

MOTHERS' PERCEPTIONS OF RESPITE CARE

BY

AMY THOMSON

A THESIS SUBMITTED TO

THE FACULTY OF GRADUATE STUDIES

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS

FOR THE DEGREE OF

MASTER OF SOCIAL WORK

FACULTY OF SOCIAL WORK

UNIVERSITY OF MANITOBA

WINNIPEG, MANITOBA

© July 2002



National Library  
of Canada

Acquisitions and  
Bibliographic Services

395 Wellington Street  
Ottawa ON K1A 0N4  
Canada

Bibliothèque nationale  
du Canada

Acquisitions et  
services bibliographiques

395, rue Wellington  
Ottawa ON K1A 0N4  
Canada

*Your file Votre référence*

*Our file Notre référence*

The author has granted a non-exclusive licence allowing the National Library of Canada to reproduce, loan, distribute or sell copies of this thesis in microform, paper or electronic formats.

The author retains ownership of the copyright in this thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without the author's permission.

L'auteur a accordé une licence non exclusive permettant à la Bibliothèque nationale du Canada de reproduire, prêter, distribuer ou vendre des copies de cette thèse sous la forme de microfiche/film, de reproduction sur papier ou sur format électronique.

L'auteur conserve la propriété du droit d'auteur qui protège cette thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

0-612-80061-X

**THE UNIVERSITY OF MANITOBA**  
**FACULTY OF GRADUATE STUDIES**  
**\*\*\*\*\***  
**COPYRIGHT PERMISSION PAGE**

**Mothers' Perceptions of Respite Care**

**BY**

**Amy Thomson**

**A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University  
of Manitoba in partial fulfillment of the requirements of the degree  
of**

**MASTER OF SOCIAL WORK**

**AMY THOMSON ©2002**

**Permission has been granted to the Library of The University of Manitoba to lend or sell copies of this thesis/practicum, to the National Library of Canada to microfilm this thesis and to lend or sell copies of the film, and to University Microfilm Inc. to publish an abstract of this thesis/practicum.**

**The author reserves other publication rights, and neither this thesis/practicum nor extensive extracts from it may be printed or otherwise reproduced without the author's written permission.**

## TABLE OF CONTENTS

ABSTRACT	5
ACKNOWLEDGEMENTS	6
CHAPTER ONE: INTRODUCTION	7
CHAPTER TWO: THE PROBLEM	10
Rationale for the study	11
What is Wesway?	12
CHAPTER THREE: LITERATURE REVIEW	15
Definitions	16
Impact of disability on family	17
Literature on respite care	22
Gender and unpaid caregiving	24
Literature on cases within Canada	30
The need for respite care services	36
CHAPTER FOUR: METHODOLOGY	39
Introduction	39
Research design and instrumentation	40
The grounded theory approach	40
Research questions	43
Research participants	44
The interview and data gathering	45
Data collection procedures	46
Ethical considerations	50
Data analysis	54
CHAPTER FIVE: THE FINDINGS	66
Family descriptions	67

FINDINGS	70
Mothers are the primary caregivers	70
Mothers played a variety of roles	71
Effects of the disability on families	71
Impact on lifestyle	73
Impact on siblings	75
Impact on marriages	76
Impact on health and well-being	76
Mothers have positive experiences caring for a child with a disability	77
Child care responsibilities impeded labour force participation	78
STRESS	78
Financial stress	80
Looking to the future	80
The educational role	81
Mothers felt their unpaid caregiving activities were not recognized	81
SOCIAL SUPPORTS	81
Women tend to seek support to deal with the stress in their lives	82
Women received support from their families	82
Support received from respite staff	83
Spousal support	84
Community support	85
Funding cuts are affecting parents' access to supports	87
RESPITE CARE	88
Mothers are satisfied with the support they receive	89
Suggested improvements/changes	90
DISCUSSION AND ANALYSIS	92
Categories and supporting literature	93
Caregiver stress	93
Caregiver coping strategies and supports	94
Respite care	96
CHAPTER SIX: CONCLUSION	98

Study design and intent	100
Limitations of the study	104
Recommendations	107
Implications of the findings to social work practice, policy and future research	108
 REFERENCES	 112
 APPENDICES	 130

### Abstract

Wesway provides many respite opportunities and services for children with disabilities in the city of Thunder Bay. The present study explored mothers' perceptions and experiences with regard to respite care services for their children with a disability. A secondary purpose of this qualitative research was to provide some understanding of the issues confronting families and in particular, the mother, as the primary caregiver in regard to the impact of having a child with a disability in the home.

The methodology used in this study involved a qualitative grounded theory approach (Glaser & Strauss, 1967). Ten mothers were interviewed. The qualitative method was used to help understand what meanings mothers give to their experiences caring for a child with a disability. From the study, several major themes were identified. These can be grouped as follows: effects of the disability on mothers, caregiver stress, caregiver coping strategies and supports and respite care.

In addition, it is hoped that these findings may serve to benefit Wesway to further enhance their services. Finally, the findings may be helpful to service care providers who engage in practice with families caring for children with disabilities. These findings may also be helpful for other families who have encountered some of the same experiences.

### Acknowledgements

Many people contributed to the completion of this project and are deserving of recognition. First, I would like to express my sincere appreciation and gratitude to the ten mothers who shared their time, their experiences and their perspectives.

A special thanks is extended to my thesis committee for their efforts in the success of this project. Tuula Heinonen, for her encouragement and support. She also provided sound, positive and critical feedback and valued suggestions as well as proof reading the paper numerous times. I would also like to thank Denis Bracken and Laura Taylor for serving on my committee and for their enthusiasm and genuine interest in my work. They both provided valuable feedback and helpful suggestions. Thank you again for all your effort, support and guidance throughout the research process.

The staff at Wesway who supported and assisted the project were very valuable in ensuring that the study was a success. Special thanks to Carol Neff and Trevor Sullivan for their time, effort and valuable insight.

I would also like to thank my family and friends for support and providing motivation when needed. Also, to Darryl for his love, encouragement, support and guidance. Through times of irritability, lack of motivation, confusion and doubt in myself, family, friends and Darryl instilled confidence in my abilities and sustained me through this endeavor.



## Mothers' Perceptions of Respite Care

### Chapter One

#### Introduction

The overall objective of the research was to conduct an exploratory study examining mothers' perceptions and experiences with regard to respite care services for their child with a disability. The research study provided an opportunity to learn about the unique strengths and struggles for families with children with special needs. The research study involved examining the impact of having a disabled child in the home and what effect respite care, particularly what effect the summer respite program had on mothers and their children.

The intent and primary purpose of the thesis was to conduct research regarding the summer respite care services offered through the organization named Wesway, which is in Thunder Bay, Ontario. Wesway is a local, non-profit, community based organization that provides a comprehensive range of respite care services for families of children with special needs. Caregiver needs, perceptions and satisfaction with various dimensions of the summer respite programs have been examined. Recommendations that might strengthen or improve the services will be provided to Wesway upon completion of the research study. Wesway provides many respite care opportunities and recreational services for children with disabilities in the city of Thunder Bay. Thus, these children are provided with an opportunity to participate in an enriching program of activities; concomitant with this opportunity, mothers are provided with a break from the care of the individual.

The research was designed to aid the student in developing her knowledge in many areas, particularly researching disabled children and their caregivers. It provided the student with the opportunity to review the literature and conduct a study relating to mothers' experiences with respite care.

As I have been employed at Wesway in the past, I realized there is a great need for respite care and more opportunities for families with disabled children. The mothers have participated in interviews which have provided feedback on their experiences and perceptions of the summer respite services they are receiving or have received in the past. Also, general satisfaction with the quality of the services, satisfaction with specific dimensions of service and their perceptions of the effects and benefits have been explored.

Many questions were asked about the mothers' experiences with summer respite care services and additionally about managing a child with a disability. The women were asked what they liked about the program and disliked and what could be improved. Their main stressors and coping mechanisms were also explored within the interviews.

The methodology used in this study followed a grounded theory approach. It consisted of qualitative interviews. Interviews were conducted to help identify the key areas that confronted mothers caring for children with disabilities who utilize respite care services. The qualitative method was also used to help understand what meanings mothers give to their experiences caring for a child with a disability.

Open-ended questions allowed the participants to discuss their personal thoughts and experiences and to elaborate on issues they felt were of particular significance. Mothers were asked questions regarding their experiences and as well, provided feedback and possible recommendations for Wesway. Women in this study spoke eloquently and humbly about their experiences. Many spoke about the joys of raising their children, but also about the stress and loss that has come with raising their children.

The impact on siblings of having a disabled brother or sister was not a main focus of the study. Although a child with a disability in the family will affect his/her siblings, this aspect was not explored directly with the siblings and they were not interviewed within this study. Mothers, however, offered information about how the disability affected the siblings which is incorporated into the analysis section.

The chapters below are in the following order. Chapter two discusses the statement of the problem and the rationale for the study. In chapter three, there is a review of relevant literature and specific definitions are provided for the study. The methodology used in the study is described in chapter four. The design and methods pertaining to this research are discussed. Chapter five represents the data that was collected from the study. In particular, the experiences of the mothers are presented and illustrated by direct quotations from the participants. This chapter will also discuss the analysis section of the study and main categories and patterns that emerged. Chapter six, the conclusion chapter, offers a brief overview of the study, considers some of the limitations of the study, and discusses recommendations for future research.

## Chapter Two

### The Problem

All children are born into families of different sizes and shapes, some with extensive financial and other resources, some stretched by the few resources they have and the demanding responsibilities they take on. The families that children with disabilities are born into are no different. But the face of families caring for members with a disability is changing. Institutional care is less and less an option. Medical technologies enable children with significant disabilities and complex medical needs to survive. This study seeks to broaden peoples' knowledge by shedding light on the realities faced by this group of individuals and their families.

Child rearing can be a rewarding, life-enriching experience. It can also be tedious, exhausting and stressful, at times. One way by which parents limit the tedium, exhaustion and stress of full-time childcare is by taking periods of time away from their children. These periods may be as short as a couple of hours, when the youngest child is with a neighbour and the older children are in school, allowing mom or dad to go grocery shopping. It may be four or five hours when the children are left with a babysitter so that mom and/or dad can go to a movie or visit with friends. The time away could be a few days, when the children go to camp or stay with friends or relatives, so that mom and dad can go on a vacation. Such natural relief periods do not occur in the lives of all families. Some families have limited support networks of friends, relatives or neighbours. Limited financial resources may prevent the use of paid babysitters. In some families, natural forms of relief do not occur because a child is disabled and this interferes

with the use of both paid and unpaid babysitters. Being the parent of a child with a disability often encompasses responsibilities and stresses far beyond those faced by most parents. This is particularly true when the child has severe disabilities. Depending on each child's situation, his or her needs for support varies, as do the kinds and extent of barriers to community inclusion experienced by the child and his or her family. Children also differ in terms of gender, ethnicity, culture, personality and interest. They are members of different types of families in various socio-economic, geographic and community contexts (Kirk, 1998). Because of this diversity, support systems must be responsive to a variety of needs and situations, and must be flexible enough to adapt as children's conditions, needs and family situations change (Kirk, 1998).

Dedicated caregivers of special needs children know that good child care is essential because it is a primary source of respite; it eases the strain in family relationships and gives parents a break from the stress associated with caring for their special needs children. It also lessens the conflict between working and rearing a child and it allows parents to reintegrate into the community (Krajicek & Moore, 1993).

### *Rationale for the Study*

A review of the literature and the writer's professional experience regarding respite care indicates that there is a great need for programs for families with children who have special needs. An interest in conducting the research study was stimulated through my work in the past as a respite worker at Wesway. Specifically, I was working with children and families and providing relief for the families. As a respite worker, I saw parents "burning out" and becoming more and more

stressed. I noticed how respite care made a difference in their lives and in the lives of their family members.

It is clear that families caring for children with disabilities have numerous stressors from everyday living. This problem of inadequate respite care and services is important for study as there are many parents struggling in society with managing their own lives and the lives of their disabled children. These services can help provide the family with support for time away from their responsibilities. Families caring for children with disabilities at home share a number of concerns. The amount of time, cost and energy usually associated with raising children increases dramatically when caring for a child with a disability (Kirk, 1998). Parents often need to take on the responsibilities of nurse, service coordinator, case manager, advocate, trainer and educator (Kirk, 1998; Petr, Murdock & Chapin, 1995; Haverstock, 1992). Such responsibilities require both time and skill and can take an extraordinary toll on parents' physical, emotional and psychological health (Kirk, 1998; Bradley, Parette & VanBiervliet, 1995). Therefore, the need and demand for respite care is essential. I feel this study is important for families, professionals and the children as we can learn and better understand their experiences and the needs of families.

#### *What is Wesway?*

Wesway is a local, non-profit, community-based organization that provides a comprehensive range of respite care services for families of people with special needs. In 1973, a small group of volunteers from the Wesley and Wayside United Churches obtained \$5,000

“seed money” from the Cambrian Presbytery earmarked to respond to an unmet need in the Thunder Bay community. The unmet need was identified to be respite care and support for families of children with developmental disabilities. Over time, funding was secured from the Ministry of Community and Social Services. In September 1979, Wesway began to provide a limited amount of respite care for children in a four-bed home on Brodie Street in Thunder Bay. It became evident that there were many families who required personalized respite care and support services. In 1998, Wesway celebrated 25 years of providing respite care services (Wesway Pamphlet, 1999).

Wesway provides personalized respite support services shaped by the families it serves. It envisions a model of respite support services to meet the needs of the community with respect and dignity. It is an organization which considers an individual's overall well-being and health to be of utmost concern. This agency aims to build community partnerships and promotes inclusion through community development. Wesway's services are generic in supporting individuals from all age groups from infancy to old age. Wesway recognizes that everyone has unique needs and preferences. It sees families as the “experts” in knowing how day-to-day routines and personal care are carried out and how respite services ought to be delivered (Wesway Pamphlet, 1999). Wesway's services consist of: host families, respite services, in-home respite choices, centre-based homes and community friends. A *host family* is a truly unique service with volunteer families welcoming a child, teen or adult into their home to provide regular or occasional respite care and support. *Respite homes* provide opportunities for individuals to come to a home-like setting with peers and trained staff available. The homes

practice social, recreational, and daily living skills for clients' discovery and development. *In-home respite choices* involve trained respite workers providing service in and out of the family home. This is considered a valued service especially chosen by older adults and families of young children with high medical needs. *Community friends* are volunteers acting as "connectors" to social and recreational opportunities in the community.



## Chapter Three

### Literature Review

Disabilities are found in both males and females from every religion, income bracket, ethnic, political, and educational background (Thompson, 1994). Disabilities may be present at birth or may occur at any time throughout a person's life. A relatively new term for non-disabled people that emphasizes this point is TAB, an acronym for "temporarily able-bodied" (Smith, Austin, & Kennedy, 1996). Many new terms emerging from the disability related fields reflect the changing attitude towards the concept of disability and the changing trends in respite care services for persons with disabilities.

This study aims to determine mothers' experiences with having a child with a disability and their perspectives on the summer respite care services. A comprehensive review of existing relevant literature was conducted to provide a background to the topics of children with disabilities and special needs, respite care and the impact disability may have on families. This is based on computer searches of Social Work Abstracts, Sociological Abstracts, Social Sciences Abstracts, and books and articles in professional journals. I have also utilized many videos and articles that were obtained through Wesway.

Through this review of literature, I aim to integrate and summarize a variety of factors which have an impact on families with disabled individuals. This review will provide a framework to assist the reader in understanding the significance of respite care and the need to evaluate it as a service.

### *Definitions*

Many definitions can be found throughout the literature written about disabilities, some focusing on diagnostic and medical descriptions, others emphasizing functional terms. As the disability fields have evolved to meet changing attitudes towards persons with disabilities, acceptable language and terms have also changed.

It has been observed that there is no neutral language with which to discuss disability (Zola, 1993; Linton, 1998) and yet the tainted language itself and the categories used influence the definition of the problem. Part of the difficulty of defining disability has to do with the fact that disability is a complicated, multidimensional concept. Because of the extensive variety in the nature of the problem, a global definition of disability that fits all circumstances, though very desirable, is in reality nearly impossible. Whereas the words “disability” and “handicap” were once used interchangeably, it is now generally accepted that the word “disability” now refers to a specific impairment or disorder, while a “handicap” is a disadvantaged condition resulting from the beliefs or actions of a person or a society (Smith, Austin & Kennedy, 1996). For the purposes of this thesis, the term *disability* will be referred to as “A limit or loss of opportunities to take part in community life because of physical and social barriers” (Albrecht, Seelman, & Bury, 2001). There are numerous opportunities for misunderstanding, given the interchangeable and sometimes idiosyncratic use of terminology and meaning, compounded by the ambiguity of the distinction between disability and handicap (Chamie, 1990; Edwards, 1997). For the purposes of this thesis and clarification, the exact definition of the concept of *handicap* is as

follows: “In the context of health experiences, a handicap is a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfillment of a role that is normal (depending on age, sex and social and cultural factors) for that individual” (WHO, 1980). While this definition acknowledges that handicap is a social phenomenon and is moderated by the expectations of a particular group of which the individual is a member, the focus is on the “disadvantage to the individual that stems from the impairment or disability” (WHO, 1980). *Impairment* is defined as anatomical or physiological abnormalities and losses in the initial Nagi formulation (Nagi, 1991). Nagi noted that impairments can vary in the number of dimensions that influence the nature and degree of disability observed (Nagi, 1977, 1991). These dimensions include: degree of visibility and disfigurement, stigma, the predictability of the underlying pathology, the prognosis and prospects for recovery or stabilization, threat of life, types and severity of limitations in function they impose and the point of onset in the life cycle (Nagi, 1991).

*Family* is referred to as a primary group whose members assume certain obligations for each other and generally share a common residence. Child care and child socialization, income support, long term care and other caregiving roles are among the functions of family life (Barker, 1995). *A parent* is referred to as the biological parent, a common law spouse, or legal guardian such as a foster parent, adoptive parent, step mother or step father of a child.

#### *Impact of Disability on Parents*

One of the biggest transitions a family makes occurs with the diagnosis of a child's

disability (Harris, 1987; Wikler, 1991). Many years later, many parents can still describe in great detail the way that they learned of their child's disability (Wikler, 1991). In an effort to understand the range of reactions that families experience, some authors have described a model of reacting to disability in stages (Drotar, Baskiewicz, Irvin, Kennell & Klaus, 1975; Gargiulo, 1985; O'Hara & Levy, 1984). Stage theories usually include stages of shock, denial, sadness, disappointment, anger, anxiety, guilt and finally, adaptation or reorganization (O'Hara & Levy, 1984).

Parents often go through a pattern of grieving similar to when a family member dies when they first realize their child has a disability (Drotar, Baskiewicz, Irvin, Kennell & Klaus, 1975). No matter what the disability (mental retardation, a sensory disability, a physical disability, learning impairment, etc.), if a child is disabled, the psychological impact can be devastating to parents and families (Karnes & Teska, 1990). Grieving is extensively described in the clinical literature in relation to the parents' emotional responses to the diagnosis of a disability with regard to their child (Karnes & Teska, 1990). The primary cause for the grief at that time is considered to be the loss of the fantasized child (Karnes & Teska, 1990). At various points in time, their loss of the fantasized normal child will be restimulated. Depending on the personal fantasies of the individual parent, these moments may occur during holidays, family reunions, birthdays, watching normal children play, the wedding of their normal child or hearing mothers of normal children chat about their child's successes or failures (Wikler, 1991).

The demands and challenges of parenting are often intensified for parents of children with

special needs (Gowen, Johnson-Martin, Goldman, & Applebaum, 1989). The child with a disability that requires the parents to access help from outside the home to meet his or her needs represents a complex situation. The parents of the family are often under considerable stress due to the amount of time and attention required by the disabled individual (Flynt & Wood, 1999). Research studies have indicated that parents of children with disabilities experience a greater level of stress than do parents of children without disabilities (Beckman, 1991; Dyson, 1997; Rodriguez & Murphy, 1997).

Psychologically, they have to face the loss of the expected normal child, accept the reality of having a less than perfect child, integrate the child into the family and shoulder the lifelong process of rearing a child who is different. The long term uncertainty of the child's viability (Gowen, Johnson-Martin, Goldman & Applebaum, 1989), future health, growth and ultimate level of functioning and the family's ability to meet the child's needs (Harris & McHale, 1989) are factors further adding to parents' psychological stress. The impact of a disability on a family is not restrictive to the individual with the disability but extends to all family members. Common ideas that exist about families of children with disabilities include the view that they experience high levels of stress and low levels of family functioning (Harris & McHale, 1989). Some researchers (Beckman, 1983; Dyson & Fewell, 1986; Friedrich & Friedrich, 1981; McKinney & Peterson, 1987) have reported increased stress in families of children with disabilities, whereas others (Frey, Greenberg & Fewell, 1989; Salisbury, 1987) have reported no difference in parental well-being and stress.

Physiologically, parents have to spend most of their time, energy and patience in taking care of their child. They have to manage their child's health and emotional and behavioural

problems and train him or her in daily living skills. Hence, they have limited time for themselves (Barnett & Boyce, 1995; Singhi, Goyal, Pershad, Singhi & Walia, 1990). Special attention required by highly dependent children may include intensive round-the-clock care or supervision, individualized feeding, and technical care. Many children with disabilities also have medical needs (multiple medications, seizure disorders or prosthetic and orthotic requirements). Socially, the additional daily responsibilities, together with society's discrimination against people with disabilities, cause them to withdraw from social activities (Barnett & Boyce, 1995).

It has been hypothesized that the diminished ability of children to care for themselves in daily activities translates into increased caregiving demands on the parents. These parents have more psychosocial stress because they face more major life events (hospitalization, major financial expenditures), daily hassles (transportation problems, fatigue), and unique difficulties (demanding therapeutic regimens, finding suitable activities for the child, and deflated personal aspirations for the parent) than other parents (Wallander & Marullo, 1997).

The adaptation of the family and parents to the special needs of the child is mediated by different factors. Some characteristics of the child might make it easier or harder to adapt to the disability. The severity and type of disability, the caregiving demands, family size and the related behavioral difficulties are possible factors affecting adaptation (Hanson & Hanline, 1992). Family stability, parental coping skills, active family and external support systems, as well as services available are elements that may facilitate the adaptation process (Flynt & Wood, 1999;

Frey, Greenberg, & Fewell, 1989). The field of family support for persons with disabilities and their relatives has gained considerable momentum since the mid-1980's with the passage of new federal policy initiatives and funding of research and training centers devoted to family issues. The notion that families are central to the well-being of persons with disabilities has gained widespread acceptance (Singer & Powers, 1993).

Finally, the socioeconomic status (SES) of parents, marital status, and marital satisfaction are also important factors. Low SES parents have more difficulty coping, however happily married parents are less stressed (Flynt & Wood, 1999). Even if families with special needs children have a much heavier task, their needs are generally the same as other families: schooling, health services, and child care. In Canada, it is believed that between six to ten per cent of children have a chronic health condition or special needs (Irwin & Lero, 1997). Approximately 40-50% of the mothers of infants and toddlers with special needs have jobs outside the home. These mothers may work for personal aspirations, but also because of the additional financial burden associated with having a special needs child (Krajicek & Moore, 1993). Unfortunately, studies reveal that parents have difficulty finding services and that the coordination of these services is also inadequate (Hanson & Hanline, 1992). The absence of resources or respite increases the burden of the parents, which may lead to physical and mental exhaustion. The accumulation of daily stress, of family tensions, isolation, misunderstanding by others, and the lack of support from the community may affect the health of these families. In order to answer the needs of their special needs child, first the parents' needs must be met (Irwin & Lero, 1997).

### *Literature on Respite Care*

The ongoing care of children with disabilities or those who are chronically ill can be an overwhelming and stressful task. As children are now likely to live at home with their families, rather than in institutionalized environments, considerable attention is being paid to the need for caregiver relief by fostering the development of respite services (Joyce, Singer & Isralowitz, 1983). Respite care generally refers to an array of services that enables families to take a break or have relief from the physical and emotional responsibilities of caring for a disabled person (Salisbury, 1986; Joyce & Singer, 1983; Upshur, 1982; Cohen, 1982). Respite services are widely believed to provide crucial support to families (Wikler, 1991). Regardless of the nature of the disability that a child experiences, parents have common support needs. Respite care reduces the burden of care on family caregivers and results in a significant reduction in levels of stress, strain, and burnout for parents (Rimmerman, 1989; Canadian Association of Community Care, 1995; Hoare, Harris, Jackson & Kerley, 1998). There is evidence to suggest that respite care can reduce family stress (Wikler, 1991), enhance family functioning (Cohen, 1982), and delay or prevent residential placement (Joyce & Singer, 1983; Bromley & Blancher, 1989; Bruininks, 1979). Proponents of respite care suggest that the most tangible benefits to families are significant reductions in stress, strain and burnout; improved well-being and family functioning; and reduction in out-of-home placements (Salisbury, 1990; Rimmerman, 1989; Halpern, 1990; Salisbury & Intagliata, 1986; Joyce & Singer, 1983; Wikler & Hanusa, 1990). In addition, some parents reported that their satisfaction with life, hopefulness about the future, ability to cope and



attitude toward their children improved with the use of respite (Cohen, 1982; Upshur, 1982; Seltzer & Krauss, 1984).

Joyce and Singer (1983) reported that respite provided parents with relief by merely knowing that a trained person was available; by being able to make plans ahead of time; by being able to stay away from home for longer periods of time; and by feeling less guilty about leaving the child. In this particular study, only a few respondents cited respite as promoting family relationships, enabling them to spend more time with family and having an energizing effect.

However, simply using respite services does not always ensure that the desired outcomes will occur. Respite care is seen as one of a variety of community programs and services that could become part of individualized treatment plans for disabled children and adults. Where families with non-disabled children may have a range of babysitting and day care options in most communities, the behavioural and medical problems of the developmentally disabled child, prevent families from being able to leave them at all (Upshur, 1978; Intagliata, 1986).

Access to needed respite has been found to improve family functioning reducing the likelihood of marital breakdown and to improve parents' attitudes toward their child (Canadian Association of Community Care, 1995; Hoare, Harris, Jackson & Kerley, 1998). As a result, not only is a child less likely to be institutionalized, but the child and his or her family members (especially primary caregivers) experience reduced social isolation, increased independence, a wider range of activities, improved well-being and social integration in the community (Cotterill, Hayes, Flynn & Sloper, 1997; Hoare, Harris, Jackson & Kerley, 1998). The mental and physical burden for

a family to provide constant care for a disabled person, sometimes for an entire lifetime, continues to be a major factor in support of maintaining traditional institutional settings (Townsend & Flanagan, 1996; Christy, 2001). Respite care has been especially beneficial for mothers who tend to be the primary caregivers. Mothers are better able to enter and maintain their status in the workforce and they indicate more positive interactions and experiences within their families (Grant, Ramcharan, McGrath, Nolan & Keady, 1998).

The importance of respite to families cannot be overestimated. In a study by Apolloni and Triest (1993), the most common reason stated for respite utilization was “sheer relief for overworked family members” (p. 241). In their earlier study (1983), over 80% of parents reported respite to be of considerable importance. Care provision in case of family emergencies and illness, practical needs, appointments, special events and recreation needs were identified as priorities with families using respite. Furthermore, the importance of respite is significant as it can allow the caregivers the break they need.

#### *Gender and Unpaid Caregiving*

While the language in the literature often uses the term “parents” when discussing the caregiving role, it is well documented that in the majority of families, mothers are the primary caregivers of their children. Indeed, the 1996 Census data shows that women tend to take on the bulk of unpaid work in the communities and much of this is in caregiving (Status of Women Canada, 1998). This trend gives rise to a number of concerns. The first is why women continue to perform the bulk of unpaid labour in communities. Contemporary feminists are critical of the

idea that women share some common trait that makes them most suited to be nurturers and caregivers. Social, economic and cultural pressures socialize women to fulfil these roles, that is, to become nurturers and caregivers (Haraway, 1991). McKeever, Angus and Spalding (1998) outline how notions of women as caregivers form the basis for health and welfare policy and that the negative effects on women are on the rise. Escalating health and social services costs are leading to a mixed economy of care in which long-term care facilities are being closed or converted to provide outpatient or ambulatory care centres, and community-based services are replacing institutions (McKeever, Angus & Spalding, 1998). Community-based services, however, are not keeping up with the demand. Families, and primarily women members, are often expected to fill the gap by carrying out previously waged caregiving duties at home without pay (Haraway, 1991).

A number of studies describe caregiving tasks as hard work requiring the combined professional skills of nurses, teachers, therapists and administrators. Mothers often make a “career out of caring” (Wickham-Searl, 1992). In fact, they perform many skills that were formerly in the realm of paid professionals. Mothers manage complex intra-and-extra family relationships, monitor children’s conditions, perform custodial, therapeutic and medical tasks, schedule appointments, act as advocates and more (Haverstock, 1992; Ambert, 1992; McKeever, Angus and Spalding, 1998). Despite all of this, their work is neither granted professional status, nor is it compensated through payment, or other opportunities. Women in this position are part of an invisible work force. They are unpaid, considered unskilled, have no vacation leave, no

sickness benefits, no workers compensation and no safety standards. Furthermore, they work on call constantly and live where they work (McKeever, Angus and Spalding, 1998; Ambert, 1992; Guerriere and McKeever, 1997).

Not surprisingly, this state of affairs has a significant impact on women's health and well-being, as well as on their social and economic opportunities and sense of security. As was outlined earlier, their participation in the paid labour force is delayed or severely restricted by the demands of caring for a child (The Roeher Institute, 1998; Booth and Kelly, 1999). It also has a negative economic effect on society more generally. Bakker (1998) describes some of the hidden social costs that arise from unpaid work including loss in women's time use and opportunity, tax contributions and increased demand on social services. The cost of caregiving is an area that continues to need attention at the policy level. However, caregiving activities are difficult to cost and measure. Caregiving activities are ongoing and they overlap with each other. They are not linear, but are balanced with other family and domestic responsibilities and are frequently interrupted by them (McKeever, Angus and Spalding, 1998). Regardless of the difficulties in measuring caregiving tasks, the impact is clear. Mothers of children with disabilities are described as anxious, burdened, exhausted, socially isolated, lonely and lacking in self-esteem (McKeever, Angus and Spalding, 1998). They report high psychological and physical stress, chronic fatigue, headaches, menstrual problems, digestive problems, depression, anxiety, interrupted sleep, and irritability (Ambert, 1992; Guerriere and McKeever, 1997; McKeever, Angus and Spalding, 1998). The literature is contradictory, however, regarding

whether or not they experience these problems to a greater degree than other mothers.

McKeever, Angus and Spalding (1998) suggest that these problems are more prevalent in mothers of children with disabilities than other women. They report, for example, that 40% of this group have trouble sleeping, compared to 28% for other women. Mothers with children with disabilities also exhibit the highest consequences in terms of emotional and physical stress (Bowman and Virtue, 1993; Traustadottir, 1988). Other studies, however, described in a review of the literature by Hoare, Harris, Jackson and Kerley (1998), show that the overall distress of mothers with and without children with disabilities is comparable. These studies suggested that the mothers experiencing highest distress have low incomes, regardless of disability. In their own study, however, these same researchers found that mothers' distress was associated with the severity of disability, increased dependency, profound locomotor disability, incontinence and sleep difficulties of their children (Hoare, Harris, Jackson & Kerley, 1988).

There is a growing body of research that is looking at the differential implications of caregiving issues for women and men. The role, responsibilities and impacts on fathers are treated with some contradiction in the literature. Most of the literature suggests that women perform the bulk of caregiving responsibilities, generally. Willoughby and Masters Glidden (1995) suggest this trend is in fact exaggerated in the case of fathers whose children have disabilities, even when mothers work. McKeever (1981), however, found that fathers report sharing responsibilities equally with their wives. While the 1996 Census data supports the findings in the literature that women carry the bulk of unpaid caregiving responsibility, very few

studies have explored fathers' perceptions of their roles and responsibilities. Most of the research available explores the experiences of female caregivers.

A small body of research examines the impact of fathers' participation in caregiving. One study suggests that when fathers do participate, both partners express greater marital satisfaction and both report greater psychological health (Willoughby and Masters Glidden, 1995). In McKeever's (1981) study of fathers of children with disabilities, fathers, like mothers, reported social, health and economic consequences including reduced participation in community activities, stress, worry and health problems such as headaches, ulcers, anxiety, hypertension and obesity.

In considering these impacts on mothers (and fathers), it is important to note two other factors. One is that while much of the literature focuses on negative impacts, mothers also describe the great benefits experienced when parenting a child with a disability. Care is described as deeply rewarding and satisfying (McKeever, Angus and Spalding, 1998; Ambert, 1992). Parents report finding a "new appreciation for life" through their relationships with their child (Guerriere and McKeever, 1997). Wyngaarden, Krauss and Mailick Selzer (1993) outline the positive effects mothers of adult children with disabilities describe. In this study, mothers developed adaptive coping skills, such as acceptance, positive reinterpretation and growth, spiritual strength and planning skills. They were described as women who actively engage with life's problems. The other important point to note is that negative impacts experienced by mothers are not caused by their child. Women clearly attribute problems such as isolation to

barriers in the community and withdrawal of relationships and support from friends and family (McKeever, Angus and Spalding, 1998). Furthermore, they perform their role within a service system that is fragmented, often inaccessible, inconsistent in commitments to inclusion, limited in choices and peopled by professionals who often have a limited understanding of disability (Hoare, Harris, Jackson, & Kerley, 1998; Sharpley, Bitsika, & Efremidis, 1997). As is evident in sections within this paper, it is lack of services such as respite and child care that restricts women's opportunities and contributes to their distress. That this may also be true to some degree for mothers of children who do not have disabilities does not detract from the urgent need for these issues to be addressed. Rather, it points to the broad applicability of solutions such as affordable and accessible daycare and more respite opportunities for families.

It is important also to recognize that women do not constitute a homogeneous group. Rather, women are variously positioned along the lines of disability, race, class, age, sexual orientation and ethnicity. Therefore, a host of social circumstances related to systemic disabilism, institutionalised racism (Vernon, 1996; Stuart, 1992), heterosexism and homophobia (Tremain, 1996; Appleby, 1994; Hearn, 1991) confront women in their role as caregiver. These issues need to be recognized and addressed.

Given the profound impacts on mothers caring for children with disabilities, McKeever, Angus and Spalding (1998) recommend that policy conceptualize caregiving as work so that compensation and working conditions can be considered. Policies that do not do this, they suggest, punish women for providing care at home. One strategy they suggest is to have

programs with occupational health components, such as lifting techniques for parents. Another is to improve working conditions through funding adequate home adaptations and amenities. Their research finds that respite, emergency and vacation care are essential. Policy-makers also need to pay attention to and address circumstances that require women to perform the bulk of unpaid work involved in caregiving (McKeever, Angus & Spalding, 1998).

#### *Literature on Cases within Canada*

Recent literature regarding cases where parents could no longer bear to watch their children suffer and they could not handle the stresses, have come into the public light. These cases demonstrate the great need for respite care and services to families with a disabled child and will be discussed below.

There have been several cases in Canada where parents or caregivers of children with disabilities took drastic action when they perceived that they could no longer provide care for their child. These individuals could no longer take the stress and overwhelming feelings and took matters into their own hands. The Robert Latimer case has led to one of the nation's most widely publicized criminal cases in recent years. This case involved Robert's 12-year-old daughter, Tracy Latimer. When the family took her home from the hospital, her parents still had no idea of the severity of their daughter's illness, but within a few months, doctors had diagnosed spastic quadriplegic cerebral palsy (Corelli, 1998). Tracy Latimer would probably never learn to walk, talk or develop mentally beyond the level of a newborn. Lying awake at night, Laura Latimer wept to think of all the things her daughter would never be able to do (Corelli, 1998).



Caring for Tracy was now almost a round-the-clock operation. Seizures were nearly continuous until an anticonvulsant drug reduced them to about five a day. When she was four, the doctors operated on her to increase movement in her left hip. At nine, another operation on her legs and feet left her encased in a body cast for six weeks. Much more drastic was the surgery needed to straighten her spine, which was like a corkscrew and had bent more and more forward, twisting her hips along with it. By the time she was 11 years old, spinal curvature was severely cramping her pelvis and internal organs. Frequent bouts of bronchitis resulted from the spine's pressure on her lungs. Doctors operated on her for eight hours, inserting two stainless steel rods, one on each side of the spine. The rods were held in place by steel cables wrapped around each vertebra and anchored into her pelvis. Tracy's pain seemed overwhelming and unbearable. She could take nothing stronger than Tylenol because more potent painkillers, when mixed with Rivotril, her anticonvulsant drug, might have interfered with her ability to breathe and swallow. The steel rods did straighten Tracy's back so that she could lie comfortably only on one side, which caused bedsores. Her bouts of bronchitis diminished but her hip problems continued. Her right hip, already dislocated, got worse (Corelli, 1998). On October 12, 1993, when Tracy was 12 years of age, Dr. Dzus recommended a fourth operation, this time to fix Tracy's right hip. It would not cure the condition but might delay further deterioration. "I felt she was in too much pain to do nothing," Dr. Dzus explains (Corelli, 1998, p. 117). The prospect of more surgery devastated Laura and Robert. As Laura later told the court, "I thought they were going to start mutilating our little girl...I didn't know how much more she could take" (Corelli, 1998, p. 117). She wished

Tracy could just go to sleep and not wake up (Beltrame, 2001). Tracy died on October 24, 1993. She died of carbon-monoxide poisoning after her father placed her in his pick-up truck's cab, which was rigged with a pipe running from the exhaust. In court, Latimer claimed that he only wanted to end his daughter's pain (Beltrame, 2001).

Experts who treat cerebral palsy patients note that the parents are often physically exhausted and emotionally drained. Dr. Mervyn Fox, an associate professor of pediatrics at the University of Western Ontario in London, said that many parents in situations similar to the Latimer's have admitted to him that they considered ending the lives of their children. "It's a very common feeling," said Fox. "It's a signal that they need support. Those of us who work with children with cerebral palsy are overwhelmed with a sense of tragedy" (Olivier & Kataquapit, 2001, p. 38).

The death of Tracy Latimer led to one of the nation's most widely publicized criminal cases in recent years, but there have been others involving disabled children. In December 1994, Cathy Wilkieson of Hamilton and her 16-year-old disabled son, Ryan, died of carbon monoxide poisoning from exhaust fumes in a car in her parents' garage. The boy, who had cerebral palsy, was in his mother's arms when they were discovered. The 43-year-old Wilkieson left a suicide note in which she said she could no longer go on but could not leave her son behind.

Two years later, 44-year-old Danielle Blais of Montreal drowned her six-year-old autistic son, Charles-Antoine in a bathtub. She slashed her wrists and then called police who got her to a hospital in time for doctors to save her life. Blais left a suicide note in which she criticized her

son's school for not understanding the behavioral problems caused by autism. Blais eventually pleaded guilty to manslaughter and was given a 23-month suspended sentence (Olivier & Kataquapit, 2001).

Katie Lynn Baker was named among others. Katie was a ten-year-old girl from Nelson, B.C., who died in 1997. She had Rett's Syndrome. She stopped eating and within three days she died in her mother's arms. There was an inquest and lots of questions by the media and government officials. Katie's mother, Cheryl McLean, said that she discussed the situation with Katie and believed that Katie did not want to suffer any more. McLean said in reports that the doctor had offered aggressive feeding in hospital as an option, or letting the disease take its natural course (Olivier & Kataquapit, 2001).

Another example of a distressed parent taking drastic action was Lisa Thompson. Her daughter, Brandie-Leigh was in the McMaster University Medical Centre in Hamilton, listed in critical condition from an overdose of prescription painkillers as her mother had put them in her drink. Thompson was arrested on November 8, 1998, after walking into a Niagara Falls police station and telling the receptionist she wanted to speak to an officer to tell them she had killed her daughter. "Brandi-Leigh was in distress when they found her" (Olivier & Kataquapit, 2001, p. 38). According to Officer Mitchell, "there is no doubt in my mind that she loves her daughter and cares for her dearly. No doubt whatsoever." (Olivier & Kataquapit, 2001, p. 39).

Thompson said her child was always in pain and had to be medicated, was fed through a tube into her stomach because she was incapable of swallowing safely, and had days when she

could not even move and appeared to be comatose. A Niagara region police officer for 28 years, stated that, "I've had a lot of cases dealing with children being abused or dying at the hands of a parent or guardian, but those are usually referred to as shaken-child syndrome," he said (Olivier & Kataquapit, 2001, p. 39). "One thing you will find, not talking about this case, because I won't, but in other cases I've been familiar with, is that basically the parents have reached their limit. Emotionally, they short-circuit; they can't cope any more" (Olivier & Kataquapit, 2001, p. 39). "When I finished with this case, I came back to the office and I said to my partner, 'I can't even categorize anything I have in my life as a problem when you look at what some people go through'" (Olivier & Kataquapit, 2001, p. 39).

Defence lawyer Charles Ryall described his client (Thompson) as "an exhausted mother, distressed and burned out" (Beltrame, 2001, p. 23). Ryall said this case had nothing to do with mercy killing or euthanasia, rather it involved "a woman who was pushed to the wall" (Beltrame, 2001, p. 23). Judge Halliday began his sentencing by stating: "The court has the greatest respect for persons with physical handicaps and delays ... and their need for protection" (Beltrame, 2001, p. 24). He later added, "There is also a consideration that must be given to caregivers of the handicapped" (Beltrame, 2001, p. 24). Halliday called for greater attention to the need for family supports for parents caring for children with significant disabilities (Beltrame, 2001).

Despite the growing body of literature and research on respite care in the field of developmental disabilities, there is still much to be learned about the contextual factors, as well

as the kinds of benefits that facilitate or inhibit the realization of respite care objectives (Intagliata, 1986).

With the dual concerns of increasing needs and limited resources, it has become essential to have a more accurate understanding of the kinds of services and programs that would increase the likelihood of disabled persons remaining in their homes while at the same time supporting or enhancing the integrity of the individual and family. Research about respite care and effects on families is increasingly becoming more and more significant for care providers.

The literature suggests that respite care can be best understood or evaluated from the perspective of the families who need and use it (Salisbury & Intagliata, 1986). The premise that "family and child needs must drive the design and development of respite services" is fundamental to ensuring the services achieve their intended purposes (Salisbury, 1986, p. 19).

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

the service for relief, for vacations or personal needs, rather than only in extreme emergencies (Upshur, 1982).

Parents have often expressed an interest in normalization for their disabled children (as described by Wolfensberger, 1972). Galloway and Chandler (1995) have emphasized that the best and most effective respite services should be integrated, continuous and normalized. They have argued that integrated respite services will influence how the disabled child will be perceived by others.

#### *The Need for Respite Care Services*

Respite has emerged as an important and essential support service for families of persons with disabilities. Increasingly, it has become one of the most prominent issues to be addressed by policy makers, service providers and researchers (Cohen & Warren, 1993; Salisbury & Intagliata, 1986; Rimmerman, 1989).

More and more, there appears to be a great need for respite care services for families. Silvana Porto wants her daughter, Jennifer, 23, who has severe developmental and physical disabilities, to have support and love in the family home, not in an institution. But the Toronto mother and other parents like her say they are overwhelmed when their children leave the school system, which has allowed these parents to lead some semblance of normal lives. "When school ends, we all fall into this black hole" (Felix, 1998, p. 34). Porto said. "There is very little out there in the way of programs for Jennifer or financial help to provide some respite for us. "We are feeling stressed and burned out," she said. "We can't continue like this" (Felix, 1998, p. 34).

A province-wide coalition of about 1,500 families has lobbied the Ontario government to provide a solution they call individualized funding. So far, the Community and Social Services Ministry has said no (Felix, 1998). Family Alliance Ontario, to which Porto belongs, wants the Ministry to create a program that would allow parents to hire respite care or create programs for their severely disabled children within a specified budget. In the long run this will be much more cost-effective than providing institutional care, they say (Felix, 1998).

Parents or guardians providing care to their disabled child tend to become "burned out" or feel like they are "at the end of their rope". "People get burned out," said Lorna Hillman, executive director of Family Caregivers Network, a ten-year old charitable organization in Victoria, B.C. "Generally they become too busy, they have no time for themselves and give up personal life things like hobbies and exercise regimes (Felix, 1998, p. 35). The pressure is tremendous and can result in extreme stress that pushes them over the edge and results in health problems. They begin to lose sleep and move into an immense tiredness. "Often times they go see their doctor and are prescribed tranquillizers and sleeping pills. Although there have not been a lot of Canadian studies measuring the impact of caregiving on the health of caregivers", says MacLellan at Mount Saint Vincent University, "I've heard enough anecdotal information to know it's a problem. Unless we start providing more support for informal caregivers, we will end up with two people in the system instead of one and ultimately, it will cost the health care system more" (Wallander & Marullo, 1997, p. 152). Health care and social work professionals need to recognize the signs of burn-out and stress in caregivers and be able to direct them to sources of support. "When someone comes in saying they

are stressed, instead of prescribing sleeping pills and tranquillizers for parents who provide care for disabled children, doctors should look for the source of the stress and if it's the burden they feel as caregivers, they should be referring them to agencies like us for support" (Felix, 1998, p. 36). "The impact of caregiving on caregivers is a major issue," said Dr. Angela Cheung, associate director of the Women's Health Program at Toronto Hospital, Princess Margaret Hospital and the Ontario Cancer Institute. "A lot of times caregivers internalize the stress they feel about not knowing how to find resources or not knowing what to do when the person they are looking after has pain, bleeding or constipation. Often they feel lost." (Felix, 1998, p.35).

Better respite services and the need for further respite care opportunities for families is evident from the literature discussed above.



## Chapter Four

### Methodology

#### *Introduction*

This chapter focuses on the way that the study was designed and carried out. Contents of this chapter include: the research design, the grounded theory approach, research questions, research participants, the interview process, data collection procedures, data analysis procedures and ethical considerations.

The methodology of choice for this study was a qualitative design. Qualitative research design facilitates a mode of empirical inquiry that explores and describes naturally occurring social phenomena. Qualitative measures describe the experiences of people in-depth. The data are open-ended in order to find out what people's lives, experiences and interactions mean to them in their own terms and in their natural settings (Patton, 1980, p. 22). A qualitative study, according to Creswell (1994), is an inquiry into understanding a social or human problem, based on building a complex, holistic picture, formed with words, reporting detailed views on informants and conducted in a natural setting. A qualitative method of research was chosen for this study to achieve a greater understanding of the experiences of mothers who have a disabled child and their experiences with respite care services. DePoy and Gitlin (1993) state that qualitative research is most useful when the researcher wishes to gain insight in to the perceptions of people and the meanings they assign to behaviours and experiences. It is clear, therefore, that a qualitative approach is suitable for this study.

### *Research Design and Instrumentation*

Research design is defined by Easterby-Smith, Thorpe & Lowe, (1991, p. 16), as, "... the overall configuration of a piece of research: what kind of evidence is gathered from where, and how such evidence is interpreted in order to provide good answers to the basic research question(s)".

The study was exploratory in nature and was intended to generate descriptive data that provided information for the respite program for future planning. Also, the research was intended to provide further insight to professionals and others on the experiences of families with children with disabilities. Exploratory research is appropriate when problems have been identified but our understanding of them is quite limited. It is conducted to lay the groundwork for other knowledge-building that will follow (Yegidis, Weinback, Morrison-Rodriguez, 1999). An exploratory design requires a flexible approach whereby the questions, as well as their order, may differ from subject to subject (Brink & Wood, 1989).

### *The Grounded Theory Approach*

One of the best-known methods of qualitative research is grounded theory. It seeks to learn what meanings people give to certain events in their lives. Grounded theory is a method that has been used extensively across a variety of social science disciplines. The basic tenet of this approach is that a theory must emerge from the data being gathered, or in other words, a theory must be grounded in the data. Therefore, grounded theory is inductive rather than deductive. Grounded theory is the discovery of theory from data systematically obtained and analyzed in social research.

The grounded theory approach is a qualitative research method that uses a systematic set of procedures to develop an inductively derived grounded theory about a phenomenon. The intent is to develop an account of a phenomenon that identifies the major constructs or categories in grounded theory terms, their relationships and the context and process, thus providing a theory of the phenomenon that is much more than a descriptive account (Corbin & Strauss, 1990).

Grounded theory is based on the premise that the meanings that people give to events in their lives are very important in understanding their responses and resilience to the events. It is based primarily on symbolic interaction, which holds that people construct their own meanings from events based, in part, on their interactions with others (Yegidis, Weinbach & Morrison-Ridriguez, 1999). Grounded theory research thus seems especially well suited to acquiring the kinds of knowledge needed by social workers. Conducting it also requires many of the very attributes that social workers possess such as interviewing skills and the ability to form relationships.

Researchers conducting grounded theory research constantly monitor and reshape their developing theories. The method involves a recurring process of proposing (based on analysis of completed interview data) and checking and verifying what has been proposed (within subsequent interviews). According to Yegidis, Weinbach & Morrison-Ridriguez (1999, p. 140), in early interviews, researchers may begin by asking general research questions based on whatever clues the literature may provide as to what they might find. If some questions turn out to be irrelevant or non-productive, they are dropped in subsequent interviews. Other, new ones, suggested by what they learned in earlier interviews may be added.

In research studies where grounded theory is used, concepts and hypotheses are derived from data and verified in the data. Its ultimate goal is to generate hypotheses, not test them (Yegidis, Weinbach & Morrison-Ridriguez, 1999). The researcher does not enter the study with preconceived hypotheses; however, it does not prevent a sensitized view about the nature of research. This approach allows meanings and explanations to emerge from participants rather than from preconceived ideas of researchers (Strauss & Corbin, 1990).

The three basic elements of grounded theory are concepts, categories and propositions (Corbin & Strauss, 1990). Concepts are the basic units of analysis since it is from conceptualization of data, not the actual data per se, that theory is developed. Corbin and Strauss (1990, p. 7) state, "Theories cannot be built with actual incidences or activities as observed or reported; that is, from raw data. The incidents, events and happenings are taken, and or analyzed as potential indicators of phenomena, which are thereby given conceptual labels". The second element of grounded theory, categories, are defined by Corbin and Strauss (1990, p. 7) as:

Categories are higher in level and more abstract than the concepts they represent. They are generated through the same analytic process of making comparisons to highlight similarities and differences that is used to produce lower level concepts. Categories are the cornerstones of developing theory. They provide the means by which the theory can be integrated.

In effect, a category is a theme or variable which makes sense of what the respondent has said. It is interpreted in the light of the situation one is studying and other interviews and the emerging theory. After a time, one category will be found to emerge with high frequency of mention and to be connected to many of the other categories which are emerging. The third element

of grounded theory is propositions which indicate generalized relationships between a category and its concepts and between discrete categories (Corbin & Strauss, 1990). Grouping concepts into categories is important because it enables the analyst to reduce the number of units with which he or she is working (Corbin & Strauss, 1998, p. 113).

Once basic research questions have been generated and the research is focused, the next aspect of research design is to select the first case. Cases (the principal units of data in the research) should be selected according to the principle of theoretical sampling which is described below as: “The process of data collection for generating theory whereby the analyst jointly collects, codes and analyzes the data and decides what data to collect next and where to find them, in order to develop the theory as it emerges” (Glaser & Strauss, 1967, p. 45).

### *Research Questions*

The research questions addressed in the study were:

- 1) How do mothers think of and see the respite care services? What are their perceptions and experiences in regard to the summer respite care services?
- 2) What are strengths and weaknesses of the summer respite care services? What are the gaps in services? How do these programs benefit the families? The children? What other services would families benefit from?
- 3) What is the mothers’ experience of having a child with a disability? What is the effect of the disability on the family? On their lives?

- 4) What are the main stressors involved in caring for a disabled child? What resources are most helpful to the primary caregiver?
- 5) Finally, how can professionals better understand the needs of families caring for children with disabilities?

### *Research Participants*

All of the subjects were mothers who have a disabled child or children involved with a respite service at Wesway. After final approval from the Joint Faculty Research Ethics Board at the University of Manitoba, recruitment of subjects occurred and the research proceeded. (The Human Research Ethics Board Approval form can be found in Appendix G.)

A letter introducing the study was posted at the agency and a copy was printed in the monthly newsletter, which provided the researcher with an opportunity to let the parents know about the research and explain the objectives and purpose of the study (See Appendix A). The researcher informed the families of what the study entailed to see if they were interested. Also, attached is a copy of the semi-structured interview guide outlining questions that were asked in the interview (See Appendix B). Depending on the subjects' responses, further questions and probing occurred in the course of responses about their experiences.

The subject's participation was completely voluntary. As the introductory letter was placed at the agency, as well as in the newsletter, those who were willing and wanting to participate were able to contact the researcher by phone. Interview times were then set up.

The researcher interviewed ten subjects. All the subjects were women who were the biological mothers and primary caregivers of the children. Male caregivers are not represented. This was unintentional and the participants who happened to come forward were women. Mothers were assured that respite services they now obtain or request in the future would in no way be affected by their participation in the study. It was also necessary to inform participants that the research was conducted independently from the agency and that services were not dependent on their participation or responses. There would be no threat of loss of service by participating in the study.

#### *The Interview and Data Gathering*

Semi-structured interviews were conducted with mothers who have received or are receiving respite care services through Wesway. Neither siblings nor grandparents were interviewed for this particular research study, however, informative information about the effects a sibling or grandparent had on their own experiences arose from the interviews with the mothers. This has been incorporated into the findings section in chapter five. The interview was tape-recorded and after completion of the interview, it was transcribed and categorized as a part of qualitative data analysis. Questions in the interview were open-ended in order to allow the subject maximum freedom in the way that they responded to them. All interviews were conducted during the months of November and December, 2001. The interviews were approximately 30 minutes to an hour. This varied, as some subjects were more open to sharing their experiences than others. All the interviews were conducted in the participants' home. The

interviews did not take place at Wesway, due to confidentiality issues. The researcher wanted the interviews to be in a relaxed environment where participants felt they could speak freely.

#### *Data Collection Procedures*

The qualitative research method was chosen for this study because it is a strategy that is particularly well suited to work that aims to describe phenomena from the participants' point of view (Field & Morse, 1985; Patton, 1980; Marshall & Rossman, 1989). This method lends itself to in-depth and detailed study of participants' subjective experiences, without the constraints of predetermined categories of analysis (Patton, 1980).

The basic research method in the study was individual interviews using samples drawn from mothers utilizing the respite programs at Wesway. The gaps and limitations of the services were explored within the interviews. The interviews also highlighted the strengths of the program or service that can be built upon in the future and these recommendations shall be given to Wesway upon completion of the research study. The interviews were conducted in three phases. The first phase involved a brief period of social conversation to enhance the participant's level of comfort with the researcher. At this particular time, the researcher reviewed the written explanation of the study with participants and offered to answer any questions the individuals may have had. During the second phase of the interview, the researcher turned on the tape recorder and formal data gathering occurred. This phase comprised the majority of the interview. The third phase of the interview consisted of a debriefing session which occurred between the participant and researcher. The debriefing period at the end of the



interviews was brief and no new data came out from this informal talking with the participants. All of the information and data came from the interview itself.

There are several strengths in the interview method that apply to my particular research study. I am trying to understand how a child with a disability affects the primary caregiver and how respite care affects the family. Also, I am trying to find out what areas need further strengthening and what areas mothers enjoy about the summer respite program. I felt the best way to do this is to listen to the mothers' experiences of respite care. By sitting down with these individuals and hearing their stories, I have come to understand what the experience has been like. The most important aspect of the interviewer's approach concerned conveying the idea that the participant's information is acceptable and valuable. A definite advantage of the interview method is the fact that I was present to explain the research study and answer and clarify any questions or concerns that the mothers had. Answers were more precise and the researcher heard firsthand about the experience from the person. This was beneficial as the researcher could clarify the respondent's answers and probe for further information once a topic of interest had been brought forward. An interview was a useful way to get large amounts of data quickly.

Another principal aspect of using the interview method is that it is flexible. The interview procedure can be used with a variety of people who are more likely to respond to face-to-face inquiry. I had the opportunity to ask probing questions and to explore an interesting answer in greater depth. Responses can be obtained from participants in areas

where specific questions are difficult to ask. In qualitative research, displays of emotion by participants are not uncommon. According to Yegidis, Weinback & Morrison-Rodriguez (1999, p. 69), "Sometimes the researcher encourages emotionality to help better understand how the participant is experiencing or has experienced some phenomenon". This was helpful in achieving my objectives of the research as I had a better understanding of their experience. Emotionality may also create difficulties in the qualitative interview. This may have turned into an ethical issue because as a researcher I may ask myself, "Is it always ethical to encourage emotionality for the sake of good data?". However, within this study, participants appeared to be emotionally stable after the interviews and did not require any counselling assistance.

All interviews were audio-taped using a small tape recorder placed in close proximity of the participants. All audio tapes were transcribed into a written form on a personal computer using the WordPerfect program. Transcription of each interview occurred immediately following each interview. Transcriptions for all interviews were conducted only by the researcher using the exact words of the respondents. This included repetitions, unrelated remarks and other utterances. The qualitative data were subsequently read, in their entirety. During these readings, recurring topics and common experiences were identified in an effort to group the common "themes" that captured the experiences of these mothers.

The combination of open-ended questions and probes for additional information involved a valuable balance between respecting the participants' perspective and allowing the researcher to

pursue theoretically relevant topics. The semi-structured format allowed participants to take the interview into areas of individual and family life not anticipated by the research protocol. The researcher collected, coded and analysed data simultaneously. Data from one case provided guidance for data collection for the next cases. The researcher documented emerging categories over the course of the study. Each individual participant was considered a separate data source. Comparisons took place among all the individuals' experiences. Constant comparison is the heart of the grounded theory process. At first, I compared one interview to the next. Theory emerges quickly. When it had begun to emerge, I compared the data to theory. For the first interview, I asked myself, what is going on here, what is the situation, how is the person managing that situation. Therefore, what categories are suggested by that sentence. I coded the second interview with the first interview in mind. I coded subsequent interviews with the emerging theory in mind. Data was broken down into discrete ideas or happenings and then were given a name that represented them. The name may be placed on the objects by the analyst because of the imagery or meaning they evoke when examined comparatively and in context, or the name may be taken from the words of respondents themselves (Corbin & Strauss, 1998, p. 105). As I continued with data analysis, I came across another event, idea or happening similar to the first. This was identified through comparative analysis as sharing some common characteristic with another happening or idea, then I gave it the same name, that is, placed it into the same code. Thus, when one classifies like with like and separate out that which one perceives as dissimilar, meaning one is responding to characteristics, or

properties inherent in the objects that strike the researcher as relevant (Corbin & Strauss, 1998).

This process occurred throughout all of the interviews and the transcribed data.

### *Ethical Considerations*

Most social work research depends on our fellow human beings. Therefore, as a researcher, I have an ethical obligation to safeguard their health and well-being. At the beginning of the research process, I had several ethical concerns regarding this study.

As subjects committed themselves to participate in the study, several procedures were necessary to ensure that confidentiality was protected. Measures were taken to ensure the rights of participants during all phases of the research process. These measures included informed consent, ensuring the physical and emotional comfort of participants and maintenance of confidentiality. One of the best ways of protecting the rights of participants is to develop procedures to help them make informed choices. Informed consent in written form was obtained from the parents prior to their participation in the study. These forms indicate participants' willingness to engage in the exploratory study (See consent form in Appendix C). Prior to the subjects signing the consent form, the researcher thoroughly explained the process. At this particular time, the researcher reviewed the written explanation of the study with the subjects and offered to answer any questions they had and to ensure some comfort with the researcher.

Near the end of the interview, there was a debriefing session that occurred between the subject and researcher. This provided the researcher an opportunity to address any final questions related to the research. The purpose of the debriefing session was twofold. First, it

provided the researcher with an opportunity to address any questions or concerns that arose as a result of the interview process. Second, the debriefing session allowed me as a social worker, to keep my role as researcher separate from my social work role. No new data arose from the debriefing session.

I considered the possibility that mothers may see me as connected to Wesway directly and its services. I made it explicitly clear to participants that the services from Wesway would in no way be affected by their participation. This was explained thoroughly in the consent form and verbally prior to the interview.

Another concern was that the research may create challenges in terms of my experiences and biases. I have experience working with families who have a disabled child or children as I have worked as a respite worker for several years prior to the research study. It was considered that this may pose a problem as I have personal knowledge and preconceived notions about what it is like for these mothers. Also, personal experience of having a relative who is disabled may also allow me to be biased.

Coming from a social work background and due to the fact that the interviews could become emotional, I felt this may cause me to fall into the social work role during the interview. At times, during the interview, I felt that I was too focused on the research and it was challenging for me, as a social worker, to remain focused and not completely fall back into the social work role. However, staying focused and completing each interview ethically and staying focused on the goals of the research occurred during this study. I identified all of the above-

mentioned issues and was aware of these circumstances and tried to remain objective within my research. As a researcher, I strived to keep an open mind in order to let empirical knowledge, not my own preferences, form the basis for any conclusions drawn from the research.

#### *Deception.*

There was no deliberate withholding of essential information nor misleading information about the research or its purposes in this study. As I have been an employee at Wesway in the past, this needed to be considered. If a participant had approached me and I already knew them or knew of their family, I would have declined from having them participate in the study. This did not occur in this research study. The impact of knowing the participants could seriously affect their responses to the questions and overall could affect the research. This could have posed ethical problems if I were to interview people I have directly helped in the past.

#### *Risks and Benefits.*

There was some emotional risk to the subjects who were involved with the research study, however this was likely not greater than what they have experienced in encounters with health care and social service providers. Due to the fact the research dealt with sensitive information and personal sharing, mothers might have felt some distress. None of the mothers interviewed required further counselling or support after the interview. No referrals were made to the Family Services, Thunder Bay.

Although, at times, it was challenging for the mothers to discuss their struggles with caring for their child who is disabled, the subjects also felt that it is important for their voices and

experiences to be heard. This allowed the researcher to provide the agency with possible recommendations to better their services for the children and their families.

*Anonymity and Confidentiality.*

A coded number on the data accumulated from the interview identified the subjects. As well, the same coded number was put on the audio tapes of the interviews. The staff at the agency did not have access to the information regarding who participated in the research study and who did not. This was done in order to preserve confidentiality and anonymity.

The information and raw data compiled for the study was only viewed and consulted by the researcher and her thesis advisor. All transcribed interview data and the audio tapes were secured in a locked cabinet, accessible only by the researcher. Upon completion and approval of the thesis, the data will be destroyed.

The information the subjects provided will remain confidential, meaning that participants will not be identified as to what they specifically said or did not say. Names of the participants will not be identified. The information that participants did provide from the interviews will be presented in the format of quotes from specific answers they had provided. Initially the information was to appear as aggregate information, however I contacted the specific subjects whom I wanted to quote and each participant signed a waiver giving me permission to specifically quote them (See Appendix F). As a researcher, I felt the information provided from the participants and the actual words they spoke of was more meaningful in quotations as it gave significant meaning and feeling as to what their true experience was.

### *Compensation.*

Upon completion of the interview process, the subjects were thanked for their cooperation and participation in the research study. Furthermore, it was explained to the subjects that they would be given the opportunity to obtain a summary or the final product of the research study through Wesway, where a copy will be held. This will be the only form of compensation the subjects will receive. Neither was there any financial cost to the subjects who participated in the study. However, due to the nature of the study, the subjects may have been left with emotional feelings, therefore referral information and assistance was offered. Upon completion of the interviews, if subjects had required counselling assistance, they were to be referred to Family Services, Thunder Bay. Family Services provides no cost for service.

### *Data Analysis*

Qualitative methods of analysis were used in this study. The aims of this study were to determine satisfaction with services, to determine whether the program should be altered, modified or expanded in scope or extent of service and to identify gaps in service for mothers with children who have a disability who utilize summer respite care services. Due to the nature of the questioning, it was up to the parent to define parent satisfaction and the definition of the gap in services. There was not a pre-defined standard as to what the term "satisfaction" or "gap" was. The researcher did not express any ideas in regard to satisfactions or gaps in the services, rather mothers expressed their sense of these issues. Furthermore, the research aimed to explore and understand the mothers' experiences with their child's disability.



The central purpose of analysis in qualitative studies is to sift, sort and organize the masses of information acquired during data collection in such a way that the categories and interpretations that emerge from the process address the original research problems.

Describing the results of research using qualitative data is a whole different arena from quantitative data description. Qualitative analysis involves the organization and interpretation of unstructured data in order to identify themes and categories that describe meanings (Roberts & Burke, 1989; Brink, & Wood, 1989). There is an ongoing process between data collection, identification of themes, coding and analysis in qualitative research (Glaser & Strauss, 1967). Within this study, the grounded theory approach was used at the time of data collection and at data analysis. Grounded theory is a method which includes a dynamic process during data collection so that the theory building occurs at this time (as well as subsequently during the data analysis phase). This entailed analysis after each interview, followed by appropriate reformulation of questions and issues. Then, the researcher proceeded to the next interview.

For the study as a whole, data collection, data ordering and data analysis were interrelated. Within this general framework, data analysis for each case involved generating concepts through the process of coding which, "...represents the operations by which data are broken down, conceptualized and put back together in new ways. It is the central process by which theories are built from data" (Strauss & Corbin, 1990, p. 57). The analysis for grounded theory involves three processes from which sampling procedures are derived and which may tend to overlap at times. There are three types of coding: open coding, axial coding and selective coding. Strauss and Corbin

(1990, p. 61), describe coding as “the process of breaking down, examining, comparing, conceptualizing and categorizing data”. Open coding refers to that part of analysis that deals with the labelling and categorizing of phenomena as indicated by the data. The product of labelling and categorizing are concepts which are the basic building blocks in grounded theory construction (Corbin & Strauss, 1990). Conceptualizing is the process of grouping similar items according to some defined properties and giving the items a name that stands for that common link (Corbin & Strauss, 1998, p. 121). In conceptualizing, one reduces large amounts of data to smaller, more manageable pieces of data. Once I had some categories, I specified their properties. I also showed how the concepts (categories) vary dimensionally along these properties. Through specification and dimensionalization, I began to see patterns such as experiences of mothers, stress level, and the effect of respite care. Thus, the foundation and beginning structure for theory building.

Open coding requires application of what is referred to as the comparative method, that is, the asking of questions and the making of comparisons. Data are initially broken down by asking simple questions such as what, where, how, when, how much, etc. Subsequently, data are compared and similar incidents are grouped together and given the same conceptual label. The process of grouping concepts at a higher, more abstract level is termed categorizing (Corbin & Strauss, 1990).

Within this study, the transcribed data was examined line-by-line. This form of coding involves close examination of data, phrase-by-phrase and sometimes word-by-word. Doing line-by-line coding is especially important in the beginning of a study because it enables the analyst to generate categories quickly and to develop those categories through further sampling along

dimensions of a category's general properties, a process of sampling called theoretical sampling (Corbin & Strauss, 1998). Within this study, line-by-line analysis was conducted and this was found to be very time consuming. Also, I analysed the data by using whole sentences or paragraphs. While I coded the paragraphs, I asked myself, "What is the major idea brought out in this sentence or paragraph?" Then, after giving it a name, the analyst can do a more detailed analysis of that concept. This approach to coding can be used at any time but is especially useful when the researcher already has several categories and wants to code specifically in relation to them (Corbin & Strauss, 1998, p. 120). The way I began to code was to write concepts down in the margins or on cards as they emerge during analysis. Codes were assigned to pieces of information of varying size such as words, phrases, sentences or paragraphs. As more and more information became available, some of the codes changed to better reflect the data. The aim was to produce concepts that seem to fit the data. I decided what pieces of the data fit together and ultimately these were the segments that were categorized, coded, sorted and then formed the patterns that were to be used to summarize my interpretation of the data. Identification of major categories emerged and were documented on index cards. The index cards served as a sorting mechanism and individual interview data was placed on these cards according to the major categories. I went through the transcripts individually and placed key quotes on the index cards which I felt were significant to the particular topic. I could not place all the interview data on index cards as there was too much of a volume of data. Therefore, notes were placed on the transcripts to identify key issues. From the transcription of interviews and line-by-line coding of the data, (see Appendices D and E) key issues and eventually categories of

interests emerged. The researcher tried to distinguish between generalizing from categorized data and awareness of the uniqueness of individual experiences. The relationships between categories were also identified and analysis and discussion centered around those that were most significant.

Whereas open coding fractures the data into concepts and categories, axial coding puts those data back together in new ways by making connections between a category and its sub-categories. Thus, axial coding refers to the process of developing main categories and their sub-categories. Procedurally, axial coding is the act of relating categories to subcategories along the lines of their properties and dimensions (Corbin & Strauss, 1998). It looks at how categories crosscut and link. A category stands for a phenomenon, that is, a problem, an issue, and event or a happening that is defined as being significant to respondents. A phenomenon has the ability to explain what is going on (Corbin & Strauss, 1998). A subcategory also is a category. However, rather than standing for the phenomenon itself, subcategories answer questions about the phenomenon such as when, why, how, who and with what consequences, thus giving the concept greater explanatory power (Corbin & Strauss, 1998). Early in the analysis and throughout, I realized which concepts were categories and which were subcategories. It became evident as coding proceeded.

Selective coding involves the integration of the categories that have been developed to form the initial theoretical framework. Selective coding is the process of integrating and refining categories. However, it is not until the major categories are finally integrated to form a larger theoretical scheme that the research findings take the form of theory. In integration, categories are organized around a central explanatory concept. Integration occurs over time, beginning with the

first steps in analysis and often not ending until the final writing (Corbin & Strauss, 1998). Once a commitment is made to a central idea, major categories are related to it through explanatory statements of relationships. The core category (i.e., the central idea, event or happening) is defined as the phenomenon. Other categories are then related to this core category according to the schema. Once the theoretical schema is outlined, the analyst is ready to refine the theory, trimming off excess and filling in poorly developed categories (Corbin & Strauss, 1998). Poorly developed categories were saturated through further theoretical sampling. Finally, the theory was validated by comparing it to raw data.

Through the process of open and axial coding, a number of concepts and categories were generated and developed. During selective coding, the core category was defined and labelled. The common themes were grouped together to form categories that represented the informants' views, thoughts and opinions. Grouping similar themes leads to an understanding of the informants' experiences, which is necessary in order to formulate relevant conclusions to a study. Numerous experiences of the mothers were identified, as well as perspectives on the respite care services each family was receiving, and then these were grouped into common categories. These categories and subcategories are illustrated below.

*Core Category: Mothers' experiences in caring for a disabled child.*

#### *Subcategories*

##### *A) Effects of the disability on mothers*

- (i) Impact on lifestyle
- (ii) Impact on siblings

- (iii) Impact on marriages
- (iv) Impact on health and well-being
- (v) Positive experiences in caring for a disabled child
- (vi) Child care responsibilities impede labour force participation

#### *B) Caregiver Stress*

- (i) Financial stress
- (ii) Future for the child
- (iii) Education for child
- (iv) Mothers overworked causing stress
- (v) Lack of available resources/funding cuts

#### *C) Caregiver coping strategies and supports*

- (i) Women received support from their families
- (ii) Support received from Wesway staff
- (iii) Spousal support
- (iv) Community resources and supports

#### *D) Respite care*

- (i) Respite care services available
- (ii) Mothers are satisfied with the support they receive
- (iii) Suggested improvements/suggestions

These will be discussed further in chapter five.

The researcher considered each individual interview a separate data source. This method supported the researcher's focus on key categories that emerged from the data. This approach was most useful to the researcher as it enabled a detailed analysis of each individual's experiences and also examined the similarities and differences between each mother's experiences. However, throughout analysis, constant comparison across interviews was done to facilitate category development and saturation. Constant comparison is key to the grounded theory method. Cross case

analysis occurred by examining the answers to each question across cases to understand the shared themes and dissimilarities. A category was considered saturated when no new information was forthcoming, that is, when no new properties, dimensions, conditions, actions/interactions, or consequences are seen in the data (Corbin and Strauss, 1998). I identified similarities and differences between the categories in an attempt to detect relationships. I then compared and contrasted the categories themselves in order to discover the relationships between them. The process is necessary in order to examine the emerging themes and patterns effectively, as the researcher can carefully consider each aspect of the data and how it fits into the study as a whole during the transcription process.

A major procedure in the data analysis process was the transcription of the recorded interviews. This allowed me to become thoroughly acquainted with the content of the interviews, and I had the opportunity to review and engage with my data. I made sense of the data by sifting and interpreting it. Transcription involves carefully listening to each tape-recorded interview and converting each word onto paper. At the core of my analysis, it would consist of more than merely the words spoken by each person during the interview, but would also include sounds that reflect non-verbal interactions such as pauses, laughing and crying. Although transcription is both time-consuming and a process, it can help the researcher formulate new questions, explore opinions and biases, and group information into meaningful categories (DePoy & Gitlin, 1993).

Prior to and during the interviewing process, I reviewed the literature thoroughly, facilitating early identification of common patterns and trends. As a researcher, I thought it was important to go into the data analysis process with a sufficient amount of relevant professional literature. The researcher needed to be aware and know what literature is available as this gave her a starting point for understanding respite needs and parental experiences.

Patton (1980) breaks down the analytic process into three interrelated components:

- 1) Analysis: the process of bringing order to the data by organizing it into patterns, categories and descriptive units
- 2) Interpretation: the process of attaching meaning and significance to the units by looking for relationships and linkages and explaining descriptive dimensions.
- 3) Evaluation: the process of making judgments and assigning value to what has been interpreted.

An inductive approach to analysis was used, meaning that the categories, patterns and relationships emerged from the data. There were no a priori assumptions about what the categories would be. In this study, the questions regarding mothers' experiences formed a well-defined framework, therefore guiding the analysis. All categories and observations built into more general patterns. In the qualitative approach, there is no point when data collection ends and analysis begins. Ideas about analysis occur while collecting data; analysis occurs simultaneously with data collection; hunches derived from analysis may inform ongoing data collection.



Establishing the trustworthiness of the study is critical if its findings are to have merit. This is of particular importance in qualitative research which is vulnerable to criticism about subjectivity and may not have the same credibility in some circles as does the more established quantitative method. Yet, Guba and Lincoln, (1985 cited in Marshall and Rossman, 1989) argue that the traditional categories of reliability and validity do not accurately respond to the assumptions of qualitative inquiry, and propose the following alternatives:

*Credibility.*

The study is “conducted in such a way as to ensure that the subject was accurately identified and described” (Guba & Lincoln cited in Marshall & Rossman, 1989, p. 145). The investigator must clearly delineate the boundaries of the setting, the population and the theoretical framework, thereby so deeply embedding the interactions with data that they cannot help but be internally valid.

*Transferability.*

Generalizing findings is not the goal of qualitative research due to the small and selected sample size. However, the researcher has the responsibility to clearly state the theoretical framework of the research, thereby allowing another researcher to judge whether the original cases can be applicable to a different setting. The role of showing how one set of findings is applicable to another context (the study’s external validity) rests with the researcher that wants to make that transfer.

### *Dependability.*

The researcher must account for the changing conditions in the object of study. Also, she must remain conscious of the changes in the design that have occurred due to an increased understanding of the setting. The assumption that a study can be replicated and therefore is reliable, is discordant with the qualitative view that the world is constantly changing. This makes replication problematic. One key to reliability is to be clear where one is in the qualitative process, that is, the research design, data collection, analysis and documentation. "The researcher must ask "Where am I" and "When am I done" many times (Kirk & Miller, 1986, p. 72).

### *Confirmability.*

Confirmability relates to the concept of objectivity. A piece of qualitative research is by its nature shaped by the investigator's subjectivity. Rather than detract from the data, this enhances it by providing an understanding of the participant's experience, thereby richly describing the situations being researched. It is, however, the responsibility of the researcher to control for biases in interpretation. Marshall and Rossman (1986) suggest that this can be achieved by checking and rechecking the data, posing rival hypotheses, constantly searching for negative instances and by asking questions of the data. Using another person to critically analyze the researcher's interpretations is another technique that can be used to control research bias. Having my thesis advisor code and analyze some of the results may have been useful, however did not occur. This is discussed further in the limitations section in chapter six.

To summarize, this was a qualitative study, designed to examine mothers' experiences of

summer respite care services through Wesway. A summary of findings will follow.

## Chapter Five

### The Findings

The intent of this research was to gain an understanding of mothers' perceptions of the respite summer program service they were provided, as well as learn about their experiences about having a child with a disability. This chapter specifically explains the research study and examines the process of how categories emerged.

Within this chapter, specific and overall findings will be identified. Also, each of the interviews will be presented using the following outline. First, a brief description of the family is provided to give the reader a synopsis of what the family looks like. While these vignettes are drawn from study participants, some details have been fictionalized. No real names have been used. This is to protect confidentiality for the families. Second, the categories that emerged in the interviews with the caregivers are described. The study was exploratory and qualitative. The study sample consisted of ten mothers of children with special needs. The research sensitized the researcher to the social reality of mothers who have a child with a disability and what respite care services can provide for their families. This sensitivity helped the researcher in identifying themes and categories. These categories represent the central issues that were encountered by the mothers in their experiences in caring for a child with a disability and utilizing respite care services. Several recommendations have been suggested for improvements of the respite program. These will be provided to Wesway upon completion of the thesis. From the

categories and emerging themes described in this chapter, conclusions were generated. These are discussed in chapter six.

*Descriptions of the Families.*

*Family One.*

This family consists of the mother, father and three children. \_\_\_\_ is twenty years of age and has Muscular Dystrophy and slight autism. Her diagnosis has been gradual and in the last year, her disability has become more strenuous on the family. The siblings are twenty-three and twenty-six and do not live in the home at this time. \_\_\_\_ requires moderate to high care at this time and this will increase as she ages. \_\_\_\_ attends a school program that places an emphasis on employment and she works once or twice a week at a local fast food restaurant.

*Family Two.*

This family consists of \_\_\_\_ who is a fifteen-year-old young man and his mother. \_\_\_\_ has mild Cerebral Palsy and a developmental delay. He attends school regularly which provides respite for his mother. He requires extensive care consisting of personal care needs, help with feedings and mobilizing. He is fairly wobbly when he walks and often requires assistance. He is non-verbal, however often expresses emotions through yelling, pointing or demonstrating to his mother and others.

*Family Three.*

This family consists of a two-parent family and three children. The children range in age from nine to thirteen. \_\_\_\_ has severe autism and is nine years old. The two other siblings are

male and they co-exist with \_\_\_\_, however they provide minimal or no care for their sister. \_\_\_\_ requires constant care and will most likely continue to in the future. She requires help with personal care needs, feedings and transportation.

*Family Four.*

This family consists of a traditional family with two parents and two children. \_\_\_\_ is sixteen years old and the disability label is autism and pervasive developmental disorder. She attends school regularly and engages in an after school job through the school program. \_\_\_\_ has one sibling who is male and is seventeen years of age. The two teenagers get along quite well and \_\_\_\_ is very protective and supportive of his sister. \_\_\_\_ is non-verbal, however she will express her needs through yelling or demonstrating to her family. She requires care in areas of personal care needs, help into bed and supervision, at times.

*Family Five.*

This family consists of a single parent family with one child. \_\_\_\_ has Multiple Sclerosis and her condition has been slowly deteriorating with age. She is eighteen years old now and attends school. The mother feels her daughter requires significant care and this will increase due to her condition deteriorating.

*Family Six.*

This family consists of a two-parent family and two children. \_\_\_\_ is ten years old and has severe autism. His sibling is 14 years old and they appear to get along. \_\_\_\_ requires full care as he cannot walk, communicates little and he requires personal care. \_\_\_\_ can crawl around,

however does not walk which is difficult for his parents as he is hard to manage. He attends school regularly. \_\_\_\_ is in a wheelchair most of the day. \_\_\_\_ will express emotions or needs through fluttering his arms or yelling. This family is finding it more and more difficult to care for their son and are considering other care options.

*Family Seven.*

This family consists of a single parent mother and her two children. \_\_\_\_ is 15 years old and has a developmental disability. He has a younger sibling and the mother indicated that there is some jealousy towards \_\_\_\_\_. He needs assistance with personal care, transportation and safety. \_\_\_\_ can minimally communicate his needs but has difficulty conversing in social situations. He will likely need ongoing support.

*Family Eight.*

This family consists of the mother and her two daughters. \_\_\_\_ is 16 years of age and often assumes the role of the other parent in the home. \_\_\_\_ has severe autism and is 12 years old. This family is very close and depend greatly on each other. \_\_\_\_ requires full time care and attends school regularly.

*Family Nine.*

This family consists of two parents, \_\_\_\_, their daughter and \_\_\_\_'s elderly maternal grandmother. \_\_\_\_ is 17 years old and has a severe developmental delay and autism. She requires a vast amount of attention and a lot of help mobilizing. She will continue to need constant supervision and care.

### *Family Ten*

This family consists of a single parent family and \_\_\_\_ who is seven years old. \_\_\_\_ has severe autism and requires constant care. His mother is active in the community and is knowledgeable about her son's disability. \_\_\_\_ attends school regularly and has a regular respite worker with whom he goes out three times a week.

### *The Findings*

The findings and discussions of categories will be addressed below. There are numerous categories that appeared significant in the interviews.

#### *Mothers are the primary caregivers.*

All of the mothers interviewed were the primary caregivers for their children. Mothers spent, on average, three to four hours per day doing hands-on personal care (bathing, toileting, feeding and providing medical care) for their children. All of the children required additional support, such as assistance with communication, supervision or help dealing with behaviour. In addition to time spent providing personal care, mothers acted as advocates, coordinators of care, and providers of transportation to school and for child care, generic and specialized health services, therapies, recreation and leisure for their children. The vast majority spent considerable time in these activities. All of the mothers in this study reported playing the role of advocate for their child. Personal care and support for their children were also provided. Coordinator of services and support providers were also roles played by all the mothers. Many of the mothers (90%) provided transportation, spending a significant amount of time doing so. Providing



support to their children with disabilities is clearly more than a full-time job for most women, requiring many hours per week of their time, in addition to their other workforce or domestic responsibilities.

*Mothers played a variety of roles.*

Mothers play a variety of roles in the support of their children. They provide transportation, advocacy, personal support, service coordination, and therapies. They deal on an on-going basis with a wide range of professionals, often consulting professionals about how to include their children in the community. Despite these busy schedules, some mothers also found the time to volunteer with an agency or organization that was relevant to their child's inclusion in the community (5 out of the 10 mothers did so). Many of the women commented that playing all of these roles is not easy. One mother said, "Trying to balance all of these services is incredibly hard. The barriers need to be broken down so I do not have to do it" (Personal Communication, November 23, 2001). On the positive side, mothers developed new skills and confidence and discovered a lot about themselves in the process. "Having a child with a disability is the most wonderful thing that's ever happened to me. I found talents and strengths that I did not know I had. My child makes people change...life is a never-ending adventure" (Personal Communication, December 9, 2001).

*Effects of the disability on families.*

Many of the mothers revealed that there are many challenges and hardships in caring for a child with a disability. They identified many changes and sacrifices which included increased

financial burdens, reduced income, emotional and physical effects, overall effects on the family, lack of time, deferral of career goals and restructuring of family roles and more.

The following table demonstrates the variety of stressors mothers experience in caring for their disabled child.

*Table One*

*Effects of Caring for a Child With a Disability on the Mother*

	C1	C2	C3	C4	C5	C6	C7	C8	C9	C10
Stress	X	X	X	X	X	X	X	X	X	X
Emotional Strain	X	X	X	X	X	X	X	X	X	X
Lack of Sleep		X	X		X		X		X	X
Lack of Time	X	X	X	X	X	X	X	X	X	X
Strain on Marriage			X	X		X			X	
Strain on Parenting other kids	X		X	X		X	X	X		
Financial Hardships	X	X	X	X	X	X	X	X		X
Deferral of Career Goals	X									
More restricted Lifestyle		X			X		X	X	X	
Exhaustion		X	X	X	X	X	X	X	X	
Challenges in providing care due to society's views				X			X			X
Stress over Child's Future			X	X	X	X		X	X	
Positive Effects –Change Of Attitude in Mother			X	X				X		X
Lack of Social Life	X		X	X		X	X	X		
Strain on Siblings	X		X	X			X	X		

One mother stated, "I was completing a degree when I became pregnant and I was going to go back and complete this after the first year of the baby's life, but this was impossible due to the high demands of caring for \_\_\_\_...yeah, it has been challenging and difficult but I love her

and would not change anything about her” (Personal Communication, November 13, 2001).

All of the mothers also indicated that there are many emotional effects of having a child with a disability. One woman stated, “Well, it is quite draining, it affects me mentally, and it can be very challenging. It’s affected me quite a bit...I am more restricted. It has been difficult for me because \_\_\_\_ takes up most of my attention...at first, I was grieving the loss of a ‘normal’ child and my initial reaction was anger” (Personal Communication, December 7, 2001).

Another respondent established the many effects her child and the disability have on her life. “Well, I am a single parent trying to survive with my daughter...it is hard when I have no one else in my home to be with her or tend to her needs. It just becomes draining; mentally, physically, well in every way” (Personal Communication, November 23, 2001).

#### *Impact on Lifestyle.*

Many mothers spoke about the significant lifestyle changes that needed to be made when caring for a disabled child. Many changes and sacrifices were described during the interviews. One woman said, “The disability affects us greatly at times, as I can never just pick up and go out. It is difficult now more than ever as she is older and it is more work to have her. I do not want to ask family to take her as she is a big responsibility. I am often stuck at home as far as holidays goes...it is too hard to bring her anywhere” (Personal Communication, November 13, 2001).

One mother spoke about how her life is consumed with her son and how it greatly affects her life positively and negatively. “I do not go out as much, I am probably more of a homebody.

It is hard, you know, because when we go out, people stare or are always looking to see what is the matter. Like, if we go to a restaurant or something and \_\_\_\_ gets excited, everyone looks and it is frustrating, not embarrassing, I just do not understand why people cannot stare and understand the disability” (Personal Communication, December 11, 2001).

Another respondent said, “I think it is the everyday living needs that affect us so greatly. Because he requires a lot of care and attention, it often will take away from the other things we would like to do” (Personal Communication, December 11, 2001).

One mother spoke about how the disability greatly impacts her life and also the life of her other daughter. “Lots of the time if I am at work, \_\_\_\_ will watch \_\_\_\_, she says she does not mind...I am not sure...she might feel like she has to...I think this type of disability is emotionally draining and impacts me and \_\_\_\_ both emotionally” (Personal Communication, December 18, 2001). Another mother said, “Sometimes I feel like I am on a roller coaster, things move so quickly...I always have something to do, going around and around...I have no time left to care for the rest of the family” (Personal Communication, December 17, 2001).

Many of the primary caregivers indicated that it has been very exhausting for the whole family caring for a child with a disability in the home because of the need for constant care and attention. A mother commented, “I have made family sacrifices and I feel like I am always tired, I never get enough sleep...\_\_\_\_ frequently wakes up during the night, which means I wake up and have to tend to his needs, it is exhausting” (Personal Communication, December 17, 2001).

Another mother described her day-to-day living to be highly stressful. “The repetitiveness of

things, you have to go over things, over and over...it becomes tiresome and challenging...it is constant watching and making sure he is okay, he is 15, I thought it would be different when he was this age" (Personal Communication, December 17, 2001).

### *Impact on Siblings.*

Mothers also indicated the effects of the disability on the siblings. One mother stated, "My two other children, I think felt I paid more attention to \_\_\_\_ which may have had an effect on them...they also had to help out a lot at home, they may have resented this" (Personal Communication, November 13, 2001). Another mother stated, "Her and her siblings, they co-exist, they do not pay much attention to her, they all get along, they are not mean to her or anything like that, they do not do a lot of helping out, as they are in college and do not live with us anymore. Although, when they were living here, I could tell at times, it was stressful for them as well, to live with the constant demands of a disabled child" (Personal Communication, November 13, 2001). Another comment was "\_\_\_\_ is always saying \_\_\_\_ gets everything and everyone comes to see \_\_\_\_...I think she feels left out" (Personal Communication, December 17, 2001). One respondent said, "My two boys find it stressful as they want some of my attention too, I try to be fair, it can be draining trying to give to each of them equally. Having three children and their needs are so different and unique, which is one of the things that helps us survive in this house is being aware of the differences...I treat them all very uniquely and what arises, arises, and who's ever needs are greatest at that moment wins out...It really affects my

life, especially because I have grown to realize what is really significant in life, which to me is family” (Personal Communication, December 3, 2001).

*Impact on Marriages.*

Mothers felt that the stress they experienced had an impact on their spousal relationships. A number of women reported strain in their marriage. They reported not having time to spend alone with their partner. Mothers indicated these feelings in the comments below. “Well, caring for a child with a disability can bring out conflicts in the two of us...we often argue about future plans for \_\_\_\_” (Personal Communication, December 3, 2001). “It’s been four months since we were last out alone, together, just the two of us...my husband sometimes wants us to have a quiet night together, but this little thing can sometimes be very hard to accomplish” (Personal Communication, December 3, 2001). Another mother said, “I don’t have enough time in between meetings, assessments and occupational therapy. I often have to fight just to find a half-hour” (Personal Communication, December 9, 2001). She commented further, “He became my priority. Everything else came second, including my marriage. He took over my life for a long time” (Personal Communication, December 9, 2001).

*Impact on Health and Well-Being.*

Many of the women interviewed said that their health and well-being were compromised due to their stress and responsibilities. When asked to rate their health on a scale of “poor, fair, good, very good or excellent”, most women (60%) rated their health good, with 40% rating it fair. In contrast, the National Population Health Survey (1996) found that significantly more

mothers rated their health as very good (40%) and fewer rated their health as merely good (26%) or fair (6%). In other words, mothers of children with disabilities in this study were less positive in reports of their own health than mothers in Canada in general. Over half of the women in this study (60%) reported they suffered from anxiety or depression and/or general symptoms of stress. They described experiencing a wide variety of symptoms of stress, including, disrupted sleep, headaches, isolation, stress, anxiety, frustration, fear, anger, agoraphobia, depression, feelings of hopelessness, feeling overwhelmed, fatigue, stomach aches, and insomnia. One woman described the way she feels as: "I am 42 and I feel like I am 90" (Personal Communication, December 9, 2001).

*Mothers have Positive Experiences Caring for a Child with a Disability.*

Mothers were very quick to point out the many positive experiences that come from having a child with a disability. Their experiences as parents of a child with a disability were a great source of strength and growth for many mothers. They report that their experiences have made them better people, increased their awareness of a wide range of issues, made them stronger, taught them "how to fight" and to look at the world and other people differently. They believe they have been given greater insights, learned acceptance, become more sensitive to others' differences, learned new talents and gained a sense of fulfilment. As one woman explained, "I live life much closer to the bone. I do not get caught up in peripheral things. We are very gifted in life. This can be a very fulfilling life if you are open to the way it changes you" (Personal Communication, December 11, 2001). Another mother expresses a positive

experience with regard to her child. “\_\_\_’s wonderful smile will often get me through the day, and make me feel like it is all worth it...his smiles. It is a challenge to take care of him, but he always has a smile, which makes me very happy...he always is in good spirits” (Personal Communication, December 9, 2001).

*Child Care Responsibilities Impeded Labour Force Participation.*

Child care responsibilities were reported by women as a major impediment to labour force participation. For example, for the mothers who were working part time (six women), all but one indicated this was the reason for their choice. As one mother stated: “I took time off without pay. I was told to make a choice between my family and my job. I have gone to half-time in my job and took a year’s absence” (Personal Communication, November 23, 2001).

*Stress*

The mothers described many stressors in caring for a child who has a disability. These include: stress with the disabled child’s school; stress from spouses wanting more time together; stress about their child’s future; financial stress; job-related stress; stress involved in keeping the family together and stress as the central person caring for the family.

All mothers admitted it is stressful to have a child with a disability. One mother spoke about those stressors, “Her disability has a great effect on my life as I usually take care of her all the time. I find it stressful everyday doing the exact same thing and there is never any change in her...I become emotional at times due to all the stress in my life” (Personal Communication, November 13, 2001).



Another mother stated, "It is very stressful for me as I am the only one in the home with \_\_\_\_, it is always me and him, him and me. I think he becomes annoyed with me too as I do with him; but do not get me wrong I love him very much, but it is hard. Sometimes I want time for just me and I cannot always have that time...I think overall my well-being is okay, well satisfactory, as I feel overwhelmed frequently" (Personal Communication, December 7, 2001).

Another mother felt particularly stressed about being overwhelmed with many responsibilities. "I see myself as the strong one and I try to keep everyone's life in order...this becomes difficult to do, I feel like I am always being pulled in different directions. There are many stresses in my life but I deal with them. I do not feel sorry for myself for having to cope with this, I just do it, it is a part of my life" (Personal Communication, December 3, 2001).

One mother spoke proudly of the changes that had occurred in their lives due to her advocating. She spoke about the improvements that had occurred in her child's functioning. She said, "If I hadn't been a strong person he would be at a very different place today" (Personal Communication, December 9, 2001). She also spoke about the changes she and others had implemented in the community. She felt a great deal of stress regarding the diagnosis of her child, and said, "It was most stressful that I didn't get the information all at once. We've made a package through the Autism Society that explains everything. I see lots of change in the community...There is more professional awareness of the needs and wants of special populations. Parents won't just believe doctors. They love their kids and won't just accept anything" (Personal Communication, December 9, 2001).

### *Financial Stress.*

Ninety percent of the women expressed concern regarding financial security and most families were struggling to make ends meet. "The stress of financial issues is big, as we have to pay for many things for \_\_\_\_ that most families would never have to consider paying for their child who is twenty years old...you do whatever it takes to alleviate stress, going to sleep, getting out of the house, sit and talk to friends, go for a walk, it is just your normal everyday whatever works" (Personal Communication, November 13, 2001). Another mother felt financially insecure. "I do not make that much money and it is expensive to provide for \_\_\_\_" (Personal Communication, November 23, 2001). Another mother identified the greatest stress for her to be the financial burden. "I have to pay for Depends (incontinence panties) which are expensive, certain foods, transportation, workers, the list goes on...it is very difficult keeping up finally as I am a single mother with two kids, one of them just happens to be special (Personal Communication, December 18, 2001).

### *Looking to the Future.*

Many of the mothers described numerous stressors, including the future care needs and options for their children. "One of my major concerns is when I think about \_\_\_\_'s future...my husband and I have not really thought about a future permanent home, I feel people are not cared for enough in those places. She needs attention all the time, and I would worry" (Personal Communication, December 4, 2001). Another mother described her situation. "My husband and I have not really considered alternative care for \_\_\_\_, but it is very hard to maintain him at home

and manage everything in my life. I feel like I do not even have a chance to parent \_\_\_\_ (sibling) and this is not fair. I want to be a good parent to both, this is not happening...this is why more and more I am considering other living arrangements” (Personal Communication, December 11, 2001).

### *The Educational Role.*

Many mothers made statements regarding dealing with their child’s school and a variety of challenging situations including dealing with the professionals, the education system and achieving the desired level of integration. When asked how they coped with the challenges of integrating their child into the school system, one mother responded, “I keep going higher and higher. If the teacher is not going to do it, I go to the Board and talk to people until someone listens to me and helps me out” (Personal Communication, December 9, 2001).

### *Mothers Felt Their Unpaid Caregiving Activities Were Not Recognized.*

Some women looked at the care they provide as a 24-hour-a-day job, and were disappointed that this was not recognized through remuneration: “They will pay a stranger eight dollars an hour, but not myself or his siblings and there is no pension for me after the years of care I will be providing...I find this completely frustrating and this adds to my stress level” (Personal Communication, December 18, 2001).

### *Social Supports*

Many of the mothers interviewed identified having a vast amount of supports and resources, while others felt isolated and lacking in supports. Many of the mothers identified

certain resources that were useful and helpful such as respite services, friends, neighbours and family.

*Women Tend to Seek Support to Deal with the Stress in their Lives.*

Over 90% of the women needed to seek support to deal with the stress in their lives. The majority looked to peers and family for support while others sought out professionals and community resources. Women also described taking the initiative to change their lives to reduce their stress. Some strategies included taking courses, going back to work and going to support groups. In one case, a family created a support system for themselves by starting a parent support group: "We have made some good friends and peer support certainly saved our sanity, but they would have no support if we had not pushed for this group" (Personal Communication, November 26, 2001).

*Women Received Support From Their Families.*

While women received some support from their spouses, many had friends, neighbours or extended family supporting them in providing care to their child. Two women commented on the inability of extended family to feel comfortable in the presence of their children with disabilities. Although mothers did tend to receive regular help from their family and friends, many also felt that they could go to them for help if they had to. When asked what help they could receive if they could not perform their caregiving role for some reason, over 70% felt they could count on a family member to step in and 20% felt they could rely on friends. "My extended family is great, they will take \_\_\_\_ for the weekends or overnights, they enjoy her and

she is part of the family. This is very helpful and it is a well-needed break...Respite services and weekend programs are also used by our family which is great...we were able to get away on a little trip for the weekend, for a little getaway without any kids, that was fabulous thanks to Wesway and my family" (Personal Communication, December 3, 2001). One woman felt she had no one to turn to should such a situation arise. "My family is many miles away so there is no physical support from them but they do provide some emotional support" (Personal Communication, December 4, 2001).

*Support Received from Respite Staff.*

All of the mothers interviewed reported receiving support from the respite staff, whether it be the respite worker or the facilitator. One mother in particular, struggled with informal supports and felt isolated at times, however she felt supported by professionals. "My mother will seldom watch \_\_\_\_, he is too big now and he is getting older, so I do not really want to ask her...The school I see as supportive as he attends every day giving me a break and they are helpful with ideas and suggestions...Wesway is also one of my biggest supports. The facilitator who helps my family is a wonderful woman who really knows and tries to understand what it must be like for me...she tries to offer as much respite as she can" (Personal Communication, December 7, 2001).

The following table demonstrates the identified supports that the interviewed women utilized.

*Table Two*

*Support Networks for the Mothers*

	C1	C2	C3	C4	C5	C6	C7	C8	C9	C10
Family	X	X	X	X				X		X
Friends	X		X	X	X	X	X		X	X
Professionals/ Social workers/Respite workers	X	X	X	X	X	X	X	X	X	X
Doctors			X							X
Husband/partner	X		X	X		X			X	
Other Children						X		X		
Group Member Friends	X			X	X					X
School/teachers		X			X					X
Church							X			

*Spousal Support.*

While 50% of the participants were married or had partners, 40% of them had daily help from their spouses. When spouses did participate in caregiving, they tended to do so in the evening. However, three women had spouses who worked late, long hours or were out of town, so they were alone in the provision of evening care as well. However, these women still did recognize their husband or partner as their main source of support. One woman stated, "My husband is someone that keeps me going and provides considerable support" (Personal Communication, December 11, 2001). Another woman said, "My husband is the person I turn to when I am feeling blue or down, even though he is away, a phone call will help...he is my sounding board, he is a big resource to me" (Personal Communication, November 13, 2001).

### *Community Support.*

All the mothers indicated that community resources and professionals have been key to helping the family and organizing services to be used. "Like I stated, the community is one of my biggest resources...people in the community keep connecting me to more and more resources, which is nice. Sometimes people do not realize what is out there" (Personal Communication, November 23, 2001). "Sometimes, I am stressed out, but I use the community...I do reach out to the community and utilize all resources I can get my hands on" (Personal Communication, November 23, 2001). Another woman stated, "There are many professionals in the community as well, who I see or talk to...they come to our home and visit with the family to see what our needs are" (Personal Communication, November 13, 2001). "The church is a place where I go, I feel like it helps me to relax and think about the positive things in life that I have, not that Kevin is not a blessing, but it is rough" (Personal Communication, December 17, 2001). One mother acknowledged that communicating to her neighbours and really getting to know people in her community was helpful to her child. "More knowledge and understanding leads to less fear and more acceptance," and she credits this decrease in stress to the fact that "more people are getting to know him in the community and watch out for him... They have more tolerance and more understanding" (Personal Communication, December 9, 2001).

Several women commented on community and parent support groups which they found to be a great support. "I really have good friends from the weekly group I attend, some of their

kids hang out with Sara and they all get along, that makes it a little bit easier.” (Personal Communication, December 4, 2001). This parent experienced a decrease in stress. “I don’t feel as alone. I am more in control. I have the help and support of other parents. We exchange information” (Personal Communication, December 9, 2001). “Some of my family are here and they are very supportive and I belong to parent groups for children with special needs, which is very helpful...it brings out lots of ideas and thoughts. I also have many wonderful friends whom I regularly speak to and see” (Personal Communication, November 13, 2001).

A number of studies have focused on the ways in which parents try to cope with the difficulties that they face (Flynt & Wood, 1989; Cullen, Macleod, Williams, & Williams, 1991). These types of studies often focus on social support (Flynt, Wood & Scott, 1992) and family resources (Reynolds, 1994), as well as on more general coping styles. Resources and ways of coping that the mothers in this study found to be helpful are illustrated and discussed below.

### *Table Three*

#### *Mothers' Coping Strategies*

	C1	C2	C3	C4	C5	C6	C7	C8	C9	C10
Talking to a Professional (Social worker, respite worker, respite facilitator, etc.)	X	X	X	X	X	X	X	X	X	X
Going for Walk	X	X		X				X		X
Getting out of the house	X	X	X			X	X	X		
Spending Time Alone	X	X	X			X				
Having a bath	X		X	X	X					X
Working Out	X		X		X		X		X	X
Listening to Music	X				X	X				X
Reading		X			X					



Talking to friends, family		X	X	X	X	X	X	X	X	X
----------------------------	--	---	---	---	---	---	---	---	---	---

Friends, colleagues and individuals with similar experiences can also provide an important source of support to families with a child with a disability. They can provide short-term assistance such as babysitting, emotional and moral support and community awareness and positive outlooks towards children with disabilities. Wikler, Hanusa, & Stoycheff (1983) suggest that smaller friendship networks and increased reliance on extended family are related to reduced parental stress in caring for a child with a disability. This was also found in my study. Many of the mothers had friends from groups in the community and found them to be a great support to them and their families.

*Funding Cuts are Affecting Parents' Access to Supports.*

Funding cuts are having drastic effects on mothers' access to supports in all sectors. One woman stated, "You cannot turn around these days without another support being taken away, limited in some way, or having user fees applied" (Personal Communication, December 5, 2001). Mothers are worried about what this will mean for themselves and are fearful about what the implications may be for their children throughout their lives. One mother expressed this fear. "I have to plan for the entire life of my children with what appears to be fewer and fewer supports...I live with incredible fear for them, who else do they have but me?" (Personal Communication, December 12, 2001). Mothers need access to supports and these issues need to be addressed. One mother put it simply, "I want her to have a life. She needs opportunities to

develop. This is not possible for me to do without needed supports and services” (Personal Communication, December 5, 2001).

### *Respite Care*

All of the mothers were receiving some form of respite care service from Wesway. Table four demonstrates the variety of respite programs offered and which ones each family utilized. Table five illustrates the positives aspects that mothers expressed about the summer program.

*Table Four*

### *Respite Care Services*

	C1	C2	C3	C4	C5	C6	C7	C8	C9	C10
In-Home Respite	X				X			X	X	X
Weekend Respite	X		X	X	X			X		
Summer Program	X	X	X	X	X	X	X	X	X	X
Host Family						X				X
Volunteer		X					X			

*Table Five*

### *Positive Aspects about the Summer Respite Program*

	C1	C2	C3	C4	C5	C6	C7	C8	C9	C10
Variety of Activities	X	X	X	X	X					
Child Enjoys the Activities And Participating	X	X	X	X	X	X	X	X	X	X
Knowledgeable, Friendly & Enthusiastic Staff	X	X	X		X	X	X	X	X	
Helps Child Learn to Function without Parents			X		X		X	X		
Helps Child to Socialize	X					X		X		X
Provides Family with a Break	X	X	X	X		X	X	X		X
Integration of Similar Interest Groups		X			X				X	

Together										
Accommodating	X	X	X	X	X	X	X	X	X	X
Organization of Programs	X	X	X	X				X	X	X

*Mothers are satisfied with the support they receive.*

All of the respondents appeared to be satisfied with the respite support they were receiving. The most common need was adequate, flexible respite which all participants stated was being met, however more opportunities for respite service were strongly suggested. Comments provided from the interviews regarding the benefits of respite care summarized such views. "Respite has been a lifesaver, it has allowed time for me and \_\_\_ to go shopping or go out for a bite to eat...we miss \_\_\_, but I think it is important to do these types of things with \_\_\_, she is getting older now and she deserves some alone time with her mother" (Personal Communication, December 18, 2001). "The services Wesway has offered have been very accommodating...I think the services they have to offer are well organized and are geared towards families and what they can do for them. I found Wesway to be easily accessible and \_\_\_ always enjoys herself" (Personal Communication, November 13, 2001).

Furthermore, many of the mothers had numerous positive features as to speak about in regard to the summer services. "\_\_\_ loves the summer programs as she very much enjoys being around people, the program really gives me and my husband a break from the constant care we need to provide" (Personal Communication, November 13, 2001). "Wesway is a big support for me, they are always trying to help families the most, and \_\_\_ has a great time at the summer

program where he can interact with kids his own age with similar disabilities. He really likes when they go swimming in the summer. Wesway is always coming up with new programs that families really enjoy and appreciate...I remember after one day that \_\_\_\_ came home, he was so happy and he could not wait until he could go again, he kept saying 'house' vaguely because I think he wanted to return to the Wesway house program" (Personal Communication, December 7, 2001). "Well, the programs are there for her as well as for us. I would just like everyone to know that these services are essential to our families and we rely heavily on them and the support they provide. Without agencies like Wesway, it would be difficult to parent our children and cope in today's society" (Personal Communication, December 11, 2001).

*Suggested Improvements for Positive Change.*

Table six demonstrates the possible suggestions for improvement that mothers had about the summer program. Several respondents had suggestions for improvements or possible changes to respite services and delivery. The mothers' comments are discussed below.

*Table Six*

*Mothers Suggested Improvements/  
Possible Recommendations for the  
Summer Program*

	C1	C2	C3	C4	C5	C6	C7	C8	C9	C10
More feedback from workers At the end of the day						X				X
Another day added to the Program			X	X		X				
Longer-Running throughout the Whole Summer (until end of August)			X	X					X	

Program Starting as soon as Kids get out of school				X		X			X	
More Opportunities for Respite	X	X	X	X	X	X	X	X	X	X

“Overall, I would suggest more opportunities for families to have more respite services. In regard to the summer program, another day of the week if possible, this would be great, imagine two whole days of the week in the summer, something to consider. There is not much that I would like to see improved as I feel Wesway’s summer program is terrific and \_\_\_ really enjoys it” (Personal Communication, December 3, 2001). “An improvement I have seen more recently in the summer program is that there is a male and female worker which I find to be very reassuring. I like the idea that there is a guy who can do lots of the lifting, it makes me feel safe, that in case she does fall, the workers will not have problems getting her up. The program is very accommodating to families’ and the individuals’ needs” (Personal Communication, December 4, 2001). “Another thing I would like to see changed or improved is that I would like to see more regularity in the weekend program, although they do call with cancellations, which is nice. Also, another day of the summer program would be very accommodating. This would allow \_\_\_ to enjoy another fun filled day with kids her own age, as well I could do errands or go to work” (Personal Communication, December 4, 2001). “I find the summer extremely difficult and long, because to keep her busy, she is used to school and she is home all day, this is always a challenge every year. The summer program was a change for her, the activities were worthwhile for her” (Personal Communication, November 23, 2001). “I would like to see the program run until the end of August. It ended the second last week of August,

that made the last part of August difficult...and perhaps the program could start right when school finishes, start right when the kids get out of school. I don't know if this is possible, but it would keep Genevieve active and busy throughout the whole summer" (Personal Communication, November 20, 2001).

\_\_\_\_\_ cannot tell me that much however he would always be smiling and appeared to be having a great time there. It is hard because of his inability to speak to know how he really feels...the workers would give a review of how the day went, but at times, though, I felt like I was being pushed out the door...I would really appreciate a little run down at the end of the day personally, rather than through the log books. I did find the books helpful, but I would like to personally speak to the worker, just briefly, it gives me a sense of following through on what he is doing and how his day went (Personal Communication, December 11, 2001).

"More time opportunities, basically would be nice, to not have to plan so much ahead of time, more emergency opportunities, such as weddings, holidays, if there was a funeral I might be stuck, because who would watch him. When someone passes away, you do not have lots of time to plan. These are the type of incidents I am talking about" (Personal Communication, December 9, 2001).

One mother also identified respite care areas which were lacking.

We did have a host family at one point, but they have retired so it is harder now. I think that this is an issue in every community, that there is a lack of services. Well as far as service goes, there are not enough people to do it, not enough people to be host families. It would be nice if the government could provide money so that families could adapt their homes, make it easier on everybody" (Personal Communication, November 23, 2001).

### *Discussion and Analysis*

The focus of this section is to discuss the overall findings in the study and to examine these findings. The first section groups the categories that emerged from the data in the study

and integrates these findings into the literature.

### *Categories and Supporting Literature*

Throughout this research process, I found it challenging to identify a core category as there were so many significant and important issues that arose from the research. However, the core category that appears to link with all of the categories in some way or another is “Mothers’ Experiences in Caring for a Disabled Child”. This category impacts on and affects every other category. The mothers in this study would not have had the experiences with respite or experiences with the level of stress described if they did not have a disabled child to care for.

#### *Caregiver Stress.*

Research has consistently demonstrated that parents of children with disabilities experience a substantial amount of stress (Beckman, 1991; Dyson, 1991). This study found that mothers faced a number of sources of stress: financial burdens, perceived stigma, demands on time as a result of caretaking and requirements for the child with a disability, physical difficulties caring for the child as the child grows older, decreased time for sleep and personal activities, social isolation from friends and family, and concerns about the child’s future. This is consistent with the literature. As Tunali and Powers (1993) found, as the child with a disability grows, parents are confronted with greater problems with behaviour, financial burdens, and uncertainty about the child’s future.

The numerous stresses confronted by families caring for children with a disability have been documented. There can be increased physical and time demands associated with providing

care to a disabled child leading to frequent parental concern over inadequate attention being paid to their siblings and marriages suffering as well (Sherman, 1995).

A major element in stress as reported by parents, particularly mothers, is the need for more time (Bristol & Schopler, 1989). However, in a study by Wikler (1991), mothers tended not to use their time for rest and personal growth, rather, their time was consumed in maintenance functions. Similarly, a study by Salisbury (1990) found that formal respite services were used for family maintenance activities such as work, meetings, social obligations and errands rather than personal renewal activities. However, one could consider that even having the freedom to run errands and to do housework without dealing with care demands at the same time can alleviate some stress. Within this study, it was found that the mothers did not have enough time in the day to get everything completed. Mothers felt stressed and wanted more time for things such as: other family commitments, work, other children, personal time and exercise.

The impact of a child with a disability on their siblings is easy to overlook. The brothers and sisters of a child with a disability often repress their feelings because they do not want to add to their parents' "burden" and because they may fear the answers to questions they have (Mori, 1983). Within this study, from what the mothers reported, there appeared to be a variety of reactions from the siblings. These included: jealousy, embarrassment, supportiveness, and acceptance.

#### *Caregiver Coping Strategies and Supports.*

Whitsett and Land (1992) suggested that coping resources may depend on an individual's



attitudes, skills and beliefs. The ability of primary caregivers to respond to the stress of having a child with a disabling condition may be based on two levels of resources available to them: informal resources and supports (available inside the family system) and external supports (resources available outside the family system). Primary caregivers who are successful in coping may use internal and external supports for strength to deal with the special needs of their children. The two resources most helpful to the mothers in this study were respite care services (external support) and family and friends' support (internal support).

Hetherington & Clingempeel (1992) indicated that certain aspects of social support are dependent on the source of the support; the size or amount of support; the accessibility of the network; the frequency of the contact; the type of individuals acting as supports (e.g., friends and family); and the adequacy of support. This study found that the more frequently the support was provided, the less stressed mothers felt.

The mothers in the study who indicated that their spouses were the most comforting resource, also stated they had strong, positive relationships. Several authors (Parke, 1986; Blacher, 1990; Flynt, Wood & Scott (1992), found that mothers of children with disabilities identified the spouse as the greatest source of personal support. Further, Friedrich and Friedrich (1981) found that intimate relationships are significant sources of personal support buffering the effects of stress.

Caring for a child with a disability is known to be demanding for families faced with the additional care problems without the services and resources needed to alleviate their stress

(Baxter, 1987; Donovan, 1988; Frey, Greenberg & Fewell, 1989; Minnes, 1988; Todd, Shearn, Beyer & Felce, 1993). Families actively seek to develop effective coping strategies. Little attention has been paid to families who are "good" at this, although attempts have been made to identify what sort of coping resources they use. Hetherington and Clingempeel (1992) have suggested the following categories: health/energy/morale, problem-solving skills, social networks, utilitarian resources and general and specific beliefs.

#### *Respite Care.*

Respite care is increasingly being recognized as a potential resource and special type of social support to families with dependent members. For many families caring for a child with a disability, respite services often provide the only relief for their burden of care (Kobe, Rojahn, & Schroeder, 1991). Most families are overwhelmingly satisfied with respite care and desire increased respite opportunities (Botuck & Winsberg, 1991). Respite has been associated with reducing the burden of families caring for a child with a disability at home by: relieving familial stress; improving parental attitudes towards their child; improving family functioning; and reducing social isolation (Botuck & Winsberg, 1991). In this study, all the mothers were very satisfied with the respite care services they were receiving and had received in the past and all of them desired more respite care opportunities.

Rimmerman (1989), in a study of maternal coping, resources and stress measured over time, showed that respite services were associated with a significant reduction in maternal stress as well as an enhancement of coping resources. One of the most striking findings was that the

impact of respite services on stress reached its positive peak at differential periods. He suggests that change in maternal stress is related to the cyclical nature of coping, perception of the child's progress or the type and quality of progress. Rimmerman (1989) suggests that the benefits of respite may be enhanced if supplemented by other family support services such as family counselling, training or in-home services.

The emphasis on maintaining persons with special needs at home has resulted in an increasing number of children with disabilities living with their families. There needs to be increased development of responsive respite care community programs to enhance quality of life and functioning to prevent family dysfunction and burnout.

## Chapter Six

### Conclusion

The purpose of this study was to discover mothers' experiences and perspectives with having a disabled child and how the respite services they are being provided affect and have an impact on their lives. The focus of this chapter is to provide an overall summary of the findings and to examine the implications of these findings. At the outset of this research, general research questions were constructed. These will be used to guide the summary. In addition, there is a brief summary of the study's design and intent and a summary of the common categories found in the data. Also, the limitations of the research are discussed. Finally, there is a discussion of the implications and recommendations of this research for policy and for practice as they relate to future research.

Children with disabilities are more and more likely to live with their families for most of their childhood. This trend benefits children and families in many ways. Mothers point out the positive impacts that arise from caring for their children, describing the ways they have grown, and say they have become stronger, learned new skills and tended to look at life in new ways. However, the stress caused by lack of supports has had impacts on families that need to be further addressed by social policy makers and professionals in the community. Mothers, in particular are affected, as they tend to be the primary caregivers of their children. This study revealed that they spend considerable time in the caregiving role, in addition to other domestic and work responsibilities, engaging in a diverse range of activities. Each family has their own

unique experiences about having a child with a disability. However, from the results of the study, it appears many families share some of the same struggles and hardships in raising a child with a disability.

A major impact on mothers is restriction in labour force participation. Though many of the women in this study wanted to be working, they were restricted from doing so by childcare responsibilities, lack of support and barriers in the workplace. The women who were working found it very challenging to manage a full or part-time job, along with all of their other child care responsibilities. Some women felt that since they were already working full-time as a primary caregiver, their unpaid contributions deserved recognition.

Mothers' health and well-being were also compromised by their responsibilities. They reported high levels of physical and emotional stress and looked to support from friends, medications and counselling to deal with it. Their clear indication that stress was caused by lack of support or opportunity, not their child, underscores the need for further exploration to address these issues.

Families need a number of different community supports and services. Overall, the conclusions appear to be that families desire more respite care services as they greatly affect the lives of the disabled member and the rest of the family. This implies that respite care services are quite valuable and should therefore continue and hopefully expand. Some families however, do not have a vast amount of other social supports in their lives. This lack of support has negative impacts on their own health and well-being and that of their whole family. They

reported that more opportunity for respite services would be an asset. Also, the recommendation that the summer program run until the end of August and also that another day of respite activities be added was suggested. All of the women reported that Wesways' respite services are flexible and accommodating and they respond to the unique and changing needs of families. The women in this study recommended an increase in resources and funding to provide families with more respite care services.

More focused attention needs to be on the needs of children with disabilities, their primary caregivers, and their families. Without an increased focus on these areas, the social isolation, burnout and economic disadvantage of these families will persist. As a mother in this study states, "The long-term cost will be twofold; the restricted potential development and contribution of their children and the social and economic costs of others and families asked to go beyond the limit" (Personal Communication, December 3, 2001).

### *Study Design and Intent*

The intent and primary purpose of the thesis was to conduct research regarding the summer respite care services offered through the organization named Wesway, which is in Thunder Bay, Ontario. Caregiver needs, perceptions and satisfaction with various dimensions of the respite programs have been examined. Recommendations that might strengthen or improve the summer services will be provided to Wesway upon completion of the research study.

The research was designed to aid the student in developing her knowledge in many areas, particularly researching disabled children and their families. It provided the student with the

opportunity to review the literature and conduct a study relating to mothers' experiences with respite care.

The methodology used in the study was qualitative. The qualitative methodology followed the grounded theory approach. Semi-structured interviews were conducted. The interviews involved identifying categories from the interview data.

From the analysis of the data, the researcher proposed some conclusions. It is hoped that these findings will assist other families with children with disabilities who utilize respite care services; help and assist professionals working with these families; and provide promising themes for future research.

The concepts and theoretical relationships in this study were derived from the data obtained from the interviews with the mothers. The researcher compared data within and across families. This kind of comparison gave the researcher greater clarity in identifying similarities and differences and gaining insight into family experiences that may be unique to one family or similar to several families. There are large demands placed on families caring for children with disabilities. It is recognized that mothers were the key informants in the study and these facts are based on their experiences and perceptions. There appeared to be several conclusions that most of the caregivers discussed and shared in their interviews. The following is a summary:

- 1) The mother in the family is the main parent responsible for keeping the family functioning and free from loss of control.
- 2) Every family's experiences and perceptions are unique.

- 3) Caring for a child with a disability in the home leads to the caregiver (mother) spending more time and attention with the disabled child than with other members of the family.
- 4) If families receive respite care and that support continues, it will lessen the stress put upon those families.
- 5) Mothers will be more protective of their children with disabilities than other children in the family.
- 6) If families do not continue to receive respite care services, their well-being and their children's well-being may suffer.

Parents, particularly mothers, spend an incredible amount of time caring for and supporting their children. On average, they spend 50 to 60 hours per week on personal care, advocacy, coordination of services and transportation directly related to their child's disability. Many of the mothers also have jobs which take up a considerable amount of time as well. In order to do so, they have taken on a number of roles that greatly increase their responsibilities and impact on their physical, emotional and social status.

Mothers face an ongoing need for respite services in the summer because of the demand of caring for a child with a disability. They want and need more hours of service in the summer, as well as the program to run throughout the whole summer. It was also suggested that another day be added to the summer program.

Women need access to supports particularly in the workforce if they choose-including both community supports for their children and a supportive employment environment.



Unpaid care, primarily by women, is replacing paid work formerly performed by paid professionals. Because it is unpaid this work tends to be invisible to the people in society and professionals. It is not recognized as skilled labour. Women are not only unpaid, they have no access to vacation or sickness benefits, retirement pensions, and their own career opportunities are compromised. This is an issue which needs further examination and exploration and policies need to be altered or introduced for change to occur.

The mothers' experiences shared similarities which are outlined below.

- 1) The mothers experienced stress and challenges in caring for a child with a disability.
- 2) The mothers identified the child's disability as having some effect on the rest of the family.
- 3) In all interviews, the mothers said that they felt stress in trying to balance the needs of the child with a disability, the needs of the other children in the home, the needs of their spouses or partners, employment and their own personal needs.
- 4) Support systems were viewed as crucial and critical to the mothers in surviving with a child with a disability.
- 5) Respite services were viewed by all the participants as a very helpful and valuable resource.
- 6) The summer respite program was found to be an important service by all of the mothers in meeting their child's needs and their own needs.
- 7) Each mother identified at least one social network they could count on (although they varied, many were similar).
- 8) The mothers had similar experiences in regards to having a child with a disability.

9) Similar self care strategies were identified by the mothers in coping with their stress in caring for a child with a disability (i.e., taking a walk, exercising, or having a bath).

### *Limitations of the study*

Some limitations of this study include: low response rate and small sample; type of sample; interviews only with mothers who were the primary caregivers; and potential researcher bias due to combined interviewer and analyst roles. The findings are not intended to be generalized to the entire population, but can be applied to similar populations, addressing similar questions.

#### *Low Response Rate and Small Sample Size.*

The sample size was small (ten respondents) and it is necessary to corroborate the results in further studies with more respondents. It would have been perhaps more beneficial to have a larger sample size in this study and some male perspectives. The reasons for low participation might have been due to caregivers feeling that they did not have the time or emotional energy to take part in the study; caregivers may have wanted to keep their experiences private; and perhaps the timing of the request to participate may have been a deterrent (near to Christmas).

#### *Type of Sample*

The particular sample of people within my study were individuals who were all living in the city and considered urban, not rural. Also, the sample was homogeneous, all being white, lower-middle class women. There were no Aboriginal participants in the sample. These factors may be limitations as I may not have had not got a good representation of the community of

Thunder Bay and the people living in it. The experiences of persons of varying social status and culture may have differed from those in my sample.

*Interviewing only women primary caregivers.*

The focus of the study was on caregivers' perceptions of respite care and experiences of having a child with a disability. There may be discrepancies in responses between spouses as a function of husbands and wives having separate subjective realities that do not coincide. Each respondent may define situations differently according to their own needs, capacities, values, attitudes and beliefs. These divergent realities or attitudes may warrant attention in further research studies. Also gaining a further family perspective, looking at the siblings, grandparents and extended family perceptions in this area may produce a more accurate perception of the family's experiences with a disabled member. In future research, it is recommended that the sex of the participants be taken into account during the selection of the participants to achieve a more balanced sample and to bring out the experiences and ideas of men who provide care to their disabled children and to compare these with those of women.

Although caregiving and child care roles typically are adopted by women, many men also assume responsibility in this arena, and their perceptions are not discussed in this study. It is unknown whether men perceive the services of Wesway differently from women, or if gender influences care provider interactions with disabled children.

If females have different values or beliefs on what respite services are like compared to men, then this factor could have skewed the results as the researcher only had the opportunity to

interview women. Furthermore, females, as the primary caregivers, may have significantly different experiences on what the effects of caring for a disabled child are, compared to their male partners. As well, women who are lone parents have a relatively different experience than those who have a spousal partner in the home. These results were demonstrated within this study as there were both single and married female parents interviewed.

*Potential Researcher Bias.*

Qualitative research involves a good deal of subjective analysis and interpretation on the part of the researcher. As both the interviewer and the analyst in the study, I bring my own standpoint to the research experience. Although this can enhance reflexivity in the research analysis, some researchers may see this as increasing the likelihood of bias. The use of a second rater to code interview data may have helped to establish inter-rater reliability in the data. I could have asked my advisor to code one or two of my interviews using the rules I have devised. This process would check to ensure that my categories and rules made sense and it would have given me an opportunity to reexamine my thinking, rather than discovering at the end of my analysis that I may have made an error in judgment.

The researcher's previous experiences, values and opinions may affect the final interpretation of the results or may influence the way in which interview questions were posed, unintentionally leading to certain types of responses. It may be possible to enhance trustworthiness of the data when such techniques are employed during the process of data

analysis. All research contains some elements of subjectivity, especially qualitative research. Some see it as enhancing the final outcome and leading to a more authentic result.

The researcher's background in this particular study includes five years experience working in the respite care services and six years of studying social work. This has given the researcher a firm belief in the need for respite services to families and a strong desire to learn from parents who provide care.

Two important threats to the validity of qualitative conclusions are the selection of data that fit the researcher's existing theory or preconceptions and the selection of data that "stand out" to the researcher (Miles & Huberman, 1994, p. 263; Shweder, 1980). However, it is clearly impossible to deal with these problems by eliminating the researcher's theories, preconceptions or values; this impossibility is one aspect of what has been called the inherent reflexivity (Hammersely & Atkinson, 1983) of qualitative research. Qualitative research is not primarily concerned with eliminating variance between researchers in the values and expectations they bring to the study, but with the understanding how a particular researcher's values influence the conduct and conclusions of the study.

### *Recommendations*

A number of suggestions and recommendations were made or implied by the participants in this study. In an effort to represent the voices of the mothers, these recommendations are outlined in this concluding section of the thesis.

- 1) Mothers suggested having another day of the week for the summer program.

- 2) Collaboration between parents and providers could be strengthened. Mothers recommended having a brief communication period at the end of the day so the parent could know what challenges their child faced in that day and what accomplishments were achieved.
- 3) Mothers suggested in general, that there be more respite care opportunities.
- 4) All mothers expressed their gratitude for the service they are being provided and wanted Wesway to know how much their service means to them and their families.
- 5) Some participants proposed that the summer program begin when the children get out of school (June) and run until the end of August. If this is not feasible at the Wesway facilities, it was suggested that activities be run elsewhere during that time.

#### *Implications of the Findings to Social Work Practice, Policy and Future Research*

Social workers are the individuals usually dealing with these parents who are stressed and feel like they cannot manage. Finding out how the caregivers feel about the service they are being provided with and improving the service can benefit the social workers who work in this field. Agencies where social workers are employed will benefit from the research as they will hear the voices of the parents particularly women care providers, who deal with disability on a daily basis. This information can help social agencies and workers in working with families in similar situations. Services that are beneficial and recommendations that will be supportive for the future will be helpful to these agencies and professionals. Overall, the research may benefit social work education as it may bring to light the many areas that are working and areas that need improvement in the respite care field. Policy implications may be significant.

Recommendations will be provided to Wesway upon completion of the study which may have an impact on the services and programs Wesway runs in the future. Innovative interventions may be suggested to help families of persons with disabilities offering greater promise for promoting well-being, strengthening families and possibly alleviating suffering. These innovations may embrace a variety of emerging practices, including parent-to-parent self-help groups, governmental support programs and an array of cognitive behavioral counselling interventions.

Improving respite and other relevant services for families may require changes to current programs and additional research. From this study, it appears that the flexibility of services (i.e., overnight weekends, offers for respite weekly, respite during vacations, etc) is key. It was verified that mothers place great value on respite care services. The literature suggests that families should have ongoing and continuous support to assist parents in managing stress (Dyson, 1991).

There exists limited research on families with children with disabilities utilizing respite care. The majority of the respite literature focuses on the elderly population. Furthermore, the researcher believes that the design of further studies could be greatly improved to achieve greater unity, meaning and significance in the results. Accordingly, further studies should be conducted to more precisely measure a family's experiences and the impact of respite care services on their lives.

The reactions of a parent to a child with a disability may depend on the sex of the parent (Gallagher, Cross & Scharfman, 1981). All ten respondents were mothers providing primary

care. Male caregivers are not represented. As indicated in the literature, a father tends to divorce himself emotionally from the child and concentrates on other activities such as work (Tavormina, Ball, Dunn, Luscomb & Taylor, 1977). This is worthy of further research and validation.

Respite and other important services for these families also require future research and study. Research on ways to assist parents with maintaining coping strategies and attaining skills over time is likely to yield important implications for the future design of services. Qualitative research has demonstrated the importance of listening attentively to caregivers' stories and issues. Their stories may provide other researchers with valuable information which can ultimately help to assist the families.

Accompanying today's advanced technologies is an increase in the number and severity of children with disabilities sustained throughout life. Many children who would have died even a decade ago are now surviving due to advanced medical technology (Horner, Rawlins, & Giles, 1987). In addition to technological advances, the population of chronically ill and technology-dependent (CITD) individuals maintained at home has increased due to hospitals' cost containment efforts of the 1980's and changing social norms (Cohen, 1982; Slater, 1986; Thomas, 1984). With the continued increase in the number of these children comes society's added responsibility for their care and well-being. These services must be increased and improved to positively reflect our changing society.

The research I have conducted and research to come in the future can provide some valuable information for social work professionals, social agencies and is especially valuable for



families who live with a disability on a day-to-day basis. For these families, having their voices heard and changes made to benefit them and their children will be of great importance.

## References

- Albrecht, G., Seelman, K., & Bury, M. (2001). Handbook of Disability Studies. London: Sage Publishing.
- Ambert, A. (1992). The Effect of Children on Parents. New York: Haworth Press.
- Apolloni, S., & Triest, G. (1993). Respite Services in Canada. Mental Retardation, 21(6), 240-243.
- Apolloni, S., & Triest, G. (1983). Child-Related Stress in Families of Handicapped Children. Topics in Early Childhood Special Educators, October, 45-53.
- Appleby, Y. (1994). Out in the Margins. Disability and Society, 9(1), 56-59.
- Attkisson, C., Hargreaves, D., & Nyugen, T. (1979). The Client Satisfaction Questionnaire. Evaluation and Program Planning, 5, 233-237.
- Bakker, I. (1998). Unpaid work and Macroeconomics: New Discussions, Tools for Action. Toronto: Sage Publishing.
- Barker, R. (1995). The Social Work Dictionary. Washington, DC: National Association of Social Workers.
- Barnett, W., & Boyce, G. (1995). Effects of Children with Down Syndrome on Parents' Activities. American Journal on Mental Retardation, 100, 115-127.
- Baxter, C. (1987). Professional Services as Support: Perceptions of Services. Australia and New Zealand Journal of Developmental Disabilities, 13, 243-253.

Beavers, J., Hampson, R., Hulgus, Y., & Beavers, R. (1986). Coping in Families with a Retarded Child. Family Process, 25, 365-377.

Beckman, P. (1983). Influence of Selected Child Characteristics on Stress in Families of Handicapped Infants. American Journal of Mental Deficiency, 88, 150-156.

Beckman, P. (1991). Comparison of Mothers' and Fathers' Perceptions of the Effect of Young Children with and without Disabilities. American Journal of Mental Retardation, 95 (5), 585-595.

Beltrame, J. (2001, January 29). At least a decade behind bars: Latimer's last chances for earlier release appear slim. Maclean's (Toronto Edition), 114, 20-32.

Berkowitz, N. (1995). Humanistic Approaches to Health Care: Focus on Social Work. Toronto: Sage Publishing.

Blacher, J. (1990). Assessing Placement Tendency in Families with Children who have Severe Handicaps. Research in Developmental Disabilities, 11, 349-359.

Blais, R. (1990). Assessing Patient Satisfaction with Health Care. The Canadian Journal of Program Evaluation, 5, 1-13.

Booth, C., & Kelly, J. (1999). Child Care and Employment in Relation to Infants' Disabilities and Risk Factors. American Journal on Mental Retardation, 104(2), 117-130.

Botuck, S., & Winsberg, B. (1991). Effects of Respite on Mothers of School-Age and Adult Children with Severe Disabilities. Mental Retardation, 29 (1), 43-47.

- Bowman, D., & Virtue, M. (1993). *Public Policy Private Lives*. Canberra ACT: Australian Institute on Intellectual Disability.
- Bradley, R., Parette, H., & VanBiervliet, A. (1995). Families of Young Technology-Dependent Children and the Social Worker. *Social Work in Pediatrics*, 21(1), 23-37.
- Brink, P., & Wood, M. (1989). *Advanced Research Design*. California: Sage Publishing.
- Bristol, M., & Schopler, E. (1989). A Developmental Perspective on Stress and Coping in Families of Autistic Children. In J. Blacher (Ed.), *Severely Handicapped Young Children and Their Families*. New York: Academic Press.
- Bromley, B., & Blancher, J. (1989). Factors Delaying Out-of-Home Placement of Children with Severe Handicaps. *American Journal of Mental Retardation*, 94(3), 284-291.
- Bruininks, R. (1979). The Needs of Families. In R. H. Bruininks & G. C. Krantz (Eds.), *Family Care of Developmentally Disabled Members* (pp. 3-12). Minneapolis: University of Minnesota.
- Canadian Association of Community Care. (1995). *Canada Home Care Labour Market Study Report*. Ottawa, Canada, Canadian Association of Community Care.
- Chamie, M. (1990). The Status and the Use of International Classification of Impairments, Disabilities and Handicaps (ICIDH). *World Health Statistics Quarterly*, 43, 273-80.
- Christy, R. (2001, February 5). Life with Cerebral Palsy. *Maclean's* (Toronto Edition), 114, 12-18.

Cohen, S. (1982). Supporting Families through Respite Care. Rehabilitation Literature, 43 (1-2), 7-11.

Cohen, S., & Warren, R. (1993). Respite Care: Principles, Programs and Policies. Journal of Mental Retardation, 94 (3), 284-291.

Corelli, R. (1998, November 23). A Child Dies: Murder for Mercy? (Tracy Latimer case). Maclean's (Toronto Edition), 111, 116-121.

Cotterill, L., Hayes, L., Flynn, M., & Sloper, P. (1997). Reviewing Respite Services: Some Lessons from the Literature. Disability and Society, 12(5), 775-788.

Creswell, J. (1994). Research Design: Qualitative and Quantitative Approaches. California: Sage Publications.

Cullen, J., MacLeod, J., Williams, P., & Williams, A. (1991). Coping, Satisfaction and the Life Cycle in Families with Mentally Retarded Persons. Issues in Comprehensive Pediatric Nursing, 14 (3), 193-207.

Davidson, P., & Adams, E. (1989). Indicators of Impact of Services on Persons with Developmental Disabilities. American Association on Mental Retardation, 27, 297-304.

DePoy, E., & Gitlin, L. (1993). Introduction to Research. St. Louis: Mosby.

DeWeaver, K. (1983). Deinstitutionalization of the Developmentally Disabled. Social Work, 36 (4), 435-438.

Doe, T. (1997, July). How Katie Baker Changed My Mind: Second Thoughts on the Slippery Slope. Horizons, 11, 21-22.

Donovan, A. (1988). Family Stress and Ways of Coping with Adolescents who have Handicaps: Maternal Perceptions. American Journal of Mental Retardation, 92, 502-509.

Drotar, D., Baskiewicz, A., Irvin, N., Kennell, J., & Klaus, M. (1975). The Adaptation of Parents to the Birth of an Infant with a Congenital Malformation: A Hypothetical Model. Pediatrics, 56, 710-717.

Dyson, L. (1991). Families of Young Children with Handicaps: Parental Stress and Family Functioning. American Journal of Mental Retardation, 95 (6), 623-629.

Dyson, L. (1997). Fathers and Mothers of School-Age Children with Developmental Disabilities. American Journal on Mental Retardation, 102, 267-279.

Dyson L., & Fewell, R. (1986). Stress and Adaptation in Parents of Young Handicapped and Non-Disabled Children. Journal of the Division for Early Childhood, 10, 25-35.

Easterby-Smith, M., Thorpe, R., & Lowe, A. (1991). Management Research: An Introduction. London: Sage.

Edwards, S. (1997). Dismantling the Disability/Handicap Distinction. Journal of Medicine and Philosophy, 22, 589-606.

Enns, R. (1999). A Voice Unheard: The Latimer Case and People with Disabilities. Nova Scotia: Fernwood Publishing.

Felix, S. (1998, August-September). The Caregivers' Burden. Canadian Healthcare Manager, 5, 33-36.

Field, P. & Morse, J. (1985). Nursing Research: The Application of Qualitative Approaches. Maryland: Aspen.

Field, P., & Morse, J. (1989). The Application of Qualitative Approaches. London: Croon Helm.

Find, K. (1995, October). Appealing an Appalling Act: His Sentence Upheld, Latimer Now Heads for the Supreme Court Robert Latimer Case. Western Report, 10, 18-19.

Flynt, S., & Wood, T. (1999). Stress and Coping of Mothers of Children with Moderate Mental Retardation. American Journal on Mental Retardation, 94, 278-283.

Flynt, S., & Wood, T., & Scott, R. (1992). Social Support of Mothers of Children with Mental Retardation. Mental Retardation, 30 (4), 233-236.

Frey, K., Greenberg, M., & Fewell, R. (1989). Stress and Coping among Parents of Handicapped Children: A Multidimensional Approach. Journal on Mental Retardation, 94, 240-249.

Friedrich, W., & Friedrich, W. (1981). Psychosocial Aspects of Parents of Handicapped and Non-Handicapped Children: A Multidimensional Approach. American Journal of Mental Deficiency, 85, 551-553.

Gallagher, J., Cross, A., & Scharfman, W. (1981). Parental Adaptation to a Young Handicapped Child: The Father's Role. Journal of the Division for Early Childhood, 3, 3-14.

Galloway, C., & Chandler, P. (1995). Families of Handicapped Children. Exceptional Children, 50, 10-18.

Gargiulo, R. (1985). Working with Parents of Exceptional Children: A Guide for Professionals. Boston: Houghton Mifflin.

Glaser, B., & Strauss, A. (1967). The Discovery of Grounded Theory. Chicago: Aldine.

Gowen, J., Johnson-Martin, N., Goldman, B., & Applebaum, M. (1989). Feelings of Depression and Parenting Competence of Mothers of Handicapped and Non-handicapped Infants: A Longitudinal Study. American Journal on Mental Retardation, 94, 259-271.

Grant, G., Ramcharan, M., McGrath, T., Nolan, M., & Keady, J. (1998). Rewards and Gratifications among Family Caregivers: Towards a Refined Model of Caring and Coping. Journal of Intellectual Disability Research, 42(1), 58-71.

Guba, E. (1978). Toward a Method of Naturalistic Inquiry in Educational Evaluation. CSE Monograph Series in Evaluation #8, Los Angeles: Center for the Study of Evaluation.

Guerriere, D., & McKeever, P. (1997). Mothering Children who Survive Brain Injuries: Playing the Hand You're Dealt. Journal of Social Psychology, 2(3), 105-115.

Halpern, P. (1990). Respite Care and Family Functioning in Families with Retarded Children. Health and Social Work, 15, 138-150.

Hammersley, M., & Atkinson, P. (1983). Ethnography: Principles in Practice. London: Tavistock.

Hanson, M., & Hanline, M. (1992). Parenting a Child with a Disability: A Longitudinal Study of Parental Stress and Adaptation. Journal of Early Intervention, 14 (3), 234-248.



Haraway, D. (1991). Gender for a Marxist Dictionary: The Sexual Politics of a Word. New York: Routledge.

Harris, V. (1987). The Family Crisis: Diagnosis of a Severely Disabled Child. New York: Haworth.

Harris, V., & McHale, S. (1989). Family life Problem, daily caretaking activities and the psychological well-being of mothers of mentally retarded children. American Journal of Mental Retardation, 94, 231-239.

Harris, V. S., & McHale, S. M. (1989). Family Life Problems, Daily Caregiving Activities, and the Psychological Well-Being of Mothers of Mentally Retarded Children. American Journal on Mental Retardation, 94, 231-239.

Haverstock, S. (1992). Learning to Care for Chronically-Ill, Technology-Dependent Children: Mothers' Experiences. Unpublished Master's Dissertation, University of Toronto, Toronto, Ontario, Canada.

Hearn, K. (1991). Disabled Lesbians and Gays are Here to Stay. Disability, 12(1), 34-36.

Health Canada. (1997). Moving Along, Going Strong. Prepared for the Health Promotion and Programs Branch, Atlantic Region.

Henson, J. (2001, February 11). Supreme Court upholds Latimer Life Sentence. Catholic New Times, 25, 5-7.

Hetherington, E., & Clingempeel, W. (Eds.). (1992). Coping with Transitions. Monographs of the Society for Research in Child Development, 57 (2-3), 1-239.

Hoare, P., Harris, M., Jackson, P., & Kerley, S. (1998). A Community Survey of Children with Severe Intellectual Disability and Their Families: Psychological Adjustment, Carer Distress and the Effect of Respite Care. Journal of Intellectual Disability Research, 42(3), 218-227.

Horner, N., Rawlins, P., & Giles, K. (1987). How Parents of Children with Chronic Conditions perceive their own Needs. Maternal and Child Nursing, 12, 40-43.

Intagliata, J. (1986). Assessing the Impact of Respite Care Services: A Review of Outcome Evaluation Literature. In C. Salisbury & J. Intagliata (Eds.), Respite Care Support for Persons with Developmental Disabilities and their Families (pp. 102-146). Baltimore, MA: Paul H. Brookes Publishing Company.

Irwin, S., & Lero, D. (1997). In Our Way-Child Care Barriers to Full Workforce Participation Experienced by Parents of Children with Special Needs and Potential Remedies. Wreck Cove, NS: Breton Books.

Joyce, K., & Singer, M. (1983). Respite Care Services: An Evaluation of the Perceptions of Parents and Workers. Rehabilitation Literature, 44, 9-10.

Joyce, K., Singer, M., & Isralowitz, R. (1983). Impact of Respite Care on Parents' Perceptions of Quality of life. Mental Retardation, 24, 153-155.

Karnes, M., & Teska, J. (1990). Toward Successful Parent Involvement in Programs for Handicapped Children. Washington, DC: Georgetown University, Child Development Centre.

Kirk, S. (1998). Families' Experiences of Caring at home for a Technology-Dependent Child: A Review of the Literature. Child: Care, Health and Development, 24(2), 101-114.

Kirk, J., & Miller, M. (1986). Reliability and Validity in Qualitative Research. California: Sage.

Kobe, F., Rojahn, J., & Schroeder, S. (1991). Predictors of Urgency of Out of Home Placement Needs. Mental Retardation, 29 (6), 323-328.

Krajicek, M., & Moore, C. (1993). Child Care for Infants and Toddlers with Disabilities and Chronic Illnesses. Focus on Exceptional Children, 25 (8), 1-16.

Larsen, D., Attkisson, C., Hargreaves, W., & Nguyen, T. (1979). Client Satisfaction Questionnaire. University of California: San Francisco.

Lebow, J. (1983). Research Assessing Consumer Satisfaction with Mental Health Treatment. Evaluation and Program Planning, 6, 211-236.

Lebow, J. (1982). Pragmatic Decisions in the Evaluation of Consumer Satisfaction with Health Treatment. Evaluation and Program Planning, 5, 349-356.

Lincoln, Y., & Guba, E. (1985). Naturalistic Inquiry. Beverly Hills, California: Sage Publications.

Linton, S. (1998). Claiming Disability: Knowledge and Identity. New York: New York University Press.

Lofland, J., & Lofland, L. (1984). Analyzing Social Settings: A Guide to Qualitative Observation and Analysis (2<sup>nd</sup> Ed.). California: Wadsworth Publishing Company.

Longo, D., & Bond, L. (1984). Families of the Handicapped Child: Research and Practice. Family Relations, 33, 57-65.

MacDonald, W. (1997). An Investigation of Burden and Respite Experienced by Families of Disabled Children Enrolled in Children's Special Services Summer Program. Unpublished Master's Thesis, University of Manitoba, Winnipeg, Manitoba, Canada.

Marginet, C. (1986). Evaluating Consumer Perceptions of Health and Social Services: A Survey of Families Successfully Caring for Children with Developmental Disabilities. Unpublished Masters Practicum, University of Manitoba, Winnipeg, MB.

Marshall, C., & Rossman, G. (1989). Designing Qualitative Research. Newbury Park, California: Sage Publications.

Mausner, S. (1995). Families Helping Families: An Innovative Approach to the Provision of Respite Care for Families of Children with Complex Medical Needs. Social Work in Health Care, 21, 95-106.

McKeever, P. (1981). Fathering the Chronically Ill Child. American Journal of Maternal Child Nursing, 5, 124-128.

McKeever, P., Angus, J., & Spalding, K. (1998). Raising Children who have Disabilities in Ontario. Toronto, Ontario: University of Toronto, Graduate Studies.

McKinney, B., & Peterson, R. (1987). Predictors of Stress in Parents of Developmentally Disabled Children. Journal of Pediatric Psychology, 12(1), 133-150.

Miles, H., & Huberman, K. (1994). Qualitative research. London: Sage Publishing.

Minnes, P. (1988). Family Resources and Stress associated with having a Mentally Handicapped Child. American Journal on Mental Retardation, 93, 184-192.

- Mori, A. (1983). Families of Children with Special Needs: Early Intervention Techniques for the Practitioner. USA: Aspen Systems Corporation.
- Nagi, S. (1977). The Disabled and Rehabilitation Services: A National Overview. American Rehabilitation 2(5), 26-33.
- Nagi, S. (1991). Disability Concepts Revisited: Implications for Prevention. Social Science and Medicine 6(1), 1-14.
- Nelson, M., Ruch, S., Jackson, Z., Bloom, L., & Part, R. (1992). Towards an Understanding of Families with Physically Disabled Adolescents. Social Work in Health Care, 17 (4), 1-25.
- O'Hara, D., & Levy, S. (1984). Families Adaptation to Learning Disability. Learning Disabilities, 3(6), 63-77.
- Olivier, L. & Kataquapit, M. (2001, January 20). Who Tracy Latimer Might Have Been. National Post, 71, 36-39.
- Parke, R. (1986). Families of Handicapped Persons. Baltimore: Brookes.
- Patton, M. (1980). Qualitative Evaluation Methods. California: Sage Publications.
- Patton, M. (1986). Utilization-Focused Evaluations. Newburg-Park, CA: Sage Publications.
- Petr, C., Murdoch, B., & Chapin, R. (1995). Home Care for Children Dependent on Medical Technology: The Family Perspective. Social Work in Health Care, 21, 5-22.
- Pietzrak, J., Ramler, M., Renner, T., Ford, L., & Gilbert, N. (1990). Practical Evaluation. Toronto: Cage Publishing.
- Pope, J., & Mays, L. (2000). Special Children, Special Risks. New York: Aldine Publishing.

Posavac, E., & Carey, R. (1990). Program Evaluation: Methods and Case Studies. Englewood Cliffs, N. J.: Prentice-Hall.

Reynolds, M. (1994). Child Disabilities. Journal of Scholastic Health, 64 (6), 238-242.

Rimmerman, A. (1989). Provision of Respite Care for Children with Developmental Disabilities: Changes in Maternal Coping and Stress over Time. Mental Retardation, 27 (2), 99-103.

Roberts, C., & Burke, S. (1989). Nursing Research: A Qualitative and Quantitative Approach. Boston: Jones & Bartlett.

Rodriguez, C., & Murphy, L. (1997). Parenting Stress and Abuse Potential in Mothers of Children with Developmental Disabilities. Child Maltreatment, 2, 245-251.

Roos, P. (1979, Eds.). Parents and Families of the Mentally Retarded. J. M. Kauffman & J. S. Payne, Mental Retardation: Introduction and Personal Perspectives (pp. 56-117). Columbus, OH: Charles E. Merrill.

Rossi, P., & Freeman, H. (1987). Evaluation: A Systematic Approach. Beverly Hills, CA: Sage Publications.

Rutman, L. (1990). Planning Useful Evaluations: Evaluability Assessment. Beverly Hills, CA: Sage Publications.

Salisbury, C. (1990). Characteristics of Users and Non-users of Respite Care. Mental Retardation, 28, 291-297.

Salisbury, C. (1987). Stressors of Parents with Many Handicapped and Non-Handicapped Children. Journal of the Division for Early Childhood, 11(2), 154-160.

Salisbury, C. (1986). Parenthood and the Need for Respite. In C. Salisbury & J. Intagliata (Eds.), Respite Care: Support for Persons with Developmental Disabilities and their Families (pp. 243-268). Baltimore, MA: Paul H. Brookes Publishing Co.

Salisbury, C., & Intagliata, J. (1986). Respite Care: Support for Persons with Developmental Disabilities and their Families. Baltimore, MA: Paul H. Brookes Publishing Co.

Seltzer, M., & Krauss, M. (1984). Placement Alternatives for Mentally Retarded Children and their Families. In J. Blacher (Ed), Severely Handicapped Young Children and their Families: Research in Review (pp. 143-175). Orlando, FL: Academic Press.

Sharpley, C., Bitsika, V., & Efremidis, B. (1997). Influence of Gender, Paternal Health and Perceived Expertise of Assistance upon Stress, Anxiety and Depression among Parents with Autism. Journal of Intellectual and Developmental Disability, 22(1), 19-28.

Sherman, B. (1985). Impact of Home-Based Respite Care on Families of Children with Chronic Illnesses. Children's Health Care, 24 (1), 33-45.

Shweder, R. (Ed.). (1980). Fallible Judgment in Behavioural Research. San Francisco: Jossey-Bass.

Silverman, David. (1999). Doing Qualitative Research. California: Sage Publications.

Singer, G., & Powers, L. (1993). Families, Disability and Empowerment. Baltimore: Brookes Publishing Company.

Singhi, P., Goyal, L., Pershad, D., Singhi, S., & Walia, B. (1990). Psychological Problems in Families of Disabled Children. British Journal of Medical Psychology, 63, 173-182.

Slater, M. (1986). Respite Care: A National Perspective. In C. Salisbury & J. Intagliata

(Eds.), Respite Care: Support for Persons with Developmental Disabilities and their Families (pp. 198-216). Baltimore, MA: Paul H. Brookes Publishing Co.

Smith, R., Austin, D., & Kennedy, D. (1996). Inclusive and Special Recreation: Opportunities for Persons with Disabilities (3<sup>rd</sup> ed.). Dubuque, IA: Brown & Benchmark.

Status of Women Canada (1998, March). Secretary of State Fry says 1996 Census Confirms Women's Hidden Contribution to the Economy. Symposium conducted at the Meeting for Women's Current Issues, Toronto, Canada.

Strauss, A. (1990). Qualitative Analysis for Social Scientists. Cambridge: Cambridge University Press.

Strauss, A., & Corbin, J. (1990). Basics of Qualitative Research. Newbury Park, CA: Sage.

Stuart, O. (1992). Race and Disability? Disability, Handicap and Society, 7(2), 177-188.

Tavormina, J., Ball, N., Dunn, R., Luscomb, B., & Taylor, J. (In Press, 1977). Psychosocial Effects of Raising a Handicapped Child on the Parents. University of Virginia.

The Roeher Institute. (1998, May). National Evaluation of NSIPD Deinstitutionalization Initiative, Final Report. Toronto, Canada: The Roeher Institute.

Thomas, A. (1984). Respite Care: Programs, Problems and Solutions. Philadelphia, PA: Charles Press Publishers Inc.

Thompson, M. (1994). An Examination of the Evolution and Role of Persons with Disabilities within American Society. [On-line]. Available:

[http://www.nmsu.edu/resources\\_references/acces/public\\_html/evolution.html](http://www.nmsu.edu/resources_references/acces/public_html/evolution.html)



Todd, S., Shearn, J., Beyer, S., & Felce, D. (1993). Career in Caring: The Changing Situation of Parents Caring for Offspring with Learning Disabilities. The Irish Journal of Psychology, 14, 130-153.

Townsend, P., & Flanagan, J. (1996). Experimental Preadmission Program to Encourage Home Care for Severely and Profoundly Retarded Children. American Journal of Mental Deficiency, 80, 562-569.

Traustadottir, R. (1988, August). Women and Family Care: On the Gendered Nature of Caring. Paper presented at the meeting on Family Support Related to Disability, Stockholm Sweden.

Tremain, S. (1996). Pushing the Limits. Toronto: Women's Press.

Tripodi, T. (1997). A Primer On Single Subject Design For Clinical Social Workers. Washington: NASW Press.

Trute, B. (1990). Child and Parent Predictors of Family Adjustment in Households Containing Young Developmentally Disabled Children. Family Relations, 39, 292-297.

Tunali, B., & Powers, T. (1993). Creating Satisfaction: A Psychological Perspective on Stress and Coping in Families of Handicapped Children. Journal of Child Psychology & Psychiatry, 34 (6), 945-957.

Tutty, L., Rothery, M., & Grinnell, R. (1996). Qualitative Research for Social Workers. Boston: Allyn & Bacon.

Tyler, D., & Newmann, R. (1991). Before and After-School Programs for Children with Special Needs. Teaching Exceptional Children, 26, 45-48.

Upshur, C. (1978). An Evaluation of Home-Based Respite Care. Mental Retardation, 20(2), 58-62.

Upshur, C. (1982). Respite Care for Mentally Retarded and Other Disabled Populations: Program Models and Family Needs. Mental Retardation, 20(1), 2-6.

Vernon, A. (1996). Feminism and Disability. London: Women's Press.

Wallerstein, J., & Marullo, D. (1997). Handicap-Related Problems in Mothers of Children with Physical Impairments. Research in Developmental Disabilities, 18, 151-165.

Whitsett, D., & Land, H. (1992). Role Strain, Coping and Marital Satisfaction. Families in Society, 73, 79-92.

Wickham-Searl, P. (1992). Careers in Caring: Mothers of Children with Disabilities. Disability, Handicap & Society, 7(1), 5-17.

Wikler, L. (1991). Chronic Stresses of Families of Mentally Retarded Children. Family Relations, 30, 281-288.

Wikler, L., & Hanusa, D. (1990). The Impact of Respite Care on Stress in Families of the Developmentally Disabled. Paper presented at the meeting of the American Association of Mental Deficiency, San Francisco, May 1990.

Wikler, L., Hanusa, D., & Stoycheff, J. (1986). Home-Based Respite Care, the Child with Developmental Disabilities, and Family Stress: Some Theoretical and Pragmatic Aspects of Process Evaluation. In C. Salisbury & J. Intagliata (Eds.), Respite Care Support for Persons with Developmental Disabilities and their Families (pp. 348-379). Baltimore, MA: Paul H. Brookes Publishing Co.

Willoughby, J., & Masters Glidden, L. (1995). Fathers Helping Out: Shared Child Care and Marital Satisfaction of Parents of Children with Disabilities. American Journal on Mental Retardation, 99(4), 399-406.

Wolfensberger, W. (1972). The Principle of Normalization in Human Services. Toronto: National Institute of Mental Retardation.

World Health Organization (WHO). (1980). International Classification of Impairments, Disabilities and Handicaps. Geneva: Author.

Wyngaarden, M., Krauss, M., & Selzer, M. (1993). Coping Strategies Among Older Mothers of Adults with Retardation. Child Care, Health and Development, 24(2), 77-86.

Yegidis, B., Weinback, R., & Morrison-Rodriguez, B. (1999). Research Methods for Social Workers. Boston: Allyn & Bacon.

Zola, I. (1993). Toward the Necessary Universalising of a Disability Policy. The Milbank Quarterly, 67, 401-26.

<http://sosig.esrc.bris.ac.uk/roads/subject-listing/world-cat/qualmeth.html>

## APPENDIX A--INTRODUCTION TO STUDY

### **DO YOU HAVE A CHILD WITH A DISABILITY? HAVE YOU OR ARE YOU UTILIZING RESPITE CARE SERVICES? WOULD YOU LIKE TO SHARE YOUR EXPERIENCES?**

Amy Thomson, a research student at the University of Manitoba, is looking for parents or guardians who have used or are presently utilizing respite care services through Wesway and would be interested in talking about their experiences. This will be a small study which is to begin in October 2001. I am hoping to include approximately ten parents or guardians who care for a child with a disability who would be interviewed.

The research study will involve one interview, asking some questions regarding each family's experiences regarding the respite care services. Your experiences and ideas will provide valuable information that will be useful in the assessment of respite care services. In particular, I am interested in learning whether respite services are effective in meeting the needs of families; what positive experiences or struggles families may have encountered; understanding families' experiences and perceptions, as well as listening to your ideas for improvements.

The interview will be approximately one hour to an hour and a half in length and will be done in person at a time and place which is convenient for you. I anticipate doing the interviews during the month of November 2001. With your consent, the interview will be tape-recorded.

This research is being conducted to benefit your child's and your own experiences with respite programs. Your input is valuable and essential to the research.

I would very much appreciate any interest and/or questions you may have regarding this study. Please contact Amy at \_\_\_\_\_ by November 15, 2001. Thank you for considering this request.

*Sincerely, Amy Thomson---Social Work Graduate Student, University of Manitoba*

## APPENDIX B--INTERVIEW GUIDE

- A) Introductions--explanation of who I am and what the study is about  
--questions or comments before we start  
--consent form review and signing

B) Formal Interview will begin

1. Can you explain to me what sort of disability your child has and how it affects your family and your life? Can you explain some of your experiences with having to utilize respite care services? (Questions and comments may stem further from exploration into this question).
2. Can you comment on the respite program(s) your family utilizes and how it affected yourself, other family members and your child with a disability?
3. What did you like about the program? In your view, what could be improved?
4. How would you like to see respite care services look in the future? Can you say more about how this would help you and your child?
5. What were your reasons for using respite care services?
6. How was the staff supportive and helpful to your child? How were they not?
7. What are some of the day-day routines in caring for a disabled child? What are main stressors, if any, involved in caring for your child? What resources are most helpful to you and your family? What are the coping mechanisms employed by your family in order to manage these stresses and demands?
8. What other types or aspects of respite services would you like to see made available to you and your family in the future?
9. Please describe the main positive features or rewards you feel you receive from caring for your child. How is this important to your family? Which parts do you consider most challenging for you? Your family?  
Additional comments or thoughts, overall???

C) Debriefing and Thank-you's



UNIVERSITY  
OF MANITOBA

Faculty of Social Work

521 Tiet Building  
Winnipeg, Manitoba  
Canada R3T 2N2  
Telephone (204) 474-7050  
Fax (204) 474-7594  
Social\_Work@UManitoba.ca

132

## APPENDIX C

### CONSENT FORM

Research Project Title: Mothers' Perceptions of Respite Care

Investigator: Amy Thomson

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

This study involves participating in a brief interview regarding mothers' perceptions of respite care that they are receiving or have received in the past. The main intent of the study is to document mothers' experiences and to assess the strengths and weaknesses of the respite care services.

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

Amy Thomson, a graduate social work student of the University of Manitoba, will conduct the study. As a researcher, I am under the supervision of the Faculty of Social



UNIVERSITY  
OF MANITOBA

Faculty of Social Work

521 Tier Building  
Winnipeg, Manitoba  
Canada R3T 2N2  
Telephone (204) 474-7050  
Fax (204) 474-7594  
Social\_Work@UManitoba.CA

133

Work, and as well, supervised through Wesway. You may have read about my research in the newsletter. The research study will be in the form of an interview, asking some questions regarding each participant's experiences regarding the respite programs. I will also be asking for your suggestions on how respite care providers can make the program meet more of your families' needs. The interview will be approximately an hour and it will normally involve only one interview.

This research is being conducted to benefit respite care providers, social workers, parents and, of course, the children. Everyone will hopefully gain from learning of the experiences of others. Future recommendations that may enhance the services will be provided to Wesway upon completion of the study. Your input is valuable and essential to the research. If you wish to see the research study's results, a copy of the final thesis will be at Wesway and may be borrowed.

The researcher will audiotape the interviews to improve accuracy. There is minimal risk to participating in the study; however there is a possibility that interview questions may emerge and foster some sensitive information. If this occurs, information will be provided regarding counselling services that can help. The Wesway facilitators will be unaware of who participated and who did not, therefore the care and services received for your child will not be affected by participating or not.



UNIVERSITY  
MANITOBA

Faculty of Social Work

521 Tier Building  
Winnipeg, Manitoba  
Canada R3T 2N2  
Telephone (204) 474-7050  
Fax (204) 474-7594  
Social\_Work@UManitoba.CA

134

The subject's participation will remain anonymous and confidential, within the limits of required reporting (e.g., child abuse and the duty to report). "Duty to report" is referring to, that in specific circumstances, individuals may be compelled by law to reveal some information (such as threats of violence, commission of crimes and suspected child abuse) that would be relevant to legal judgments. This meaning, that the researcher is obligated to tell authorities if she suspects any of the above-mentioned situations, where harm could be inflicted or had been inflicted to others.

The information the subject's provide will remain confidential, meaning that the interview information will not be released, except as aggregate information and as a part of the research study.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. Any current or future services received from Wesway will not be affected by my participation in the study. Participation in the research study is voluntary and you are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without any disadvantage or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

Amy Thomson, Principal Investigator  
Tuula Heinonen, Supervisor

This research has been approved by the Joint Faculty Research Ethics Board. If you have any concerns or complaints about this research, you may contact the above-named persons (Amy Thomson or Tuula





UNIVERSITY  
OF MANITOBA

Faculty of Social Work

521 Tier Building  
Winnipeg, Manitoba  
Canada R3T 2N2  
Telephone (204) 474-7050  
Fax (204) 474-7594  
Social\_Work@UManitoba.CA

135

Heinonen). If you have any questions about the ethics or ethical process with regards to this research, please contact the Joint Faculty Research Ethics Board through the Human Ethics Secretariat at (204) 474-7122. A copy of this consent form has been given to you to keep for your records and reference.

I have read this form, have had an opportunity to ask the researcher any questions I have about the research, understand what my participation in the study entails and am willing to participate in this study. My signature indicates my agreement and consent to be involved in this study.

Participant's Signature

Date

Investigator and/or Delegate's Signature

## APPENDIX D

## List of Codes

## A) Disability (D)

D: Description of the disability	D-DESC-DIS
D: Severity and type of disability	D-SEV-DIS
D: Care required for disabled child presently	D-CARE-P
D: Care required for disabled child in the future	D-CARE-F

## B) Perspectives of the disability (PD)

PD: Effects of disability on primary caregiver	PD-EFF-PC
PD: Effects of the disability on the siblings	PD-EFFDIS-S
PD: Parental roles	PD-PR
PD: Maintaining disabled child at home	PD-MAINT-HOM
PD: Permanency planning	PD-PP

## C) Caring for a child with a disability (CCD)

CCD: Understanding the parent's experience	CCD-UNDPAR-EX
CCD: Rewards from caring for disabled child	CCD-REW-CC
CCD: Impact on lifestyles	CCD-IMP-LIF
CCD: Challenges	CCD-C
CCD: Daily routines	CCD-DR

## D) Feelings/Emotions

FE: Common feelings among parents	FE-COMFEEL-P
FE: Increase in Family Functioning	FE-INC-FF
FE: Isolation	FE-ISOL
FE: Feeling better about self	FE-BETT-S

## E) Family Stress

FS: Stress on the family as a whole  
FS: Stress on the primary caregiver  
FS: Stress on the siblings  
FS: Difficult developmental transitions  
FS: Stress on the marriage  
FS: Family stability  
FS: Family finances/economics

FS-STR-FAM  
FS-STR-PC  
FS-STR-S  
FS-DIF-DT  
FS-STR-MAR  
FS-FAM-STAB  
FS-FAM-FIN

#### F) Coping Strategies

CS: Support systems  
CS: Community resources  
CS: Family and friends resources  
CS: Parental coping skills

CS-SUPP-SYS  
CS-COM-RES  
CS-FF-RES  
CS-PAR-COP

#### G) Respite Care Services

RC: Experiences with respite care  
RC: Respite care services  
RC: Reasons for using respite care  
RC: Likes about respite care  
RC: Improvements for respite care  
RC: Future for respite care services  
RC: Increase in family functioning

RC-EXP-RC  
RC-RESCAR-S  
RC-REAS-RC  
RC-LIK-RC  
RC-IMP-RC  
RC-FUT-RC  
RC-INC-FF

## APPENDIX E

## Definitions of Codes

*A) D: The descriptive data about the child's disability*

DESC-DIS

The description of the child's disability

SEV-DIS

The severity and type of disability the child has

CARE-PD

How much care the disabled child requires presently

CARE-F D

How much care the disabled child requires in the future

*B) PD: The mother's perspective of the effects of the child's disability on her and the family*

PD-EFFDIS-PC

The effects of the child's disability on primary caregiver

PD-EFFDIS-S

The effects of the child's disability on the siblings'

PD-MAINT-HOM

The primary caregiver's perspective of maintaining the disabled child at home

PD-PP

The primary caregiver's perspective of permanency planning for her child with a disability

*C) CCD: The primary caregiver's experiences and perspectives on caring for a child with a disability*

UNDPAR-EX

Understanding what it is like from the parent's perspective on having a child with a disability

REW-CC

The mother's perspective on the rewards from caring for a disabled child

## CCD-IMP-LIF

The impact the disability has on families' lifestyles

## C

The mother's perspective on the challenges from caring for a disabled child

## PR

The parental roles of the families with a child with a disability

## DR

The daily routines of the child with a disability and the family

*D) FE: The feelings and emotions felt by the parent on having a child with a disability*

## COMFEEL-P

The common feelings among parents on having a child with a disability

## ISOL

The feelings of isolation

## BETT-S

The feeling better about self

*E) FS: The stresses experienced by members of the family*

## STR-FAM-W

The stressors on the family as a whole

## STR-PC

The stressors on the primary caregiver

## STR-S

The stressors on the siblings

## DIF-DT

The difficult developmental transitions of the child with a disability and the stress this causes for the family

## STR-MAR

The stressors on the marriage

## FAM-STAB

The family's stability level overall

## FAM-FIN

The family financial situation

*F) CS: The strategies used by the family to help cope with the stressors*

SUPP-SYS

The family's support systems

COM-RES

The community resources the family uses

FF-RES

The family and friends resources used by the family

PAR-COP

How primary caregiver copes with stresses (on her own)

*G) RC: Information on the families and their experiences with respite care services*

EXP-RC

The parent's experiences and with respite care

RESCAR-S

The respite care services the family utilizes and enjoys

REAS-RC

The reasons the family uses respite care services

LIK-RC

What the parent likes about respite care services

IMP-RC

What the parent would like to see improved in the respite care services

FUT-RC

What the parent would like respite care services to look like in the future

INC-FF

What the increase in family functioning has been, if any, due to respite services



UNIVERSITY  
OF MANITOBA

Faculty of Social Work

521 Tier Building  
Winnipeg, Manitoba  
Canada R3T 2N2  
Telephone (204) 474-7050  
Fax (204) 474-7594  
Social\_Work@UManitoba.CA

141

## APPENDIX F

### WAIVER

Research Project Title: Mothers' Perceptions of Respite Care

Investigator: Amy Thomson

Please take the time to read this carefully and to understand any accompanying information.

This waiver form is to provide the researcher, Amy Thomson with your permission and approval to have the information you provided in the interview to be in quotation format within the presentation of the paper. It was initially to appear in aggregate form, however the researcher felt the information provided from the participants and the actual words they spoke of was more meaningful in quotations as it gave significant meaning and feeling as to what their true experience was.

The information you provided will remain confidential, meaning your name will not be identified within the paper.

Your signature on this form indicates that you have understood to your satisfaction the information regarding the change of the format of how the information will be written in the paper. A copy of this waiver form has been given to you to keep for your records and reference.

I have read this form, have had an opportunity to ask the researcher any questions I have about the waiver, understand what the changes of how the information will be presented and am willing to allow this change. My signature indicates my agreement.

Participant's Signature

Date

Investigator and/or Delegate's Signature

Date



UNIVERSITY  
OF MANITOBA

Office of the President

Office of Research Services  
244 Engineering Building  
Winnipeg, MB R3T 5V6  
Canada  
Telephone (204) 474-8418  
Fax (204) 261-0325

142

APPENDIX G

APPROVAL CERTIFICATE

13 November 2001

TO: Amy Thomson  
Principal Investigator

FROM: Wayne Taylor, Chair  
Joint-Faculty Research Ethics Board (JFREB)

Re: Protocol #J2001:083  
"Children with Disabilities & Parents' Perceptions of Respite Care Services"

---

Please be advised that your above-referenced protocol has received human ethics approval by the **Joint-Faculty Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement. This approval is valid for one year only.

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.