type Factor in Selection**

Value Label	Frequency	Percent
Yes	19	79.2
No	3	12.5
Missing	2	8.4

Table 10

**Family Services Workers Ranked Benefits of Summer Program (N=24)**

Benefits of Summer Program	Mean	Std Dev	Minimum	Maximum
PROVIDE RECREATION FOR CHILD	3.71	.55	2	4
SOCIALIZATION FOR CHILD	3.63	.58	2	4
SOCIALIZATION FOR CHILD	3.54	1.06	1	4
IMPROVED CHILD QUALITY OF LIFE	3.50	1.02	0	4
CONTENT SUITED TO CHILD	3.33	.70	2	4
MET NEED OF FAMILY	3.17	.76	1	4
ALLEVIATE STRESS OF PARENTING	3.04	.95	1	4
PARENTAL CHOICE	3.00	1.41	0	4
IMPROVED FAMILY QUALITY OF LIFE	2.92	1.06	0	4
DEGREE PROGRAM INTEGRATED	2.92	1.32	0	4
AVOID LOSS OF SKILLS	2.79	1.14	0	4
PROVIDE FAMILY WITH RESPITE	2.46	1.25	0	4
PARENTS SOCIALIZE WITH FRIENDS	2.33	1.17	0	4
IMPROVED CHILD FUNCTION WITHIN FAMILY	2.29	1.04	0	4

N.B. In all cases: Valid N=24.

**Appendix 2**  
**Parent Information**

**Appendix 2**

Table 11

**Fathers' Employment Status**

<b>Fathers Employed</b>	<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>
No	6	17.6	21.4
Yes	22	64.7	78.6
<b>Total</b>	<b>28</b>	<b>82.4</b>	<b>100.0</b>

Table 12

**Mothers' Employment Status**

<b>Mothers Employed</b>	<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>
No	12	35.3	38.7
Yes	19	55.9	61.3
<b>Total</b>	<b>31</b>	<b>91.2</b>	<b>100.0</b>

Table 13

**Father's Education Level**

Level of Education	Frequency	Percent	Valid Percent
elementary	0	0	0
partial high school	3	8.8	10.7
completed high school	5	14.7	17.9
community college/technical school	8	23.5	28.6
some university/no degree	3	8.8	10.7
one university degree	6	17.6	21.4
more than one university degree	2	5.9	7.1
other	1	2.9	3.6
missing	6	17.6	missing
<b>Total</b>	<b>n=34</b>		

Table 14

## Mother's Education Level

Level of Education	Frequency	Percent	Valid Percent
elementary	0	0	0
partial high school	4	11.8	12.9
completed high school	8	23.5	25.8
community college/technical school	10	29.4	32.3
some university/no degree	3	8.8	9.7
one university degree	5	14.7	16.1
more than one university degree	0	0	0
other	1	2.9	3.2
missing	31		
Total	n= 34		

Table 15

**Fathers' Occupation**

Occupation	Frequency	Percent	Valid Percent
Professional	8	23.5	33.3
Skilled craftsman	2	5.9	8.3
Service	4	11.8	16.7
Labourer	9	26.5	37.5
Retired	1	2.9	4.2
Missing	10	29.4	
	34	100.0	

Table 16

**Mothers' Occupation**

Occupation	Frequency	Percent	Valid Percent
Professional	7	20.6	25.0
Skilled craftsman	2	5.9	7.1
Service	4	11.8	14.3
Labourer	4	11.8	14.3
Clerical	4	11.8	14.3
Homemaker	7	20.6	25.0
Total	28	82.4	100.0
Missing	6	17.6	
	34	100.0	



Table 17  
**Family Income Per Year**

Income Level	Frequency	Percent	Valid Percent	Cumulative Percent
1) Under \$10,000	1	2.9	3.3	3.3
2) \$10,000-\$20,000	3	8.8	10.0	13.3
3) \$20,000-\$30,000	3	8.8	10.0	23.3
4) \$30,000-\$40,000	5	14.7	16.7	40.0
5) \$40,000-\$50,000	8	23.5	26.7	66.7
6) \$50,000-\$60,000	1	2.9	3.3	70.0
7) \$60,000-\$70,000	3	8.8	10.0	80.0
8) \$70,000-\$80,000	2	5.9	6.7	86.7
9) \$80,000-\$90,000	1	2.9	3.3	90.0
10) \$90,000-\$100,000	1	2.9	3.3	93.3
11) Over \$100,000	2	5.9	6.7	100.0
NS	4	11.8	missing	
Total	34	100.0	100.0	

Table 18  
Number of Children

Number of Children	Frequency	Percent	Valid Percent	Cumulative Percent
1 Child	4	11.8	12.9	12.9
2 Children	12	35.3	38.7	51.6
3 Children	6	17.6	19.4	71.0
4 Children	6	17.6	19.4	90.3
5 Children	2	5.9	6.5	96.8
7+ Children	1	2.9	3.2	100.0
Missing	3	8.8		
Total	34	100.0		

Table 19  
Birth Order

	Frequency	Percent	Valid Percent
1	10	29.4	33.3
2	7	20.6	23.3
3	10	29.4	33.3
4	1	2.9	3.3
6	1	2.9	3.3
7	1	2.9	3.3
Missing	4	11.8	
Total	34	100.0	

**Appendix 3**  
**Letter of Study Introduction**

Dear

Children's Special Services is interested in learning about the experiences of families who receive support services. In particular, we are interested in learning whether support services are effective in meeting the needs of families; what positive experiences or problems families may have encountered; as well as understanding families' ideas for improvements.

Children's Special Services is currently sponsoring an *evaluation of summer recreation experiences*. The specific purposes of the evaluation are to:

- learn more about the reasons families use summer recreation experiences for their child(ren);
- identify the elements which help to make summer recreation experiences positive and useful for families and children; and
- find out where problems might have occurred and explore ways of solving them.

The evaluation will be conducted by graduate student researchers from the Faculty of Social Work of the University of Manitoba. The researchers are under the supervision of the Faculty of Social Work, and are trained to carry out this type of evaluation. All information collected during the evaluation will be kept in the strictest confidence and Family Service Workers or Children's Special Services will not be informed as to whether you chose or did not choose to participate in the research. In addition, once a final report is prepared, any information a family may have provided will be destroyed.

*In the near future, I will be calling to ask if you would be interested in participating in the evaluation. This request is completely voluntary. If you agree, I will ask your permission to refer your name and telephone number to the Faculty of Social Work researchers. If you decline to participate in the evaluation, your name will be deleted from the participants' list and no one will call you.*

If you do agree to participate in the evaluation, a researcher from the Faculty of Social Work will call to arrange a meeting with you. The researcher will ask to meet you in your home and will have a standard set of questions which may take an hour (or less). Any information you provide will be treated with respect and confidence. No family will be identified in any way and you may choose not to answer any questions even if you agree to participate in the evaluation.

If you have any questions, please feel free to call me at

Thank you for considering this request.

Sincerely,

Family Service Worker

**Appendix 4**  
**Letter of Consent**

**Interview Consent Form**  
**Evaluation of The Summer Program for Children with Disabilities**

I understand that this study involves interviewing parents of children with disabilities who attended the summer recreational programs. The main intent of the study is to assess the strengths and weaknesses of the summer program attended by children during the summer of 1994. The study will also explore some of the issues related to child care burden and family resources.

I am willing to be interviewed in my home. I understand that the interview will take approximately one hour of my time. If I do agree to this interview now, I know that I can stop at any time I want to. I know that I can choose to not answer a specific question if I do not want to.

I understand that this research is being conducted through the University of Manitoba and is independent of the Provincial Department of Family Services. I understand that the information provided about our experience with the summer program will remain confidential and will not be shared with my family services worker. I understand that Children's Special Services and my social worker will not be advised of my decision to participate or to not participate in this study.

I am prepared to have the researchers contact my family services worker to review file information regarding my child's participation in the summer recreation program. I know that all information collected will be protected as strictly confidential and will not be released except as general information as part of the program evaluation. That is, I know that no one person or family will be identified in any of the information stored in research files or released as a study report.

I have read this form and I have had an opportunity to ask the interviewer any questions I have. I am willing to participate in the study.

Parent: \_\_\_\_\_ (Please print)

Interviewer: \_\_\_\_\_

Date (DD/MM/YY) \_\_\_\_\_

**Appendix 5**  
**Parent Survey Questionnaire**



Family ID \_\_\_\_\_

Interview ID \_\_\_\_\_

Date \_\_\_\_\_

Interview with:

Mother \_\_\_\_\_  
Father \_\_\_\_\_  
Both \_\_\_\_\_  
Other \_\_\_\_\_

1. First name of child \_\_\_\_\_

2. Date of Birth \_\_\_\_\_  
Day Month Year

3. Is your child a (Circle number of your answer)

- 1 BOY
- 2 GIRL

4. What disability best describes this child?

- \_\_\_\_\_ developmental delay
- \_\_\_\_\_ cerebral palsy
- \_\_\_\_\_ emotional disturbance (e.g. hyperkinetic)
- \_\_\_\_\_ epilepsy
- \_\_\_\_\_ hearing loss
- \_\_\_\_\_ vision loss
- \_\_\_\_\_ autism
- \_\_\_\_\_ physical disability
- \_\_\_\_\_ other (specify) \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

\_\_\_\_\_ don't know

5. In your view:

TO WHAT EXTENT WILL THIS CHILD'S DISABILITY AFFECT HIS/HER MENTAL OR INTELLECTUAL DEVELOPMENT?

Not at all	Mildly	Moderately	Severely
1	2	3	4

TO WHAT EXTENT WILL THE DISABILITY AFFECT PHYSICAL DEVELOPMENT?

Not at all	Mildly	Moderately	Severely
1	2	3	4

TO WHAT EXTENT WILL ONGOING SPECIALIZED MEDICAL ATTENTION BE REQUIRED?

Not at all	Mildly	Moderately	Severely
1	2	3	4

HOW MUCH ASSISTANCE WILL THIS CHILD REQUIRE OVER THE YEARS TO PERFORM EVERYDAY ACTIVITIES LIKE EATING, BATHING, TOILETING?

Not at all	Mildly	Moderately	Severely
1	2	3	4

## INFORMATION ON SUMMER PROGRAM

1. First, what were your reasons for using a summer program? \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

2. What program did your child attend? \_\_\_\_\_

3. For what length of time? \_\_\_\_\_

4. Were you able to enrol your child in the program you wanted? \_\_\_\_\_

5. Why did you choose this program? \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

6. How important were the following factors in using a summer program? (use the same scale as above)

	4 Very Important	3 Important	2 Slightly Important	1 Not Important
a) It provided child care so parent could attend work				_____
b) It provided socialization for child				_____
c) It provided physical development for child				_____
d) It provided recreation for the child				_____
e) It provided me with a break from child care duties				_____
f) It allowed me to attend to my other children				_____
g) Any other reasons (please mark on scale of importance)				_____

6. The program provided time for extra rest and sleep.

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

7. The program provided you with more time for yourself.

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

8. The program encouraged the independence of your disabled child.

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

9. The program allowed your child to meet more non-family members.

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

10. The summer program improved family harmony.

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

11. The program improved your child's ability to take part in games.

1	2	3	4
Strongly Disagree	Disagree	Agree	Strongly Agree

12. The program enabled you to spend extra time with your other children.

1	2	3	4
Strongly Disagree	Disagree	Agree	Strongly Agree

13. The program allowed you to devote time to your spousal relationship.

1	2	3	4
Strongly Disagree	Disagree	Agree	Strongly Agree

PARENT SATISFACTION WITH SUMMER PROGRAM  
QUESTIONNAIRE

We have some questions about your child's participation in the summer program. We are interested in your honest opinions, whether they are positive or negative. Please answer all of the questions.

YOUR FIRST REACTION TO EACH QUESTION SHOULD BE YOUR ANSWER.

Please mark the degree to which you agree or disagree with the following statements by circling the number which best matches how you feel.

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

1. The summer program had a positive effect on the whole family.

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

2. My child strengthened his/her self-help skills at the summer program (such as feeding, and dressing him/herself).

1	2	3	4
Strongly disagree	Disagree	Agree	Strongly Agree

3. The summer program improved your disabled child's functioning within the family.

1	2	3	4
Strongly Disagree	Disagree	Agree	Strongly Agree

4. The summer program relieved the strain that your disabled child places on you.

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

5. The program allowed you time for socializing with friends and relatives.

1	2	3	4
Strongly Agree	Agree	Disagree	Strongly Disagree

14. The program helped me to cope better with the care needs of my child.

1	2	3	4
Strongly Disagree	Disagree	Agree	Strongly Agree

15. I think summer programs help children stay at home and out of special settings such as institutions or group homes.

1	2	3	4
Strongly Disagree	Disagree	Agree	Strongly Agree

16. Did you get the type of recreational program you wanted for your child?

4	3	2	1
No definitely not	No not really	Yes generally	Yes definitely

17. To what extent did the program meet the needs of your family?

4	3	2	1
Almost all of our needs were met	Most of our needs were met	Only a few of our needs were met	None of our needs were met

18. If a friend were in need of a similar summer activity for a child with a disability would you recommend this summer program?

4	3	2	1
No definitely not	No I don't think so	Yes I think so	Yes definitely

19. How satisfied were you with the length of time your child spent at the summer program?

4	3	2	1
Quite dissatisfied	Mildly dissatisfied	Mostly satisfied	Very satisfied

20. If you were to use a summer program again, would you use this same program?

4	3	2	1
No definitely not	No I don't think so	Yes I think so	Yes definitely

21. Do you think the program staff were knowledgeable about the special needs of children with disabilities?

4	3	2	1
No definitely not	No I don't think so	Yes I think so	Yes definitely

22. Do you think the program staff had the necessary expertise to work with children with disabilities?

4	3	2	1
No I don't think so	Possibly	Yes, they had some expertise	They were very skilled

23. Was the program able to provide suitable recreational activities for your child?

4	3	2	1
Yes definitely	Yes I think so	No I don't think so	No definitely not

24. Do you think the summer program provided your child with an opportunity to enhance his/her physical development?

4	3	2	1
Yes it has helped a great deal	Yes it helped helped somewhat	No it really didn't help	No it seemed to make things worse

25. How would you rate the overall quality of the summer program?

4	3	2	1
Excellent	Good	Fair	Poor

26. You were satisfied with that level of quality for the summer program?

4	3	2	1
Definitely yes	Yes somewhat	No not really	No definitely not

27. Do you think the summer program introduced you to new recreational resources for you and your family?

4	3	2	1
Yes it has	Yes somewhat	No I don't think so	No definitely not

28. In an overall, general sense, how satisfied were you with the summer program?

4  
Very  
satisfied

3  
Mostly  
satisfied

2  
Mildly  
satisfied

1  
Quite  
satisfied

29. Were you satisfied with the communications between the summer program staff and yourself?

4  
Yes I was

3  
Yes somewhat

2  
No I wasn't

1  
No definitely  
not



Please rank these alternative choices according to what would be highest priority to lowest priority for you right now in taking care of your disabled child:

- \_\_\_\_\_ transportation assistance
- \_\_\_\_\_ cash assistance program
- \_\_\_\_\_ crisis respite services
- \_\_\_\_\_ regular respite services
- \_\_\_\_\_ advice regarding access to services for your disabled child
- \_\_\_\_\_ medical care for your child
- \_\_\_\_\_ marital counselling to assist parents
- \_\_\_\_\_ family counselling to help home situation
- \_\_\_\_\_ housekeeping service to help with household chores
- \_\_\_\_\_ professional advice in regard to financial planning
- \_\_\_\_\_ summer recreational program for your disabled child

What is father's age? \_\_\_\_\_

What is mother's age? \_\_\_\_\_

Are you presently married?

	1	NO	-----	Single Parent
	---	2	YES	1 YES
				2 NO

In this section, please describe your reaction to the following questions.

30. Did the program have a positive or negative impact on you and your family, and if so, how?
31. Did the program increase or decrease the stress of caring for your disabled child?
32. Did the summer program improve the "quality of life" for you and your family. Please explain.
33. Do you think the program staff had a positive attitude or a negative attitude towards children with disabilities?
34. Could you please identify what you liked the most, and what you liked the least about the summer program.
35. What other types of summer programs would you like to see made available to you and your family in the future?
36. Do you think the program staff were supportive and helpful to your child?

What is father's level of education?

- 1 ELEMENTARY
  - 2 PARTIAL HIGH SCHOOL
  - 3 COMPLETED HIGH SCHOOL
  - 4 COMMUNITY COLLEGE/TECHNICAL SCHOOL
  - 5 SOME UNIVERSITY/NO DEGREE
  - 6 ONE UNIVERSITY DEGREE
  - 7 MORE THAN ONE UNIVERSITY DEGREE
  - 8 OTHER (please specify)
- 

What is mother's level of education?

- 1 ELEMENTARY
  - 2 PARTIAL HIGH SCHOOL
  - 3 COMPLETED HIGH SCHOOL
  - 4 COMMUNITY COLLEGE/TECHNICAL SCHOOL
  - 5 SOME UNIVERSITY/NO DEGREE
  - 6 ONE UNIVERSITY DEGREE
  - 7 MORE THAN ONE UNIVERSITY DEGREE
  - 8 OTHER (please specify)
- 

Are you currently employed?

Father

- 1 NO
- 2 YES

Mother

- 1 NO
- 2 YES

What is your principal occupation?  
Please specify: \_\_\_\_\_

---

\_\_\_\_\_  
\_\_\_\_\_

---

How many children do you have in total? (circle number)

- 1
- 2
- 3
- 4
- 5
- 6
- 7 OR MORE

What is the number in order of birth of your handicapped child?

- 1 FIRST CHILD
- 2 SECOND CHILD
- 3 THIRD CHILD
- 4 FOURTH CHILD
- 5 FIFTH CHILD
- 6 SIXTH CHILD
- 7 LAST CHILD

Last year what was your total gross family income (before deductions and income tax)?

- 1 UNDER \$10,000
- 2 \$10,000 - \$20,000
- 3 \$20,000 - \$30,000
- 4 \$30,000 - \$40,000
- 5 \$40,000 - \$50,000
- 6 \$50,000 - \$60,000
- 7 \$60,000 - \$70,000
- 8 \$70,000 - \$80,000
- 9 \$80,000 - \$90,000
- 10 \$90,000 - \$100,000
- 11 OVER \$100,000

**Section P11 — BEHAVIOR PROBLEMS INDEX**

**CHECK  
ITEM 24**

*Refer to age of sample child.*

- 1  Under 5 years old (Cover Page)  
2  5+ years old (Intro)

**INTRO:**

Now I am going to read some statements that describe the behavior of many children. Please tell me whether each statement has been **OFTEN** true, **SOMETIMES** true, or **NOT** true of — during the past 3 months?

The first statement is: "Has sudden changes in mood or feelings." Has that been **OFTEN** true, **SOMETIMES** true, OR **NOT** true of — in the past 3 months.

*Record response and continue with statement 2.*

*Read list repeating categories and/or time reference as needed.*

	Often true (a)	Sometimes true (b)	Not true (c)
1. Has sudden changes in mood or feelings.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
2. Feels or complains that no one loves —.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
3. Is rather high strung, tense, or nervous.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
4. Cheats or tells lies.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
5. Is too fearful or anxious.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
6. Argues too much.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
7. Has difficulty concentrating, cannot pay attention for long.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
8. Is easily confused, seems to be in a fog.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
9. Bullies, or is cruel or mean to others.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
10. Is disobedient at home.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
11. Is disobedient at school.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
12. Does not seem to feel sorry after — misbehaves.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
13. Has trouble getting along with other children.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
14. Has trouble getting along with teachers.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
15. Is impulsive, or acts without thinking.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
16. Feels worthless or inferior.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
17. Is not liked by other children.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
18. Has a lot of difficulty getting — mind off certain thoughts, has obsessions.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
19. Is restless or overly active, cannot sit still.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
20. Is stubborn, sullen, or irritable.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
21. Has a very strong temper and loses it easily.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
22. Is unhappy, sad or depressed.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
23. Is withdrawn, does not get involved with others.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
<i>If child is 12+ years old, go to 29.</i>			
24. Breaks things on purpose, deliberately destroys — own or others' things.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
25. Clings to adults.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
26. Cries too much.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
27. Demands a lot of attention.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
28. Is too dependent on others.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
<i>If child is under 12 years, go to Cover Page</i>			
29. Feels others are out to get —.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>

**Section P11 — BEHAVIOR PROBLEMS INDEX — Continued**

	Often true (a)	Sometimes true (b)	Not true (c)	
30. Hangs around with kids who get into trouble.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	103
31. Is secretive, keeps things to [himself/herself].	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	103
32. Worries too much.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	104

Notes

**Appendix 6**  
**Family Services Worker Questionnaire**

Date \_\_\_\_\_

Family ID \_\_\_\_\_

Worker ID \_\_\_\_\_

Interviewer ID \_\_\_\_\_

## FAMILY SERVICES WORKER QUESTIONNAIRE

Please answer the following questions as they relate to this specific child and his/her family.

1. Name of Child \_\_\_\_\_

2. Date of Birth \_\_\_\_\_

3. How long have you known this child and his/her family?

\_\_\_\_\_

4. What summer program did this child attend? \_\_\_\_\_

5. For what length of time? \_\_\_\_\_

6. How important were the following factors in your assessment of this family's need for a summer recreational activity for their child?

A) Child care for a parent to attend work.

4	3	2	1	0
Very Important	Important	Somewhat Important	Not important	Not a Factor

B) Socialization for the disabled child.

4	3	2	1	0
Very Important	Important	Somewhat Important	Not important	Not a Factor

C) Continuation of programming to avoid the loss of skills acquired during the school year.

4	3	2	1	0
Very Important	Important	Somewhat Important	Not important	Not a Factor



D) The availability of transportation to and from the program.

4	3	2	1	0
Very Important	Important	Somewhat Important	Not important	Not a Factor

E) To provide the family with some respite.

4	3	2	1	0
Very Important	Important	Somewhat Important	Not important	Not a Factor

F) To provide recreation for the child.

4	3	2	1	0
Very Important	Important	Somewhat Important	Not important	Not a Factor

G) To alleviate some of the stress of parenting a child with disabilities.

4	3	2	1	0
Very Important	Important	Somewhat Important	Not important	Not a Factor

H) The degree to which the program was integrated.

4	3	2	1	0
Very Important	Important	Somewhat Important	Not important	Not a Factor

I) Were there any other reasons? Please specify and rank from 4 to 1.

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---

---

7. How important were the following factors in the selection of a specific summer program for this child.

A) Parental choice.

4	3	2	1	0
Very Important	Important	Somewhat Important	Not important	Not a Factor

Please indicate what, if any, factors were important in the parent's choice.

---

---

B) Other siblings were attending the program.

4	3	2	1	0
Very Important	Important	Somewhat Important	Not important	Not a Factor

C) The physical setting was appropriate for the unique needs of this child.

4	3	2	1	0
Very Important	Important	Somewhat Important	Not important	Not a Factor

D) The program was close to home.

4	3	2	1	0
Very Important	Important	Somewhat Important	Not important	Not a Factor

E) The program was wheelchair accessible.

4	3	2	1	0
Very Important	Important	Somewhat Important	Not important	Not a Factor

F) The program was affordable.

4	3	2	1	0
Very Important	Important	Somewhat Important	Not important	Not a Factor

G) The content of the program seemed to be most suited to the needs of the child.

4	3	2	1	0
Very Important	Important	Somewhat Important	Not important	Not a Factor

H) Were there any other reasons? Please be specific.

---

---

### FAMILY SERVICES WORKER EVALUATION OF SUMMER PROGRAM

8. To what extent did the program meet the needs of this family?

4	3	2	1	0
Almost all of their needs were met	Most of their needs were met	Only a few of their needs were met	None of their needs were met	Not a factor

9. If you were to seek this kind of service again for this child, would you use the same program?

4	3	2	1	0
No definitely not	No I don't think so	Yes	Yes, definitely	Not a factor

10. Were the program staff knowledgeable about the special needs of children with disabilities?

4	3	2	1	0
No definitely not	No I don't think so	Yes, but just adequately	Yes and exceeded usual expectations	Not a factor

11. Do you think the program staff had the necessary skills to work with children with disabilities?

4	3	2	1	0
No definitely not	No I don't think so	Yes, but just adequately	Yes and exceeded usual expectations	Not a factor

12. Was the program able to adapt the recreational activities to allow this child optimal participation?

4	3	2	1	0
No definitely not	No I don't think so	Yes, but just adequately	Yes and exceeded usual expectations	Not a factor

13. Do you think the summer program introduced this child to new recreational resources?

4	3	2	1	0
No definitely not	No I don't think so	Yes	Yes, definitely	Not a factor

In your estimation, what was the effect of the summer program on the following areas of family functioning.

A. The summer program relieved the strain that the disabled child placed on the family.

4	3	2	1	0
Strongly disagree	Disagree	Agree	Strongly agree	Not applicable

B. The summer program provided the parents with time for extra rest and sleep.

4	3	2	1	0
Strongly disagree	Disagree	Agree	Strongly agree	Not applicable

C. The program provided the parents with more time for themselves.

4	3	2	1	0
Strongly disagree	Disagree	Agree	Strongly agree	Not applicable

D. The program enabled parents to spend extra time with their other children.

4	3	2	1	0
Strongly disagree	Disagree	Agree	Strongly agree	Not applicable

E. The program allowed each parent to donate time and energy to their spousal relationship.

4	3	2	1	0
Strongly disagree	Disagree	Agree	Strongly agree	Not applicable

F. The program helped parents to cope better with the care needs of the disabled child.

4	3	2	1
Yes it helped a great deal	Helped somewhat	No it did not help	No definitely not

G. The program provided the child with an opportunity to develop his/her social skills.

4	3	2	1
Yes it helped a great deal	Helped somewhat	No it did not help	No definitely not

H. The program enabled the child to develop or enhance his/her physical development.

4	3	2	1
Yes it helped a great deal	Helped somewhat	No it did not help	No definitely not

I. The program helped with the continuation of programming to avoid the loss of skills.

4	3	2	1
Yes it helped a great deal	Helped somewhat	No it did not help	No definitely not

J. The summer program improved the quality of life of the family.

4	3	2	1
Yes it helped a great deal	Helped somewhat	No it did not help	No definitely not

K. The summer program improved the quality of life of the disabled child.

4	3	2	1
Yes it helped a great deal	Helped somewhat	No it did not help	No definitely not

**L** Attendance at the camp strengthened the disabled child's self-help skills (e.g. feeding, and dressing).

<b>4</b> Yes it helped a great deal	<b>3</b> Helped somewhat	<b>2</b> No it did not help	<b>1</b> No definitely not
---	-----------------------------	-----------------------------------	----------------------------------

**M.** The program appeared to improve the disabled child's functioning within the family.

<b>4</b> Yes it helped a great deal	<b>3</b> Helped somewhat	<b>2</b> No it did not help	<b>1</b> No definitely not
---	-----------------------------	-----------------------------------	----------------------------------

**N.** The program allowed time for parents to socialize with friends.

<b>4</b> Yes it helped a great deal	<b>3</b> Helped somewhat	<b>2</b> No it did not help	<b>1</b> No definitely not
---	-----------------------------	-----------------------------------	----------------------------------

**O.** The program allowed the parent(s) to maintain employment outside the home.

<b>4</b> Yes it helped a great deal	<b>3</b> Helped somewhat	<b>2</b> No it did not help	<b>1</b> No definitely not
---	-----------------------------	-----------------------------------	----------------------------------

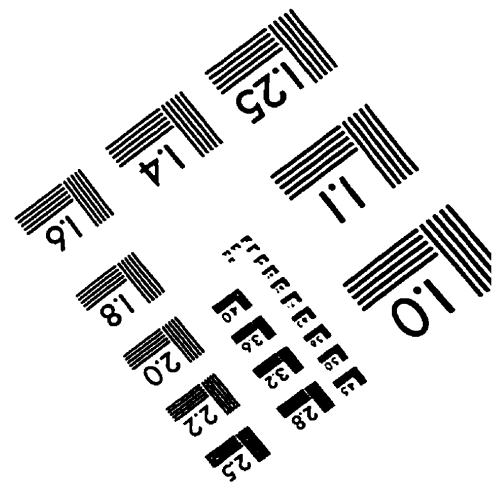
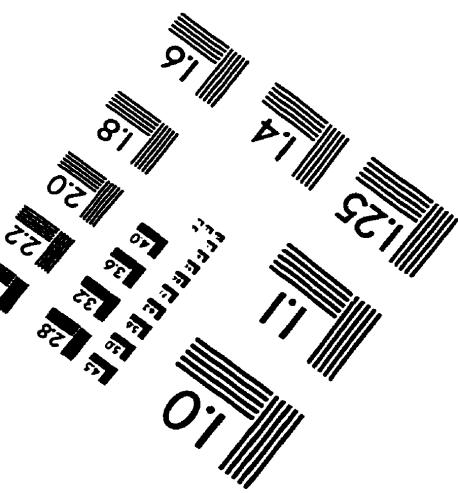
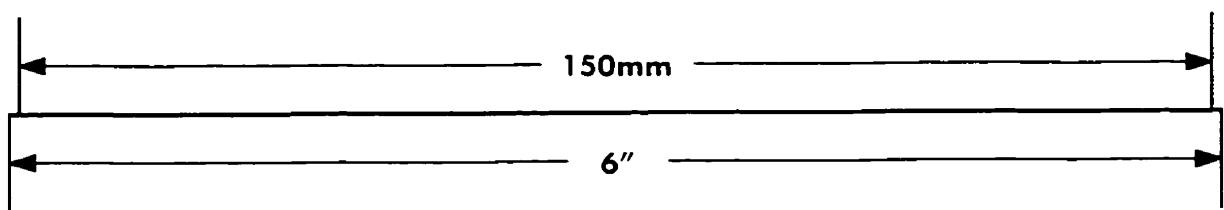
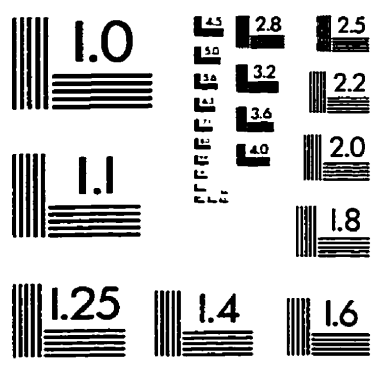
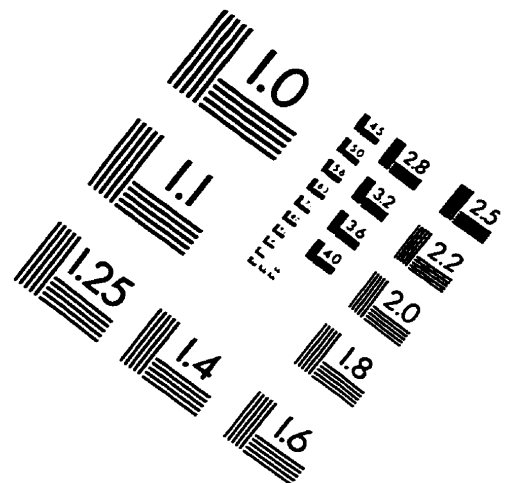
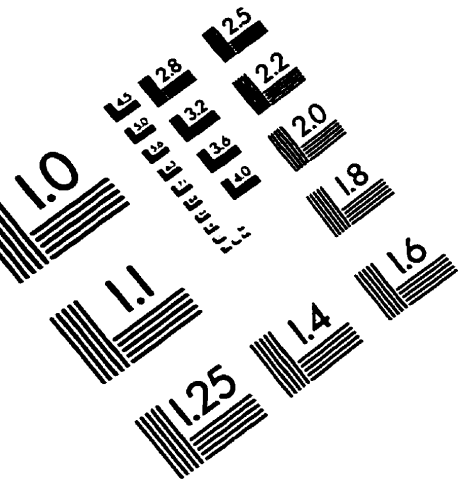
**P.** What type of program was preferable for this child - segregated or integrated?

---

Please explain why.

**Q.** Was the summer program type, that is segregated or integrated, a factor in the selection of a summer program for this child?

# IMAGE EVALUATION TEST TARGET (QA-3)



APPLIED IMAGE, Inc  
1653 East Main Street  
Rochester, NY 14609 USA  
Phone: 716/482-0300  
Fax: 716/288-5989

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