

The Parenting with a Disability Research Project

BY

Elizabeth Struthers

A Thesis submitted to
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In Partial Fulfillment of the Requirements for the Degree of

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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.

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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