

Relationship of Selected Demographic  
Factors and Parents' Perception of Need  
in Raising and Educating Severely or  
Profoundly Mentally Handicapped  
Children

by

Klara Margaret Somogyi

A thesis submitted in partial  
fulfillment of the requirements for  
the degree of Master of Education  
in the Department of Educational Psychology  
University of Manitoba



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RELATIONSHIP OF SELECTED DEMOGRAPHIC FACTORS AND  
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KLARA MARGARET SOMOGYI

A thesis submitted to the Faculty of Graduate Studies of  
the University of Manitoba in partial fulfillment of the requirements  
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MASTER OF EDUCATION

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## ABSTRACT

This study examined the relationship between selected demographic variables and parents' perceptions of need in raising and educating their severely or profoundly mentally handicapped children. 110 respondents were requested to return completed questionnaires which were distributed through a major school division in Winnipeg. Follow-up interviews were conducted with some of the respondents.

The selected demographic variables were as follows: (1) having a mentally handicapped child as well as non-handicapped children, (2) age of parents, (3) single or dual parent families, (4) Catholic or non-Catholic, and (5) socio-economic status of parents.

The survey questionnaire consisted of 8 categories of need including: (1) Need for Information, (2) Educational Need, (3) Need for Support, (4) Need for Explaining to Others, (5) Community Service Needs, (6) Financial Need, (7) Family Functioning Need, and (8) Future Need.

The data based on the statistical analysis using Mann-Whitney U Test showed that some parental needs related to demographics followed the expectations hypothesized based on the literature. No significant difference of need was indicated in any category for parents having a mentally

handicapped child as well as non-handicapped children. Older mothers indicated higher frequency of need in the categories of "Future Need" and "Need for Explaining to Others". Single parents indicated higher frequency of need in the categories of "Need for Support", "Need for Explaining to Others", and "Financial Need". Non-Catholic mothers indicated higher frequency of need in the category of "Need for Community Services". Non-Catholic fathers indicated a higher frequency of need in the categories of "Need for Support", "Community Service Need", "Family Functioning", "Financial Need", and "Future Need". The component variables comprising socio-economic status include mother's and father's occupation and mother's and father's level of schooling and family income. Mothers of low status occupations indicated a higher frequency of need in the "Need for Support" and "Need for Explaining to Others" categories. Mothers who are not high school graduates indicated high frequency of need in "Explaining to Others" and "Financial Need" categories. Fathers who are not high school graduates indicated high frequency of need in the "Explaining to Others" category only. Parents with low income levels indicated a higher frequency of need in the "Explaining to Others", "Financial Need" and "Family Functioning" categories.

An important feature of the data was the overriding need for parents to "Explain to Others". This need cut across all demographic variables.

The descriptive findings based on frequency of high need responses indicated parents concerns included the following: (1) future needs, (2) services presently available, (3) mentally handicapped child's independent living skills, (4) extra-curricular programs which appropriately meet needs of mentally handicapped child, (5) how to handle child's behavior, (6) reading material about other parents who have a similar child, (7) child's educational program, and (8) how to teach my mentally handicapped child.

Recommendations and educational implications focus on the issue of providing information to professionals, researchers and policy makers about parental need to fulfil legislation and to plan effective, co-operative educational programs.

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IN LOVING MEMORY OF LOUIS SOMOGYI

1925-1983

A FATHER WHO INSTILLED IN HIS DAUGHTERS

AN APPRECIATION FOR

THE VALUE OF EDUCATION AND

THE POWER OF KNOWLEDGE

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## CHAPTER I

### INTRODUCTION

"The field of mental retardation is a window  
through which to study our society."

(Sarason & Doris, 1979, p. 17)

#### Background Information

The normalization principle has emerged over the past four decades and has been a major factor in changing society's treatment of mentally handicapped individuals. The philosophy of normalization was developed by Bank-Mikkelsen and Bengt Nirje in Scandinavia during the 1950s and has been defined as "making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society" (Nirje, 1969, p. 181). The conditions of everyday life referred to include those in the living, working and leisure environment of mentally handicapped individuals.

The influence of the philosophy of normalization is evident from the changes in direction of public policy and legislation in recent years. For example, the Canadian Charter of Rights and Freedoms, Section 15, grants

equality of rights for all individuals including "the right of equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, nationality or ethnic origin, colour, religion, sex, age or mental or physical disability".

The Manitoba Public Schools Act also reflects evidence of the influence of the normalization philosophy. This act requires that "every school board shall provide or make provisions for education in Grades 1 to 12 inclusive for all resident persons who have the right to attend school". Section 14[4] of the Act constitutes mandatory legislation for school divisions/districts to provide education programs for all children including those children with special learning needs.

In the past, society expected parents to institutionalize their mentally handicapped child, but more recently expectations have changed and parents are now encouraged to have these children raised at home and educated in the community.

The changes brought about in the delivery of services to the mentally handicapped through the influence of normalization and integration into the regular classroom have also had a major impact on the parents of mentally handicapped children and the way in which they relate to their children. Greater demands are placed on parents by the requirements to raise their

mentally handicapped children at home and educate them in the community. Parents have been forced to respond to these new demands but the response may not always have been advantageous for the children nor successful for the family. There is growing evidence that an unforeseen side-effect of the philosophy of normalization is the increase strain on the family unit especially for those families already suffering from stress because of the presence in the family of a child with a severe mental handicap.

The increased role of parents under the philosophy of normalization is also apparent in the changes to the Public Schools Act (Section 41[4]) which states:

"For students with special needs this means that . . . the program planning process will involve a team approach, the team consisting of all those who have information that is relevant to the student--parents, educators, support personnel and students if possible."

(Section 41[4], p. 34)

This section of the Public Schools Act reflects recent trends in educational philosophy which stress the importance of examining parental roles and parental needs in raising and educating mentally handicapped children (Patton, Beirne-Smith & Payne, 1990; Gallagher, 1989). Some studies have suggested Individualized Family Service Plans (IFSP) which have been

legislated in the United States of America by Public Law 99-457 a 1986 Amendment to the Education for All Mentally Handicapped Children Act. This act mandates services for parents and families as well as the handicapped child (Krauss, 1990).

The consultative-collaborative model, which has evolved to some degree as a result of the philosophy of normalization is espoused in the current educational philosophy (Fox, 1988; Barley, 1987; Cone, Delawyer & Wolfe, 1985; Winton & Turnbull, 1981; Beckman-Bell, 1981). This model suggests collaborative goal setting between parents and the educational team to program effectively for the mentally handicapped child. The assumption of the model, being that, parents would more likely invest in a goal or activity for which they themselves provide input. On the other hand, professionals require adequate information about parental needs and family functioning in order to consult and collaborate effectively.

Critical to the implementation of the consultative-collaborative model is the concept that parental perceptions of needs and problems are assessed as well as professional perceptions. Once professionals have a clear idea about parents needs and problems in raising and educating a severely mentally handicapped child, professionals can contribute more effectively and

realistically to collaborative goal setting for the educational programming of the child.

The principle of normalization has influenced legislation, public policy and educational policy for mentally handicapped in such a way as to give parents greater responsibility for the care of their children and the opportunity to become more involved in the implementation of that policy. It has become increasingly evident that the role of parents is central to the effective delivery of services as more mentally handicapped children are being raised at home and educated in the community. It has become essential to know how parents are coping with the demands of their new role and the expectations placed on them by the community-based service delivery model.

A review of the research literature, however, reveals a lack of information about how parents of children with severe mental handicap feel about issues central to the effective delivery of services. A survey of the literature also identifies the fact that parents of the severely mentally handicapped are faced with extraordinary demands that few can imagine and fewer still can understand. A major impediment to the delivery of effective services by professionals responsible for working with parents in a new co-operative relationship is the lack of understanding of the problems parents face. There is a need for professionals involved with children with severe

mental retardation to be better informed of the attitudes of parents, their perceptions of the problems and their expressed needs. In identifying the problems and needs of parents it would be necessary to take into account specific demographic factors that may have a bearing on the responses of parents to their perceptions of their own problems and needs.

To obtain information related to the perception of parents of severely mentally retarded children regarding their problems and needs a census was taken of the population in the Winnipeg School Division #1 in which parents were asked to respond to specific questions dealing with the following areas of need: need for information, educational need, need for support, need for explaining to others, community service need, financial need, need for family functioning and future need. It is anticipated that the results will be useful in helping professionals, researchers and policy makers to understand parental need and involve them more effectively in co-operative planning. The results should also be useful in developing more extensive public policy and more effective educational programming for mentally handicapped children and their parents.

### Problem Statement

The principle of normalization has influenced legislation, public policy and educational policy for mentally handicapped children. Parents of mentally handicapped children are faced with changed expectations to raise their children at home and educate them in the community. While there is evidence that some parents successfully care for their mentally handicapped child at home more research is necessary to understand more fully the problems and extraordinary demands faced by parents experiencing difficulties. It is necessary to identify parents' perceptions of need in providing adequate care and education for their mentally handicapped children.

### Purpose of the Study

- I. There are two main purposes of the study: to identify the degree of need of parents of mentally handicapped children in the areas of: information, education, support, explaining to others, community service, financial, family functioning and future arrangements.
- II. to investigate the relationship of these perceived needs and certain demographic variables including: (1) number of children in the family, (2) age of parents, (3) marital status of parent, (4) religion of the parents, and (5) socio-economic level of the parents.

### Research Questions

1. Do parents who have a mentally handicapped child as well as non-handicapped children perceive greater needs than parents who only have a mentally handicapped child?
2. Do older parents who have a mentally handicapped child, and who have had to provide more difficult care-giving demands over a longer span of time, perceive greater need than do younger parents who have not had to provide care-giving demands for as long?
3. Do single parent families of mentally handicapped children perceive greater needs than dual parent families with mentally handicapped children?
4. Do Catholic parents of mentally handicapped children perceive less needs than do non-Catholic parents?
5. Do parents of mentally handicapped children from lower socioeconomic background perceive greater needs than parents from higher socioeconomic backgrounds?

### Operational Definition of Terms

For the purpose of this study, the following definitions were used:

Family need--is defined as a family's expressed desire for services to obtain or outcomes to be achieved (Bailey & Simeonsson, [in press]).

Family need--is something that is desired or lacking, but wanted or required to achieve a goal or attain a particular end (Dunst, Trivette & Deal, 1988).

Stress--a crisis provoking event or situation for which the family has little or no preparation (Hill, 1958).

Social stressor--a set of circumstances that require change in the individual's on-going life pattern (Holmes & Rahe, 1967).

Stress--is the pattern of physiological and psychological responses and stressors that are both immediate and delayed (Rabkin & Struening, 1976).

Burnout--is the condition from which people suffer when they need to provide help and assistance from birth to death. The five stages are 1) psychological, 2) social, 3) psycho-emotional, 4) intellectual, and 5) introspective.

High Status Occupation--Occupations which scored higher than 70 percent on the Duncan Socio-economic Status scale. For example: professionals, technical and kind workers, managers and administrators except farm (Powers, 1982).

Low Status Occupation--Occupations which scored lower than 70 percent on the Duncan Socio-economic Status scale. For example: sales workers, clerical and kind, craftsmen and labourers (Powers, 1982).

Low Income--Income related to size of city and size of family under the poverty level (Statistics Canada, 1989).

High Income--Income related to size of city and size of family over the poverty level (Statistics Canada, 1989).

Statistics Canada Scale for urban centre over 500,000 people: Income under which is considered to be below poverty level.

|           |   |                |
|-----------|---|----------------|
| 1 person  | - | \$12,148       |
| 2 persons | - | \$16,027       |
| 3 persons | - | \$21,440       |
| 4 persons | - | \$24,706       |
| 5 persons | - | \$28,790, etc. |

Younger Parents--Parents under thirty-five years of age.

Older Parents--Parents thirty-five years of age and over.

High Level of Schooling--Grade twelve education and post high school education.

Low Level of Schooling--Less than grade twelve education.

Socio-economic Level--For the purpose of this study researcher will consider the following components: mother's and father's level of schooling, mother's and father's occupation and family income.

### General Limitations of the Study

Perhaps the most important limitation of the study is that the response rate was 31%. Because this rather low response rate was anticipated a census of this population was approached rather than a random sample. Little could be done to encourage a higher rate of response due to the procedure prescribed by Winnipeg School Division Number 1 and out of respect for the confidentiality and anonymity of the respondents. The researcher was unable to do a personal follow-up other than a general follow-up letter distributed through the participating schools in the same manner in which the survey was distributed. Also, it needs to be noted that this particular population of parents of severely and profoundly mentally handicapped students has been extensively surveyed that particular school year and the researcher had to be sensitive to further demands of parents' time. Finally, many of the parents are from low socio-economic backgrounds. Their willingness to respond is notoriously low. Also, their reading ability is low and a number are illiterate. The readability level of the Family Needs Survey according to the Dale-Chall formula for predicting readability was between 9th and 10th grade level. Also, the Winnipeg School Division Number 1 has a high proportion of multicultural and English as a Second Language population in the core area. Some parents do not read sufficient English to answer the surveys properly.

Mildly mentally handicapped students or any severely or profoundly mentally handicapped students who are mainstreamed are not identified by the school division, the parents of these children did not participate in the survey. Therefore, findings can only be applied to the parents of severely and profoundly mentally handicapped children.

Some parents responded to the survey questions but did not give information on their demographics. This caused the loss of data in a number of cases reducing the number of respondents to below 31% who responded.

The lack of sufficient psychometric properties for the survey instrument presents some limitations as well.

## CHAPTER II

### REVIEW OF THE LITERATURE

"Sorrow concealed, like an oven stoppe'd  
Doth burn the heart to cinders."

- William Shakespeare

In this chapter, current literature will be examined in order to explore the nature of parental stress and parental need in raising and educating severely or profoundly mentally handicapped children. The family stress theory and the psychopathology of handicap will be examined in an attempt to provide a background to understanding the process parents of severely or profoundly mentally handicapped children experience. Related research dealing with demographic factors which contribute to parental stress and which create parental need will also be examined. The demographic factors include: number of children in the family, age of the parents, marital status of the parents, religion of the parents and socio-economic level of the parents.

## I - Family Stress Theory

The foundations for a great deal of family stress research since 1970 has been Hill's (1949) ABCX model of family stress and crisis (Minnes, 1988). The model is based on war induced separations and reunions. The model examines family crisis in terms of the degree of disruption or disorganization in the family system. The ABCX model determines the family's ability to cope with a potential crisis situation, and is dependent upon the interaction of three factors: the stressor event (the A factor); existing resources (the B factor); and the family's perception of the handicapped child (the C factor) (Minnes, 1986).

The ABCX Model was expanded upon by McCubbin et al, (1980) and renamed the Double ABCX model. McCubbin expanded this conceptualization to include the following: coping strategies used by families; interactions with resources outside the immediate family; and the family's efforts to reduce stress. He also emphasized the "pile-up" factor or accumulation of various life stresses over time which would interfere with family adaptation.

The use of the Double ABCX model as a theoretical framework is appropriate in view of the recent recognition of its usefulness in research concerning families of handicapped children (McCubbin, Nevin, Cauble,

Larsen, Comeau & Patterson, 1982; Minnes, 1986). The Double ABCX model presents a multidimensional perspective which focuses on multiple factors that may mediate stress and facilitate coping with a handicapped child (Byrne & Cunningham, 1985). The model also represents a realistic portrayal of the day to day demands and pressures in parenting mentally handicapped children.

The stressor event (the A factor). These factors associated with the stressor event include the type of handicap, the degree of handicap and the gender of the handicapped child. A brief overview of these factors provides a more detailed perspective to understanding some of the specific demands on the family unit.

Variations in parental stress have been reported by parents of mentally handicapped children. The measure of stress varies according to the type of handicap (Holroyd, 1982). Families of autistic children reported more stress overall than did families of Down's syndrome and psychiatric clinic children. Research by Minnes (1984, 1986) revealed that parents of mentally retarded children consistently reported higher stress than parents of normally intelligent children with a congenital limb deficiency. The differences in stress were reported related to the following issues: dependency and management, limits

on family opportunities, life span care, terminal illness stress and personal burden.

The degree of handicap was found to be related to parental stress (Holroyd, 1982). Parents of mildly retarded children reported significantly fewer limits on family opportunities than parents of moderately or severely retarded children. Parents of mildly retarded children also reported less concern related to life-span care and terminal illness stress. Child behavior problems associated with limited adaptive behavior were significant predictors of parental stress (Friedrich, 1983). Parents of more severely handicapped children were less able to deny their child's handicap due to the child's appearance and behavior (Weller, 1974).

Research on the relationship between parental stress and gender of the handicapped child indicates that couples with male handicapped children experience more marital disharmony than those with female handicapped children (Farber, 1959). Young parents with a firstborn male child with a genetic handicap and mental retardation were at greater risk for divorce than parents of female children with similar handicaps (Roesel and Lawlis, 1983). Parents of male children were faced with greater management problems as the male children grew older and became stronger (Bristol, 1979).

Existing resources (the B factor). The second major factor which comprises the ABCX model is the existing resources. These resources determine the family's ability to meet the demands and needs of a stressor event (McCubbin and Patterson, 1983). These resources include the internal or systemic characteristics of the family which contribute to its role structure and organization and external or social support received from extended family, friends, professionals and agencies (Minnes, 1988).

The internal or systematic family resources include internal organization, flexible role relationships and shared power. These resources facilitate personal growth and autonomy and reduce vulnerability to stress and crisis (Pratt, 1976). Other aspects of family functioning which have been cited include family resources such as affectional relations, marital adjustment, parental-child relations, power structures, decision-making patterns, previous experiences with crisis communication patterns and self-esteem and degree of independence in the family (Burr, 1973).

The external family resources include strengths and resources within the immediate family system as well as social support systems outside the immediate family (Minnes, 1988). The contribution of kin, friends, neighbors, social service agencies and self help groups all have an important impact upon stress management (McCubbin, 1980). Social support has been shown to have

a beneficial effect on dealing with life transitions and crisis (Cobb, 1976). Social support has also been considered in the mediation of stress associated with a handicapped child (Minnes, 1986).

The family's perception of the handicapped child. The meaning that a family attaches to a stressful event plays an important role in stress management (McCubbin and Patterson, 1983). Whether or not an event leads to crisis or breakdown or dysfunction in a family will depend upon the explanation used by the family to understand why it occurred and what can be done to alleviate stressful situations (Minnes, 1988). The perception of the handicapped child by the family will be influenced by differential perceptions of mothers and fathers, spiritual resources and socio-economic factors (Minnes, 1988).

The differential perceptions of mother's and father's to the birth of a handicapped child were noted by Lamb (1983). Earlier studies reported that fathers responded less emotionally than mothers. Fathers were more concerned about the long-term economic and social dependency of their child. Mothers were found to respond more emotionally and expressed concerns about the time involved in care-giving demands, the emotional strain of maintaining family harmony and integration (Gumz & Gubrium, 1972). Fathers have been more accepting of daughters than sons (Grossman, 1972).

Spiritual or religious resources were found to be related to parents perception of the handicapped child (Farber, 1960; Zuk, 1962). A correlation was shown between successful coping with a handicapped child and religious association particularly with the Catholic church. The intensity of the association rather than frequency of church attendance was found to be important. Distress and/or acceptance was different among Catholic families as opposed to Protestant and Jewish families (Korn, Chess & Fernandez, 1978).

Socio-economic factors also affect parents perceptions of a handicapped child. Farber (1960), found that the gender of a handicapped child is perceived differently by various socio-economic status (SES) groups. Higher SES families expressed greater preference for residential care than did parents in lower SES groups despite the fact that these parents reported lower financial stress (Minnes, 1986). Other studies reported lower class families more accepting of a handicapped child. Lower class families looked at out of home placements due to "role organization crisis" (Farber, 1968).

## II - The Psychopathology of Handicap

Since stress is a major factor in people's lives and is intimately tied with mental health (Hobfoll, 1989), it is necessary to look at the psychopathology

of handicap for parents of mentally handicapped children. Some psychologists use the phrase "a handicapped child is a handicapped family". Psychologists say this when they see families who have become socially isolated, siblings who have become maladjusted and homes which have become broken as the result of the presence of a handicapped child (Bicknell, 1983).

Psychologists have examined responses known as the bereavement response commonly associated with loss, death and dying. In the psychopathology of handicap, the bereavement response is somewhat modified. It refers to the loss of the perfect child who has not arrived or who has been taken away through illness or accident. It is comprised of the following stages: shock, panic, denial, grief, guilt, anger, bargaining and acceptance (Bicknell, 1983). Parents work through these stages at different rates. If working through one of these stages is incomplete it pervades the rest of the stages. Some parents work through the stages of the bereavement response more slowly than others (Bicknell, 1983).

Parents who do not work through the bereavement response completely may establish a pattern of behavior that could lead to maladaptive responses, causing endless unhappiness in the family. These maladaptive responses include: shopping around (endlessly seeking second and third opinions), over-protection, over-rejection (failure to bond), ambivalence, chronic sorrow,

isolation (from family members, and professional help), disharmony, scapegoating, late rejection, infantilization, and over-identification (Bicknell, 1983). These maladaptive emotional responses cause the family additional stress and give rise to additional family needs.

There is an essential difference between the bereavement response and the response to the arrival of a handicapped child. The bereavement response is classically seen as the loss of a person. The presence of the handicapped child in a family, however is a constant reminder of imperfection, its antecedents and consequences. The presence of the child also creates extra work, disturbed nights and the continued disappointments as milestones fail to be achieved (Bicknell, 1983).

The aspect of a constant reminder of imperfection supports Olshansky's (1962) theory of chronic sorrow which is defined as the long term internalization of a depressive mood. However, he argued that chronic sorrow is a natural and understandable response to a tragic fact. He does not see it as a neurosis, pathology or maladaptive response.

### III - The Demographic Factors

Several demographic factors have been identified as contributing additional stress to the lives of families of mentally handicapped children. The

specific factors explored will include: the number of children in the family, the age of the parents, the marital status of the parents, the religion of the parents and the socio-economic level of the parents.

The number of children in the family. The number of children in the family may be a source of stress for parents because the needs of the mentally handicapped child may reduce the time and ability of the parents to give adequate time and effort to the nurturance of their non-handicapped child. The issue of the presence of a mentally handicapped child is just one of several problematic elements in the family (Turnbull & Turnbull, 1986). In addition to dealing with the presence of a mentally handicapped child in the family the parents must consider their other family members, maintain a household and pursue a career (Farber, 1968). A case in point is Helen Featherstone's (1980) description of a situation where she felt the school asked too much.

I remember the day when the occupational therapist at Jody's school called with some suggestions from a visiting nurse. Jody has a seizure problem which is controlled with the drug Dilantin. Dilantin can cause the gums to grow over the teeth . . . . The nurse had noticed . . . this overgrowth, and recommended, innocently enough, that (his) teeth be brushed four times a day, for five minutes, with an electric toothbrush. The school suggested that they could do this once on school days, and that I should try to do it the other three times a day . . . . This new demand appalled me . . . Jody . . . is blind, cerebral palsied, and retarded. We do his physical therapy daily and work with him on sounds and communication. We feed him each meal on our laps,

bottle him, bathe him, dry him, put him in a body cast to sleep, launder his bed linens daily, and go through a variety of routine designed to minimize his miseries and enhance joys and his development. (All this in addition to trying to care for and enjoy our young children and making time for each other and our careers.) Now you tell me that I should spend fifteen minutes every day on something that Jody will hate, an activity that will not help him to walk or even defecate, but one that is directed at the health of his gums. This activity is not for a finite time, but forever. It is not guaranteed to help, but "it can't hurt". And it won't make the overgrowth go away but it may retard it. Well, it's too much. Where is that fifteen minutes going to come from? What am I supposed to give up? Taking the kids to the park? Reading a bedtime story to my eldest? Washing the breakfast dishes? Sorting the laundry? Grading students' papers? Sleeping? Because there is not time in my life that hasn't been spoken for, and for every fifteen-minute activity that is added one has to be taken away (p. 87).

Turnbull and Turnbull (1986) address family interaction issues as a source of stress. For example, child-child interaction may create significant stress for the non-handicapped sibling and in turn become a further source of stress for the parents.

The age of the parents. The age of the parents may be a factor in the stress experienced by parents of mentally handicapped children. The issue of providing care giving demands for long periods of time warrants attention. Beckman-Bell (1981) point out that in addition to care-giving demands for mentally handicapped children being more difficult, there is often a need to perform these activities well beyond the period in which most children are performing them independently. The increased responsibility from the

extremely demanding care-giving causes both psychological and physical stress. The longer the parents must provide these additional care-giving demands the more stress they are likely to experience. This could lead to parental burnout.

Hagen (1981) addressed the issue of parental burnout. He identified five stages for people who need to provide help and assistance from birth to death. The five stages are: 1) psychological . . . when people begin to feel tired and drained; 2) social . . . when people become irritable; 3) psycho-emotional . . . when the person begins to perceive himself/herself as always meeting someone else's needs; 4) intellectual . . . when the burnout starts to affect the mind; and 5) introspective . . . when the person begins to question his or her own value systems.

Featherstone (1981) looked at the care-giving demands including providing basic routine care such as feeding, handling, i.e., lifting, holding, cuddling, bathing, toileting and dressing the child, provision of medical care such as having to suction a child with respiratory disorders, vigilant care of a child with a seizure disorder, having to perform physiotherapy on a child with very little muscle tone and an unusually high number of hospitalizations and visits to physicians. As parents age these demands become more difficult, contributing to stress and burnout.

The marital status of the parents. The marital status of the parents may be another factor in the stress experienced by parents of mentally handicapped children. Whether the parents' marriage remains intact or whether parents separate or divorce will have a direct effect on the stress level in the family.

Research indicates that a child with an exceptionality can have a negative impact on the parent's marriage (Turnbull & Turnbull, 1986). Divorce, marital disharmony and husband desertions have been disproportionately high in marriages where there is a child with an exceptionality (Gath, 1977). Featherstone (1981) discusses how the child's handicap attacks the fabric of a marriage in four ways. It elicits powerful emotions in both parents. It acts as a dispiriting symbol of shared failure. It reshapes the organization of the family and creates fertile ground for conflict. The consequence of marriage breakdown creates problems and stress for the parent who retains the responsibility for the care of the child.

Many single-parent families are the result of separation and divorce, an increasing proportion are the result of births to unmarried women (Vadassy, 1986). Regardless of the reason for single parent status, single parents have unique needs and additional stressors when parenting a mentally handicapped child. Single mothers reported significantly higher stress than

married mothers of mentally handicapped children (Beckman, 1985). Single mothers also reported that their family had many problems and was not well integrated. They also reported more financial problems than married mothers (Holroyd, 1984). Single mother's marital status is affected by a handicapped child in that it may reduce her chances for remarriage (Wickler, 1979). Wickler also found that the greatest stated need of single mothers was respite care.

The religion of the parents. The religion of the parents may be another factor in how much stress parents of mentally handicapped children experience. The role of religious beliefs in one's adaptation to life experiences serves as a "buffer" to many of the stresses associated with raising a handicapped child (Folkman, Schaefer & Lazarus, 1979). Much of the tragic impact of the retarded child on the parents involves a sense of guilt (Featherstone, 1981). Catholic mothers were more accepting of a handicapped child than non-Catholic mothers (Zuk, 1959, 1962). Catholic mothers tended to deny the responsibility for the child's condition believing that God had given them this child as a gift or for some purpose. Acceptance and distress in Catholic families as opposed to Protestant and Jewish families were reportedly different (Korn, Chess & Fernandez, 1978). Protestant and

Jewish doctrine is not quite as explicit about acceptance nor absolution (Zuk, 1961).

The socio-economic level of the parents. The socio-economic level of the parents of mentally handicapped children is a factor in how much stress parents experience. If we examine the effect of socio-economic status on parents of mentally handicapped children we find that while high status parents tend to have a strong emotional reaction to the diagnosis, low status parents are often not so severely shaken by the diagnosis since the label of mental retardation is not greatly divergent from other labels associated with low status (Farber & Rowitz, 1986).

Another aspect of socio-economic level is the financial component. Hobfoll (1989) suggests that financial resources can be used to buy services and therefore reduces stress. For example, services might include a babysitter or care-giver to provide the mother with time to rest or spend with her spouse and other children. Another example of a service would be those offered by a housekeeper. This service would enable the mother to have more time and energy to nurture her handicapped child as well as other family members. These financial resources or object resources are linked to socio-economic status which has been shown to be an important factor in stress resistance (Dohrenwend, 1978).

### Summary

Although the focus on parental stress and parental need in raising and educating severely and profoundly mentally handicapped children is a relatively new one, there is a general agreement in the current literature that parents of mentally handicapped children do experience stress. The stress gives rise to extra-ordinary needs. The family stress theory and psychopathology of handicap provide background information which assists in understanding difficulties faced by these parents. The specific demographic factors which appear to contribute to parental stress in raising and educating mentally handicapped children include: number of children in the family, age of the parents, marital status of the parents, religion of the parents and socio-economic level of the parents.

## CHAPTER III

### METHOD

#### Source of Data: Winnipeg School Division #1

Winnipeg School Division #1 is the largest school division in the Province of Manitoba, Canada. It is situated in the City of Winnipeg, an urban centre with a population of over 600,000. Winnipeg School Division #1 has a total population of approximately 33,000 students. The school division population is diverse, encompassing the core area with some low socio-economic populations. The division is comprised of multi-ethnic groups, and includes middle and high socio-economic populations. Because of this diversity the school division provides a wide range of educational services.

#### The Population

The population in this study was comprised of 110 sets of parents of severely and profoundly mentally handicapped students who were in segregated programs throughout the Winnipeg #1 school division. The students were between 6 and 21 years of age. Parents of mildly and moderately mentally handicapped students in mainstreamed setting were not included because the school division indicated that parents of these children

may not wish to be identified. The age range of the parents was 27 to 59 years of age. The socio-economic levels ranged from total family incomes below poverty level (under \$15,000 in 1989) to total family income of well over poverty level (over \$60,000 in 1989). The marital status of 24 out of the 34 respondents was indicated as married, 20 being biological parents and 3 foster parents. Only 1 parent has been remarried after indicating that divorce had been a result of the stress related to the presence of the mentally handicapped child. Of the 10 respondents indicating their marital status as single, 7 were single mothers raising the child alone, 1 respondent was a single father whose wife had died, 1 single mother was a widow and 1 single mother was living with common law husband.

### Instrument

The survey instrument used in this study was the Family Needs Survey developed in 1988 by Bailey and Simeonsson. The items chosen for the survey were based on a review of the literature, discussion with early interventionists, previous surveys conducted in North Carolina, and clinic experience of Bailey and Simeonsson (1988). The thirty-five item scale, included in the appendix, was divided into 35 questions and six categories including: Needs for Support,

Explaining to Others, Community Services, Financial Needs, Family Functioning, and Needs for Information.

Incorporated into the original instrument were minor modifications made by this researcher based on the following: The change to question 17 was based on changing the word 'priest' to 'clergyman' to indicate a more appropriate inter-denominational term. The change to question 36 was based on the medical service delivery system of Manitoba, Canada rather than the U.S. medical service delivery system. Further, this researcher added 15 questions to the authors' original thirty five based on the literature review. Finally, two additional categories were added by the researcher: "Educational Needs" and "Future Needs" (see Appendix).

The survey took parents approximately 30 minutes to complete. Three response choices were possible on the instrument including: definitely do not need help, not sure and need help. The survey instrument also included open ended questions in which the parents could articulate other areas of need or elaborate on needs they had indicated earlier.

The authors of the instrument reported a test-retest reliability with a subset of 20 families over a six-month period was .67 for mothers and .81 for fathers.

The authors report that the instrument, though it has limited psychometric properties, is viewed by the families as useful and acceptable. One of the two creators of the instrument has the following caution, ". . . even if the instrument has excellent psychometric properties, if it is not viewed favorably by families, then it likely will not fulfil its intent" (Bailey, in press, p. 4).

### Pilot Survey

To validate the original 35 question survey as well as 15 additional questions the researcher conducted a pilot study.

The modified instrument was piloted with a group of 5 dual parent families who belong to a volunteer parent support group for parents of mentally handicapped children called 'Parent to Parent'. These parents were asked to indicate how much time was required to complete the survey. They were asked to indicate what questions were not clear and what questions they had difficulty understanding, if any. Each group of parents were contacted by telephone. Upon indicating interest in participating they were sent a survey instrument by mail with a self-addressed stamped envelope. They were asked to respond within one week. Both parents were asked for input.

The response from the pilot study was as follows: Four of the five families responded. The survey took approximately thirty minutes to complete and the questions were thought of as being clearly stated and relevant.

### Procedure and Design

Initial contact was made by telephone with the superintendent's department in the Winnipeg School Division Number 1. This was followed by a letter outlining the purpose of this study and identifying the intended population. Following the initial contact the superintendent's office informed the researcher that approval would be given if the TMH (Trainable Mentally Handicapped) Parent Advisory Board gave its approval. The Advisory Board received the idea very positively and was interested in being informed of the findings.

The superintendent's department identified 10 schools which had the 110 severely and profoundly handicapped students in segregated settings. The researcher delivered and discussed the survey with the teachers or principals handing out the surveys in the various schools predetermined by the school division. Appointments were pre-arranged by telephone. The distribution of the surveys was handled by each school identified in order to ensure

confidentiality and anonymity of the parents. The total number of surveys distributed was 110.

The survey package consisted of a cover letter, self-addressed, stamped envelope and a survey. The cover letter explained the purpose of the study and indicated that participation would be on a voluntary basis. Parents who wished to participate in a follow-up interview could indicate this on the survey form. To encourage return rates a short follow-up letter was distributed to the schools to be sent to parents stressing the importance of their response for the success of the study.

#### Follow-up Interviews

Written surveys with follow-up interviews have the potential for expanding and individualizing programs to meet the unique needs of child and family (Bailey & Simeonsson, 1986).

Follow-up interviews were conducted by the researcher. The purpose was to ensure that questions were interpreted as intended and to give respondents an opportunity to elaborate, clarify and confirm response. The researcher conducted follow-up interviews with five groups of respondents. It seemed more useful to look at kinds of respondents and cluster them into groups. The respondents selected represented: a single mother, a single

father, a foster parent, one dual, biological set of parents of higher socioeconomic background and one dual, biological set of parents of lower socioeconomic background.

### Analysis of Data

A descriptive analysis based on the information gathered from the frequency distributions and a statistical analysis of the significant relationships indicated by the Mann-Whitney U Test.

The SPSS-X system was used to conduct the analysis and results for two procedures: frequency distribution and a Mann-Whitney U test which is one of the most powerful of the non-parametric tests and it is a most useful alternative to the parametric t test when the researcher wishes to avoid the t test's assumption, or when the measurement in the research is weaker than interval scaling (Seigel, 1956). The Mann-Whitney U test compares two groups when data are being rank ordered. Probability value was determined as significant at .05.

Data compiled focused on the following research questions as stated in Chapter I.

### Research Question 1

Do parents who have a mentally handicapped child as well as non-handicapped children perceive greater needs than parents who only have the mentally handicapped child?

Previous research states that the retarded child is just one of several potentially problematic elements in a family (Farber, 1968). The parents must consider other family members, maintain a household and pursue a career (Turnbull & Turnbull, 1986). Therefore the following hypotheses were proposed for each research question. Experimental hypotheses were used because the researcher is predicting a direction. These hypotheses will be used with a one-tailed test.

### Hypothesis 1

Parents who have a mentally handicapped child as well as non-handicapped children will indicate a higher frequency of need in the following categories: Need for Information, Educational Need, Need for Support, Need for Explaining to Others.

### Research Question 2

Do older parents who have a mentally handicapped child who have had to provide more difficult care-giving demands over a longer span of time perceive

greater needs than do younger parents who have not had to provide care-giving demands for as long?

Previous research states that in addition to care-giving demands for mentally handicapped children being more difficult, there is often a need to perform these activities well beyond the period in which most children are performing them independently (Beckman-Bell, 1981). The issue of parental burnout is addressed by Hagen (1981) who describes the five stages of people who need to provide help and assistance from birth to death including psychological, social, psycho-emotional, intellectual and introspective. Therefore the following experimental hypothesis was proposed for research question 2.

#### Hypothesis 2

Older parents of mentally handicapped children will indicate higher frequency of need in the following categories: Need for Support, Community Service Need, Financial Need and Future Need.

#### Research Question 3

Do single parent families of mentally handicapped children perceive greater needs than dual parent families with mentally handicapped children?

Previous research states that a child with an exceptionality can have a negative impact on the parents' marriage (Turnbull & Turnbull, 1986).

Divorce, marital disharmony and husband desertions have been disproportionately high in marriages where there is a child with an exceptionality (Gath, 1977). Single mothers reported significantly higher stress than married mothers of mentally handicapped children (Beckman, 1983). Therefore the following hypothesis has been proposed for research question 3.

#### Hypothesis 3

Single parent families will indicate a higher frequency of need than dual parent families in the following categories: Need for Information, Educational Need, Need for Support, Explaining to Others, Community Service Need, Financial Need, Family Functioning and Future Need.

#### Research Question 4

Do Catholic parents of mentally handicapped children perceive less needs than do non-Catholic parents?

The previous research states that much of the tragic impact of the retarded child on the parents involves a sense of guilt (Featherstone, 1981). Zuk (1959, 1962) reported that Catholic mothers were more accepting than non-Catholic mothers. Acceptance and distress in Catholics as opposed to Protestant and Jewish families were reportedly different (Korn, Chess &

Fernandez, 1978). Protestant and Jewish doctrine is not as explicit about acceptance or absolving (Zuk, 1961).

Therefore the following hypothesis has been proposed for research question 4.

#### Hypothesis 4

Non-Catholic parents of handicapped children will indicate a higher frequency of need than Catholic parents in the following categories: Need for Support, Need for Explaining to Others, Community Service Needs and Family Functioning.

#### Research Question 5

Do parents from lower socio-economic backgrounds experience greater needs than parents from higher socio-economic backgrounds?

The previous research states that while high status parents tend to have a strong emotional reaction to the diagnosis of their child as mentally handicapped, low status parents are often not so severely shaken by the diagnosis since the label of mental retardation is not greatly divergent from other labels associated with low status (Farber & Rowitz, 1986). Socio-economic status has been shown to be an important factor in stress resistance (Dohrenwend, 1978). Financial resources can be used to buy services to reduce stress (Hobfoll, 1989).

Therefore, the following hypothesis can be proposed for research question 5.

#### Hypothesis 5

Parents of mentally handicapped children from lower socio-economic backgrounds will indicate a higher frequency of need in the following categories: Need for Information, Educational Need, Need for Support, Community Service Need, Financial Need, Family Functioning and Future Need.

## CHAPTER IV

### RESULTS AND DISCUSSION

The purpose of this study was to examine the relationship between selected demographic variables and parents perception of need in raising and educating their severely and profoundly mentally handicapped children. This chapter presents the findings in response to the Family Need Survey.

The findings will be discussed in three sections. Section one will report the findings using the Mann-Whitney U Test. Section two will report the descriptive findings based on frequency distribution. The responses to question 1 to 50 will be reported first and the responses to the eight categories will be dealt with next. The third section will report the responses to the open ended questions on the needs survey.

#### Statistical Findings

##### Hypothesis 1

Parents who have a mentally handicapped child as well as non-handicapped children will indicate a higher frequency of need in the following categories: Need for Information, Educational Need, Need for Support, Need for Explaining to Others.

The findings of this study indicate no significant difference in need in any category between parents who have a mentally handicapped child only and parents who have a mentally handicapped child as well as non-handicapped children (see Table 1).

Table 1 Mann-Whitney U Test - Number of Children in the Family and Parents' Expressed Needs

| Category                      | n <sub>1</sub> =<br>(Only<br>Child) | n <sub>2</sub> =<br>(Sibling) | Z       | I-Tailed<br>P value |      |
|-------------------------------|-------------------------------------|-------------------------------|---------|---------------------|------|
| Need for Information          | 4                                   | 26                            | -0.2450 | 0.4033              | N.S. |
| Educational Need              | 4                                   | 26                            | -0.3651 | 0.3575              | N.S. |
| Need for Support              | 4                                   | 26                            | -0.1980 | 0.4216              | N.S. |
| Need for Explaining to Others | 4                                   | 25                            | -0.7631 | 0.2277              | N.S. |
| Community Service Need        | 4                                   | 24                            | -0.3004 | 0.3819              | N.S. |
| Financial Need                | 4                                   | 25                            | -0.4778 | 0.3160              | N.S. |
| Family Functioning            | 4                                   | 26                            | -0.6153 | 0.2692              | N.S. |
| Future Need                   | 4                                   | 27                            | -1.1787 | 0.1195              | N.S. |

SIB = 1 only child M.H. = n<sub>1</sub>  
SIB = 2 siblings to M.H. child = n<sub>2</sub>

4 in cell - limitation

N.S. = not significant  
\* = significant  
α = .05

Contrary to earlier expectations based on the literature, the frequency of need was not significantly different for parents with a mentally handicapped child alone or with siblings in any category. Both groups indicated need. This

suggesting that the presence of a mentally handicapped child clearly results in specific family needs.

#### Hypothesis 2

Older parents of mentally handicapped children will indicate higher frequency of need in the following categories: Need for Support, Community Service Need, Financial Need and Future Need.

The findings of this study reveal a significant difference between younger mothers and older mothers in two categories. Younger mothers indicated a higher frequency of need under the "Needs for Explaining to Others" category, while older mothers indicated a higher frequency of need in the "Future Need" category only (see Table 2).

Table 2 Mann-Whitney U Test - Mother's Age and Expressed Needs

| Category                      | n <sub>1</sub> =<br>(Under<br>35) | n <sub>2</sub> =(35<br>and<br>over) | Z       | 1-Tailed P<br>value |      |
|-------------------------------|-----------------------------------|-------------------------------------|---------|---------------------|------|
| Need for Information          | 10                                | 16                                  | -0.4236 | 0.3489              | N.S. |
| Educational Need              | 10                                | 18                                  | -0.3240 | 0.3797              | N.S. |
| Need for Support              | 9                                 | 17                                  | -0.7050 | 0.2455              | N.S. |
| Need for Explaining to Others | 9                                 | 18                                  | -1.8236 | 0.0424              | *    |
| Community Service Need        | 9                                 | 16                                  | -0.6888 | 0.2612              | N.S. |
| Financial Need                | 9                                 | 17                                  | -0.9232 | 0.1979              | N.S. |
| Family Functioning            | 10                                | 18                                  | -0.3862 | 0.3619              | N.S. |
| Future Need                   | 10                                | 18                                  | -1.7061 | 0.0663              | *    |

MAG = 1 - under 35 = n<sub>1</sub>

MAG = 2 - 35 and over = n<sub>2</sub>

N.S. = not significant

\* = significant

α = .05

The literature suggest that older parents of mentally handicapped children would indicate higher frequency of need in a number of need categories due to having to provide lifelong caregiving demands. The results of this study indicate higher frequency of need perceived in the "Future Need" category and "Need for Explaining to Others" category for older parents.

There was no significant difference for father's age in any category of need (see Table 3).

Table 3 Mann-Whitney U Test - Father's Age and Expressed Needs

| Category                      | n <sub>1</sub> =<br>(Under<br>35) | n <sub>2</sub> = (35<br>and<br>over) | Z       | I-Tailed P<br>value |      |
|-------------------------------|-----------------------------------|--------------------------------------|---------|---------------------|------|
| Need for Information          | 3                                 | 20                                   | -1.1476 | 0.1255              | N.S. |
| Educational Need              | 3                                 | 22                                   | -0.5188 | 0.3019              | N.S. |
| Need for Support              | 3                                 | 21                                   | -0.7048 | 0.2405              | N.S. |
| Need for Explaining to Others | 3                                 | 22                                   | -1.1279 | 0.1296              | N.S. |
| Community Service Need        | 2                                 | 20                                   | -0.6372 | 0.2620              | N.S. |
| Financial Need                | 3                                 | 21                                   | -0.7946 | 0.2134              | N.S. |
| Family Functioning            | 3                                 | 22                                   | -0.8017 | 0.2113              | N.S. |
| Future Need                   | 2                                 | 33                                   | -0.0946 | 0.4623              | N.S. |

FAG = 1 - under 35 = n<sub>1</sub>  
 FAG = 2 - 35 and over = n<sub>2</sub>

2 or 3 in cell - 1 limitation

N.S. = not significant

\* = significant

α = .05

### Hypothesis 3

Single parent families of mentally handicapped children will indicate a higher frequency of need than dual parent families of mentally handicapped children in all categories of need.

The findings of this study indicate a significant difference for single parents indicating a higher frequency of need in the "Need for Support", "Need for Explaining to Others" as well as the "Financial Need" categories (see Table 4).

Table 4 Mann-Whitney U Test - Dual or Single Parent Families and Expressed Needs

| Category                      | n <sub>1</sub> =<br>(Single<br>Parent) | n <sub>2</sub> =<br>(Dual<br>Parent) | Z       | I-Tailed<br>P value |      |
|-------------------------------|----------------------------------------|--------------------------------------|---------|---------------------|------|
| Need for Information          | 7                                      | 18                                   | -1.6113 | 0.0535              | N.S. |
| Educational Need              | 8                                      | 19                                   | -1.0522 | 0.1463              | N.S. |
| Need for Support              | 7                                      | 18                                   | -2.0722 | 0.0191              | *    |
| Need for Explaining to Others | 7                                      | 19                                   | -2.3151 | 0.0103              | *    |
| Community Service Need        | 8                                      | 16                                   | -0.5227 | 0.2988              | N.S. |
| Financial Need                | 7                                      | 18                                   | -1.8720 | 0.0306              | *    |
| Family Functioning            | 8                                      | 19                                   | -1.3090 | 0.0953              | N.S. |
| Future Need                   | 8                                      | 19                                   | -0.4188 | 0.3376              | N.S. |

DUA = 1 dual parent = n<sub>2</sub>  
DUA = 2 single parent = n<sub>1</sub>

N.S. = not significant  
\* = significant  
 $\alpha$  = .05

#### Hypothesis 4

Non-Catholic parents of mentally handicapped children will indicate a higher frequency of need than Catholic parents of mentally handicapped children in the following categories: Need for Support, Need for Explaining to Others, Community Service Needs and Family Functioning categories.

The findings of this study reveal a significant difference for non-Catholic mothers with a higher frequency in the "Need for Community Services" category (see Table 5). This result supports the related literature.

Table 5 Mann-Whitney U Test - Mother's Religion and Expressed Needs

| Category                      | n <sub>1</sub> =<br>(Roman Catholic) | n <sub>2</sub> =<br>(Non Roman Catholic) | Z       | I-Tailed P value |      |
|-------------------------------|--------------------------------------|------------------------------------------|---------|------------------|------|
| Need for Information          | 9                                    | 15                                       | -0.2685 | 0.3941           | N.S. |
| Educational Need              | 9                                    | 15                                       | -0.0000 | 0.5000           | N.S. |
| Need for Support              | 8                                    | 15                                       | -0.0325 | 0.4870           | N.S. |
| Need for Explaining to Others | 9                                    | 15                                       | -0.4396 | 0.3301           | N.S. |
| Community Service Need        | 7                                    | 14                                       | -2.1631 | 0.0525           | *    |
| Financial Need                | 8                                    | 15                                       | -1.1421 | 0.1267           | N.S. |
| Family Functioning            | 9                                    | 15                                       | -0.4516 | 0.3258           | N.S. |
| Future Need                   | 9                                    | 15                                       | -1.2726 | 0.1015           | N.S. |

MRL = 1 Roman Catholic = n<sub>1</sub>  
MRL = 2 Non-Roman Catholic = n<sub>2</sub>

N.S. = not significant  
\* = significant  
 $\alpha$  = .05

The findings reveal a significant difference for non-Catholic fathers with a higher frequencies in the categories of "Need for Support", "Community Service Need", "Family Functioning", "Financial Need" and "Future Need" categories (see Table 6).

The demographic variable for hypothesis 4 reads "parents". Since most mothers and fathers who responded to the survey reported belonging to different religious groups the variables "mothers" and "fathers" seems more appropriate (see Table 6).

Table 6 Mann-Whitney U Test - Father's Religion and Expressed Needs

| Category                      | n <sub>1</sub> =<br>(Roman<br>Catholic) | n <sub>2</sub> =<br>(Non<br>Roman<br>Catholic) | Z       | I-Tailed P<br>value |      |
|-------------------------------|-----------------------------------------|------------------------------------------------|---------|---------------------|------|
| Need for Information          | 7                                       | 11                                             | -1.5061 | 0.0660              | N.S. |
| Educational Need              | 8                                       | 12                                             | -0.9237 | 0.1778              | N.S. |
| Need for Support              | 7                                       | 12                                             | -1.7938 | 0.0364              | *    |
| Need for Explaining to Others | 8                                       | 12                                             | -1.4173 | 0.0782              | N.S. |
| Community Service Need        | 7                                       | 10                                             | -2.6367 | 0.0042              | *    |
| Financial Need                | 7                                       | 12                                             | -2.8861 | 0.0019              | *    |
| Family Functioning            | 8                                       | 12                                             | -2.2510 | 0.0122              | *    |
| Future Need                   | 8                                       | 12                                             | -2.4992 | 0.0062              | *    |

FRL = 1-Roman Catholic = n<sub>1</sub>  
FRL = 2-Non-Roman Catholic = n<sub>2</sub>

N.S. = not significant

\* = significant

α = .05

The results verify what the literature says about Catholic parents and the issue of acceptance being less difficult for them.

It must be noted that non-Catholic fathers indicated a higher frequency in the "Financial Need" category. Upon re-examining the data, it was discovered that approximately 60% of the non-Catholic fathers are in low income levels.

#### Hypothesis 5

Parents of mentally handicapped children from lower socio-economic backgrounds indicate a higher frequency of need in all categories of need including: Need for Information, Educational Need, Need for Support, Community Service Need, Financial Need, Family Functioning and Future Need.

The component variables which make up socio-economic status examined by this researcher include mother's and father's level of schooling, mother's and father's occupation and family income. This study revealed mothers of low status occupations indicated a higher frequency of need in the "Need for Support" and "Need for Explaining to Others" categories (see Table 7).

Table 7 Mann-Whitney U Test - Mother's Occupation and Expressed Needs

| Category                      | n <sub>1</sub> =<br>(Low<br>Status) | n <sub>2</sub> =<br>(High<br>Status) | Z       | I-Tailed P<br>value |      |
|-------------------------------|-------------------------------------|--------------------------------------|---------|---------------------|------|
| Need for Information          | 4                                   | 23                                   | -0.8567 | 0.3916              | N.S. |
| Educational Need              | 5                                   | 24                                   | -1.5178 | 0.1291              | N.S. |
| Need for Support              | 5                                   | 23                                   | -2.0214 | 0.0432              | *    |
| Need for Explaining to Others | 5                                   | 24                                   | -1.8399 | 0.0658              | *    |
| Community Service Need        | 4                                   | 22                                   | -0.0361 | 0.9712              | N.S. |
| Financial Need                | 5                                   | 23                                   | -1.0282 | 0.3039              | N.S. |
| Family Functioning            | 5                                   | 24                                   | -1.9231 | 0.0545              | N.S. |
| Future Need                   | 5                                   | 24                                   | -0.2592 | 0.7955              | N.S. |

MOC = 2 = High - high status = n<sub>2</sub>

MOC = 1 = Low - low status = n<sub>1</sub>

4 or 5 per cell limitations

N.S. = not significant

\* = significant

α = .05

The "Need for Support" expressed by low status occupation mothers is supported by the literature on this issue. Other areas of need stated in the hypothesis were not supported. The high frequency response in the "Need for Explaining to Others" category is contrary to what the literature says about low status parents being accustomed to low status labels.

The findings of this study revealed no significant difference for fathers' occupation in any category of need (see Table 8).

Table 8 Mann-Whitney U Test - Father's Occupation and Expressed Needs

| Category                     | n <sub>1</sub> =<br>(High<br>Income) | n <sub>2</sub> =<br>(Low<br>Income) | Z       | I-Tailed<br>P value |      |
|------------------------------|--------------------------------------|-------------------------------------|---------|---------------------|------|
| Need for Information         | 7                                    | 17                                  | 0.0000  | 1.000               | N.S. |
| Educational Need             | 7                                    | 19                                  | -0.8956 | 0.3705              | N.S. |
| Need for Support             | 7                                    | 18                                  | -0.3967 | 0.6916              | N.S. |
| Need for Explaining to Other | 7                                    | 19                                  | -1.0701 | 0.2846              | N.S. |
| Community Service Need       | 6                                    | 17                                  | 0.1782  | 0.8586              | N.S. |
| Financial Need               | 7                                    | 18                                  | -0.3597 | 0.7191              | N.S. |
| Family Functioning           | 7                                    | 19                                  | -0.4679 | 0.6398              | N.S. |
| Future Need                  | 7                                    | 19                                  | -0.0968 | 0.9229              | N.S. |

FOL = 2 = High - above poverty level = n<sub>1</sub>  
FOL = 1 = Low - below poverty level = n<sub>2</sub>

N.S. = not significant

\* = significant

α = .05

The findings of this study revealed that for mothers who are not high school graduates have a high frequency of need in the "Explaining to Others" and "Financial Needs" (see Table 9).

Table 9 Mann-Whitney U Test - Mother's Level of Schooling and Expressed Needs

| Category                      | n <sub>1</sub> =<br>(Grade<br>12 and<br>over) | n <sub>2</sub> =<br>(Under<br>grade<br>12) | Z       | I-Tailed P<br>value |      |
|-------------------------------|-----------------------------------------------|--------------------------------------------|---------|---------------------|------|
| Need for Information          | 13                                            | 14                                         | -0.6091 | 0.5425              | N.S. |
| Educational Need              | 14                                            | 15                                         | -0.9283 | 0.3532              | N.S. |
| Need for Support              | 13                                            | 14                                         | -0.8789 | 0.3795              | N.S. |
| Need for Explaining to Others | 14                                            | 14                                         | -1.7695 | 0.0768              | *    |
| Community Service Need        | 14                                            | 12                                         | -0.8092 | 0.4184              | N.S. |
| Financial Need                | 14                                            | 13                                         | -2.4377 | 0.0148              | *    |
| Family Functioning            | 14                                            | 15                                         | -1.0352 | 0.3006              | N.S. |
| Future Need                   | 14                                            | 15                                         | 0.1200  | 0.9045              | N.S. |

MSC = 2 = Grade 12 and over = n<sub>1</sub>

MSC = 1 = Under Grade 12 = n<sub>2</sub>

N.S. = not significant

\* = significant

α = .05

Fathers with low level of schooling indicated high frequency of need in the "Need for Explaining to Others" category (see Table 10).

Table 10 Mann-Whitney U Test - Father's Level of Schooling and Expressed Needs

| Category                      | n <sub>1</sub> =<br>(Under<br>Grade<br>12) | n <sub>2</sub> =<br>(Grade<br>12 and<br>over) | Z       | I-Tailed P<br>value |      |
|-------------------------------|--------------------------------------------|-----------------------------------------------|---------|---------------------|------|
| Need for Information          | 12                                         | 12                                            | -0.5801 | 0.5618              | N.S. |
| Educational Need              | 13                                         | 13                                            | -0.9279 | 0.3537              | N.S. |
| Need for Support              | 13                                         | 12                                            | -1.5074 | 0.1317              | N.S. |
| Need for Explaining to Others | 13                                         | 14                                            | -2.5402 | 0.0111              | *    |
| Community Service Need        | 11                                         | 12                                            | -0.4699 | 0.6384              | N.S. |
| Financial Need                | 12                                         | 13                                            | -0.4200 | 0.6745              | N.S. |
| Family Functioning            | 13                                         | 13                                            | -1.4529 | 0.1463              | N.S. |
| Future Need                   | 13                                         | 13                                            | -0.3147 | 0.7530              | N.S. |

FSC = 2 = Grade 12 and over = n<sub>2</sub>  
FSC = 1 = Under Grade 12 = n<sub>1</sub>

N.S. = not significant

\* = significant

α = .05

The findings of this study revealed a significant difference for low income and high income levels. Parents with low income levels indicated a higher frequency of need in the "Need for Explaining to Others", "Financial Need" and "Family Functioning" categories (see Table 11).

Table 11 Mann-Whitney U Test - Total Family Income Level and Parent's Expressed Needs

| Category                      | n <sub>1</sub> =<br>(Under<br>Poverty<br>Level) | n <sub>2</sub> =<br>(Over<br>Poverty<br>Level) | Z       | I-Tailed<br>P value |      |
|-------------------------------|-------------------------------------------------|------------------------------------------------|---------|---------------------|------|
| Need for Information          | 15                                              | 12                                             | -1.3476 | 0.1778              | N.S. |
| Educational Need              | 15                                              | 14                                             | -0.2714 | 0.7861              | N.S. |
| Need for Support              | 14                                              | 13                                             | -1.3675 | 0.1715              | N.S. |
| Need for Explaining to Others | 14                                              | 14                                             | -1.3995 | 0.0164              | *    |
| Community Service Need        | 13                                              | 13                                             | -0.1038 | 0.9173              | N.S. |
| Financial Need                | 13                                              | 14                                             | -2.3737 | 0.0176              | *    |
| Family Functioning            | 15                                              | 14                                             | -2.4608 | 0.0139              | *    |
| Future Need                   | 15                                              | 14                                             | -0.7100 | 0.4777              | N.S. |

INC - 1 = Under poverty level = n<sub>1</sub>

INC - 2 = Over poverty level = n<sub>2</sub>

N.S. = not significant

\* = significant

α = .05

### Descriptive Findings

The following section deals with descriptive findings based on the frequency of high need responses provided by parents of mentally handicapped children along with discussion.

For questions 1 to 50 the highest frequency of need (over 50%) were indicated for the following questions: (see Frequency Table 12) 2, 3, 5, 6, 10, 17, 34, 49 and 50.

Table 12 Parental Need in Raising and Educating a Mentally Handicapped Child  
Frequency Table

| Categories                          | Question | 1 | 2 | 3  | %    |                                                                        |
|-------------------------------------|----------|---|---|----|------|------------------------------------------------------------------------|
| Need<br>for<br>Information          | 1        |   |   | 14 | 41.2 |                                                                        |
|                                     | 2        |   |   | 19 | 59.4 | how to handle child's behavior                                         |
|                                     | 3        |   |   | 18 | 54.5 | how to teach my child                                                  |
|                                     | 4        |   |   | 11 | 34.4 |                                                                        |
|                                     | 5        |   |   | 29 | 85.3 | services presently available                                           |
|                                     | 6        |   |   | 31 | 91.2 | future services                                                        |
|                                     | 7        |   |   | 9  | 26.5 |                                                                        |
|                                     | 8        |   |   | 15 | 45.5 |                                                                        |
|                                     | 9        |   |   | 8  | 24.2 |                                                                        |
| Educational<br>Needs                | 10       |   |   | 18 | 54.5 | child's educational program                                            |
|                                     | 11       |   |   | 11 | 32.4 |                                                                        |
| Need for<br>Support                 | 12       |   |   | 6  | 18.8 |                                                                        |
|                                     | 13       |   |   | 9  | 28.1 |                                                                        |
|                                     | 14       |   |   | 11 | 35.5 |                                                                        |
|                                     | 15       |   |   | 7  | 22.6 |                                                                        |
|                                     | 16       |   |   | .  | .    |                                                                        |
|                                     | 17       |   |   | 18 | 56.3 | reading material about other parents who<br>have child similar to mine |
|                                     | 18       |   |   | 12 | 35.7 |                                                                        |
|                                     | 19       |   |   | 15 | 46.9 |                                                                        |
|                                     | 20       |   |   | 9  | 28.1 |                                                                        |
|                                     | 21       |   |   | 8  | 25.0 |                                                                        |
|                                     | 22       |   |   | 8  | 25.0 |                                                                        |
| Need for<br>Explaining<br>to Others | 23       |   |   | 8  | 25.8 |                                                                        |
|                                     | 24       |   |   | 5  | 15.6 |                                                                        |
|                                     | 25       |   |   | 5  | 15.6 |                                                                        |

| Categories              | Question | 1 | 2 | 3  | %    |                                                                      |
|-------------------------|----------|---|---|----|------|----------------------------------------------------------------------|
| Need for Explaining     | 26       |   |   | 8  | 25.0 |                                                                      |
|                         | 27       |   |   | 9  | 28.1 |                                                                      |
| Community Service Needs | 28       |   |   | 3  | 9.4  |                                                                      |
|                         | 29       |   |   | 3  | 9.1  |                                                                      |
|                         | 30       |   |   | 12 | 36.4 |                                                                      |
|                         | 31       |   |   | 2  | 6.3  |                                                                      |
|                         | 32       |   |   | 4  | 12.5 |                                                                      |
|                         | 33       |   |   | 12 | 35.3 |                                                                      |
|                         | 34       |   |   | 20 | 60.6 | extra-curricular programs which appropriately meet needs of my child |
| Financial Needs         | 35       |   |   | 7  | 21.9 |                                                                      |
|                         | 36       |   |   | 5  | 15.2 |                                                                      |
|                         | 37       |   |   | 6  | 18.8 |                                                                      |
|                         | 38       |   |   | 7  | 21.2 |                                                                      |
|                         | 39       |   |   | 8  | 24.2 |                                                                      |
| Family Functioning      | 40       |   |   | 7  | 21.9 |                                                                      |
|                         | 41       |   |   | 9  | 28.1 |                                                                      |
|                         | 42       |   |   | 3  | 9.4  |                                                                      |
|                         | 43       |   |   | 8  | 25.0 |                                                                      |
|                         | 44       |   |   | 10 | 31.3 |                                                                      |
|                         | 45       |   |   | 2  | 6.3  |                                                                      |
|                         | 46       |   |   | 3  | 9.4  |                                                                      |
|                         | 47       |   |   | 3  | 9.4  |                                                                      |
|                         | 48       |   |   | 6  | 18.8 |                                                                      |
| Future Needs            | 49       |   |   | 20 | 60.6 | Child's independent living skills                                    |
|                         | 50       |   |   | 21 | 63.6 | provisions for community living skills                               |

Question 2--59.4% of respondents indicated they need more information about how to handle their mentally handicapped child's behavior.

Question 3--54.5% of respondents indicated they needed more information about methods of teaching their mentally handicapped child.

Question 5--85.3% of respondents indicated they need more information about services presently available for their mentally handicapped child.

Question 6--91.2% of respondents indicated they need more information about services that their mentally handicapped child might receive in the future.

Question 17--56.3% of respondents indicated they needed reading material about other parents who have a mentally handicapped child similar to theirs.

Question 34---60.6% of respondents indicated they needed extra-curricular programs which appropriately meet the special needs of their mentally handicapped child.

Question 49--60.6% of respondents indicated that they need to know more about their mentally handicapped child's future independent living skills.

Question 50--63.6% of respondents indicated they need to know what kind of provisions for living in the community will be available for their mentally handicapped child.

The next cluster of questions described are those for which the frequency was in the 40% range. This includes questions 1, 8 and 19.

Question 1--41.2% of respondents felt the need for information about their child's condition or disability.

Question 8--45.5% of respondents indicated need for more information about how to deal with their mentally handicapped child's puberty.

Question 19--46.0% of respondents indicated need for help in dealing with the mentally handicapped child's temperament such as crying, whining, etc.

#### Other Findings: Responses to Open Ended Questions

The responses to the open ended questions resulted in several clusters of responses.

Question 1--What are your greatest family needs at this time?

Parents reported daycare, before and after school programs, finding qualified babysitters or respite workers particularly for working parents or single parents as their current greatest family need. The parents reported the need for respite to enable them to have time to spend alone, with a spouse or with other family members as well as more time to rest.

The second cluster of family need were in the area of recreational needs for the mentally handicapped child such as instructional games and activities, summer programs, summer recreation or camps geared specifically to the needs of handicapped children.

The third cluster of need dealt dealing with self-abusive behavior and self-stimulating inappropriate behavior, seeking information about correcting or managing such behaviors.

Future concerns for living and working arrangements for the mentally handicapped child were also raised as well as concerns regarding puberty and reaching developmental potential.

The final cluster of "greatest family need" focussed around effective and alternative methods of communication with the mentally handicapped child. Many parents wished to learn about augmentative communication systems such as "signing" or "Bliss Symbolics".

Question 2--To what extent would your answers differ if there was no mentally handicapped child present in your family?

One cluster of parents reported that they would not be required to provide supervision or custodial care for a "grown" child nor would they have to get a babysitter or respite worker if there was no mentally handicapped child present in their family. Many respondents replied with a general statement of "our lives would be a lot different". Several parents indicated that having a handicapped child affected their decision about the wife returning to work and fathers' employment opportunities. For example, parents reported their opportunity to work in locations where education and

support services were limited for mentally handicapped children would be hampered. Also, working in other countries was limited as many countries will not allow entry of mentally retarded individuals into their country.

In summary, the responses provided by parents of mentally handicapped children to the open ended questions revealed the extra-ordinary demands parents of mentally handicapped children face on a daily basis. The responses reveal how their personal lives are limited and restricted as well as their family functioning and career opportunities.

## CHAPTER V

### DISCUSSION

This study examined the relationship between selected demographic variables and parents' perception of need in raising and educating mentally handicapped children. A review of the literature generated five hypotheses. These hypotheses will be re-stated along with a brief statement about the data including statistical findings, descriptive findings and open-ended responses. Recommendations for further research as well as educational implications will be included in this chapter.

#### Hypothesis 1

Parents who have a mentally handicapped child as well as non-handicapped children will indicate a higher frequency of need than parents who have a mentally handicapped child only in the following categories: Need for Information, Educational Need, Need for Support, Need for Explaining to Others.

This hypothesis is not supported by the study's data. The literature suggests the addition of a mentally handicapped child makes a difference, adding stress and responsibility to the family's situation. But, in the study both groups of parents indicated a high frequency of need. A limitation of the

findings for this hypothesis is that there were only four parents per cell with only mentally handicapped children, while there were 24 and 26 parents who had additional children (see Table 1). With such a low representation in the "only mentally handicapped child" category there is the possibility that the responses of this group are not representative of the category of parents.

#### Hypothesis 2

Older parents of mentally handicapped children will indicate higher frequency of need in the following categories: Need for Support, Community Service Need, Financial Need and Future Need.

The study supports an aspect of this hypothesis. The literature presents the view that older parents who have to provide difficult care-giving demands for a longer period of time will be subject to burnout, fatigue and stress.

The present study shows that older mothers have a higher frequency of need in the "Future Need" category: they will have concerns about aging and illness and ability to care for their mentally handicapped child. They are concerned with future needs of their mentally handicapped child include independent living skills and provisions for living in the community. They also indicated higher incidence of the "Need for Explaining to Others" was a category which unexpectedly was significantly higher for older mothers. This may be attributed to the current times of community living in which mentally

handicapped individuals are more visible than during an era in which they were hidden or segregated. Consequently, mothers may feel a greater need to explain their child's condition to others in the community.

There was no significant difference for father's age in any category of need (see Table 3). This is likely due to the fact that mothers provide the primary care giving for the mentally handicapped child. The father is often far removed from many day-to-day problems, visits to the doctor, grocery shopping and other expeditions out into the community. The traditional role of the father as breadwinner takes him away from home and the many problems and situations with which the mother deals. Also, perhaps because of the fact that men are socialized to believe they must be strong and it would be a sign of weakness to admit the need for help may be an explanation. However, a problem in the interpretation of these data is the fact that there were only 2 or 3 responses per cell for younger fathers (see Table 3). Again the possibility exists that the responses are not representative of this group.

### Hypothesis 3

Single parent families will indicate a higher frequency of need than dual parent families in all categories of need.

Evidence supports the hypothesis in the areas of the "Need for Support", "Need for Explaining to Others" and "Financial Need" category.

Single parents need for support is evident in the fact that he/she has the entire responsibility of raising the mentally handicapped child.

This is also evident in the "Need for Explaining to Others" category. There is no other significant person to assist and support the single parent with a mentally handicapped child in community settings such as sports events, cultural events and educational situations. Such settings often highlight the differences of the handicapped child. Also, the notion of chronic sorrow (Olshansky, 1962) comes to mind. When parents with mentally handicapped children see non-handicapped children the same age as their child performing in a concert, competing or participating in sporting events, graduating from high school and so on, the long term depressive mood pervades. Here again, if the parent is single, this chronic sorrow is intensified and must be endured alone.

As expected single parents indicated a high frequency of need in the "Financial Need" category. The cost of raising and educating a mentally handicapped child are considerable, such as qualified adult babysitters or special caregivers. The number of years a babysitter or caregiver is needed for severely mentally handicapped children far exceeds the number of years this would be required for non-handicapped children. Furthermore, the cost of medication, diapers, special devices, special shoes and special toys is high.

Transportation costs are great, particularly if the mentally handicapped child is also physically handicapped. Recreation for structured special programs such as Riding for the Disabled Program are costly. The need for special, structured programs is apparent when it is realized that severely and profoundly mentally handicapped children cannot simply be sent out to play.

The categories of "Need for Information", "Educational Need", "Community Service Needs" were not indicated as high need for single parents. The "Family Function Need" category was also not indicated as high need, yet the literature suggested the contrary. Holroyd (1974) reported that single mothers particularly reported too many time demands, stifled personal development as well as feeling the family had many problems and was not integrated. The reason for the difference in the current study may be the fact that many single parents who responded to this survey are already being provided with information and community services and the educational services to meet the needs of their mentally handicapped child. Or, it may be that these single parents are so overwhelmed by the care-giving demands of their child they have not yet had the opportunity to assess needs in these areas. Also, some of these single parents may be receiving help from extended family members such as grandparents as was indicated in the follow-up interviews. Consequently some of these needs may be met.

#### Hypothesis 4

Non-Catholic parents of handicapped children will indicate a higher frequency of need than Catholic parents in the areas of "Need for Support", "Need for Explaining to Others", "Community Service Needs" and "Family Functioning".

The current study supports this hypothesis for non-Catholic mothers in the "Community Service Need" category only.

The low frequency indication of need for support by non-Catholic mothers may be due to the fact that the source of emotional support for these parents comes from sources other than religious ones.

The data supports the hypothesis for non-Catholic fathers in several categories including Need for Support, Community Service Need, Financial Need, Family Functioning and Future Need.

The analysis of the data showed that over 60% of the non-Catholic fathers are in the low income levels. It is also very likely that due to lack of sufficient finances these fathers also experience a need for support, community services and family functioning.

#### Hypothesis 5

Parents of mentally handicapped children from lower socio-economic backgrounds will indicate a higher frequency of need in all categories of need including: Need for Information, Educational Need, Need for Support,

Community Service Need, Family Functioning and Future Need. Socio-economic status include mother's and father's occupation and level of schooling and total family income.

The current study supports "Need for Support" and "Need for Explaining to Others" categories regarding mother's occupation. In turn, the need for support expressed by low status occupation mothers is also supported by the literature. This can be expected since the type of occupation is clearly tied with financial resources which affect the degree and kind of support and the degree and kind of assistance in relating with other members of the community.

The high frequency response in the "Need to Explain to Others" category is contrary to the literature regarding the issue of low status parents accepting low status labels. One reason for this may be that the current study's definition of low status differ from the definition used by researchers in the literature. Another reason parents may have indicated a high frequency response is that mentally handicapped individuals have become highly visible in this era of community living whereas they were rarely visible in an era of segregation. Parents, perhaps, now feel they need to explain their child's handicap if the child is included in everyday outings into the community.

If a mentally handicapped child displays age inappropriate behavior, self-stimulatory or self injurious behavior parents will likely feel the need to explain the mentally handicapped child's behavior. If a mentally handicapped child is in a supermarket with his family and sits on the floor, yells out or pulls someone's hair in the checkout line, the parent likely feels the need to apologize and also explain.

Furthermore, if a mentally handicapped child also has a physical abnormality or handicap and people likely will stare or withdraw and the parent may feel the need to explain the child's condition.

The evidence presented in Chapter IV does not support any category of the hypothesis for father's occupation which is contrary to the literature on the issue of low status labels being readily accepted by parents of low status occupations.

Mothers with low level of schooling (under grade 12) indicated high frequency of need in the "Need for Explaining to Others" and "Financial Needs" category. The financial need may be tied to the fact that mothers with low level of schooling likely receive low wages.

Father's low level of schooling significantly different from fathers of high level of schooling in the "Need to Explain to Others" category only.

For family income evidence presented in Chapter IV supports high frequency of need under the "Need for Explaining to Others", "Financial Need" and "Family Functioning" only although the expectation was that all categories would indicate high frequency of need except the "Need for Explaining to Others". The high frequency responses for financial needs and family functioning needs would verify that financial resources have the power to buy resources, to help meet extra expenses and help make family functioning easier. It is likely that low income families would be unable to buy resources or services to ease the stress of the presence of the mentally handicapped child in the family.

### Summary

The five hypotheses examined the relationship of demographic factors of number of children, age of parents, marital status of parents, religion of parents and socio-economic status of parents of mentally handicapped children with parents' perception of need. Most of the aspects in each hypothesis found support in the literature. The most salient feature of the data was the overriding need expressed by most parents in the "Need to Explain to Others" category.

The following aspects of the 5 hypotheses were supported by the data analyzed in this study:

1. Older mothers indicated a higher frequency in the "Future Needs" and "Explaining to Others" categories.
2. Single mothers indicated a higher frequency in the "Need for Support", "Need for Explaining to Others" and "Financial Need" categories.
3. Non-Catholic mothers indicated a higher frequency in the "Community Service Need" category.
4. Non-Catholic fathers indicated a higher frequency in "Community Service Needs", "Need for Support", "Financial Needs", "Family Functioning Needs" and "Future Needs" categories.
5. Low-status occupation mothers indicated a higher frequency in "Need for Support" and "Need for Explaining to Others" categories.
6. Low-level schooling mothers indicated a higher frequency in "Need for Explaining to Others" and "Financial Needs" categories.
7. Low-level schooling fathers indicated a high frequency in "Need for Explaining to Others".
8. Lower family income parents reported higher frequency of need in the "Explaining to Others", "Financial Need", and "Family Functioning" categories.

Perhaps the most important finding of this research is that one category of need cut across all demographic variables, the "Need to Explain to Others". One possible explanation for this finding is that mentally handicapped individuals have become more visible due to more frequent outings into the community and their presence there may give rise to situations, in which parents may feel the need to explain the child's handicap.

#### Specific Limitations to the Study

One of the most important limitations of this study, as mentioned in Chapter I, is that the findings are based on a low population. Of the 110 surveys distributed only 31% of the parents responded. The researcher was unable to do a personal follow-up either through a face-to-face meeting or telephone conversation with the parents due to the procedure prescribed by the Winnipeg School Division #1. The only individuals with whom contact was established by the researcher were those individuals who indicated interest in a follow-up interview and who provided a phone number.

The fact that there were only 4 or 5 parents per cell, in some cases, presents limitations as too few respondents per cell would not be sufficiently representative of this population.

A limitation of the pilot study was that 4 of the 5 sets of dual parents who gave feedback may not have been representative of the general population which responded to the survey. The 4 sets of parents were highly educated and on the upper end of the socio-economic scale. Three sets of parents were contacted by phone and one set of parents was met informally to discuss the survey instrument.

The limitation of the follow-up interviews was that the interviews were not tape recorded. This, however, was out of consideration for the comfort level and privacy of the parents who participated in the follow-up interview. Three sets of parents were interviewed face-to-face by the researcher and two sets of parents participated in the follow-up interview by telephone. One single mother expressed a preference for a telephone interview since she was not able to get a "sitter" for her mentally handicapped child. The single father also participated in the follow-up interview by telephone.

The lack of sufficient psychometric properties of the survey instrument results in obvious limitations. The instrument reported reliability but not validity. Although this appeared to be the best instrument available it did not adequately deal with educational need and future need for parents of severely or profoundly mentally handicapped children.

### Conclusion of Descriptive Findings

The general conclusion from the descriptive findings which cut across all demographic variables indicate three high priority areas of need for parents of mentally handicapped children. These areas include 1) a need for more information about services that their mentally handicapped child might receive in the future (including provisions for community living), 2) a need for more information about services presently available for their mentally handicapped children (particularly extra-curricular programs which appropriately meet the needs of their child), and 3) a need for more information about how to handle their child's mentally handicapped behavior.

Question 2--59.4% of respondents indicated they need more information about how to handle their child's behavior.

It would seem that in a society which perpetuates competition and conformity inappropriate behavior displayed by children affects the comfort level of the parents at home and especially out in the community. Also, a child's inappropriate behavior reflects upon parenting skills. Despite great effort on the part of the parents to correct or eliminate inappropriate behavior the child may continue to persist in such behavior due to low functioning level or frustration as a result of lack of communication skills.

Question 3--54.5% of the respondents indicated they needed more information about methods of teaching their child.

Parenting is one role for which there is no training. When the demands of parenting are compounded by the presence of a mentally handicapped child it is more difficult for parents to teach their child effectively. Parents rarely have previous experience or training to fulfil the role of teaching a handicapped child.

Question 5--85.3% of the respondents indicated they need more information about services presently available for their mentally handicapped child.

Parents appear to be unaware of services available in the community or are unaware of how to access this information.

Question 6--91.2% of the respondents indicated they need more information about services that their mentally handicapped child might receive in the future.

The significantly high percentage reporting need for this item suggests the lack of information or the lack of ability to access information about future needs, including information about child's educational programs and access to morning and after school programs. It would appear that some parents are not being involved in the Individual Education Plans and

programming for their child, or if they are, the communication about programming is not clear or effective.

Question 17--56.3% of the respondents indicated they needed reading material about other parents who have a mentally handicapped child similar to theirs.

Reading material about mentally handicapped children is available in various journals and books. Parent to Parent, a volunteer support group of parents in Winnipeg has begun to build a library with such material. Canadian Association for Community Living and other such groups and association have material. It would appear that some parents are not aware of such material.

Question 34---60.6% of the respondents indicated they needed extra-curricular programs which appropriately meet the special needs of their mentally handicapped child.

Special programs are available for handicapped children but are limited. Government funding for special programs is limited. Parents do not appear to know how to access information about the existence of special programs for their mentally handicapped child.

Question 50--63.6% of the respondents indicated they needed to know what kinds of provisions for living in the community will be available for their mentally handicapped child.

Question 50 has to do with concerns about future needs. It would appear that older parents have more concerns about future needs; they wonder who will provide care for their "grown" mentally handicapped child if parents become ill or too old or die. Parents are also concerned about whether these services will be available in a community residence or an institution.

The next cluster of questions described are those for which the frequency was in the 40% range. This includes questions 1, 8 and 19.

Question 1--41.2% of respondents felt the need for information about their child's condition or disability.

Question 8--45.5% of the respondents indicated need for more information about how to deal with their child's puberty.

Some parents of severely and profoundly retarded children choose not to deal with the issue of their child's sexuality. They think of their child as "an eternal child", particularly when the functioning level is very low. The notion of sexuality of mentally handicapped individuals is highly controversial and many complex ethical issues arise.

Question 19--46.9% of the respondents indicated need for help in dealing with their mentally handicapped child's temperament such as crying, whining, etc.

The comfort level of parents at home and in the community is usually affected by their child's temperament. It can interfere with trips outside the home and the socialization of the child. Parents indicated that they require more help in dealing with their mentally handicapped child in home and out of home settings.

It should be noted that question 16 was avoided or disregarded by all respondents. This question deals with the need to talk with a clergyman who could help parents with their problems.

In summary, the findings of the frequency distribution in this section reveal that the highest frequency of need, that is questions with a response of over 50%, is indicated in the following categories: Need for Information, Educational Need, Need for Support, Community Service Need and Future Need.

#### Summary for Open Ended Questions

In summary, the open ended questions reveal that parents reported their greatest family needs as: day care; before and after school programs; finding qualified babysitters or respite workers; recreational programs and activities for their mentally handicapped child; dealing with self-abusive and self-stimulatory behavior; future concerns for living and working arrangements

and finally, the need to learn ways in which to communicate with their mentally handicapped child.

From the findings in this study the following recommendations are tentatively proposed:

#### Recommendations for Educators and Support Services Providers

The success of meeting the needs of mentally handicapped students and meeting the needs of their families will depend greatly on how well informed educators and support service providers are in the area of parent perception of needs. Since educators and support service providers play a vital role in planning programs for mentally handicapped students and their families background information is necessary for effective planning and delivery of services.

I. This background information may become available through such surveys as the "Family Needs" survey which will provide a valuable insight and it would reduce the number of individuals in the community to whom parents of mentally handicapped children would feel the need to explain their child's condition.

Other information of benefit to educators and support service providers and policy makers are:

1. Older mothers' future needs.

2. Single mothers' needs regarding support and finances.
3. Non-Catholic mothers' and fathers' needs about community services.
4. Non-Catholic fathers' needs related support, finances, family functioning and future needs.
5. Low-status occupation mothers' financial needs.
6. Low-income family parents' needs regarding finances and family functioning.

Such information would provide educators and service providers with greater insight in the following areas:

1. assessing needs of mentally handicapped children and their families with sensitivity to particular needs of particular groups of parents;
2. planning for involvement of appropriate support services;
3. planning curriculum;
4. completing Individual Education Plans (IEP).

Furthermore, such information gives professionals an appreciation for the needs and stress in families with mentally handicapped children and encourage them to assume an advocacy role for parents and the mentally handicapped child, thereby fulfilling the intent of the legislation in the Manitoba Public Schools Act, Section 41[4] more adequately.

II. Professional development should be provided for policy makers including such data as findings from the "Family Needs" survey so that informed decisions can be made before implementing new policies affecting the education of mentally handicapped children and their families.

III. Access to information about existing services, reading materials and support systems should be provided to parents of mentally handicapped children. Provision of this information could be provided in a frequently updated directory.

IV. Workshops should be provided for parents and family members of mentally handicapped individuals to learn how to: 1) communicate more effectively with their severely mentally handicapped child; 2) deal with the behaviors of their severely mentally handicapped child; and 3) teach age appropriate adaptive behavior skills to their severely mentally handicapped child.

V. Improve communication between parents and professionals to ensure that parents and the mentally handicapped child's needs are being met by sharing background information.

### Implications for Study of the Problem

The implications for study of this problem are educational and political. Few educators, service providers or policy makers are sufficiently aware of the nature of stress and need experienced by parents who are raising and educating their severely or profoundly mentally retarded children in the community. Once needs are identified, provision of appropriate and necessary services can be recommended with a view to insure assistance to parents of mentally handicapped children. Assistance to parents would enable them to cope with stress more effectively and to meet the physical, emotional, social and educational needs of their mentally handicapped child.

Educators would find the information gathered from this study useful in planning effective, co-operative educational programming. Service providers would find the information useful in planning intervention and support for the mentally handicapped child and the family. Policy makers would also find the information valuable and directive in planning and developing more extensive public policy.

### Educational Implications

The role of special educators is evolving into a more challenging, complex and demanding professional experience. The role encompasses not

only sound pedagogy but awareness of the total picture of the special needs of the mentally handicapped child and special needs of the family. This awareness is necessary for effective planning of educational experiences as set forth in the child's Individual Education Plans. Curricula need to be developed in methods of teaching parents, teachers, and other professionals such as communicating more effectively with mentally handicapped children and to teach age appropriate adaptive behavior skills to mentally handicapped children. Also, the educational implication of developing age appropriate, functional curriculum in a natural setting for severely and profoundly handicapped students exists.

#### Recommendations for Further Research

1. There is a need for further research to discover the ramifications for parents lives and relationships related to the birth order of a mentally handicapped child.
2. Study the more recent social phenomenon of single parents and the mentally handicapped child. This would include single fathers as well as single mothers. This population is increasing in number and has unique and specific needs.

3. Study the relationship between coping mechanisms and stress management among different cultures and how they each deal with the presence of a mentally handicapped child.

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## APPENDICES

Appendix A  
Family Needs Survey

## FAMILY NEEDS SURVEY

Instructions: Listed below are some of the needs expressed by parents of special children. Please reach each statement and decide if you need help in this area. Then circle (1, 2, or 3) which represents your response.

|             |                                                                                    | Definitely<br>do not<br>need help<br>with this | Not<br>sure | Definitely<br>need help<br>with this |
|-------------|------------------------------------------------------------------------------------|------------------------------------------------|-------------|--------------------------------------|
| <hr/> <hr/> |                                                                                    |                                                |             |                                      |
|             | <u>Needs for Information</u>                                                       |                                                |             |                                      |
| 1.          | I need more information about my child's condition or disability.                  | 1                                              | 2           | 3                                    |
| 2.          | I need more information about how to handle my child's behavior.                   | 1                                              | 2           | 3                                    |
| 3.          | I need more information about how to teach my child.                               | 1                                              | 2           | 3                                    |
| 4.          | I need more information on how to play with or talk to my child.                   | 1                                              | 2           | 3                                    |
| 5.          | I need more information on the services that are presently available for my child. | 1                                              | 2           | 3                                    |
| 6.          | I need more information about services that my child might receive in the future.  | 1                                              | 2           | 3                                    |
| 7.          | I need more information about how children grow and develop.                       | 1                                              | 2           | 3                                    |
| *8.         | I need more information about how to deal with my child's puberty.                 | 1                                              | 2           | 3                                    |

|                          |                                                                                                 | Definitely<br>do not<br>need help<br>with this | Not<br>sure | Definitely<br>need help<br>with this |
|--------------------------|-------------------------------------------------------------------------------------------------|------------------------------------------------|-------------|--------------------------------------|
| *9.                      | I need to know how to deal with reactions of strangers (toward my child's physical appearance). | 1                                              | 2           | 3                                    |
| <u>Educational Needs</u> |                                                                                                 |                                                |             |                                      |
| *10.                     | I need more information about my child's educational programs.                                  | 1                                              | 2           | 3                                    |
| *11.                     | I need access to morning (prior to school) and after school programs for my child.              | 1                                              | 2           | 3                                    |
| <u>Needs for Support</u> |                                                                                                 |                                                |             |                                      |
| 12.                      | I need to have someone in my family that I can talk to more about problems.                     | 1                                              | 2           | 3                                    |
| 13.                      | I need to have more friends that I can talk to.                                                 | 1                                              | 2           | 3                                    |
| 14.                      | I need to have more opportunities to meet and talk with other parents of handicapped children.  | 1                                              | 2           | 3                                    |
| 15.                      | I need to have more time just to talk with my child's teacher or therapist.                     | 1                                              | 2           | 3                                    |
| **16.                    | I need to talk more to a clergyman who could help me deal with problems.                        | 1                                              | 2           | 3                                    |

|                             |                                                                                                 | Definitely<br>do not<br>need help<br>with this | Not<br>sure | Definitely<br>need help<br>with this |
|-----------------------------|-------------------------------------------------------------------------------------------------|------------------------------------------------|-------------|--------------------------------------|
| 17.                         | I need reading material about other parents who have a child similar to mine.                   | 1                                              | 2           | 3                                    |
| 18.                         | I need to have more time for myself.                                                            | 1                                              | 2           | 3                                    |
| *19.                        | I need more information about how to deal with my child's temperament (crying, whining, etc.).  | 1                                              | 2           | 3                                    |
| *20.                        | I need more help to deal with feelings such as guilt, anger, denial, grief, etc.                | 1                                              | 2           | 3                                    |
| *21.                        | I need to know if I'm being a good parent.                                                      | 1                                              | 2           | 3                                    |
| *22.                        | I need help providing care-giving demands.                                                      | 1                                              | 2           | 3                                    |
| <u>Explaining to Others</u> |                                                                                                 |                                                |             |                                      |
| 23.                         | I need more help to explain my child's condition to his or her siblings.                        | 1                                              | 2           | 3                                    |
| 24.                         | I need more help in explaining my child's condition to either my spouse or my spouse's parents. | 1                                              | 2           | 3                                    |
| 25.                         | My spouse needs help in understanding and accepting our child's condition.                      | 1                                              | 2           | 3                                    |

|                           |                                                                                                                       | Definitely<br>do not<br>need help<br>with this | Not<br>sure | Definitely<br>need help<br>with this |
|---------------------------|-----------------------------------------------------------------------------------------------------------------------|------------------------------------------------|-------------|--------------------------------------|
| 26.                       | I need help in knowing how to respond when friends, neighbors, or strangers ask questions about my child's condition. | 1                                              | 2           | 3                                    |
| 27.                       | I need help in explaining my child's condition to other children,                                                     | 1                                              | 2           | 3                                    |
| <u>Community Services</u> |                                                                                                                       |                                                |             |                                      |
| 28.                       | I need help locating a doctor who understands me and my child's needs.                                                | 1                                              | 2           | 3                                    |
| 29.                       | I need help locating a dentist who will see my child.                                                                 | 1                                              | 2           | 3                                    |
| 30.                       | I need help locating babysitters or respite care providers who are willing and able to care for my child.             | 1                                              | 2           | 3                                    |
| 31.                       | I need help locating a day care centre or preschool for my child.                                                     | 1                                              | 2           | 3                                    |
| 32.                       | I need help in getting appropriate care for my child in our church or synagogue nursery during church services.       | 1                                              | 2           | 3                                    |
| *33.                      | I need help to care for my child when I am fatigued, ill or in need of surgery.                                       | 1                                              | 2           | 3                                    |

|       |                                                                                                                                                                            | Definitely<br>do not<br>need help<br>with this | Not<br>sure | Definitely<br>need help<br>with this |
|-------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------|-------------|--------------------------------------|
| *34.  | I need extra-curricular programs which appropriately meet the special needs of my child.                                                                                   | 1                                              | 2           | 3                                    |
|       | <u>Financial Needs</u>                                                                                                                                                     |                                                |             |                                      |
| **35. | I need more help in paying for expenses such as food, housing, medically related expenses not covered by our medicare system, i.e. medication, clothing or transportation. | 1                                              | 2           | 3                                    |
| 36.   | I need more help paying for therapy, day care or other services my child needs.                                                                                            | 1                                              | 2           | 3                                    |
| 37.   | I or my spouse need more counselling or help in getting a job.                                                                                                             | 1                                              | 2           | 3                                    |
| 38.   | I need more help paying for babysitting or respite care.                                                                                                                   | 1                                              | 2           | 3                                    |
| 39.   | I need more help paying for toys that my child needs.                                                                                                                      | 1                                              | 2           | 3                                    |
|       | <u>Family Functioning</u>                                                                                                                                                  |                                                |             |                                      |
| 40.   | Our family needs help in discussing problems and reaching solutions.                                                                                                       | 1                                              | 2           | 3                                    |

|                     |                                                                                                            | Definitely<br>do not<br>need help<br>with this | Not<br>sure | Definitely<br>need help<br>with this |
|---------------------|------------------------------------------------------------------------------------------------------------|------------------------------------------------|-------------|--------------------------------------|
| 41.                 | Our family needs help in learning how to support each other during difficult times.                        | 1                                              | 2           | 3                                    |
| 42.                 | Our family needs help in deciding who will do household chores, child care and other related family tasks. | 1                                              | 2           | 3                                    |
| 43.                 | Our family needs help on doing recreational activities.                                                    | 1                                              | 2           | 3                                    |
| *44.                | I need more time alone with my spouse.                                                                     | 1                                              | 2           | 3                                    |
| *45.                | I need help in dealing with in-laws.                                                                       | 1                                              | 2           | 3                                    |
| *46.                | I need help in dealing with other extended family members.                                                 | 1                                              | 2           | 3                                    |
| *47.                | I need to know how to deal with the guilt of working outside the home.                                     | 1                                              | 2           | 3                                    |
| *48.                | I need more information about how to deal with my non-handicapped children.                                | 1                                              | 2           | 3                                    |
| <u>Future Needs</u> |                                                                                                            |                                                |             |                                      |
| *49.                | I need help with concerns about my child's independent living skills.                                      | 1                                              | 2           | 3                                    |
| *50.                | I need to know what kinds of provisions for living in the community will be available for my child.        | 1                                              | 2           | 3                                    |

Instrument: Family Needs Survey; Bailey & Simensson (1988)

\* Questions marked with a single star indicate additions to original instrument.

\*\* Questions marked with a double star indicate minor modifications or origin authors' questions.

## DEMOGRAPHICS

1. Number of children in your family \_\_\_\_\_
2. Mother's age \_\_\_\_\_
3. Father's age \_\_\_\_\_
4. Highest level of schooling completed by mother \_\_\_\_\_
5. Highest level of schooling completed by father \_\_\_\_\_
6. What is your marital status?      ☐ single      ☐ married  
                                                 ☐ separated      ☐ divorced  
                                                 ☐ common-law
7. Are you a dual parent family? \_\_\_\_\_
8. Are you a single parent family? \_\_\_\_\_
9. If you are a single parent family,  
did the stress related to the presence  
of the mentally handicapped child contribute  
to the separation of the family unit? \_\_\_\_\_
10. Mother's religion \_\_\_\_\_
11. Father's religion \_\_\_\_\_
12. Mother's occupation \_\_\_\_\_
13. Father's occupation \_\_\_\_\_

14. Total family income in 1989

Under \$15,000 \_\_\_\_\_

Between \$15,000 - \$25,000 \_\_\_\_\_

Between \$25,000 - \$35,000 \_\_\_\_\_

Between \$35,000 - \$45,000 \_\_\_\_\_

Between \$45,000 - \$55,000 \_\_\_\_\_

Over \$60,000 \_\_\_\_\_

Do you wish to participate in a follow-up interview? Yes \_\_\_\_\_ No \_\_\_\_\_

If yes, please provide: Name \_\_\_\_\_

Phone Number \_\_\_\_\_

## Appendix B

### Letter to the Superintendent's Department

Klara M. Somogyi  
15 Yanofsky Way  
Winnipeg, Manitoba  
R2P 1V1  
Tel: 474-9023 (bus.)  
334-7418 (res.)

Executive Assistant to Chief Superintendent  
Winnipeg School Division #1  
1577 Wall Street East  
R3E 2S5

Dear Mr. Edmond,

I am a graduate student in Educational Psychology at the University of Manitoba. I am also the parent of a mentally handicapped child. Presently, I am undertaking studies related to parental roles and stress in families associated with educating children with mentally handicaps.

The current literature indicates that there are a number of variables which cause parents of mentally retarded children stress. Consequently, I am asking parents to complete a survey through which they can share some of their experiences to determine what are the variables. This information should be valuable in providing recommendations for intervention and improvement in services.

I invite your co-operation in helping to distribute a survey package to all the parents of mentally handicapped children in your division. This manner of distribution would ensure confidentiality for the parents and the children. Participation, naturally, would be on a purely voluntary basis as stated in the cover letter to the parents.

In terms of my own planning and preparation, as soon as a decision is made by you regarding your preparedness to co-operate, I will require: the total number of students in your division classified as mentally handicapped, excluding the mildly mentally handicapped who are mainstreamed; the names

of the schools which these students attend; and a letter from you to the schools identified indicating that I have been given permission to conduct this survey, which is to be sent home to parents with the children.

I am prepared to assist with the distribution of survey packages to the individual schools. Also, I am prepared to make appointments with the respective principals and visit each school and meet with the persons who will be distributing the survey. The surveys will be coded to assist in monitoring distribution.

Enclosed is a draft of the questionnaire as well as a copy of the cover letter to parents.

Should you require additional information, do not hesitate to contact me at the University of Manitoba in the Department of Educational Psychology at 474-9023, or at home at 338-7418.

I am extremely anxious for your co-operation to obtain the information contained in the survey so that I may speak with some certainty about the experiences and attitudes of parents of mentally handicapped children.

Yours Sincerely,

Klara M. Somogyi

**Appendix C**  
**Cover Letter to Parents**

15 Yanofsky Way  
Winnipeg, Mamitoba  
R2P 1V1  
April 10, 1990

Dear Parents,

I am a graduate student in Education Psychology at the University of Manitoba. I am also a parent of a mentally handicapped child. Presently, I am unvestigating the relationship between parental roles and stress in education of children with mental handicaps.

I would appreciate your assistance in completing the attached survey. The information you provide will allow us to recommend changes and improvements in program planning and in services currently available.

Participation in the survey is on a voluntary basis. All surveys will be treated as strictly confidential. If, however, you are willing to participate in a follow-up interview, please indicate this on the survey. If you wish to obtain information about the overall results of my study please indicate this on the survey as well.

The attached survey will take about thirty minutes of your time. Please complete it and return it to be in the stamped, self-addressed envelope by April 27th, 1990.

Should you require additional information, do not hesitate to contact me in the Department of Education Psychology at the University of Manitoba at 474-9023, or at my home at 334-7418.

Yours sincerely,

Klara M. Somogyi

Appendix D  
Follow-up Letter to Parents

15 Yanofsky Way  
Winnipeg, Manitoba  
R2P 1V1

Dear Parents,

This is a follow-up letter to remind parents who have received the Family Needs Survey that if you have not as yet completed the survey, would you please consider completing it and returning it as soon as possible.

I am extremely anxious to obtain sufficient completed questionnaires to enable me to speak with some certainty about the experiences and attitudes of parents of mentally handicapped children so that this research will be credible when recommending interventions and improvements in services.

Therefore, I look forward to your finding time to complete and return the information I require. Thank you.

Yours sincerely,

Klara M. Somogyi

Appendix E  
Frequency Distribution Data

### Frequency Distribution Data Table

#### Parental Need in Raising and Educating a Mentally Handicapped Child

| Categories                    | Question | 1  | 2 | 3  | %    |                                                                      |
|-------------------------------|----------|----|---|----|------|----------------------------------------------------------------------|
| Need for Information          | 1        | 13 | 7 | 14 | 41.2 |                                                                      |
|                               | 2        | 9  | 4 | 19 | 59.4 | *how to handle child's behavior                                      |
|                               | 3        | 7  | 8 | 18 | 54.5 | *how to teach my child                                               |
|                               | 4        | 13 | 8 | 11 | 34.4 |                                                                      |
|                               | 5        | 1  | 4 | 29 | 85.3 | **services presently available                                       |
|                               | 6        | 0  | 3 | 31 | 91.2 | **future services                                                    |
|                               | 7        | 19 | 6 | 9  | 26.5 |                                                                      |
|                               | 8        | 11 | 7 | 15 | 45.5 |                                                                      |
|                               | 9        | 19 | 6 | 8  | 24.2 |                                                                      |
| Educational Needs             | 10       | 9  | 6 | 18 | 54.5 | *child's educational program                                         |
|                               | 11       | 18 | 5 | 11 | 32.4 |                                                                      |
| Need for Support              | 12       | 21 | 5 | 6  | 18.8 |                                                                      |
|                               | 13       | 15 | 8 | 9  | 28.1 |                                                                      |
|                               | 14       | 11 | 9 | 11 | 35.5 |                                                                      |
|                               | 15       | 15 | 9 | 7  | 22.6 |                                                                      |
|                               | 16       | 24 | 6 | .  | .    |                                                                      |
|                               | 17       | 13 | 1 | 18 | 56.3 | *reading material about other parents who have child similar to mine |
|                               | 18       | 16 | 4 | 12 | 35.7 |                                                                      |
|                               | 19       | 14 | 3 | 15 | 46.9 |                                                                      |
|                               | 20       | 15 | 8 | 9  | 28.1 |                                                                      |
|                               | 21       | 16 | 8 | 8  | 25.0 |                                                                      |
|                               | 22       | 15 | 9 | 8  | 25.0 |                                                                      |
| Need for Explaining to Others | 23       | 19 | 4 | 8  | 25.8 |                                                                      |
|                               | 24       | 22 | 5 | 5  | 15.6 |                                                                      |
|                               | 25       | 25 | 2 | 5  | 15.6 |                                                                      |

| Categories              | Question | 1  | 2  | 3  | %    |                                                                       |
|-------------------------|----------|----|----|----|------|-----------------------------------------------------------------------|
| Need for Explaining     | 26       | 21 | 3  | 8  | 25.0 |                                                                       |
|                         | 27       | 19 | 4  | 9  | 28.1 |                                                                       |
| Community Service Needs | 28       | 23 | 6  | 3  | 9.4  |                                                                       |
|                         | 29       | 25 | 5  | 3  | 9.1  |                                                                       |
|                         | 30       | 18 | 3  | 12 | 36.4 |                                                                       |
|                         | 31       | 29 | 1  | 2  | 6.3  |                                                                       |
|                         | 32       | 25 | 3  | 4  | 12.5 |                                                                       |
|                         | 33       | 17 | 5  | 12 | 35.3 |                                                                       |
|                         | 34       | 8  | 5  | 20 | 60.6 | *extra-curricular programs which appropriately meet needs of my child |
| Financial Needs         | 35       | 21 | 4  | 7  | 21.9 |                                                                       |
|                         | 36       | 24 | 4  | 5  | 15.2 |                                                                       |
|                         | 37       | 23 | 3  | 6  | 18.8 |                                                                       |
|                         | 38       | 22 | 4  | 7  | 21.2 |                                                                       |
|                         | 39       | 22 | 3  | 8  | 24.2 |                                                                       |
| Family Functioning      | 40       | 16 | 9  | 7  | 21.9 |                                                                       |
|                         | 41       | 16 | 7  | 9  | 28.1 |                                                                       |
|                         | 42       | 23 | 6  | 3  | 9.4  |                                                                       |
|                         | 43       | 11 | 13 | 8  | 25.0 |                                                                       |
|                         | 44       | 18 | 4  | 10 | 31.3 |                                                                       |
|                         | 45       | 28 | 2  | 2  | 6.3  |                                                                       |
|                         | 46       | 26 | 3  | 3  | 9.4  |                                                                       |
|                         | 47       | 23 | 6  | 3  | 9.4  |                                                                       |
|                         | 48       | 23 | 3  | 6  | 18.8 |                                                                       |
| Future Needs            | 49       | 7  | 6  | 20 | 60.6 | Child's<br>*independent living skills                                 |
|                         | 50       | 6  | 6  | 21 | 63.6 | *provisions for community living skills                               |