

The Parenting with a Disability Research Project

BY

Elizabeth Struthers

A Thesis submitted to  
The Faculty of Graduate Studies  
In Partial Fulfillment of the Requirements for the Degree of

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**ELIZABETH STRUTHERS ©2005**

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### Abstract

The research project explores the perspectives of parents with disabilities. The study addresses three questions. What are the additional disability related challenges that parents with disabilities encounter with their children? How do they cope or adapt in order to overcome these issues? What recommendations can be suggested to help others who are contemplating parenthood or who are already parents? The thesis represents a cross disability perspective and includes participants with a range of disabilities. The parents' children were between the ages of two to twenty three. In-depth telephone interviews were conducted with eight parents who were either blind/visually impaired, had chronic illnesses, mental health issues or physical disabilities. Findings from this study indicate that parents with disabilities have additional disability related challenges and encounter attitudinal barriers. They discussed their abilities to cope or adapt to disability related challenges as parents with disabilities. They reported on the informal and formal supports. They mentioned recommendations to improve social supports and offered advice for parents or perspective parents with similar disabilities. There are also common issues for all of the disability groups. It was concluded that the joys and rewards that the participants of this study experienced outweighed the barriers and prejudice they encountered as parents with disabilities.

## Table of Contents

## Introduction

- Statement of the Problem and Rationale for the Study 1
- A Personal Note 1
- Purpose of the Research Project 3
- Background Information 4
- Theoretical and Empirical Evidence 5
- Relevance of Social Work 8
- Summary 10

## Chapter One

## Parenting with a Disability: Current Research and Theoretical Perspectives1 12

- Introduction 12
- Constructs Involved in Research 12
- Theoretical Perspectives 14
- Empirical Evidence 20
- Empirical Literature of Deaf Parents 20
- Empirical Literature of Blind and Visually Impaired Parents 23
- Empirical Research of Parents with Physical Disabilities or chronic illnesses 24
- Empirical Research of Parents with Mental Health Concerns 29
- Discussion of Empirical Literature 34
- Methodology 35
- Identification of Empirical and Theoretical Gaps 36
- Summary 38

## Chapter Two

## Methodology 39

- Research Questions and Hypotheses 39

• Research Design	39
• Sample Definition and Recruitment	40
• Data Collection	42
• Analysis Plan	44
• Ethical Considerations	45

### Chapter Three

Results	47
• Introduction	47
• Biographies of Research Participants	48
• Common Trends	69
• Summary	74

### Chapter Four

Discussion and Implications	79
• Introduction	79
• Discussion	79
• Limitations of the Research	83
• Recommendations and Advice to Improve Social Supports for Disabled Parenting	86
• Future Research	88
• Conclusion	90

References	93
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### Appendix A

Telephone Interview Guide	99
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### Appendix B

The Parenting with a Disability Research Project Consent Form	102
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## Introduction

### **Statement of the Problem and Rationale for This Study**

#### A Personal Note

My journey as a person with a disability began at my birth. I was born with a multitude of anomalies to my extremities such as my toes, fingers, skin and eyes. My visual impairment was the most significant disability. Doctors diagnosed me as having a microphthalmos in both eyes with marked inferior and inferonasal colobomata of the retina. I have no macular function and no central visual acuity but I have a sliver of peripheral vision in my right eye. I have gradually learned to adapt with this extremely limited vision. As a young child I learned about the world through colourful pictures and I was taught basic reading skills with words printed in bold, black ink on large pieces of paper. As I got older I was able to read regular printed material with a powerful magnifier set on four legs so I could slide it along the page. In junior high, a magnifying glass was built into the right lens of a pair of glasses. I was also able to listen to textbooks on audio cassettes. As an adult attending university courses at the University of Winnipeg, I learned how to use a computer to write essays and exams with the aid of a screen magnification software package. I currently use ZoomText Extra, a screen magnification software package and a CCTV reader to read regular printed material.

I have always been a person who has wanted to nurture and care for others. I had a vivid imagination as a child and spent many wonderful hours

playing with my toys, particularly with my dolls. I loved to make up stories about families and I was always the mother caring for her young children. As a young adult I enjoyed having many pets such as guinea pigs, a hamster, two rabbits and a toy poodle named Snuffie.

I was the youngest of four children and did not have opportunities to baby sit other children in the neighbourhood. However, I did wonder what it would be like to become a parent with a visual impairment. While I was growing up I did not know any parents who had disabilities and did not receive any positive messages that I would be able to parent adequately.

The inspiration for this research project originated several years ago when I was taking a parenting course in the Department of Family Studies. At that time I was also taking some child studies courses and had an opportunity to work with infants in the Child Development Centre at the University of Manitoba. This proved to be both a challenging and rewarding experience. My limited vision made it difficult for me to keep track of more than one child at a time. I also found it difficult to prepare crafts that required me to use my vision such as cutting out shapes. I ensured that these projects were implemented by enlisting another person to help me to prepare them. Activities I enjoyed doing with the children were singing songs, playing with toys in the water table or having a tea party in the play kitchen.

While I was taking these child studies courses I wondered how parents would overcome any additional challenges of having a disability. I completed a short assignment for the parenting course to find out what it was like for parents

who have disabilities. I retrieved four newspaper articles from the library at the Society for Manitobans with Disabilities, an organization for people with physical disabilities. I was fascinated by these articles and learned that people found ways to overcome obstacles. Parents needed to ensure that physical adjustments were in place before children were born. Items such as cribs, highchairs and playpens had to be adapted so parents could manage the baby from their position in a wheelchair. Disabled Parents relied on supportive professionals, family or friends for advice and to help with activities that they were unable to do with their children. I learned that disabled parents also encountered negative attitudes from others about not being capable of caring for children because they were disabled. However, I was excited to read that children adjusted positively to their parent's disability. I learned that children of disabled parents were more compassionate and understanding of others with disabilities. They were more independent than other children and helped their parents with household chores. Thus, these articles were the impetus for conducting the current research project.

#### Purpose of the Research Project

The aim of this research project was to explore the perspectives of parents who were blind/visually impaired, chronically ill, have mental health concerns or who had physical disabilities. Parents with disabilities have additional parenting challenges that are not experienced by non disabled mothers and fathers. These are the issues that were examined and parents'

solutions to overcome them were explored. Suggestions and recommendations from disabled parents were also discussed. It was assumed that parents with disabilities encounter additional environmental and attitudinal barriers that are not experienced by other parents. The study also set out to explore the issues common to all groups of disabled parents.

### Background Information

Persons with disabilities have the same rights as non-disabled people. Consequently, adults with disabilities should be able to have intimate relationships and have the option of whether to become parents or not. Many disabled women have been discouraged by those around them to consider the option of parenthood (Asrael, 1982). However, Asrael (1982) stated that great numbers of women who are supported by medical resources are demanding that they have the choice of being parents or not.

Section 15 of the Canadian Charter of Rights and Freedoms (1982) describes the equality rights for Canadian citizens.

(1) Equality before and under law, and equal protection and benefit of law: Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination based on race, national or ethnic origin, colour, religion, sex, age, or mental or physical disability.

This quotation states that all people, including individuals with disabilities should have equal rights. It explains how equality before the law is applied.

There were 4.2 million Canadians with disabilities in Canada in 1991 and this represented 16% of the country's population. These statistics were taken

from the Health and Activity Limitation Survey (Statistics Canada, 2001). Most of these individuals lived in households. Ninety three per cent of all persons with disabilities 15 and over lived in households. Sixty nine per cent of the group were members of a family, 56% were husbands, wives, or common-law partners, 5% were lone parents, and 8% were dependent children. Twenty seven per cent were not part of a family, and the remaining 4% did not state their family situation. There were no specific data regarding parents with disabilities. In 2001 the Participation and Activity Limitation Survey (PALS) was conducted following the census. A sample of people who answered 'Yes' to the disability filter questions during the 2001 census were included in the PALS survey. According to PALS there were 3.4 million people with disabilities and 936, 000 were parents with children (Statistics Canada, 2004).

#### Theoretical and Empirical Evidence

The cross-disability perspective is the inclusion of all disability groups. These groups have united to eliminate injustice for all people with disabilities. The disability rights movement has moved toward a cross-disability perspective. Driedger (1989) described this perspective. Many organizations consisting entirely of people with various types of disabilities have been emerging since the 1970's. These groups began to realize that their input and participation was not included in society. Disabled People's International (DPI) was formed in 1981 as a result of this recognition. The mandate of DPI is the voice of people with disabilities. The beliefs of DPI are for disabled people to be integrated into

society and they should participate with the same rights as everyone else. As quoted by Driedger (1989), "its members hold that by speaking unitedly they are stronger than when each disability group speaks out on its own concerns." (p.1)

Society has viewed people with disabilities from the perspective of a medical model. As noted by Crow (1996) this model saw people with disabilities only as individuals with a medical or physical condition. Crow stated,

It wasn't my body that was responsible for all my difficulties, it was external factors, the barriers constructed by the society in which I live. I was being dis-abled - my capabilities and opportunities were being restricted - by prejudice, discrimination, inaccessible environments and inadequate support. Even more important, if all the problems had been created by society, then surely society could un-create them. Revolutionary!" (p. 206)

Disabled people wanted their independence and equal rights. Crow (1996) stated that their own model of disability, the social model of disability was formed because people with physical, sensory, mental, intellectual or emotional distress were denied opportunities. Disabled people were discriminated against and there were barriers that excluded them from participating in society. The purpose of the model was to focus on how society treated persons with disabilities. Emphasis was placed on the prejudice from society and any other social barriers that had affected them. The model focussed on inaccessible environments and the need for resources such as adaptive technology to enable them to participate more fully in society. Therefore, disabled people felt these obstacles could be eliminated if all disability groups united as one voice.

The Independent Living Movement has a set of organizational principles and cross-disability is one of its guiding values. People in the movement stated

that all Independent Living Resource Centres should offer programs and resources that include individuals with all types of disabilities (Kowbuz, 1993).

The Parenting Network (Parenting Network, 2005) is a program offered at the Centre for Independent Living in Toronto, and it provides a variety of resources and supports for parents with all types of disabilities. The program offers peer support opportunities and one to one support. Resources such as books and newsletters regarding parenting with a disability are available. Workshops and seminars with topics related to parenting with a disability are frequently offered. There is also research and development of new models of support for parents with disabilities.

Nurturing Assistance (Nurturing Assistance, 2005) is a program affiliated with the Independent Living Centres. It is a program that provides funding for parents with disabilities to hire, train and pay a nurturing assistant to help them physically care for their young children. Parents may also receive nurturing assistants from attendant services or other outreach programs who have received government funding to assist consumers with disabilities. Nurturing assistants help parents with activities such as bathing, changing diapers, lifting, carrying and nursing a child.

Thus, the Independent Living Centres offer resources and programs to support consumers with disabilities to live independently. The centres are managed by disabled persons who assist others to fully participate in society.

The current research project was conducted from a cross-disability perspective. Individuals with varying conditions and limitations were selected

from different disability groups. Library data base searches reveal that research conducted from a cross-disability perspective is limited. The majority of studies have examined the issues of specific disability groups such as blind, deaf or parents with multiple sclerosis. Since there is preference from the disability movement to have an inclusive approach to research, the cross-disability perspective was timely. The current study was intended to add to the knowledge relating to parenting theory by using an inclusive approach rather than studying only one group of people with disabilities. It is hoped that other researchers will be encouraged to embrace this perspective. The current study can contribute to existing empirical literature by providing a positive point of view regarding parents who have disabilities.

#### Relevance to Social Work

It is hoped that social workers will adhere to the philosophy of the Independent Living Movement when they assist parents with disabilities. The philosophy of the Canadian Association of Independent Living Centres (cailc, n.d.) states, "Canadians with disabilities have skills, determination, creativity and a passion for life." They want to utilize these strengths and assets by contributing to the economic, political and cultural life of their communities. The problem is that barriers such as old attitudes and outdated laws still exist. There are also inflexible approaches to hiring as well as lack of accessible housing and customer services. Social workers can play a significant role by assisting parents with disabilities to promote disability awareness to governments,

communities and organizations. They can help to reduce attitudinal barriers and stigma. They can educate communities, governments and local organizations about disabled people=s capability of being parents. Social workers can act as facilitators for disabled groups to help them advocate for new laws and policies to increase employment opportunities. They can also help to improve accessibility in communities. The more opportunities that people with disabilities have, the easier it will be to fulfill the roles of parents. If social workers have a role in eliminating barriers, people with disabilities will be able to take risks, make choices and have opportunities to contribute to society.

The Independent Living Movement was developed in the 1970's on University of California Campuses and since that time has reached other countries of the world. It was noted on the web site that the movement's philosophy has changed the way people view and respond to disability. The Canadian Association of Independent Living Centres (cailc, n.d.) states,

The Independent Living Movement is founded on the right of people with disabilities to:

- Live with dignity in their chosen community;
- Participate in all aspects of their life; and
- Control and make decisions about their own lives.

IL differs from a traditional model of delivering services to people with disabilities in many important ways. The emphasis is on peer support offered to people with disabilities by people with disabilities. The emphasis is also on self-direction, driven by the belief that people with disabilities know best how public resources can be invested to assist them. Finally, the approach is not to use medicine to fix or cure people with disabilities, but rather to develop the capacity of individuals to remove the personal and community barriers in society that prevent people with disabilities from realizing their full potential.

Professionals such as social workers can help disabled parents achieve their

goals by ensuring that there are no barriers to stop them from fully participating in society. Therefore, it is hoped that social workers will be educated about the obstacles that are faced by parents with disabilities. There should be university courses, seminars and written information to inform workers of how these difficulties can be overcome. Results of this study will be distributed to social services agencies as a resource for staff that includes information about parenting issues for those with disabilities. Social workers and students will also have library access to the current project. The document is a source of knowledge that will provide their clients who are parents or who are considering the option of parenthood with useful information about parenting with a disability. They may be able to provide appropriate parenting services by assisting parents with disabilities to make their own decisions. They can also assist parents with disabilities to live independently in their own homes and communities by ensuring that there are appropriate services in place to meet the needs of this population.

### Summary

This chapter has provided an overview of the current research project. Empirical and theoretical evidence has been discussed as a means of putting forward a rationale for the study. Relevance of social work has been included to determine the roles that social workers have in helping individuals with disabilities to realize their potential and in particular, to help parents with disabilities to provide adequate parenting for their children.

This report of the research is organized in the following manner. Chapter 1 is an overview of the literature regarding the perspectives of parents with disabilities. Chapter 2 is a description of the methods used to conduct the research project. Chapter 3 outlines the results obtained from the study and the final chapter is a discussion of the findings. .

## Chapter One

### **Parenting with a Disability: Current Research and Theoretical Perspectives**

#### Introduction

Parents with disabilities will have perceptions of what it is like to care for children. This section will explore empirical and theoretical literature that discusses experiences of disabled parents.

#### Constructs Involved in Research

There is some terminology regarding disability that should be defined before reviewing the literature. The broad term of disability will be defined first. Charlton (1998) states that disability is based on social and functional criteria. It is not a medical category but a social one and is socially constructed. He explains that if a culture treats people as having a disability then they will have one. He states that the category of disability includes people with socially defined functional limitations. Charlton (1998) also states that many activists would define disability as a condition imposed on people by society. This definition describes how people with disabilities are often treated by others in society.

Cossette and Duclos (2002) discussed the Participation and Activity Limitation Survey (PALS) which was funded by Human Resources Development Canada and conducted by Statistics Canada in 2001. It is a national survey that was designed to collect information about adults and children with disabilities. The research examined the health conditions and problems of Canadians whose

daily living activities were limited due to a disability. Information was collected on the prevalence of various disabilities, supports for persons with disabilities, their employment profile, their income and their participation in society. The PALS Survey responses determined the identification of disabilities among adults aged 15 and over.

Cossette and Duclos (2002) reported that mobility disabilities affected the greatest number of adults. Survey results revealed that nearly 2.5 million Canadians had difficulty walking half a kilometer, or up and down a flight of stairs, about 12 steps without resting, moving from one room to another, carrying an object of 5 Kg (10 pounds) for 10 metres (30 feet) or standing for long periods. Adults had activity limitations related to agility and 2.3 million Canadians reported having difficulty bending, dressing or undressing themselves, getting in and out of bed, cutting their toenails, using fingers to grasp or handling objects, reaching in any direction, or cutting their food. More than 10 % of the adults who participated in the survey reported having activity limitations related to pain or discomfort. Respondents reported limitations in the amount or kind of activities that they could do because of a long-term pain that is constant or re-occurs from time to time such as back pain. Adults with visual disabilities had difficulty seeing ordinary newsprint or clearly seeing the face of someone from 4 metres (12 feet). Cossette and Duclos (2002) stated that one million adults reported a hearing disability. Participants had difficulty hearing what was being said in a conversation with one other person, in a conversation with three or more other people or in a telephone conversation.

Cossette and Duclos (2002) stated that many adults also reported disabilities that were less visible. Adults who reported memory problems were limited in the amount or kind of activities they could do due to frequent periods of confusion or difficulty remembering things. These difficulties may have been associated with Alzheimer=s disease, brain injuries or other conditions. Adults with psychological difficulties reported limitations such as the amount or kind of activities they could do due to the presence of an emotional, psychological or psychiatric condition such as phobias, depression, schizophrenia, drinking or drug problems.

This section has provided a brief discussion of some of the terminology and definitions that are applied to people with disabilities. The next section discusses some theoretical findings related to parents with disabilities.

### Theoretical Perspectives

Feminist analysis can be applied to the lives of parents with disabilities when they are trying to overcome differences, inequities, and lifestyle pressures. Women with disabilities, in particular have been faced with oppression. This was a group of women who were, for the most part, ignored by the women's movement and the disability movement. In 1985 the Disabled Women's Network (DAWN Canada) was formed. It is a progressive, feminist, cross-disability organization dedicated to social and economic justice. It works towards access, equity and full participation of women with disabilities through public education, coalition building, lobbying, self-advocacy, resource development and

information and communication technology (DAWN Ontario, 2004). Blackford (1999) discussed some similarities that disabled women have in common with other women. There is an ideal female body image for women. There have also been some social expectations that women should be dependent. These societal beliefs have resulted in the powerlessness and limited rights of some women. Blackford (1999) also noted that the issue of women's reproductive rights has emerged as an area of contention. However, the women's movement has asserted that a woman has the right to choose motherhood. Disabled girls and women feel that their lives are as worthy as other women's lives but many of them have been denied the right to conceive. Blackford (1999) also stated that women with disabilities are supposed to care within a traditionally organized nuclear family.

Blackford (1999) stated that it has been suggested that parenting with a disability can be damaging for children and this can create family dysfunction. This explains why there has been little support from the women's movement, male dominated disability movement, self-help groups and health care organizations. Parents with disabilities have faced barriers that are also common to non disabled parents. Obstacles that have made it difficult for them to provide adequate parenting for their children include limited income, and lone parenting. Parents with disabilities encounter additional barriers such as inadequate access to housing, workplaces, and children's schools. Medical equipment is inappropriate and there is inadequate accessible baby furniture for

parents with physical limitations. Blackford (1999) explained that these are issues that only recently have been addressed by organizations such as the Independent Living Movement, the Disabled Women's Network, and the women's caucus committees within the Council of Canadians with Disabilities and Disabled Peoples International.

Blackford (1999) argued that by using some of the feminist principles, families in which a parent has a disability are not dysfunctional.

A learned respect for difference along with equity in the distribution of responsibility and in the practice of taking time for each other sometimes frees family members from restrictive traditional expectations. Through the intimate experience of caring for and knowing a person with a disability and through feeling cared-for and understood by a person with a disability oppression associated with disability prejudice and with familialism is reduced. (p. 282)

This quote explains that parenting does not have to be practiced by following traditional expectations. Blackford (1999) is describing how feminist analysis is changing how parenting is viewed. She also felt that feminists can learn from mothers with disabilities and from family members who live with a parent who has a disability. Blackford (1999) believed that while having more equitable responsibility within families, caring and supporting each other makes us more human.

Three ecological models were cited. The ecological congruence model was developed by S. Kenneth Thurman (1985). He felt that it would be a useful framework for studying ecological systems and in particular with families in which there is a parent with a disability.

Thurman's model consists of three major dimensions that are described

as continuums. The deviancy continuum refers to the function of a label that is placed on an individual and/or his or her behaviour. The competency continuum refers to the functional ability. The tolerance for difference continuum is used to determine the goodness of fit between the individual and the environmental-social context.

Thurman (1985) stated that a family in which one of its members has a disability could affect the development of congruent ecology. The ecological congruence or the lack of it in families in which there are individuals with disabilities could depend on the degree of a parent's competence, whether one or both parents have disabilities, the type of disability a parent has, degree of disability and the time of onset of the disability. A disabled parent's competency level affects how he or she will provide adequate parenting for the family to function. If the parent is unable to function adequately other members may not be able to tolerate family dysfunction. This may cause some degree of ecological incongruence in the family. The parent's inability to function adequately due to the disability may put additional responsibilities onto other family members.

Duis (1997) used an ecological approach to examine parent versus child stress in diverse family types. She applied family systems theory and the social ecological theory to determine causes of stress for the different types of families in her study. Family systems theory defines the family as a system in which one person's behaviour affects and is affected by all other family members.

Social ecological theory explores the relationships between a person and

the settings and environment in which he or she lives. The individual is surrounded by a variety of environmental influences. These systems are represented by concentric circles. The microsystem, the circle closest to the individual represents the family and school. The exosystem is a more distant circle that represents indirect influences such as a parent's employment, extended family, or community support services.

A third ecological model discussed by Tim Booth and Wendy Booth was cited on their web site, Supported Parenting for mothers and fathers with learning difficulties, a gateway to the work of parents with learning difficulties research programme at the University of Sheffield (Supported Parenting, 2004). This model focuses on parental competence and looks at how it is influenced by environmental pressures on the family and the social support that is received. Environmental pressures affect the parenting load and the parent's ability to cope. Parents' ability to cope affects the type and level of support they need. Social support either inhibits or promotes parental competence depending on whether the parent is able to manage a parental task. The parents' level of competence influences how they are perceived by the social system.

Booth and Booth (Supported Parenting, 2004) discussed forms of support that helps or hinders their ability to parent. Competence-inhibiting support refers to parents who are incapable of managing on their own. Support tends to be demotivating, crisis oriented and unresponsive to parents' views of their needs.

Competence-promoting support occurs when parents feel in control and they are encouraged to handle their problems on their own. This type of support

reinforces and develops their skills and sense of self-worth.

All three models have similarities. They all focused on the family and its stressors such as having a parent or child with a disability. The ecological models discussed by Duis (1997) and Booth and Booth (Supported Parenting, n.d.) discussed external influences outside the family and how they affected family functioning.

There were some differences between the models as well. The ecological congruence model discussed by Thurman (1985) focused more specifically on family influences such as parental disability and its impact on other family members. It looked at the competency level of the parent within the family. The model discussed by Booth and Booth (Supported Parenting, n.d.) discussed parental competence in relation to level of social support and the ecological models discussed by Duis (1997) examined the broader environmental context.

Ecological models are useful in understanding family functioning. Duis (1997) stated that these models could be used to assess needs and stressors that occur within and outside the family. The goal of intervention is for the family to make use of internal and external resources that will help all of its members to function.

An ecological approach has been applied to the current research project. All three models have relevance to the study. Thurman's ecological congruence model explored the competence of parents with disabilities and how competency levels effected family functioning. This model was applied during interviews by asking questions to determine how families functioned when a

parent has a disability. Questions concerning the implications for children who have parents with disabilities and the impact of a disabled parent on family life were asked. Participants were also questioned about the impact of their health and well being on children and family life. The ecological social theory was useful in determining how environments and settings influenced families. This model was applied by asking questions about resources and services that were used outside the family to help parents cope or adapt to parenting with a disability. Participants were asked about the important people in their lives. The ecological model by Tim Booth and Wendy Booth was applied. They were interested in knowing how environmental pressures effected the parenting load and how parents were able to cope with these pressures. I applied this model by exploring the impact of messages and attitudes from other people and how they influenced participants' ability to cope with them. Thus, the ecological approach was useful in determining family functioning when a parent has a disability and the influence of environmental factors that help or hinder parenting ability.

### Empirical Evidence

A review of the empirical literature is presented next. The literature of each disability group will be discussed separately followed by a general discussion of the common issues that are faced by all of the groups.

### Empirical Literature of Deaf Parents

Many deaf adults grow up in families with hearing parents. Hoffmeister, (1985) stated that 95% of deaf parents marry other deaf adults. The majority of

these couples have hearing children. Deaf children born to deaf parents are considered to be natives but only make up 5% to 10% of the deaf community (Singleton & Tittle, 2000).

There is a lack of child rearing information for deaf parents and limited exposure to parent models. Findings from the study conducted by Jones, Strom and Daniels (1989) with 18 deaf parents and their hearing children indicate that deaf parents with children between the ages of 7 to 11 wanted access to child rearing information. They wanted to know how sons and daughters of their children=s age should act, ways to keep and make fair rules, methods to help youngsters develop self-confidence, guidelines to teach decision making and techniques for encouraging responsibility. However, many deaf parented families are involved in the deaf community and it provides opportunities for them to discuss problems, discover new practices and learn from others experiences (Hoffmeister, 1985).

The majority of deaf parented families are able to accomplish basic child rearing tasks and nurturing of their children. Many of these families are also able to remain close throughout adulthood (Hoffmeister, 1985). However, Meadow-Orlans (1995) stated that deaf parents will find it difficult to monitor children=s safety or behaviour due to their deafness. They will also be unable to teach and monitor their children=s spoken language.

There are often conflicts with extended family such as a deaf adult's hearing parents (Hoffmeister, 1985). These parents may have been

overprotective and over controlling of their deaf child and may continue to do so after the birth of a hearing child to a deaf parent. There may also be conflicts over proper child rearing practices.

Many hearing children act as interpreters for their deaf parents. Preston (1996) conducted a four year study with hearing men and women who were raised by deaf parents. A recurrent theme was that the men and women who participated in the research project recounted their childhood role as interpreter for their deaf parents. This study also found that daughters were more likely than sons to act as interpreters for their parents regardless of their age or birth order. Children often have to communicate for their parents on the telephone, during medical appointments and shopping trips. Children often make decisions for parents when professionals do not understand the separateness between the child being an interpreter, a son or daughter, or an intermediary for the parent. Most children do not mind this task until they have had a negative experience or have been involved in a conflict situation (Hoffmeister, 1985; Jones et al. (1989). There were reports by children between the ages of 12 to 18 in the study conducted by Jones et al. (1989) that they felt embarrassed if others stared or mimicked their deaf parents when they were signing. However, participants stated that they enjoyed being bilingual in both spoken English and American Sign Language. The parents in this study thought it was an advantage to have their children interpret for them but they did wonder when it was appropriate for children to interpret for them. How often is it reasonable to expect them to do it and under what circumstances should it be expected?

Deaf parented families for the most part are faced with different types of issues than other parents with disabilities. There will now be a discussion of the literature regarding blind/visually impaired parents.

#### Empirical Literature of Blind and Visually Impaired Parents

A discussion of blind parents by Meadow-Orlans (1995) outlined issues that these mothers or fathers experience. Like deaf parents they often do not have access to self-help groups or parenting classes due to their blindness or limited vision. Basic care giving tasks are more challenging for these parents but solutions such as strapping babies for diaper changes, using harnesses and shoe bells for safety and marking medicine bottles in Braille were mentioned. Challenging issues that blind parents may face with older children are helping them with homework, and children being embarrassed to have a blind parent. Blind parents may also have concerns about monitoring a child's appearance. Adolescents can be helpful to parents when they learn to drive a car and can read mail for them.

Conley-Jung and Olkin (2001) studied the experiences of visually impaired mothers with young children. They conducted interviews with 42 visually impaired mothers to find out how they managed tasks, what their concerns as visually impaired mothers were and their access to social supports and resources. One of the key findings was that the mothers needed to respond to the reactions of others. Mothers stated that they experienced these attitudes by feeling pressured to conform to more traditional sighted ways of mothering.

They explained that they functioned in these ways until they developed more suitable methods. These mothers suggested that there needs to be more interventions in place to change the attitudes and expectations of others.

Children sometimes resent having blind parents. Deshen and Deshen (1989) conducted an ethnographic study of the relationships of blind parents and their sighted children. It was found that children in their study became troubled and conscious of their parent's blindness. Some of the children displayed hostile feelings if they were asked to help parents such as attending to them as guides. If the parents had limited incomes they were not able to give their sighted children the same material items as their peers. It was also noted that the children did not have many of the same experiences as their peers such as going camping or for car rides. There were also reports by sighted adolescents that they experienced stigma and attitudinal barriers from other people when they realized that they had blind parents. This research was conducted with participants from Middle Eastern immigrant culture in Israel where parents are seen as generationally superior and where the disability rights movement is not in existence (Kelly & Sikka, 1997).

Blind and visually impaired parents face many physical barriers as do many parents with chronic illnesses and physical disabilities. The next section is a discussion of literature regarding parents who have a chronic illness or who have physical limitations.

## Empirical Research with Parents who have Physical Disabilities and Chronic Illnesses

Parents with physical disabilities, depending on the level of their impairments, may need more help with care giving tasks than deaf and blind parents (Meadow-Orlans, 1995). There are a variety of methods for parents with physical disabilities to complete these tasks (Greer, 1985). Shaul, Dowling and Laden, 1985) interviewed ten physically disabled mothers and many of them expressed that environmental modifications might be necessary for them to parent adequately. At the time of the study few commercial resources were found. The women reported that they resorted to home made modifications such as devices to transport their infants.

Kornblum and Anderson (1985) conducted an exploratory study and interviewed 12 mothers or fathers who had type 1 diabetes to determine how the chronic illness affected the roles, rules and relationships in families. Five themes were raised in interviews. One of the themes concerned decisions about whether to have children or not due to the chronic illness. The second one concerned spousal roles. Children's development and the parent-child relationship was the third theme. The fourth theme concerned interactions with extended family and the fifth one concerned resources outside the home.

Society's view of parent's with physical disabilities is seen as a hindrance (Greer, 1985). A study conducted by Crist (1993) is evidence that children may not be negatively affected when raised by a parent with a disability.

Contingent interaction during work and play tasks between mothers with multiple sclerosis and their daughters was compared with a group of non disabled mothers and their daughters. Receptiveness, directiveness and dissuasiveness were the three behavioural composites that were observed. Crist (1993) defined receptiveness as acceptance or approval of the other person. There is also encouragement to maintain contact. She defined directiveness as attempting to command, control or supervise another person. She also described dissuasive behaviours as discouraging, disapproving, or non accepting mother-daughter interaction resulting in limited attention toward others. It was found that there was no significant difference between the two groups on the behavioural composites for either mothers or their daughters.

Greer (1985) discussed the issue of how much personal assistance a child should be expected to provide for a parent with a physical disability. Children may become resentful if parents physically depend on them for assistance. However, a child's competence may improve with these added responsibilities. Blackford (1988) discussed issues experienced by the children of chronically ill parents. She stated that children often have to fulfill household chores that were previously done by an ill parent. Blackford (1988) claimed that increased chores and responsibilities allow less recreation time for these children. Kornblum and Anderson (1985) also stated that responsibility issues of children may cause them to feel resentful. This is only the view of three researchers and children of parents with disabilities may or may not feel resentful if they have additional responsibilities.

Children of parents with physical disabilities may be tolerant of differences depending on their familiarity with disability and the age of the child (Greer, 1985). Kornblum and Anderson (1985) stated, "children of diabetic parents have the potential opportunity to learn lessons about sensitivity to others about family interdependence first hand" (p. 106). Shaul et al. (1985) asked the parents in their study if they could think of any advantages of being a parent with a physical disability. There were reports that children were more independent and helpful than children in non disabled households. It was also found that children were more sensitive to other stigmatized individuals.

It was noted that discipline can be a challenging task for parents with physical disabilities. Greer (1985) stated that it may be an issue for parents if they rely on physical punishment and it may be a task that is reserved for the non disabled parent. Greer (1985) pointed out that it could be a heavy burden for the parent who does not have a disability. In the study by Shaul et al. (1985) it was noted that mothers with physical disabilities found alternative ways to discipline their children and resorted to verbal authority.

Buck and Holmann (1981) studied maladjustment of children who were raised by fathers with disabilities. They examined the personality, behaviours, values and family relationships between children and fathers with spinal cord injury (SPI). Findings from this study suggested that adult children of fathers with SPI are as well adjusted as children without a parent who has a disability.

The RTC National Survey of Parents with Disabilities was conducted in the United States by Berkeley Planning Associates (BPA) and the Research and

Training Center at Through the Looking Glass, an organization for parents and children with disabilities. Barker and Maralani (1997) discussed the findings in their final report. The survey was conducted to determine service needs, current service system options, gaps and problems in service delivery, and positive solutions to barriers faced by parents who have disabilities. Over 1200 parents with disabilities responded to the survey. Overall, four out of five respondents reported that they had a physical disability. Some of the participants may have had more than one disability but 70% of the sample reported a physical type of impairment. Over one quarter of the sample reported a sensory disability, one in five reported a cognitive disability, one in seven had a psychiatric disability and 4% had other types of disabilities.

Survey results indicated many barriers for parents with disabilities. Employment was identified as an area in which disabilities had a negative effect. It was found that recreation, transportation and having access to the community was seen as more difficult for this population. Pregnancy and birthing was found to be an area affected by respondents disabilities. Parents reported that they needed more assistance in recreation with their children, traveling outside the home with them and chasing or retrieving children. Barriers to child care were reported with cost being the most commonly reported barrier. Of those respondents who reported that they used adaptive parenting equipment almost half reported that cost is the biggest barrier to obtaining this type of equipment. 79% of respondents reported that they needed some type of personal assistance services. About three fourths of the sample used some type of personal

assistance and fifty-seven percent used personal assistance services for parenting tasks. 34% reported that they went without some of the personal assistance they needed in order to get help caring for their children. 42% of the sample reported that they faced at least one attitudinal barrier. About one third of respondents reported that they had been discriminated against as a person.

There was an open ended question in the RTC National Survey of parents with disabilities to determine blessings or positive aspects of parenting with a disability. Parents wrote comments such as their children's love and being able to have more time with them. Some parents reported that their children have learned to be more compassionate, tolerant of differences and more open to others. There were some reports of children being more resourceful. Some parents stated that having children had positive effects on them in a personal way. This allowed them to have a greater understanding of their children's needs. They were better able to advocate for children and felt that they were better organized. There were also reports that the disability pulled the family together. For other respondents it has helped them to cherish life and their children. There were statements from parents saying that they were able to focus on the things that were important in their lives. The majority of parents responded to the open ended question and only 7% of those parents said there were no positive effects of being a parent with a disability.

The next section is a discussion of empirical literature concerning issues faced by parents with mental health disabilities. This group does not encounter physical or sensory limitations but there are other similarities.

## Empirical Research with Parents who have Mental Health Concerns

Ahern (2003) conducted a demographic analysis of children of clients attending mental health community clinics in Western Australia. Ahern wanted to identify the number of clients attending mental health clinics who had children. 438 clients completed the survey and 55% of them reported that they had children. Results indicated that there were seven times more children living with a parent who was diagnosed with depression than clients diagnosed with schizophrenia. The author recommended that children of parents with mental health issues also need to be included in mental health services.

Handley, Farrell, Josephs and Hanke (2001) conducted the Tasmanian children's project. The purpose of the study was to identify the number of children whose parent/carer had a mental illness. They wanted to determine the types of supports that parents, children and service providers felt were needed. They also wanted to find out what level of supports were available and where the service gaps were.

The parents reported that it was important to remain connected emotionally with their children and to keep the family unit together. They wanted their children to understand their mental illness and they wanted to know that they were physically and emotionally okay. Parents also discussed their lack of understanding about mental illness. They expressed concerns about their parenting role, discussed their perceptions of the impact of mental illness on their children, the impact it had on themselves and the impact it had on the

whole family. They wanted quality child care, more support after they were discharged from hospital, and more family friendly adult mental health centres.

The problem area discussed by service providers was their concern of children not being able to understand their parents' mental illness and having difficulty dealing with the symptoms associated with the illness. Service providers stated that mental illness is disruptive to parenting of children. They also expressed a concern that parents have a reduced awareness of their children's needs. They suggested that there needs to be more education about mental illness. Other supports they felt parents needed were respite and structured support programs. They spoke of the need for better integration of adult and children's services at mental health clinics. There needs to be more consideration of children's needs and parents issues should become part of the assessment and case management of adults.

Children were also interviewed. They indicated that they struggled to understand their parents' mental illness. They didn't recognize the signs of the illness, didn't understand how to manage it and they talked about their parents' hospitalization and its impact on them. When the children discussed managing the illness they mentioned ideas such as parentification and adultification. They expressed feelings of emotional and physical pain when they were separated from their parents due to the mental illness or hospitalization. Children stated that it was worse if no one told them their mother was going to be hospitalized, especially if they were planning a special event together such as a birthday. Children stated that they would like more family support, information about

mental illness, counselling and support groups.

Sameroff, Seifer and Zax (1985) suggested that many offspring of parents with schizophrenia have mental disturbances. They discussed the results of previous research projects that lead to two conclusions. One conclusion was that children born to schizophrenic women had many developmental problems. The second one was that developmental problems of offspring were not the simple result of maternal schizophrenia. The authors discussed the comparison of offspring of white, middle class mothers with no mental illness with children of schizophrenic mothers. They stated that children whose mother had schizophrenia had lower cognitive, linguistic, motor performance scores, poorer emotional behaviour, poorer adapted behaviour in the home and worse behaviour in the testing situation.

Sameroff et al. (1985) discussed a longitudinal study that they were conducting. They suggested that environments where caretakers had high levels of stress either through economic or emotional instability caused their children to have high levels of incompetent behaviour.

Thomas and Kalucy (2003) suggested that parents with mental illness lack motivation to care for their children. The authors conducted research and interviewed parents with mental illness. Their results suggested that a lack of motivation among parents who were mentally ill led to long periods of inactivity. In their article they described the lack of motivation to mean "not feeling like doing anything" and "disorganized, not knowing what to do or being able to get started." The researchers found that there was little interaction between parents

and their children. Parents had difficulty understanding how the illness might affect their children. They sometimes had difficulty participating in activities with their children or helping them to socialize and this led to children being isolated. The illness was often not discussed with children and they had difficulty understanding their parent=s mental health issues. Parents relied heavily on support if there was a spouse or grandparents available. Childrens" care and household tasks were often neglected if there was not support available.

In summary, researchers have suggested that parents with mental health concerns have large numbers of children who have developmental problems or incompetent behaviour. Parents have a reduced awareness of children's needs and they lack motivation to care for them or give them opportunities to socialize. Sameroff et al. (1985) and Thomas and Kalucy (2003) have looked at parenting with a disability by exploring the problems of children and did not look at external factors in society that could limit parenting ability. Kirshbaum and Olkin (2002) stated that many professionals believe disability limits parenting ability and this leads to maladjustment in children. Children's problems are often seen to be causally related to their parents' disabilities. This is only one approach that views persons with disabilities as incapable or defective. It does not explore any environmental barriers that might effect parenting ability and does not consider the fact that disabled people have the same rights as everyone else.

Several of the articles pointed out that there needs to be more education about mental illness for family members and more support such as support groups for children and respite for parents when they are emotionally unavailable

for their families. It was also noted that children had difficulty understanding their parents' mental illness and didn't like to be separated from them when they had to be hospitalized. Therefore, to improve parenting ability and family functioning environmental factors need to be available. Factors could include improving mental health services that include all family members, more resources or support for families and information to educate families about mental illness. The next section is a discussion of all the empirical literature.

#### Discussion of Empirical Literature

There are some issues that are common to all disability groups. Stigma was a re-occurring theme throughout the literature for parents with disabilities. They have to cope with oppressive attitudes and stigmatizing messages from others.

The provision of adequate resources and social supports was another common theme. Blind and deaf parents stated that they would have liked to receive more child rearing information. Researchers have suggested that there needs to be access to self-help groups and parenting classes. Blind and physically disabled parents stated that they needed more help with care giving tasks. Parents with physical limitations reported that there were limited accommodations available such as adaptable baby furniture. Research findings of parents with mental health concerns suggested that more support such as respite, structured support programs for families after parents are discharged, counselling for children and support groups for children.

Another common theme was the possibility of over-burdening children when a parent has a disability. Several researchers pointed out that children may feel resentful about having additional responsibilities when a parent has a disability or is ill and they may resent having less time for recreational activities. Thus, it was evident from research findings that parents with disabilities need to be resilient and develop their own methods to overcome their additional parenting challenges.

### Methodology

Much of the research in this field of study was conducted using qualitative methods. Deshen and Deshen (1989) conducted their research by relying on informal conversations and observations of blind parents and their children. The Parental Needs Inventory was administered and structured interviews were conducted to evaluate the success of deaf parents in the study by Jones et al. (1989). Structured interview methods were also used in the studies conducted by Conley-Jung and Olkin (2001) and Shaul et al. (1985). Kornblum and Anderson (1985) conducted interviews in their study with parents who had type 1 diabetes. Thomas and Kalucy (2003) conducted interviews to determine lack of motivation for parents with mental illness. Questionnaires and interviews were the method of study in the Tasmanian children's project conducted by Handley et al. (2001). Videotaping was the method used in the study done by Crist (1993). Preston (1996) used the life history approach with the participants in his study. Crist (1993) used a comparison or control group. She looked at the differences

between the interactions of mothers with multiple sclerosis and their daughters and compared them with those of non disabled mothers and their daughters. A demographic analysis was conducted by Ahern (2003) to determine numbers of at-risk children of adult clients attending community mental health clinics. It was noted that only one researcher, Prilleltensky (1998), used focus groups. The RTC National Survey was the method used with disabled parents in the United States to determine what their challenges and strategies were. The only longitudinal study identified was conducted by Samaroff et al. (1985) in their study concerning care taking environments with high levels of stress.

#### Identification of Empirical and Theoretical Gaps

Library data base searches revealed that literature concerning parents with disabilities and their children is limited. Search results suggested that most of the research focused on issues with disabled children. Kirshbaum (2002) also made reference to this issue and stated that there is less examination with these children as they grow up, leaving a gap in the literature. It is evident that professionals need more information concerning adults with disabilities. It would also be beneficial for today=s children to have access to research material that has been conducted and compiled by adults with disabilities.

The research findings cited in this report reveal that several research projects are dated. Several studies cited in the literature review were conducted in the 1980's and early 1990's. It was noted that there was not as much research done in recent years. This suggests that more recent research needs

to be conducted with parents who have disabilities.

Kirshbaum (2002) suggested that much of the literature looked at the problems in families when parents have disabilities. Early research was done using clinical cases rather than community-based samples. Buck and Hohmann (1983) also explored this issue of maladjustment in children due to parental disability or illness. They stated that much of the early literature was speculative and research was based on inadequate methodologies and limited studies. It was also evident that there was limited literature on the positive effects of parenting with a disability. Therefore, more research needs to be conducted with this population to determine how care givers cope and to explore their needs when they are faced with additional parenting challenges.

There is limited theoretical literature in respect to the study of parents with disabilities. Thurman (1985) discussed the ecological congruence model but stated that there is no empirical research done with this model. The only other model that was cited concerning parents with disabilities was the one used by Booth and Booth (Supported Parenting, n.d.) in their work with parents who had learning difficulties. Thus, it is apparent that more theoretical literature is necessary when conducting research with parents who have disabilities.

A strength of the literature cited in this report is the use of qualitative research methods. The majority of researchers used interviewing as their method for collecting data. It was noted from conducting interviews in the current study that this was an excellent way to gather in-depth information from participants about their experiences as parents with disabilities.

There was only one research project in the literature review that used a comparison or control group to determine differences of mothers with disabilities and mothers who were not disabled. There could be more research done to compare the differences between disabled and non-disabled parents and their families.

There was limited research done using the cross-disability perspective. The majority of research projects cited in the literature review conducted research with only one disability group at a time. Researchers did not examine common themes among more than one group. It was also noted that the majority of studies did not have any discussion of parents having more than one disability. There have been many organizations of persons with a variety of disabilities emerging since the 1970's and 1980's that have a cross-disability perspective. It is surprising that many researchers have not chosen to embrace the perspective and explore the common experiences of all disability groups.

### Summary

This chapter has included definitions and terms related to disabilities. Theoretical perspectives were explored using feminist analysis and three ecological models. Empirical literature was cited and there was a discussion of the findings that included the research methods that were used in studies. Gaps in the empirical and theoretical literature were also identified. The next chapter is a detailed explanation of the research design for the current study.

## Chapter Two

### Methodology

#### Research Questions and Hypotheses

Three questions were addressed during the process of this research project. What additional disability related challenges do parents with disabilities encounter with their children? How have they coped or adapted in order to overcome these issues? What recommendations can be suggested to help others who are contemplating parenthood or who are already parents? It was postulated that parents with disabilities would be faced with environmental and attitudinal barriers that other parents do not have to deal with in regard to their child rearing experiences. It was also hypothesized that there will be issues common to all disability groups.

#### Research Design

Qualitative research methods were used to gather information from parents who were blind/visually impaired, had chronic illnesses, mental health concerns or who had physical disabilities. In-depth interviewing was the method used to collect data. Interviews were conducted by telephone and the first set of interviews took approximately an hour to an hour and fifteen minutes. A second set of interviews took approximately fifteen minutes to a half hour.

The rationale for choosing the telephone interviewing method of data collection was that many participants lived out of province. It was also the method used by Conley-Jung and Olkin (2001) in their study to examine the

transition to parenthood for visually impaired mothers and their young children. Parents in the current study were able to choose times that were convenient for them such as when their children were in school or after they had gone to bed. Long distance charges were minimal with a cost of five cents per minute. This made it possible to talk with participants for an hour or more. It was also more convenient for me to conduct interviews from my home. Telephone interviewing saved me time and energy. I had more time to transcribe the results from the tape recorded conversations.

#### Sample Definition and Recruitment

The groups that were selected for this research project were parents with physical disabilities, chronic illnesses, mental health concerns and those who were blind/visually impaired. This population included parents who had disabilities prior to the birth of their children and parents whose disabilities occurred after their children were born. There was a restriction on the ages of the children and only children who ranged in age from infancy to twelve years of age were included in the study. However, this restriction was expanded to also include parents who had young adults still living in the home. These restrictions regarding the population were chosen so that it was possible to explore the disability issues and their impact on the parent's experiences from the time of pregnancy until the child reached adolescence. I wanted to determine how the disability affected child care tasks. As children get older they become more independent and need less child care assistance.

There were eight participants in the current study and there was representation from all of the disability groups chosen for the research. Several participants had more than one disability. Three participants identified physical disabilities, three participants identified that they were blind or visually impaired, three participants stated that they had chronic illnesses, and one participant stated that she had mental health issues and a head injury. One of the participants was chosen to participate in a pre-test.

Research volunteers were recruited by enlisting the assistance of organizations that work with people who have disabilities. A vocational rehabilitation counsellor at the Canadian National Institute for the Blind (C.N.I.B.) was approached for assistance to find participants for the study. The counsellor requested that a document be sent to her by e-mail. The written document included information about the study, description of how participants would be involved, a statement ensuring confidentiality, proof of ethics approval by the University of Manitoba and contact information for anyone wishing to participate in the project. The counsellor forwarded this information to other C.N.I.B. offices across Canada. Five out of eight participants were referred to the research project as a result of that e-mail. They lived in other Canadian provinces. Therefore, advertising to recruit volunteers proved to be an appropriate method of finding participants for the study. Padjett (1998) stated that this is an excellent approach to avoid coercion. Staff of other organizations such as the Independent Living Resource Centre, the Moods Disorders Association of Manitoba, the Schizophrenia Society of Manitoba and the University of Manitoba,

Disability Services were approached requesting their help in finding participants.

These organizations also asked for a written document regarding the study.

The only responses from these groups came from students with disabilities at the University of Manitoba. Snowball sampling was another method of recruiting participants. The participant, also known as the pretest was recruited by a woman who works in the disability community. Another participant referred a friend who also agreed to take part in the study.

Most of the prospective volunteers who expressed interest in participating in the study replied to the request by sending an e-mail with details about their disability and information such as number of children, their ages and sex.

Participants who met the criteria for the research project had consent forms mailed to them. They were asked to read the forms, sign them and mail them back to the specified address. Once consent forms were received, the process of scheduling and conducting interviews began.

#### Data Collection

A pre-test interview was undertaken to ensure that the appropriate information was being obtained. During the pre-test interview the participant was asked if she understood the questions. She was asked if there were any questions she thought were repetitive. It was decided that two questions would be omitted from the original interview guide as they were similar to previously asked questions. The participant was also asked if there were any questions she thought could be added to the interview guide. She suggested that a

question inquiring about resources that parents with disabilities used be included. Another reason for conducting the pre-test was to determine if the right amount of time had been specified for interviewing. Timing was frequently checked during the interview to determine the amount of time that was required for each question and the entire interview.

Once the pre-test interview had been completed, other interviews took place. Prior to Interviews participants were told they took approximately an hour to an hour and fifteen minutes and they were asked if they would be comfortable talking on the telephone for that length of time. Ninety minute cassette tapes were used and they had forty-five minutes per side. A timer was set up to remind me when the first side of the tape was nearing the end. When the timer's bell rang I allowed the participant time to wrap up the conversation before switching the tape to the other side. A telephone device was plugged into the tape recorder in order for conversations to be recorded clearly through the use of the phone. Questions were read out to participants with the aid of a CCTV reader that enlarged the print of the interview guide onto a computer monitor. Each question was read once and then participants were asked to respond separately to each part of the question. See Appendix A for the telephone interview guide. These questions determined the participant's additional parenting challenges, their adaptations to issues, and any recommendations they suggested to help other parents who have similar situations.

I transcribed six out of eight interviews and a friend typed the other two. Each transcript was coded and themes were determined. Once this procedure

was completed, copies of transcripts and documents outlining themes of interviews were e-mailed to participants to read. One blind participant could not listen to the information on her computer and was provided with audio taped information regarding the themes of her interview. A second set of interviews was conducted after the data had been coded and themes had been determined for each transcript. In the second interviews participants were asked if the themes of their interviews accurately reflected what had been said. They were also asked if the themes accurately reflected what they had wanted to say and were there any comments they wanted to add or delete. These conversations were analyzed and information was added to the data already collected.

#### Analysis Plan

Information obtained from the interviews was the raw data such as recorded information on tapes. Cassette tapes were marked with pseudonyms such as "Pre-test" or "Participant Two" etc. The audio tapes were transcribed after each interview. "WordPerfect" and "Microsoft Word" were the word processors that were used. Each conversation was typed verbatim and included long pauses, sighs, sobs, laughter, ums and ers. Documents were set with larger than normal margins to allow space for coding. The person being interviewed was not described by name but was given a pseudonym such as "participant one, participant two etc." Each line of each transcript was coded to determine what it meant. Memoing was done in the margins of each transcript. The method of coding that was used was constant comparative analysis. As

themes emerged from the initial coding I went back over the data to ensure that it was coded according to the original themes. As I went back through the information new codes occurred. I observed repetition but redundancy was not an issue. Padgett (1998) referred to this process as saturation, "a term meaning the cooking process is drawing to an end" (p. 79). Once the initial coding was done subcategories and categories were developed. After the codes were condensed into categories I began to analyze the data to determine the themes. Padgett (1998) pointed out that no matter what results occur in a study it is important to link the analysis back to the original knowledge base or literature. Therefore, it was necessary to determine if the findings of my study were consistent with existing research.

### Ethical Considerations

Ethical requirements were addressed. A consent form that described what the study was about and how participants can be involved was distributed to prospective volunteers. If anyone wished to participate in the study a signature on the form was required prior to becoming a research subject. Information provided by participants was confidential in computer files and was not shared with anyone outside of the research project. Names were not provided with any research results. Participants had an opportunity to review the results of their interviews to ensure that transcribed information was accurate. Participants were also provided with a copy of the research findings once they were completed.

The research project was approved by an ethics board at the University of Manitoba in the fall of 2003. Recruitment of volunteers began in November, 2003. Interviews were conducted from December 2003 to March of 2004. Transcription of interviews occurred from January to August 2004. Data analysis began in the winter of 2004 and was completed in August 2004. The next chapter provides a detailed account of the results that were obtained from the interviews.

## Chapter Three

### Results

#### Introduction

This chapter discusses the results of the study in detail. Eight parents were interviewed and they had a range of disabilities. Four participants had physical limitations, two identified chronic illnesses, four were blind or visually impaired and one individual identified a mental health concern. Several participants disclosed that they had more than one disability.

There is a brief biography of each research participant. Following the introduction of each person there is a discussion of the results for each participant's interview. Data for each interview is known as personal themes. There is also a discussion of the common trends. This refers to common data that was observed in all eight interviews.

Information from each interview was determined to be a personal theme if the participant made more than one statement about a particular topic or repeatedly referred to something throughout the interview. Personal themes were grouped into four categories. The first group was referred to as additional parenting challenges. Themes placed in this group were disability related challenges that effected parent's child rearing experiences. These were statements such as not being able to carry, lift or hold a child if a parent had a physical disability or chronic pain. The second group of personal themes was referred to as attitudinal barriers and a theme was placed in this group if a participant discussed any negative messages they had received from others

about their ability to parent as a person with a disability. Formal and informal supports was the third group of personal themes. A theme was placed in this category if a participant discussed formal supports such as a support group for parents with disabilities or informal supports such as supportive spouses or help from extended family. The fourth group of personal themes was referred to as coping and adapting to additional parenting challenges. A theme was placed in this category if a participant discussed ways they coped or adapted to additional disability related challenges such as adapting the activity or the environment.

The common trends, found throughout the eight interviews were derived from the personal interview themes. If more than one participant made reference to a particular topic or if statements were made by more than one participant they were included as a common trend. Once the common trends had been obtained they were grouped into categories of themes.

## Biographies of Research Participants

### Participant One

Participant One also known as the pretest participant was a single parent and did not have a partner living with her in the home. She had three sons who were 15, 22 and 23 years of age at the time of the interview. Participant One lived with her 15 and 23 year old sons. Her 22 year old son lived with his dad. Her older sons have pursued post secondary education. The youngest son was in grade 10. One of his interest was playing hockey. This participant worked full time and was taking courses towards a Masters Degree.

Participant One had paralysis at birth and her left arm was paralyzed. The name of her disability was Erb Duchenne Syndrome and it progressively got worse as she got older. She used a computer and could type with one hand. During the interview she stated that she was able to type quite fast with it. However, she did use Naturally Speaking on her computer when she needed to type longer documents.

Participant One's themes are as follows:

#### Additional Parenting challenges for parents with disabilities

- inability to participate in physical activities with children such as swimming or playing parent child hockey games
- concern of losing her independence due to her physical disability and becoming dependent on the children

#### Attitudinal barriers

- attitudinal barriers to parenting with a disability were messages such as you shouldn't have kids if you can't look after yourself, you won't get married and have a family if you have a disability and there's stigma that you can't give a child as much as someone else can

#### Informal and formal supports

- Participant discussed enjoying the companionship of her children
- Informal supports such as the children's dad who takes son to hockey when participant can't, son stays with dad on weekends and older brother will pick him up from hockey when mom is too tired

### Coping and adapting to additional parenting challenges

- activities that she does with her children are different such as having discussions and playing games
- participant discussed that she coped with her disability by not disclosing it to anyone

Participant One's children were the oldest of the sample in this study.

She stated in her interview that she depended on them to do tasks that she was physically unable to do herself and she felt that this was a concern. She didn't want to lose her independence and become dependent on her children. In her interview she stated,

physically I can't do what I used to be able to do and that's a concern because I seem to depend more and have to ask them more and more to do more physical work and like repairs and things like that, painting and my concern is when they're all gone I won't have any one to ask and I don't want to have to bother them to you know come back to do these things.

Participant One emphasized the fact that she enjoyed the companionship of her children.

You're never really lonely, you always have someone around you or someone you can talk to or they're very good as they get older as well for companionship. Lots of companionship when they are younger because you always have them around but even as they get older they become almost your friends. Knowing that there's always someone just having a family member. It's a support system definitely a support system even when they were younger it is a type of support system just someone there all the time that shows that they care.

Participant One coped with her disability by choosing not to disclose it to other people. She stated that she hid her disability so well that she was able to avoid some messages regarding parenting with a disability. "A lot of people did not

notice unless they knew me well and they knew and so that's why I didn't allow I didn't socialize a lot or interact a lot so people would not find out." She stated in the interview that she would do things differently now by not hiding the fact that she has a disability and she would be more open about it.

### Participant Two

Participant Two had adopted two children. The oldest daughter was five years old and her younger daughter was seventeen months old. At the time of the interview the participant's youngest child had been in her home for only five months. During the interview the participant stated that she had a battle with the ministry to adopt her second child because she was single and had a disability. She hired a lawyer but when the ministry found out that she was planning to have her children in daycare part time they were positive about the situation. The oldest child's interests were soccer, swimming, skating, gymnastics, playing with other children and participating in a music program. At the time of the interview Participant Two was single and had no partner.

Participant Two had a cervical spinal injury that was sustained in 1983. She was an incomplete quadriplegic. Half of her spinal chord was effected. At the time of her injuries her neck was broken and she also sustained a head injury.

The themes of Participant Two's interview are as follows:

Additional parenting challenges of being a parent with a disability

- concern of feeling badly about not being able to carry children around and

has limited ability to lift them.

- participant has limitations of doing physical activities such as sports with her children due to her spinal injury
- participant's biggest challenge as a single mom is her health and making sure her children are attended to
- participant was dissatisfied with the occupational therapy services in her community when occupational therapists gave her inappropriate advice without knowledge of her disability

#### Formal and informal supports

- informal supports such as participant knowing another parent with a similar disability and finds it inspirational to have similarities with that person
- informal supports such as Participant having a good support system of friends
- formal supports such as daycare for children so she can have some time alone with each child and also has some time for herself

#### Coping or adapting to additional parenting challenges

- participant found other ways to participate in sports activities with her children such as wearing an aerobics belt so she can go in the pool with her daughter, she can walk beside her in the water and can do a form of a side stroke
- participant adapts to the physical limitations of tasks such as dressing her youngest daughter who is very heavy

Participant Two's interview themes focussed on her physical limitations

and how she adapted in order to care for her children. For example, she described how she learned to dress her youngest daughter who is very heavy for her to manage with her limited physical abilities.

I lay her down on the bed, change her diaper and then I put her pants on and then I turn her over on my knees, then I pull them up in the back and then I put her between my legs, the strongest muscles I have and she's probably about three quarters of the way up her leg and then I put her top on there and then she sits on me while I put on her socks and her shoes and her coat and her hat.

There were also several themes that emphasized informal supports such as friends, and knowing other parents with disabilities. She stated that she had a strong support system of friends who have looked after the children when she needed to have a weekend without them or when she was ill and needed medical attention.

### Participant Three

Participant Three was married and lived with her husband who did not have a disability. She and her spouse had a five year old daughter who had just started school. Their child enjoyed doing crafts, drawing, colouring and writing. Participant Three did not work outside the home and during the interview she stated that she was helping the Canadian National Institute for the Blind to provide sensitivity training to the school where her daughter attended. She belonged to a social club for people with disabilities and joined a committee of people with disabilities whose goal it was to make decisions about issues such as lobbying for blind people to have access to Handi Transit.

Participant Three had Retinitis Pigmentosa (rp) and had no central vision.

She had four degrees of peripheral vision, had no clarity, no colour and no detail. She also stated in her interview that she was autosomal recessive.

The themes of Participant Three's interview are as follows:

#### Additional parenting challenges of being a parent with a disability

- participant's daughter has been sheltered, restricted and there was a concern about daughter's social development being delayed due to mom's visual impairment
- there is no public transportation for blind people in participant's community and participant was isolated in her home with her child because she did not want to jeopardize her safety
- participant discussed things being more challenging due to the loss of her vision such as measuring medication, getting teachers to write correspondence for mom in black marker and getting child on school bus a big concern because of her safety

#### Attitudinal barriers for parents with disabilities

- attitudinal barriers from health care professionals and the general population such as people not knowing what the white cane is for, doctor offering surgery to have her tubes tied because he felt it would be negligible and irresponsible for her to have kids, and a nurse would not let her be alone with her baby in the hospital after she was born
- husband is not supportive, does not understand the disability, is uncomfortable when she uses the white cane and will not go for sighted guide training

### Formal or informal supports

- an informal support for participant is her volunteer who is also a parent with a disability, she is a role model and is someone participant can identify with
- a formal support for participant was the support of a health visitor from her local health unit during the first two years of her daughter's life to talk with mom, read information for her and to provide child with an opportunity to do major crafts that mom was unable to help her with

### Coping or adapting to additional challenges as a parent with a disability

- participant discussed accommodations such as requesting that school bus stop at the driveway in front of her home to pick up or drop off her daughter, helping to provide sensitivity training to her daughter's school so staff and students will understand about the disability, living room in participant's home was made into a safe environment for child to play in, and medicine dropper marked with a high visibility marker

Participant Three's interview themes focussed on the issues of being isolated in her home with her daughter and no public transportation for blind people in her community. Participant Three also faced many attitudinal barriers from health care professionals, the general population and her husband who was not supportive of her as a blind woman. During her interview she described an encounter with a gynecologist.

I went to a gynecology appointment and the doctor just knowing I had just been diagnosed. I discussed genetics with her. She offered to book surgery to try to tie the tubes or whatever they do so I couldn't have kids and I was just astounded that this doctor would. She very assertively told me that this is a genetic eye disease which is a strain on society and that

to knowingly have kids knowing the high risk of them having rp it would be negligible and irresponsible and she felt that I should have this done.

This was an experience that made Participant Three feel terrified to use her white cane while she was pregnant. She thought people were judging her for being pregnant because she was blind. There were also a range of themes regarding accommodations as a parent with a disability.

#### Participant Four

Participant Four lived with her husband and their two children. Her spouse did not have a disability. At the time of the interview their daughter was ten and their son was eight years old. The children went to a French school and spoke French at home as well. Their son played hockey and both children played soccer. They liked to swim and they both took piano lessons. The participant also stated that her daughter was good at drawing. Participant Four spent time volunteering in the multiple sclerosis office and volunteered to help a blind parent with various tasks.

Participant Four had multiple sclerosis. She was diagnosed approximately eighteen years ago and it got worse after having children. She made the decision to not work full time any more and began receiving governmental disability transfer payments. The participant stated that "she has gone down hill in the last four or five years." She lived with fatigue, had trouble walking and had a lot of back pain. She was able to get around with the aid of a cane.

The themes of Participant Four's interview are as follows:

### Attitudinal barriers

- the participant hates pity when people find out about her MS

### Additional challenges of parenting with a disability

- a concern as a parent with a disability is feeling guilty and being a burden because she can't do activities with her children like other parents can such as skiing and hiking
- concern as a parent with MS is that the participant has to count on children to help to get groceries, making their beds and getting their own breakfast
- can not go to places such as the skating rink to watch her son play hockey or to the school because these buildings aren't accessible for people with disabilities

### Informal and formal supports

- participant knows other parents with disabilities and volunteers to help a blind parent
- Informal support such as husband who is good to help when she is depressed and helps with household tasks
- Informal supports such as parents, family and friends who look after the children when she needs a break or helping with tasks such as taking the children shopping for school clothes when she does not have the energy
- Formal resource such as funding from the MS society for a homemaker for three hours per week to clean the house because participant is not physically able to do this household chore

Many of the themes in Participant Four's interview centered around supports from her husband, parents, family and friends. Two themes expressed concerns about not being able to do physical activities with her children or concerns that she has to depend on them to help her. It was evident throughout her interview that she had a positive attitude about her disability and one of her themes expressed her dislike when people pitied her because she has a chronic illness. "And keeping a positive attitude. I find that's my biggest, biggest, morale booster." She stated, "when people get her down she tries to tell them that it is not so bad and boosts them up a bit."

#### Participant Five

Participant Five was married and he and his wife had nine year old twin boys. One of the boys loved sports and played hockey. The other child was more artistic and was taking guitar lessons. The participant stated that he belonged to a local multiple sclerosis society group for individuals and parents. They would gather to talk about issues such as how to talk to their kids.

Participant Five's wife did not have a disability.

Participant Five lost his vision in 2001 and stated that he was legally blind in 2002. He was down to 5% vision at the time of the interview. He used a computer with a 22 inch monitor with a voice synthesizer to hear what was on the screen. Since he was not able to drive he went everywhere with his seeing eye dog. He has had diabetes for over thirty years and was diagnosed with multiple sclerosis in 2002. Some of the symptoms he mentioned were headaches,

numbness in his feet, lower back pain and numbness in his arms and hands when lying down.

The themes of Participant Five's interview are as follows:

#### Additional Parenting Challenges as a Parent with a Disability.

- participant discussed a concern that the MS will take away his physical mobility
- activities with children are different from those of other parents because they can drive and participant has to schedule trips with children by bus

#### Informal and Formal Supports

- informal support such as participant having a supportive wife who tries to understand the way he feels.
- informal supports such as participant knowing other parents with MS, parents who are blind, and parents with physical disabilities
- formal resource such as participant belonging to a local MS group for individuals and parents where they talk about how they can talk to their kids

Participant Five's interview themes focussed on supports from his wife, other parents with disabilities and belonging to a local MS group for individuals and parents. Participant Five lost his vision several years after his children were born.

Before I lost my vision you know I get home from work and if the boys wanted to go somewhere you know we 'd jump in the car, jump in the van and we'd go. And now it's you know if we want to go somewhere we have to schedule it so we can do it by the bus.

He stated in his interview that he was able to walk everywhere with his guide dog

or take the bus. He said if he lost his physical mobility due to the MS, he would certainly lose his independence and he would not be able to escort his sons on bus trips.

### Participant Six

Participant Six lived with his spouse and they both worked for disability organizations. He had two children, a thirteen year old daughter who lived in his home and a twelve year old son who did not reside with him. His daughter was interested in collecting things such as beanie babies and playing computer games. He stated that both children were interested in sports.

Participant Six and his spouse both had disabilities. His spouse was legally blind and he was totally blind. He stated he was a paraplegic and his legs were paralyzed from a car accident that occurred ten years ago. He used a manual wheelchair and had a guide dog trained to guide him in his wheelchair. Both Participant Six and his spouse used the computer. He used JAWS, a voice synthesizer to hear what is on the computer monitor and his spouse used ZoomText, a screen magnification software package that enlarges the images on the screen. His wife also used a CCTV reader, a machine that enlarges regular printed material. Other adaptive items in their home included talking clocks, a talking thermometer and a talking timer. They used the Handi Bus, a transportation service for people with disabilities to get around the city.

The themes of Participant Six's interview are as follows:

### Attitudinal Barriers

- concern as a parent with a disability is about society's perception of people with disabilities not being able to be parents
- participant's wish is for more disability awareness for parents with disabilities so societal views may change

### Additional Parenting Challenges for a Parent with a Disability

- concern as a parent with a disability is not being able to drive and activities with children are different because other people have cars
- participant is unable to go to some friend's homes with his wife and children that are not accessible for people with physical disabilities such as not having an accessible washroom

### Coping or Adapting to Additional Parenting Challenges

- cope with reactions of others by turning it into an educational aspect or awareness component when confronted with questions about parenting with a disability

### Informal and Formal Supports

- informal supports from parents in-law, other family members and friends who help with children such as taking them swimming or playing sports with them
- formal support is participant facilitating a support group for blind parents with sighted kids where he and other parents have opportunities to provide peer support for each other

Many of Participant Six's themes centered around society's perception of

disabled people not being capable of being parents because of their disabilities. He discussed his wish for more disability awareness for the general population to decrease society's perceptions of people with disabilities not being able to parent adequately. Several times throughout the interview he discussed how he did his own type of disability awareness when people asked him questions.

Certainly trying to turn a negative into a positive and do an awareness aspect to it. I mean, I have quite a few people ask me questions. I also actually have a guide dog that's been especially trained for me to guide me in my wheelchair so we always go into the malls and those sorts of things and then of course a few people you know turn their heads and wonder and some people come over and ask questions and...but as far as the parenting aspect I'm, you know, again you just explain to people how you do this, or you - someone might say, how do you cook? So you explain to them. Or, how do you do this or how do you do that and you turn it into an educational aspect.

His themes also reflected other barriers such as not being able to drive and not being able to go to friends' homes that were not accessible for people in wheelchairs. Participant Six had informal supports such as his parents in-law. He had formal supports such as the disability organizations for which he and his wife worked and the support group he facilitated for blind parents.

#### Participant Seven

Participant Seven lived with her husband who had no disability and they had two children. She also had two step children who were adults and not living at home. Participant Seven stated that her eight year old daughter "was a tomboy who was into sports and playing with the boys." She played soccer, hockey and was on a curling team. Their son was ten years old at the time of the interview, was artistic and enjoyed working with computers. Participant

Seven's husband had been in the military and after he retired he stayed home with her to help look after their young children. At the time of the interview he was working at another job outside of the home. Participant Seven was a university student and was in school full time.

Participant Seven had a visual impairment in one eye due to a vehicle accident approximately six years ago and her eyesight was progressively getting worse. She had a head injury and didn't have a good memory after she was involved in a head on collision with two moose. She stated that she has had a bad arm since 1989. She suffered with major depression and dissociative disorders. She had major depression before her children were born. She had mood swings and personality shifts known as multiple personality disorder. Participant Seven was on medication but when it was ineffective she needed to be hospitalized.

The themes of Participant Seven's interview are as follows:

#### Additional Parenting Challenges for a Parent with a Disability

- there are no resources for parents with disabilities and if there were it would have prevented participant from going into a crisis stabilization unit
- concern as a parent with a disability is not being able to be active enough for her children such as not being able to take them places they wanted to go, participant cannot go to public places because she becomes anxious and her memory problem can get her lost
- participant knows other parents with disabilities and her wish is for a support group because disabled parents feel isolated

- impact of disability on children and family life was the insecurity of knowing if mom will be home and when will she be home during times of hospitalization

#### Informal and Formal Supports

- Informal support is husband who was participant's biggest emotional support, did the cooking, cleaning and was home to help look after the children when they were young.

#### Attitudinal Barriers

- attitudinal barriers regarding participant's mental health problem scares people and she copes with the reactions of others by going into denial and does not take medication
- Attitudinal barriers to becoming and being a parent were messages such as participant "didn't have what it takes", she wasn't stable enough and her confidence was affected when she had babies because she was questioned about being able to do things or not

Several themes in Participant Seven's interview centered around other people's attitudes, the messages she received about her mental health concerns and her ability to parent her children. When the participant was asked if she received any messages about her inability to parent with a disability she stated,

Yeah, heard about that a lot. I even got that from my husband. In the form of not having what it takes, being told you know not being stable enough because of being somebody that goes in and out of depression. Wow what kinda life can you supply or be...what kinda person can you be for a child? Kinda got that. It made you think. But to me, it just made me more determined.

She discussed how she coped with other people's reactions towards her as a

person with a mental health concern.

- P. You can hit really fearful people. They get really frightened. It almost makes you fearful of yourself. You start thinking you're a monster.
- I. I guess people feel frightened because they don't - you know understand about the disability.
- P. Yeah, well they think that you're gonna start switching, it's almost like they think you're 10 different people and start switching in front of them. That's not how it is. So, stand on your head and do weird tricks. That's not the way it is. For some reason they think that.
- I. Well, people think all kinds of weird things, don't they?
- P. Well, even the doctors do, the one's that don't understand eh? So, you can even run into that problem with doctors.
- I. I'm sure. New doctors that aren't very well - who haven't educated themselves very well.
- P. So, that makes it even harder. So when you have doctors that don't understand and hear you, you tend to panic and start to fear yourself. You go unstable.

Participant Seven discussed the insecurity her children felt about her absences when she was hospitalized. She stated that her absences, when she was hospitalized were the biggest impact of her disability on her children.

The biggest one is them never knowing whether I'm gonna be there tomorrow because there's been many times when they've gone to school and come home and I'm not here, I'm in the hospital. So they - they have that insecurity of not knowing if Mom's gonna be home and when is she gonna be back.

She said that it has effected her daughter the most. She will come in at night to check if her mother is still home. She knew other parents with disabilities but they also had problems and felt isolated. She stated in her interview that she wished for an adult support group where she could go to talk so she wouldn't have to depend so much on her husband for emotional support. Participant Seven did not identify many formal or informal supports but she referred to her husband as a major source of support.

### Participant Eight

Participant Eight had an eleven year old son as a single parent. She also had a two year old daughter whose father she was engaged to at the time of the interview. She did not live with her fiancé because his employment took him out of the community. He had two daughters from a previous relationship and when he was not working they were all at her home. Participant Eight's children lived with her but her fiancé's children were only there when he was. Participant Eight's eleven year old son enjoyed playing soccer and football. He also enjoyed reading, and riding a bicycle. She stated that her two year old daughter was an inquisitive kid and was connected to all the children. Participant Eight has returned to university as a mature student and she was taking courses on a part time basis.

Participant Eight had fibromyalgia, a chronic illness that affects her muscles, and she has severe pain. It is an illness that has many different elements and the participant stated that it is hard to describe because it's variable. She could go through different phases in a day or she could have a day where she is not impaired at all. She had stiffness and difficulty sleeping due to the pain. When she couldn't sleep the pain became worse. Participant Eight has had severe flare ups that have effected her mobility. She has found it difficult to physically complete her school work and when she has tried to finish assignments she reverted back to the pain level. Her medication caused her

thinking to become foggy and she couldn't focus. She was able to drive but she found it difficult to get in and out of the car. As a student with a disability she was eligible for a disability study grant that enabled her to purchase adaptive technology to assist her with her studies. She used a recorder to take notes in class and was able to download the lectures to her computer to help her type her notes.

The themes of Participant Eight's interview are as follows:

#### Additional Challenges of a Parent with a Disability

- concern as a parent with a chronic illness is that participant can not always do what she wants for her kids such as making sure the house is clean or making meals because of the amount of pain and movement required for some activities
- concern as a parent with a chronic illness is that she doesn't want her kids to look after her in the future
- participant is sensitive to touch and can not let her two year old child sit on her lap or she can not pick her up in case she drops her due to her pain
- participant has found it difficult to accept offers of assistance but is learning to accept them and ask for help

#### Informal and Formal Supports

- informal support is participant's fiancé who is a major source of support
- formal resources such as participant receiving a childcare subsidy for her daughter to be in daycare while she attends classes at the university and a

food hamper from her child's school at Christmas when she and her fiancé were unable to give them anything that year

- informal support such as co-workers/friends at the company where fiancé works and where she was employed are a safety net for her because she knows that if she ever was in an emergency they would make sure that her fiancé came home immediately

#### Coping or Adapting to Additional Parenting Challenges

- activities aren't always different from those of other parents because participant adapts the activity or changes the environment
- participant coped with her physical limitations due to her pain and adapted by doing things such as teaching her child to put her arms around her mothers neck making it easier to lift her out of her car seat

Participant Eight's themes focussed on her limited ability to do things that she wanted to do for her children due to her chronic pain. She discussed a concern of not being able to pick her youngest child up or hold her on her lap.

During her interview she stated,

And as far as my daughter goes you know. I mean now she can walk and stuff but you know having to say to her I'm sorry I can't pick you up. I'm not strong enough to do it. I'm afraid I'll drop you. And I mean even last week she was asking me to pick her up but I said I'm sorry I can't pick you up - which is really one of the first times I've said it to her directly and she stopped asking right away. So she understands but that in a way made me feel even worse.

She expressed a concern about not being able to ensure that the house was clean or that meals were made. However, she did state that she was able to manage making meals regardless of the pain. She spoke at length about

adapting activities that she does with her children so activities are not much different from those of other parents. Her concern of not wanting her children to look after her in the future was raised more than once during the interview. She talked about her difficulty accepting offers of assistance from others but stated that she was learning to accept them and to ask others for help when she needed it. She mentioned formal supports such as the child care subsidy for her daughter to attend child care while she took courses and the hamper from her child's school with enough food for all four children at Christmas time. She also spoke several times about her fiancé who was a major source of support in her life.

#### Common Trends

Several common trends emerged from the research that was conducted. They are statements that were obtained from the group of participants and they are a more general representation of the study than those that were found in the individual interviews. It was observed from conversations with participants that their disabilities were unique and the issues they described were somewhat different from those of other participants. Therefore, the individual interview themes were more specific and more descriptive of the individuals experiences than the common trends.

The common trends were derived through observations of the personal themes. The statements were grouped according to the questions that were the purpose for conducting research with parents who had disabilities. The first

question was "What were the additional challenges parents with disabilities encounter with their children?" The second was "How did parents with disabilities cope or adapt to overcome these issues?" Statements discussing additional challenges were grouped according to the first question and ways that parents coped or adapted were grouped according to the second question. A third group of trends was the attitudinal barriers and messages that participants received about being a parent with a disability. Informal and formal supports that participants used as parents with disabilities were a fourth group of trends. There were some trends that were not relevant to the questions and they were placed in a fifth group.

#### Additional Parenting Challenges

One of the challenges discussed was that activities with children were limited or different due to the parent's disabilities. All participants discussed this issue. They stated limitations such as not being able to drive, inability to participate in physical activities, not being able to assist a child to make crafts and not being able to read to children. Another trend that was discussed by four participants was concerns of needing to depend on children to help them or to look after them. One of the participants stated,

the fear of acquiring more disabilities, becoming more of a burden. The concern I'm having is becoming taken care of by your kids. Well it is because I work in a personal care home. I see disabilities all day and people have to - even the community - how people are telling me how they have to live with family sometimes. And family taking care - while kids taking care of parents and it's kind of - I would like to remain as independent as I can for a long time cause I can not do what I used to be able to do. I used to be able to build things and that and now I can't.

Physically, I can't do what I used to be able to do and that's a concern because I seem to depend more and have to ask them more and more to do more physical work and like repairs and things like that, painting and my concern is when they're all gone I won't have any one to ask and I don't want to have to bother them to you know come back to do these things.

Two participants mentioned that they initially found it difficult to accept offers of assistance from others. Over time they have learned to accept help and to ask for it when they felt it was needed. The participants who identified themselves as being blind or visually impaired stated that it was more challenging to get around with their children because they could not drive a car. Two participants who identified themselves as having physical limitations and one who had chronic pain stated that they found it difficult to lift, carry or hold children. Two participants who had physical limitations stated that they were unable to go to public buildings or other people's homes that weren't accessible for people with physical disabilities.

#### Attitudinal Barriers

Secondly, participants expressed concerns regarding attitudinal barriers and society's perception of people with disabilities being able to parent. One parent's response to this issue was "society is a handicap for people with disabilities."

#### Adapting or Coping with Additional Parenting Challenges

In the third group of trends participants discussed ways of coping or adapting to issues. One of the participants said that when people asked him

questions about parenting with a disability he would explain things to them and turn his answers into an educational aspect. Two participants discussed how they adapted activities so they were able to participate. One participant stated that she changed the environment of the activity such as placing her child on a chair rather than trying to sit down on the floor to play with her. The other participant said she was unable to participate in sports with her children but found ways to adapt some types of activities. The participant was able to be in the pool with her children by walking beside them in the water. She also wore an aerobics belt and was able to do a form of side stroke. Watching their children play sports, going for groceries together, talking, singing, playing table games, doing crafts, reading together, telling stories, going for trips on the bus and watching movies together were some activities participants enjoyed doing with their children.

#### Informal and Formal Supports

In the fourth group of trends participants talked about informal and formal supports. Six out of eight participants stated that they knew other parents with disabilities. Seven out of eight participants referred to their children and spouses as the most important people in their lives. Extended family and friends were another source of support. Participants also mentioned formal resources such as the child care subsidy, daycare, support groups for parents with disabilities and funding for a homemaker for three hours a week so a participant could have her home cleaned. Another resource that was mentioned by a participant was a

medicine dropper marked with a high visibility marker so she could see to measure medication for her child.

### Miscellaneous Trends

In the Sixth group of trends Five out of eight participants stated that their children were more empathetic and understanding towards people with disabilities. And finally, all the participants stated that if they had a chance to do it all again, they would.

The common trends of the study are as follows:

#### Additional Challenges of a Parent with a Disability

- activities were limited or different due to the parent's disabilities such as not being able to take children on outings if the parent could not drive or participate in sports activities with children
- participants raised concerns of being dependent on children to help them or look after them
- a challenge for some participants to accept offers of assistance from others or to ask for help after the onset of the disability as they were used to being independent
- not being able to lift, carry or hold their children was a concern expressed by some participants with physical disabilities or chronic pain
- not having access to some public buildings and private homes with their children was a concern for some participants with physical limitations

### Attitudinal Barriers

- participants received negative messages from family members, the general population and health care professionals concerning their ability to parent

### Coping and Adapting to Additional Parenting Challenges

- adapting activities or changing the environment of the activity such as sports, swimming and games so parent could participate

### Informal and Formal Supports

- participants used resources such as daycare, a homemaker to clean the house, and belonged to support groups for parents with disabilities
- participants gave and received support from other parents with disabilities
- children and spouses/partners were the most important people in participants' lives, but they also received support from extended family and friends

### Miscellaneous Trends

- children were more empathetic and understanding towards people with disabilities
- participants said if they had a chance they'd do it all again

### Summary

It was observed that there were some differences in the trends between the disability groups. Only the blind and visually impaired participants discussed

concerns of not being able to drive their children to activities. Participants with physical limitations and chronic pain had difficulty lifting, carrying or holding their children. Participants with physical limitations stated that some buildings were not accessible for people with disabilities. These were issues that were not expressed by participants in the other disability groups.

There were several trends that were reflective of all participants and it was observed that they would be thoughts expressed by many parents who do not have disabilities. Even though the participants stated that the activities they did with their sons and daughters were different due their limitations these are still activities that other mothers and fathers would do with their children. Many other parents would also say that their partners and children are the most important people in their lives and if they had a chance they would do it all again. Therefore, the experiences of parents with disabilities are similar to those who do not have additional challenges. The majority of the participants stated that their children were empathetic and understanding towards other people with disabilities. I felt this was one of the most liberating findings obtained from this research. One participant stated, "being a parent with a disability raises kids to be more aware of what's on the inside rather than what's on the outside." Another statement was "Maybe the kids are more in tune with the different types of people not everyone being the same." Another participant talked about her five year old daughter's sensitivity to people with special needs.

And I do think my disability has strongly effected her sensitivity cause I've never talked about disability and she talks about it all the time. And she's very sensitive to people with any special need or that are sick. I mean,

the next time she sees them she will ask them without my prompting, not that I would prompt her. Are you feeling O.K. now?

She is also sensitive to her mother's disability and will say things to her like "you know mommy if I could when I was in the orphanage I wanted to leave China and if I could have picked a parent I would not change anything about you except your disability. I would take it away." The participant said that she goes around telling people her mom has a broken arm which is how she sees her mother's disability at the age of five. Participant Three described her daughter's empathy towards her as a blind person.

One of the really nice things I experienced as a parent who is disabled or visually impaired is my daughter whose obviously the most empathetic little girl I've ever known. She was still in a crib so she would not have been - she was maybe a year and a half years old and she was trying to tell me something. She was late talking. She was trying to tell me something and I couldn't understand. And I said honey I just don't understand and in frustration she took my hand, took her blanket, punched, like strongly, put her blanket in my hand with her hand and then pulled it up to show me what she wanted. She wanted me to cover her up but she didn't want to do it herself. She wanted me to do it and kissing her and stuff but I hadn't covered her and she didn't know how to tell me that then. Every time she does it on a daily basis. She'll look up and say look at this and she puts my hand to touch and that's the most liberating feeling of I don't know how to say it. I've never felt like anybody's ever understood. Anyone I'm talking to, any worker with blind or visually impaired, except my daughter. My daughter understands from living with me exactly what I can and can not see.

Participant Seven stated that an advantage of being a parent with a disability is that her children respect people with disabilities.

For example there's a child in my daughter's class that has ADHD and he has a lot of trouble controlling himself. And all the children tease him and give him a hard time. And what she's done is she's decided that she will help him. So, she's come up with a plan that if he (her friend) behaves in class, she'll give him her stickers when she behaves in class, she'll give him her stickers when she behaves and just that incentive she's trying so

hard to behave when the teacher's just floored. It was her decision. She made this plan all by herself, and she (teacher) called me on it, and I'm just well, you know that's because she experiences this at home. They learn disability.

Participant Seven also stated,

the kids don't point at people that have disabilities when you see other children pointing and staring. And they'll be the first ones to open a door for someone that needs help. Without question they'll be right there when you see even adults not do it. So, it's teaching a generation on how to act.

Thus, it is evident that these children have received positive messages about people with differences and will understand that they are just as capable as anyone to participate in society.

Another topic that emerged during interviews that was not related to parenting issues was participant's use of computer technology and other assistance to help them with daily living. All of the participants had computers. I was able to correspond with all of them by e-mail to discuss their interest in participating in the study and to arrange interview times. Six out of eight parents used adaptive software packages such as Naturally Speaking, JAWS and ZoomText. One participant stated that there were items in his home such as a talking clock, a talking thermometer and a talking timer. Two participants used guide dogs, one participant used a manual wheelchair and another participant used a cane to help her walk.

In summary, participants discussed additional parenting challenges they encountered concerning their disabilities. There were several discussions about attitudinal barriers or messages participants received from other people and the

impact they had on them. Participants recounted examples of how they coped or adapted to overcome disability related situations concerning their roles as parents. Other themes emerged such as children being more empathetic and understanding towards people with disabilities. All of the participants also stated that if they had a chance to have children all over again, they would. The next chapter is a general discussion of the current research project.

## Chapter Four

### Discussion and Implications

#### Introduction

This chapter discusses findings and examines the implications of the current research results. Limitations of the current research project are addressed. Recommendations such as more formal resources and advice for parents or prospective parents who have disabilities are discussed as well as suggestions for further research in this area.

#### Discussion

There were common issues for all disability groups in the literature review and the current research findings. The issue of being stigmatized as parents with disabilities was a re-occurring theme as discussed by Jones et al. (1989); Conley-Jung and Olkin (2000); Dshen and Dshen (1989) and Barker and Maralani (1997). Several participants in the current study also discussed negative messages that they had received from others or attitudinal barriers that affected them as parents with disabilities. This is a negative experience that many people with disabilities encounter. Meadow-Orlans (1995) explained that historically there have been attitudes of fear, scorn and pity that have influenced the lives of individuals with disabilities. She stated that all disabled groups are effected by stigmatization. Social views that stem from historical attitudes still exist and people still treat individuals who have disabilities with scorn, fear,

distaste or pity. There have also been myths that have affected the experiences of parents with disabilities. Shaul et al. (1985) cited several pervasive cultural myths that exist for women with physical disabilities.

Pervasive cultural myths are:

- women with physical disabilities are overly dependent on other people. However, most disabled people live independently and have productive lives
- physical disability is contagious or inherited but only a small number of disabilities are genetically inherited
- physically disabled people are asexual. It is sometimes difficult for non disabled people to understand that people with physical disabilities are also capable of having intimate relationships and being sexually active
- being disabled is depressing and dreary and a disabled person should not bring a child into that world. Not too many disabled people dwell on this negative existence. They enjoy the same types of activities as the general population does.
- physical mobility is essential to child-rearing. It is difficult for the general population to understand that even though a disabled mother might have mobility restrictions it is still possible for her to raise a child (p. 134).

These myths suggest that stigma continues to exist but it is hoped that through research and education such as disability awareness or sensitivity training seminars, attitudinal barriers will be reduced. As previously mentioned, one of the participants in the current research project stated that when people asked him how he managed as a parent with a disability he always turned the situation into an opportunity to educate them about how he was able to overcome additional parenting challenges. Therefore, other people with disabilities can also educate people about their disabilities by telling them that they are capable of being parents and explaining how they are able to overcome obstacles. There were other common themes such as the provision of adequate resources and social supports discussed by Jones et al. (1989), Meadow-Orlans

(1995), Shaul et al. (1985), Barker and Maralani (1997) and Handley et al. (2001).

Current research also points to the fact that there are limited formal resources for parents with disabilities. Two participants out of the eight identified that they participated in support groups for disabled parents. One participant stated that she received funding from the MS society for a homemaker who assisted her to clean her home. Two parents had their children enrolled in daycare but this is a resource that all parents can use.

Another common theme in the literature discussed by Jones et al. (1989), Dshen and Dshen (1989), Greer (1985), Blackford (1988), Kornblum and Anderson (1985) and Handley et al. (2001) was the possibility of over-burdening children when a parent has a disability. In the current findings, participants expressed concerns of being dependent on their children. They did not want to burden them with the responsibility of their care. Greer (1985), Kornblum and Anderson (1985), Shaul et al. (1985) and Barker and Maralani (1997) pointed out that children are more tolerant and sensitive to people who are different from themselves.

Parents who participated in the current research project also stated that they felt their children were more sensitive and understanding toward others with disabilities. Participants recounted examples of how their children were more understanding of other people's differences. Findings from Barker and Maralani (1997) and Dshen and Dshen (1989) suggested some parents with disabilities found transportation and traveling with their children outside the home was

limited.

Participants in the current study also reported that transportation was an issue when they were unable to drive. One participant discussed the fact that there was no access to Handi Transit for blind people in her community. Two other participants stated that activities with children were different from those of other parents because they were not able to drive.

There were some differences between the previous research findings and those of the current study. Greer (1985) and Shaul et al. (1985) discussed the issue of discipline as an area of concern for parents with physical disabilities. None of the participants in the current study discussed concerns of disciplining their children. They may not have used physical punishment to discipline them or did not see this issue as an additional challenge due to their disabilities. In the current research findings, all participants reported that activities with children were limited or different due to limitations regarding their disabilities. This was an issue that was discussed minimally in the literature. Parents with disabilities who responded to the survey conducted by Barker and Maralani (1997) pointed out that they found it more difficult to participate in recreational activities with their children. Thomas and Kalucy (2003) stated that children of mentally ill parents are isolated when their parents lack motivation to participate in activities with them or help them to socialize.

It was also observed that the majority of the previous research concerning parents with disabilities only focussed on one disability group. The current research project was conducted from a cross disability perspective and a range

of parents with disabilities were interviewed. Barnes and Mercer (2003) discussed the fact that disabled people were viewed as unfortunate by society because they were unable to enjoy social interactions such as marriage, parenthood and other everyday functions. They were an oppressed group and encountered discrimination in the built environment, employment, leisure and personal relationships. What emerged from their individual, personal troubles was a collective of injustice. Disabled people as a collective challenged society to listen to what they had to say, and to accept them as an integral part of society. It is evident that many voices together make a stronger stand against the dominant, oppressive views of society. The voices of parents with disabilities, in this study, who spoke generously about their experiences throughout the research process were a strong collective of individuals who pointed out that disabled people are able to be parents.

#### Limitations of the Research

The population that was selected for the study was a diverse sample. There were variations regarding age, sex, type and onset of disability. Three participants acquired disabilities after they had children and there were several interview questions they were unable to accurately answer. In particular those questions concerning parenting with a disability prior to children's birth and after they were born. The original criteria for selecting participants for the study had been to interview parents who had disabilities prior to having children but it was difficult to find enough participants to meet this requirement. Ages of children

ranged from two years to twenty three years of age. The original age criteria for children was from infancy to twelve years of age. This criteria was also extended to include more participants. Education levels, socio-economic status and employment also varied among the participants. Meadow-Orlans (1995) pointed out that there are differences among each disability group. She stated,

Variations in etiology contribute to functional and social diversity and age at onset or degree of impairment are associated with cognitive functioning and educational achievement, especially among those who are deaf. (p. 58)

These were issues that were difficult to control considering the range of demographic characteristics and disability groups that were included in the study.

It was not possible to generalize the findings of this research project and the sample that was recruited is not representative of all parents with disabilities. The perspectives of these participants may not be similar to other disabled parents.

The recruitment of parents with mental health concerns was limited. Staff were approached who worked for mental health agencies but there were no responses from prospective participants. A staff person at the Moods Disorders Association of Manitoba approached parents on my behalf. Consent forms were faxed to the organization but they were never signed and returned. However, there was one parent with mental health issues included in the sample. There is not enough information from one individual's interview to make inferences or comparisons, particularly with previous research findings.

One participant dropped out of the research process after she had

participated in the first interview. When the parent was approached to discuss her themes from the first interview she chose not to participate. Therefore, this limited the data of the study. Padjett (1998) discussed several threats that affect the credibility and trustworthiness of qualitative research., including reactivity, the researcher's biases, and the respondents' biases.

In respect to reactivity, the researcher's presence in the field can affect the research. During interviews, I chose to disclose that I had a visual disability. My role as interviewer may have influenced the interviewee's attitudes, beliefs and perspectives regarding disability issues in general.

Possibly my biases as a disabled person may have distorted the research. I am not a parent with a disability and did not need to worry about expressing my own opinions or discussing personal experiences that may have influenced interviewees' responses. There was some general discussion about using adaptive technology and some disability related issues. Perhaps disclosing personal information may have influenced how the respondent answered the questions. Padjett (1998) explained that it is important to maintain an emotional balance as a researcher in the field. It is important not to become too close or distant from the situation. Therefore, there were some occasions when I was too close to the situation regarding disability issues. I had conversations with participants about using Handi Transit, a public transportation service for people with disabilities. I also spoke with respondents about the adaptive technology I use and its effectiveness. My opinions regarding these topics could have influenced interviewees' responses.

Credibility related to the reliability of the coding and identifying themes is a limitation. I conducted the data analysis and the findings of the research project are at the discrepancy of my own interpretation.

#### Recommendations and Advice to Improve Social Supports for Disabled Parenting

Participants offered suggestions regarding improvements for parents with disabilities. Several participants stated that there is a need for more support groups for parents and people with disabilities. One participant discussed the fact that these groups are often offered in the evening and some parents would not be able to attend them due to their parenting responsibilities at home. She suggested that they should be offered during day time hours while children were in day care or at school. She indicated that they could have childcare available for parents when they attend support groups. She also stated that there could be support groups for children of parents with disabilities.

Participants' mentioned that there needs to be more education or disability awareness regarding parenting with a disability. There needs to be more information for the general population. There could be more sensitivity training in the schools for teachers and children. Health care professionals also need information so they can provide adequate services to disabled parents and their families. They need to learn that people with disabilities are capable of being parents and that many of them are choosing this option. Participant Six suggested that educating the public could be done by offering seminars, written

documentaries and through public speaking presentations.

Participants made comments about what they would say to a person with a similar disability who is considering parenthood. Participants stated that they would tell someone with a similar disability to “go for it”, “just do it” and “definitely recommend it.” Participant Seven stated,

I would tell them to go ahead and go for it. There's gonna be obstacles. But as many obstacles that are there there's gonna be gates to open them. It all depends on your outlook. Anyone can find a fence to stop them, but if your outlook is positive, you'll find a gate to open them, it all depends on just how much you want that child and if you really really want that child, you'll find a way to make it work.

As quoted by another participant,

I believe that everybody if they desire to be a parent should not let the disability interfere with the decision. Depending on what the disability is it makes things not always easy but don't give up the opportunity to be a parent.

Other suggestions offered by participants were to make use of resources, services and to ensure that they had a good support network of people in their lives.

#### Recommendations to Improve Social Supports for Parents with Disabilities

- there is a need for more support groups for parents with disabilities
- need for more education or disability awareness regarding parenting with a disability for the general population, teachers and health care professionals

#### Advice for Perspective Parents with Similar Disabilities

- participants said they would tell other people with disabilities “to go for it and have children”, “do it”, and they definitely recommend having children
- make sure you use resources, services and make sure you have a good

support network of people in your life

### Future Research

Most of the literature that was found for the current study focussed on the perspectives of parents with disabilities. It appeared that there were fewer articles regarding children of parents with disabilities. This is an area where more research could be conducted. One of the participants in the current study suggested that children of parents with disabilities be interviewed to determine their perspectives of having a disabled parent. It was observed that there were few articles regarding grandparents with disabilities. Grandparents are often important people in the lives of children and want to take an active role in caring for them and be a part of their activities. Therefore, it would be interesting to explore their perspectives regarding their additional challenges as grandparents.

Parents' perception of their children as being quite resilient was a finding of the current research project. Participants stated that they felt their children were more tolerant and understanding of other people who were different than themselves. Parents also commented on their children's sensitivity and understanding regarding their disabilities. This was an unanticipated finding and further research could be conducted with this particular topic. Future studies could explore parents' perceptions of their children's acceptance of having a parent who has a disability. Researchers could conduct qualitative research to determine how parents feel their children respond to their differences in the home, when they are in public together and when the children are with their

peers.

Researchers could interview children to determine their perceptions of having parents' with disabilities. In-depth interviews could explore children's responses of how they feel about living with a disabled parent. Studies could determine their level of sensitivity or understanding of living with someone who has a disability. Interviewers could ask children questions about how they feel when they are out in public with their parents and how they respond to their friends when they find out their mom or dad has a disability. Interviewers could also determine children's level of tolerance and understanding of other people who are different. They could be questioned about how they would react and whether or not they would feel comfortable helping someone with a disability.

Previous research has explored the problems in families when a parent has a disability. Kirshbaum and Olkin (2002) pointed out that research has suggested that professionals see disabled people's ability to parent as very limiting and this could lead to maladjustment in children. The authors also stated that previous research has examined people with disabilities from a pathological lens. Future research should be conducted from a different perspective.

Kirshbaum (2000) discussed a disability culture perspective of conducting research. This perspective focuses on the social meaning and social obstacles of people with disabilities and their families as the primary problem rather than pathologising the families or individuals. She stated that there is scant research on the positive outcomes for parents and their children. Future research could focus on how parents with disabilities deal with obstacles rather than

emphasizing their problems and turning the results into a positive perspective.

## Conclusion

It was hypothesized that parents with disabilities who participated in the project would encounter additional environmental and attitudinal barriers that are not experienced by other parents. It was also thought that there would be issues common to all groups of disabled parents. Information obtained from interviews with participants revealed that they did encounter inaccessible buildings, limited public transportation for parents and their children, limited support groups, and attitudinal barriers. There were issues that were common to more than one disability group such as attitudinal barriers or messages from others and difficulty participating in physical activities with children.

The current research project has attempted to explore positive outcomes by asking participants questions to identify the additional challenges faced by parents with disabilities. They discussed ways of adapting such as use of resources, suggested advice for other parents with similar disabilities and the joys and rewards of being parents. Participants made positive comments about having children such as "The amazement. It's all worthwhile." Participant two stated, "I look at my life before then and it seems empty. Having children definitely changes the focus of your life and obviously it was a great experience. It is a great experience or I wouldn't have adopted a second." Participant three quoted in her interview, "she's more cherished because she is such a gift that I didn't even know what a gift she was before I had her. It wasn't until the life

situation made me realize more and more I wish it was twins you know but so anyway she's just rewarding." As quoted by Participant Four, "when I was diagnosed with MS I thought it was the end of the world. I would never have children you know you always think the worst. So having children was like the biggest accomplishment. It was like you know, I was ecstatic." When another participant was asked what the joys and rewards of being a parent were he answered, "watching the boys grow up or do things, things that make them happy." Another parent stated, "I love seeing them learn new things. They're both at such different ages that it's interesting." Participant Six also discussed some of the joys and rewards he encountered as a parent and he stated, "enjoying the everyday aspects of them and ... it certainly can be fun, it can be joyful." In general, participants all discussed challenges of being parents' with disabilities. Interview results revealed that they were resilient and found ways to overcome obstacles that affected their roles as parents. It was concluded that the joys and rewards that the participants of this study experienced outweighed the barriers and prejudice they encountered as parents with disabilities. Disabled parents experiences, regardless of additional challenges aren't any different than those of other parents. Therefore, it findings of the project have produced positive outcomes.

I learned from conducting this research project that people are resilient. Participants talked about how they managed as parents with disabilities and it was evident that they were determined to overcome any obstacles that stood in their way. For example, I thought it was fascinating to talk to a participant who

chose to adopt two children. It was also interesting to speak with another interviewee who was in the process of adopting a child. I did not think of adoption as being a topic that would be discussed when I originally undertook this study.

I discovered that there was a lot of overlap among the four disability groups that were chosen for the study. Several participants had more than one disability and could fit into a variety of disability groups. Most of the research findings that were cited in the literature review discussed the issues of parents with only one disability and there was no mention of multiple limitations. This also made me realize how determined people are.

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## Appendix A

### Telephone Interview Guide

Participation is voluntary and you do not have to answer any question that makes you uncomfortable.

1. Please tell me a little bit about yourself so I can get to know you?

Probes:

- Who is in your family?
  - Tell me about your disability?
  - How long have you had this disability?
  - What do you do/what is a typical day in your life?
  - Who are the important people in your life?
  - Tell me about your children such as their sex, age(s), interests?
  - Do your children live with you?
  - Do you have a partner or spouse living in the home with you?
  - Does your partner or spouse have a disability? If so, what is it?
  - Do you get help with your children? Examples might be day care or respite.
  - What resources do you use as a parent with a disability and how easily are they accessible to you?
2. What are the concerns of parents who are blind/visually impaired, have physical disability or who have physical disabilities, chronic illnesses or mental health concerns?

3. What are the experiences in regard to knowing other parents who are blind/visually impaired, have physical disabilities, chronic illnesses or who have or who have mental health concerns?
4. How do parents who are blind/visually impaired, those with physical disabilities, chronic illnesses or mental health concerns cope with the reactions of others regarding their status as disabled parents?
5. What types of activities do blind/visually impaired parents, those with physical disabilities, chronic illnesses or mental health concerns do differently from non disabled parents and in what ways are they different from those of other parents?
6. What messages have you received over the years regarding parenthood?

Probes

- before you had children
- when you announced your pregnancies
- after you had children
- how have you been affected by these messages?

7. What is being a parent like for you?

Probes

- joys and rewards (past and present)
- impact of disability on children and family life
- impact of children on your own health and well-being
- what sort of supports do you get from partner, family friends, etc.

8. What do you wish for or did you wish for in the past that would make your job as a parent easier and more rewarding?
9. What would you say to a parent with a similar disability who is considering parenthood and asks for your advice?
10. If you had a chance to do it all again....would you? What would you do differently? What in your opinion, could be done to improve things for parents with disabilities?
11. Can you think of any advantages or disadvantages of being a parent who is blind/visually impaired, has a physical disability, a chronic illness or mental health concern?
12. What else would you like to contribute to this discussion? Are there any other important areas that we missed?

The questions were adapted from studies conducted by Conley-Jung & Olkin (2001); Shaul, Dowling & Laden (1985) and Prilleltensky (1998)

## Appendix B

## The Parenting with a Disability Research Project Consent Form

Researcher: Elizabeth Struthers

Supervisor: Dr. Don Fuchs

## Description of the Research Project

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.

The purpose of the research project is to determine the perspectives of parents who are blind/visually impaired, have a chronic illness, a mental health concern or a physical disability. The additional disability related challenges parents encounter with their children will be explored. Children of these parents must be between birth and twelve years of age. Parents will be asked how they have coped or adapted in order to overcome these issues and what recommendations can be suggested to help others who are contemplating parenthood or who are already parents?

Participants will be asked to participate in two telephone interviews.

Telephone interviews will be tape recorded. The interviews will be transcribed verbatim from cassette tapes by a hired note taker.

Confidentiality will be maintained throughout the research process. Only the researcher, note taker and other members of the research committee will have access to information collected throughout the study. Participants will not be identified by name within the research findings. All information obtained from participants will be stored on computer files or in filing cabinets and will not be shared with people outside of the research project.

Research Participants will be asked to review the themes that will emerge after the interview has been transcribed to ensure that the statements they provided were accurate. Participants will be provided with a report of the research findings at the end of the study. They will receive a letter of thanks for participating in the research project along with a resource package consisting of pamphlets, newsletters, and listings of web sites for parents with disabilities.

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 researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice 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

This research has been approved by the [insert full name of appropriate REB]. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at 474-7122 or e-mail . A copy of this consent form has been given to you to keep for your records and reference.

Elizabeth Struthers  
Telephone:

Participant's Signature \_\_\_\_\_  
Date \_\_\_\_\_

Researcher's Signature \_\_\_\_\_  
Date \_\_\_\_\_

If you wish this form can be made available to you in an alternate format of your choice to ensure you review and provide your consent to participate in the research project.