VISION REHABILITATION SERVICES IN NEWFOUNDLAND AND LABRADOR: IDENTIFYING THE NEEDS, BARRIERS, AND PATHWAYS

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VISION REHABILITATION SERVICES IN NEWFOUNDLAND AND LABRADOR: IDENTIFYING THE NEEDS, BARRIERS, AND PATHWAYS

by

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ABSTRACT

In Newfoundland and Labrador there are over 15,000 people that self identify as living with vision loss (Statistics Canada, 2006) and one in eight people can expect to live with significant vision loss after the age of 75 (CNIB, 2008). Given that the proportion of the population over the age of 65 is growing faster in Newfoundland and Labrador than anywhere else in Canada age-related vision loss will have a significant impact. Despite this prediction and the documented benefits of vision rehabilitation services, underutilization is a concern. The purpose of this research was to identify the needs, barriers, and pathways to accessing and using vision rehabilitation services in the province. A qualitative research approach was used to explore the topic and individual interviews were conducted with sixteen participants. The research informs the expansion and improvement of vision health and rehabilitation programs and the work of the CNIB Newfoundland and Labrador Vision Rehabilitation Committee.

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Chapter 1

Introduction

The purpose of this study was to explore the needs, barriers and pathways to accessing and using vision rehabilitation services in the province of Newfoundland and Labrador. This thesis is a report of the results of a qualitative study carried out with a small sample of clients of CNIB in Newfoundland and Labrador. This first chapter of the thesis outlines the purpose of the study, presents the research question, and provides information on the context of the problem and its significance to social work practice and policy. The chapter concludes with a discussion of the theoretical framework.

Purpose of the Study

The purpose of this qualitative research study is to assist the CNIB Newfoundland and Labrador Vision Rehabilitation Committee in the development of a provincial vision health strategy by identifying the needs, barriers and pathways to accessing and using vision rehabilitation services in Newfoundland and Labrador. Information obtained from this research will be used to aid the committee, comprised of community members and groups with an interest in the area of vision loss, in the development of a vision health strategy for Newfoundland and Labrador. The goals of the strategy are to facilitate the best quality of life for people living with vision loss in the province of Newfoundland and

Labrador and reduce the incidence of vision loss and blindness through public education and early detection (CNIB, 2010). There is national and international data supporting the importance of vision rehabilitation services and the use of assistive technology for people with vision loss (CNIB, 2010; Gold & Zuvela, 2005; Muzychka, 2009) but there is limited research about the availability and utilization of these services in Newfoundland and Labrador.

The Research Question

The effects of vision loss are profound and costly, with direct and indirect implications for individuals and government. Many individuals living with vision loss are unemployed or underemployed, socially isolated, living below the poverty line, and face three times the risk for depression than the general population (Burhmann, Fielden, & Hodge, 2007). For governments, the impact of vision loss means increased costs in social assistance, social supports and programs, and early reliance on home and community care as well as social welfare systems (Access Economics Pty Limited, 2009).

For the purpose of this study the definition of vision loss as provided by the CNIB has been used: "…any chronic visual deficit that impairs everyday functioning and is not correctable by ordinary eyeglasses, contact lenses or surgery. Visual impairment can

range from mild or moderate to very severe where no useful vision remains" (CNIB, 2007, p. 6). Vision loss can be a result of eye problems that are present from birth as a result of genetic disorders that cannot be medically corrected, conditions that appear later in life, infections, accidents, environmental factors or as a result of other broader underlying medical problems, including diabetes, specific cancers, and multiple sclerosis (CNIB, 2011b; Jin & Wong, 2008; Muzychka, 2009; Pollard, Simpson, Lamoureux, & Keeffe, 2003).

The impacts of vision loss can be minimized with vision rehabilitation services (Lighthouse International, 2010; Muzychka, 2009; Pollard et al., 2003). The term vision rehabilitation refers to supports and training aimed at enhancing the independence and mobility of people with vision loss in their homes and communities (Gold & Zuvela, 2005). Vision rehabilitation enables the development of skills and strategies needed to help people with vision loss enjoy safe, independent, and productive lives (Lighthouse International, 2010). Vision rehabilitation services considered in this study include low vision services, orientation and mobility training, independent living skills training, child and family services, career and employment services, counselling, assistive technology, and other support services such as access to community resources and information about concessions.[1] Assistive technology refers to the devices that aim to help a person achieve

[1] Concessions are discounts or exemptions granted by some businesses to legally blind individuals. Concessions vary by location but may include discounted admission to movies and events, discounted companion travel fares, and directory assistance exemptions.

a safe, independent, and productive life. It is important for all persons living with vision loss to avail of vision rehabilitation services and become skilled in the use of assistive technology.

The utilization of vision rehabilitation services at the onset of vision loss maximizes a person's independence and improves the development of new and modified life skills (Pollard et al., 2003). According to The Chicago Lighthouse (2011) it is most beneficial for a person to access vision rehabilitation services before their vision reaches 20/60.[2] Nevertheless, research has demonstrated that persons with mild to moderate levels of vision loss are less likely than those with severe vision loss to be aware of vision rehabilitation services (Mwilambwe, Wittich, & Freeman, 2009).[3] It has also been documented that even when the population with mild to moderate vision loss are aware of vision rehabilitation services they may choose not to avail of them because they believe such services are for people that are totally blind (Gold & Zuvela, 2005; Matti, Pesudovs, Daly, Brown, & Chen, 2010; Pollard et al., 2003).

Research from Canada, Australia, and Britain has found underutilization of vision rehabilitation services to be an issue. It is reported that only a small amount of those that

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[2] A person with 20/60 vision would need to stand twenty feet away from a letter that someone with normal (20/20) vision could see from sixty feet away (Newcomb, 2006).

[3] The World Health Organization (2003) defines mild vision loss as being between 20/30 and 20/60, moderate vision loss as ranging from 20/70 to 20/160 and finally severe vision loss is 20/200 or greater which is legally blind.

could benefit from vision rehabilitation are accessing any type of service (Gold & Zuvela, 2005; Overbury, Wittich, Ferraresi, & Southall, 2008; Pollard et al., 2003) and awareness of these services is low (Mwilambwe, Wittich, & Freeman, 2009). CNIB is the main provider of vision rehabilitation services in Newfoundland and Labrador. At a time when the demand for CNIB's services should be increasing they are experiencing a similar underutilization of vision rehabilitation services (CNIB, 2008).

The objectives of this research are

- to identify the needs associated with accessing and using vision rehabilitation services in the province;
- to identify the barriers preventing people with vision loss from accessing and using vision rehabilitation services in the province; and
- to identify potential pathways to accessing and using vision rehabilitation services in the province.

Based on the outlined objectives the research question is:

What are the needs, barriers, and pathways to accessing and using vision rehabilitation services in the province of Newfoundland and Labrador?

The framework of needs, barriers and pathways are used to explore: individual needs related to vision rehabilitation services, the barriers that prevent people from using

vision rehabilitation services, pathways to learning about, accessing, and using vision rehabilitation services, and about what more can be done to promote these services in the general public.

Context of the Problem

Researchers, eye care professionals, and service providers believe Canada is on the brink of an epidemic of age-related eye disease, due largely to the aging of the population. The number of people with vision loss in Canada has increased 37% in the last 10 years and is projected to double between 2006 and 2031 (Muzychka, 2009). No other province in Canada is likely to experience the impact of population aging as significantly as Newfoundland and Labrador. As a result of outmigration and lower fertility rates the proportion of the population of Newfoundland and Labrador over the age of 65 has expanded more quickly than any other province. This is a trend that is expected to continue for the next several decades (Department of Health and Community Services, 2007). Population aging will also have an impact on the number of persons in the province who will experience vision loss. There are over 15,000 people in Newfoundland and Labrador that self-identify as having a "seeing disability" (Statistics Canada, 2006). In addition to this, one in eight people in the province can expect to live with significant vision loss after the age of 75 (CNIB, 2008). It is anticipated the demographic shift will result in a dramatic increase in vision health diseases in

Newfoundland and Labrador leading to a potential crisis in vision health and rehabilitation resources (Muzychka, 2009). Without the development of vision related policies the province will not be able to adequately respond to the issue.

Government of Newfoundland and Labrador strategies and policies are not void of attention to vision health issues. The Provincial Healthy Aging Policy Framework is a document aimed at improving the independence, health, and well-being of seniors in the province. Despite its focus on seniors the framework takes a lifelong approach to healthy aging, including a lifetime approach to vision health. One of the goals of this framework is "increased support for a lifelong approach to protect oral health, vision, hearing and speech" (Department of Health and Community Services, 2007, p. 18).

The government has also begun developing a Strategy for the Inclusion of Persons with Disabilities. A series of public consultations were held to inform this new strategy. The consultations were in response to the Government of Newfoundland and Labrador's (2007) document *Our Blueprint for the Future*. The Government of Newfoundland and Labrador has stated they are committed to enhancing the inclusion of persons with disabilities in all aspects of society. The consultations were held to engage people with disabilities in developing recommendations and strategies to address barriers to public services, education, and employment opportunities for people with disabilities (Human Resources, Labour and Employment, 2010).

These government initiatives are necessary but not sufficient in addressing the growing number of people living with vision loss in the province of Newfoundland and Labrador. There is a need for a provincial vision health strategy and associated policies to address the unique aspects of vision loss such as the prevention of vision loss, access to affordable assistive technology, and universal access to vision rehabilitation programs and services.

Significance of the Research for Social Work

A review of the literature revealed there is limited research related to social work practice within the areas of vision loss and vision rehabilitation. However, social workers have a long history of working within the broader field of disabilities advocating with and on behalf of people with disabilities and working to eliminate the societal barriers experienced by the population (Mackelprang & Salsgiver, 1996).

People living with vision loss may experience significant psychosocial problems due to their disability. Losing all or part of one's sight can have a profound effect on a person's quality of life and has the potential to affect all aspects of their life including employment, personal relationships, daily activities, and community participation. The experience of living with vision loss can mean the loss of opportunities, access, and independence. Thus, social work involvement in the field of vision rehabilitation may

occur at all levels of practice: macro: social work at the societal level; mezzo: social work at the community level; and micro: social work with individuals and families.

At the macro level social workers can be involved in the development and amendment of national and provincial policies and practices that affect people living with vision loss. At the mezzo level social workers work with communities, agencies, organizations, and groups to ensure their programs and services are available and accessible to people with vision loss. Finally, at the micro level social workers provide direct service to individuals and families affected by vision loss.

Along with this conceptualization of the levels of social work practice, a framework of social work roles developed by Steven Hick (1998) is helpful to consider the involvement of social workers in a vision rehabilitation model:

Educator: Social workers may be involved in providing people with information related to vision health, living with vision loss, and programs and services. Social workers may also have a role in teaching individuals, families, communities, and organizations a variety of skills ranging from practical vision rehabilitation skills to communication skills.

Advocate: Social workers may advocate on behalf of individuals, families, groups, or communities on issues related to vision loss such as the rights to equal

employment opportunities, funding for assistive devices, or issues related to accessibility.

Analyst/Evaluator: Social workers have strong analytical and evaluation skills that can be used to determine the effectiveness of available programs and services for people with vision loss.

Broker: Social workers may link individuals, groups, organizations, or communities with resources, programs, and services for people living with vision loss.

Facilitator: Social workers may play the role of group facilitator in a number of settings: client groups, community groups, or advocacy groups.

Counsellor: A social worker may help individuals and families develop ways of coping with vision loss. They can help people recognize and manage feelings, identify and support strengths, break down problems into manageable pieces, and assist people in focusing on goals and ways of achieving them.

More specifically, the Newfoundland and Labrador Social Workers Act (2010) defines social work as:

> The assessment, remediation and prevention of psycho-social problems and the enhancement of the social, psycho-social functioning and well-being of individuals, families, groups and communities by:
>
> 1. Providing direct counselling and therapy services to a client,
> 2. Developing, promoting and delivering human service programs, including those done in association with other professions,
> 3. Contributing to the development and improvement of social policy, and
> 4. Conducting research in the science, technique and practice of social work (2010 cS-17.2 s2).

As noted above, the goals of the CNIB vision health strategy that served as the motivation for this research study were to facilitate the best quality of life for people living with vision loss in the province and reduce the incidence of vision loss and blindness through public education and early detection (CNIB, 2010). These goals are in line with the practice of social work in Newfoundland and Labrador and are therefore suitable for a Master of Social Work thesis research topic.

Social workers have the capacity to work in a variety of areas and in a number of different roles. Given their broad scope of practice social workers could play an essential role in the design, implementation, and evaluation of programs and services that address the needs, barriers, and pathways identified by participants in this research study.

Theoretical Framework

The theoretical framework guides the research and the data analysis. It is a way of explaining, predicting, and understanding the phenomena being studied (Rubin & Babbie, 2007). A social inclusion framework was used in this study because vision rehabilitation programs and services are an essential component in the social inclusion of people with vision loss. In developing a provincial vision health strategy it is important to know if the current model of vision rehabilitation services in Newfoundland and Labrador facilitates the inclusion of people with vision loss or if people are experiencing barriers to accessing vision rehabilitation programs and services. It is also beneficial to identify individual pathways to vision rehabilitation services to understand how people find and access these services and if there are potential pathways that may be explored.

People living with vision loss are at an increased risk of experiencing social exclusion due to the nature of the disability. "Seemingly ordinary, everyday activities such as traveling to familiar and unfamiliar places, caring for a child or an ailing parent, reading a newspaper and succeeding at work can all present extraordinary challenges. Family relationships may become strained. And without assistance in adjusting to vision loss, many people (particularly seniors) may live in isolation and fear" (CNIB, 2011a, How does vision loss affect people? ¶ 1).

Many people with vision loss live without the protective factors that help decrease the risk of social exclusion. Protective factors are traits, situations, or circumstances that

contribute to a person's social inclusion and include having adequate income and housing, satisfying personal relationships, a social support network, access to health services, access to transportation, skills and resources to find and obtain needed services, and higher levels of education (Federal/Provincial/Territorial Ministers Responsible for Seniors, 2007). Protective factors also include being in good health, feeling safe in one's neighbourhood, feeling connected and valued by others, and experiencing meaningful roles in society (p. 11). Vision rehabilitation training enhances the independence of people with vision loss and assists them in developing and maintaining these protective factors in their lives.

The concept of social exclusion emerged in the 1970s and 80s as a response to the growing social divides in European society (Frazee, 2003; Saloojee, 2001). These social divides evolved from new labour market conditions and the inadequacy of existing social welfare provision to meet the changing needs of more diverse populations (Frazee, 2003). More recently, Stanley (2007) describes social exclusion as the existence of barriers which make it difficult or impossible for people to participate fully in society or obtain an acceptable standard of living. The condition of vision loss results in barriers such as the need for alternative formats of text, safe mobility training, and access to assistive technology for education, employment and home.

Social exclusion has been associated with an increased chance of premature death, depression, increased disability from chronic diseases, mental health problems, increased

use of health and support services, caregiver burden, poor general health, and a reduced quality of life (Federal/Provincial/Territorial Ministers Responsible for Seniors, 2007). Social exclusion has been identified by the World Health Organization as a social determinant of health (World Health Organization, 2010). According to the World Health Organization (2010) social exclusion consists of:

> dynamic, multi-dimensional processes driven by unequal power relationships interacting across four main dimensions - economic, political, social and cultural - and at different levels including individual, household, group, community, country and global levels. It results in a continuum of inclusion/exclusion characterised by unequal access to resources, capabilities and rights which leads to health inequalities (¶ 1)

A social inclusion framework is a response to social exclusion. This framework highlights the need for all members of society to be able to participate as valued, respected, and contributing members of society (Frazee, 2003). It aims to open systems up to difference (The Roeher Institute, 2003) and calls for the validation and recognition of diversity and of people's lived experiences (Frazee, 2003).

Social inclusion is about eliminating the physical, social, economic, and political barriers separating people (Frazee, 2003; Hutchinson & Lee, 2004). It involves engaging in inclusive practices and the continuous evaluations of institutions, laws, policies, and practices to ensure the social inclusion of all populations is promoted (Saloojee, 2001).

Respect for differences needs to occur and barriers removed to ensure that everyone is able to effectively and equitably participate in all areas of society (Saloojee, 2001; The Roeher Institute, 2003).

There are many dimensions of social inclusion (Shookner, 2002). Several are relevant to those living with vision loss. Economic inclusion requires that people have adequate incomes to meet their basic needs and to participate in society. It involves the elimination of poverty and the reduction of disparities amongst various groups (p.5). This is an important component of inclusion for people with vision loss because only 25% of working-age people with vision loss are employed (CNIB, 2011a). This is despite the fact that the majority of people with vision loss are highly educated and qualified. This high rate of unemployment is contributed to outdated employer attitudes about the abilities of people with vision loss. Many people with vision loss live in poverty as a result of discrimination (CNIB, 2011a).

Functional inclusion enables people to be actively involved in society, values their social roles, and recognizes their competence while providing opportunities for personal development (Shookner, 2002). The functional abilities of people with vision loss are often overlooked in favour of outdated stereotypes that minimize the abilities and independence of people with vision loss.

Participatory inclusion involves empowerment and the freedom of choice. It provides people with the opportunity to contribute to their community and access

programs along with being involved in decision making (Shookner, 2002). People with vision loss often find themselves powerless and outside of the decision making process due to societal beliefs about the abilities of people with vision loss such as ideas they cannot travel independently, cannot participate in sports, and are not as educated as the general population.

Physical inclusion includes access to transportation, public places, and community resources. It provides opportunities for interactions between people and society in healthy and supportive environments (Shookner, 2002). Transportation is a recognized barrier for people with vision loss, especially in rural areas. A lack of public transportation limits access to public places and community resources because people with vision loss do not have the option to drive and do not always have friends or family available to provide transportation.

Political inclusion involves the development of policies and legislation that socially protect vulnerable groups and removes systemic barriers (Shookner, 2002). For people with vision loss political inclusion may include funding programs for assistive devices and policies promoting the employment of people with disabilities.

Relational inclusion includes belonging, respect, recognition, and access to resources (Shookner, 2002). People with vision loss often feel as though they are on the outskirts of society. There is little respect for and recognition of their abilities. They

have limited access to resources due to high rates of unemployment and an often inaccessible society.

Finally, structural inclusion focuses on community capacity building and options for change. It includes inter-departmental and inter-governmental links, accountability, and open channels of communication (Shookner, 2002).

Vision loss has profound impacts for individuals and society therefore individuals, organizations, and government must come together to bring about societal change to promote the inclusion of people with vision loss. They must work together to change the structures that exclude people with vision loss and make society convivial and accessible for all.

The Federal/Provincial/Territorial Ministers Responsible for Seniors (2007) developed a guide to assist organizations and governments in the screening of existing and planned programs and practices to determine their impact on social isolation. This guide was prepared in response to the recognition that social isolation is a significant risk for older adults with serious consequences on their quality of life. People with vision loss have a similar risk of social isolation, therefore the guide can be applied to the experience of inclusion for persons with vision loss.

Using the guide as a starting point, it can be seen that there are ways for organizations that offer vision rehabilitation programs and services, to promote the inclusion of people with vision loss in their programs and policies

- involve people with vision loss in planning, implementing, and evaluating the programs and policies that affect them;
- conducting a local scan of resources available to people with vision loss; and
- identifying local resources that can be utilized in program delivery.

According to the guide organizations can also identify and address real and potential barriers to participation by

- using flexible approaches that address the psychological, social, and physical aspects of living with vision loss;
- making efforts to approach those with vision loss that are isolated or at risk of becoming isolated;
- increasing accessibility to services by providing information and education to people with vision loss using a variety of methods that are sensitive to potential barriers (i.e. literacy, communication, etc.);
- addressing the transportation needs of people with vision loss; and
- ensuring their staff and volunteers are supported and provided with

ongoing training opportunities (Federal/Provincial/Territorial Ministers Responsible for Seniors, 2007).

Summary

The effects of vision loss have direct and indirect implications for individuals and government and are a growing concern in Newfoundland and Labrador due to population aging. Individuals living with vision loss face many barriers and are at a greater risk of becoming socially isolated. The predicted growth in service needs will have a profound impact on government policies and programs and for social work practice in the province. Vision rehabilitation services help enable people with vision loss live independent and fulfilling lives and to participate fully in society. However, not all people are accessing and using these specialized services. This research aims to explore the needs, barriers, and pathways associated with accessing and utilizing vision rehabilitation services in Newfoundland and Labrador.

It is anticipated this research will facilitate and inform the expansion and improvement of programs and services aimed at vision health and rehabilitation and the work of the CNIB Newfoundland and Labrador Vision Rehabilitation Committee. It will also add to existing knowledge about the experience of vision rehabilitation in this

province and about social work practice in that context. Most importantly it will give voice to those living with vision loss in Newfoundland and Labrador.

Chapter 2

Literature Review

Introduction

The purpose of the literature review is to determine what is known about a topic. A primary goal of this research was to understand access and utilization of vision rehabilitation services in Newfoundland and Labrador. Issues that emerged in the literature review were considered in terms of their relationship to the service user and their relevance as needs, barriers, or pathways. In addition to a review of the literature, the *HCS Disability Supports Project* (Goss Gilroy, 2007) and the *Environmental Scan of Vision Health and Vision Loss in the Provinces and Territories of Canada* (Muzychka, 2009) provided information about programs and services specific to Newfoundland and Labrador. This chapter will provide an overview of vision rehabilitation needs and services and the barriers and pathways to their access and utilization as identified in a review of relevant literature.

Vision Rehabilitation Services

In order to understand the needs, barriers, and pathways related to accessing and using vision rehabilitation services it is important to gain an understanding of vision rehabilitation services which are a key support for people living with vision loss. While

vision rehabilitation training cannot restore lost sight it can help a person maximize existing vision and to develop techniques to maintain an independent lifestyle. Vision rehabilitation services can enable a person to adjust emotionally to living with vision loss, travel safely, take care of their home, meet their career goals, and enjoy leisure activities (Lighthouse International, 2010).

CNIB is the main provider of vision rehabilitation services in Newfoundland and Labrador with other professionals providing some basic vision rehabilitation programs and services. For example, Itinerant Teachers work with CNIB to provide vision rehabilitation services to children and school aged youth in the areas of independent living skills and assistive technology. In addition to Itinerant Teachers, a limited number of optometrists provide low vision assessments to their patients. This research focused on the experiences of clients of CNIB.

Vision rehabilitation services provided by CNIB include

- low vision assessments: functional assessments of visual abilities, information and training in the use of low vision devices, and instruction on how to maximize residual vision;
- orientation and mobility training: instruction on how to move safely around the home, or when travelling outside;
- assistive technology services: information about the availability, selection, use, and purchase of devices best suited to individual needs. This is

accomplished through demonstration, assessment, training, technical support, and instruction on how to use current computer programs to access information and communicate independently;

- independent living skills training: life-skills training to help manage the essentials of daily living, with an emphasis on maintaining independence - including safe and effective methods of cooking and doing household tasks such as laundry, banking, writing, and personal care;
- career and employment services: employment assessments, helping individuals explore career interests, developing employment plans, marketing to potential employers, and investigation of job opportunities and accommodations;
- child and family services: supportive counselling, service coordination, information, advocacy, and programming for children and their families. Early intervention specialists work with children from birth to school age and their families to assess developmental needs associated with vision loss, taking into consideration additional disabilities, and environmental needs to help schools accommodate students with vision loss;
- adjustment to vision loss counselling: support to people as they adjust to vision loss. This can be accomplished through individual, family, or group counselling. Client group programs provide a venue to discuss

work, home life, activities of daily living, or leisure and community participation; and

- support services: information and advocacy support for resources available from CNIB as well as resources available from community partners focusing on social issues such as concessions, housing, finances, and leisure pursuits.

Health care providers, eye care professionals, and individuals with vision loss rely on organizations like CNIB to deliver vision rehabilitation services because often no other alternative exists (Muzychka, 2009). However, a lack of sustainable funding and increased difficulties with fundraising is making it difficult for CNIB to provide a consistent service even within small regions (CNIB, 2008). According to CNIB, the cost of providing vision rehabilitation services for people with vision loss in Canada was $32.8 million in 2007. In addition to this, the cost of special library services for people with vision loss in Canada was $7.4 million. Only 23% of these funds are provided by government. The balance is provided by support from the public (Access Economics, 2009).

Identified Vision Rehabilitation Service Needs

For the purpose of this research, the term need refers to the supports and services needed to enable a person to access and use vision rehabilitation services. Unless

indicated, the needs identified below are not specific to one vision rehabilitation service but to vision rehabilitation services in general.

Professional awareness and referral. There is a need for increased referral to vision rehabilitation services amongst all professionals. In a study by Pollard et al. (2003) only 46% of participants, adults with a visual impairment who were current patients at the Royal Victorian Eye and Ear Hospital, had been referred to vision rehabilitation services by an eye care practitioner. Other research indicates that the majority of those living with vision loss that are aware of vision rehabilitation services have been told about the services by family members and friends not their eye care specialist (Overbury et al., 2008). These findings are particularly problematic as it has been demonstrated that people are more likely to access the services if their eye care specialist discusses the services with them (Pollard et al., 2003).

There is a common misconception among professionals and the general public that vision rehabilitation services are intended for people with no vision and not for or needed by those with various levels of vision loss (Gold & Zuvela, 2005). Eye care specialists are likely to only inform those with more severe vision loss about vision rehabilitation services (Overbury et al., 2008; Pollard et al., 2003). In many cases eye care specialists substantially underestimate the effect of vision loss on a person's quality of life and people are left to find and access vision rehabilitation services on their own (Overbury et al., 2008).

There is also a need for early referral as it is important for people with vision loss to avail of vision rehabilitation training at the onset of their vision loss. It is recognized that the earlier a person with vision loss begins vision rehabilitation training the higher their likelihood of a successful outcome (Pollard et al., 2003). With early utilization a person becomes accustomed to using new tools, techniques, and adaptive devices. This may make it easier for them to accept the need for more advanced training and assistive devices if their vision loss advances (Muzychka, 2009). Despite the benefits of early access to vision rehabilitation training people with vision loss have reported that referrals to vision rehabilitation services often occur at the very end of the treatment process (Pollard et al., 2003). Eye care specialists must be aware of the full spectrum of services available, effectively interact with organizations that provide the services, and be knowledgeable in making referrals to these organizations (Muzychka, 2009; Overbury et al., 2008).

The National Eye Institute (2010) in the United States has recognized the need for increased referrals and is developing a program with the goal of educating eye care specialists about vision rehabilitation services. The program will be designed to increase patient referrals, develop, test, and evaluate measurable strategies, identify opportunities and barriers, and provide information to health care professionals and their patients about vision rehabilitation services. This program is still in the development stage.

Psychological and emotional support. The debilitating psychological and emotional affects of vision loss are an important issue that is often overlooked in the current models of vision rehabilitation services. Research shows approximately 31% of people with vision loss have depressive symptoms (Temisjian et al., 2008). Many people may feel a loss of independence and autonomy and attempt to conceal their vision loss to protect their pride (Pollard at al., 2003). This can lead to an increase in social isolation and make it difficult for people to initiate or be receptive of vision rehabilitation services. This is why it is important for individual and group counselling programs to be included as part of all vision rehabilitation models. Accessing counselling at the onset of vision loss will increase the likelihood of a person accepting and availing of other essential vision rehabilitation services. It is known that there is an emotional transitional period in which it takes time for people to feel comfortable accessing and using vision rehabilitation services (Southall et al., 2008).

Assistive technology. People with vision loss are in need of access to assistive technology devices. Assistive technology refers to devices that enable people living with vision loss to improve their quality of life and perform tasks they would otherwise have difficulty accomplishing (CNIB, 2011b). It enables people to participate more fully at home, work, and in their communities. Devices can range from low tech items such as

talking clocks, hand magnifiers, and large button phones to high tech items such as CCTVs[4], adaptive computer software, and high powered electronic magnifiers.

Assistive technology funding and training. People with vision loss are in need of funding for assistive technology to improve access to devices and in turn their quality of life. In a study conducted by Gold, Zuvela, & Hodge (2006) over 50% of respondents indentified high prices as the reason they could not purchase required assistive devices. Muzychka (2009) also reports that many people with vision loss are unable to purchase assistive technology or have to settle for cheaper alternatives that do not meet their needs.

Providers of vision rehabilitation services indicate the rising cost of assistive technology in provinces without subsidy is a serious burden and significantly affects the ability of people with low or fixed incomes to benefit from vision rehabilitation services (Gold et al., 2006). According to Muzychka (2009) Canadians who are in need of assistive technology are paying the majority of costs out of their own pockets with government and the health care systems providing minimal subsidies. While provincial governments offer general supports to those with disabilities few provinces put forward programs specifically for people with vision loss. A survey of provincial and territorial programs showed no or limited details in most jurisdictions regarding the inadequate

[4] CCTVs are video magnifiers consisting of a video camera connected to a monitor. Materials can be placed under the camera and an enlarged image of the material is displayed on the monitor.

funding available for assistive technology, a finding which was confirmed by the Assistive Technology Links program of Industry Canada (Industry Canada, 2010).

An exception is Ontario, which offers an Assistive Devices Program (ADP) that covers optical aids such as magnifiers, telescopes, specialized glasses, reading and writing systems, including audio-book machines and Braillers. This program is available to any Ontario resident who has a valid Ontario Health card issued in their name and has had a physical disability for a minimum of six months. The program stipulates that the equipment must be needed on a daily basis both inside and outside of the home and cannot be required exclusively for sports, work, or school (Government of Ontario, 2010). The ADP does not pay for equipment available from other funding sources. There are specific eligibility criteria which apply to each device category but these criteria are not public knowledge (Goss Gilroy, 2007). The ADP is a cost share program with the amount of subsidy provided dependent on factors such as the device required, applicant age, and the availability of other sources of funding (Government of Ontario, 2010).

Saskatchewan is another exception offering a service called the Aids to the Blind Program. This is operated by CNIB Saskatchewan under a government contract and is available to consumers who meet certain medical criteria. The Saskatchewan program loans Braillers, audio-book machines, and magnifiers. The program also helps subsidize the cost of watches, talking calculators, and low-vision eyewear (Muzychka, 2009).

In Newfoundland and Labrador, there is no universal subsidy for those looking to acquire funding for assistive technology. Some assistive technology is provided by government and community funding to eligible students, the newly employed, and those looking to retain employment. As in Ontario, eligibility requirements vary widely and are not public knowledge (Goss Gilroy, 2007). Although this assistance is beneficial, many people in Newfoundland and Labrador may not meet the eligibility criteria and have no guarantee their needs will be met through the patchwork of organizations and programs that have attempted to fill the gaps (Goss Gilroy, 2007).

Assistive technology subsidies are imperative to ensure people with vision loss have access to the devices they require (CNIB, 2008). There is a need to coordinate the numerous agencies in Newfoundland and Labrador that are currently providing funding for assistive technology in order to create a timely, effective, and streamlined process for acquiring devices (Goss Gilroy, 2007).

Once a person has access to assistive technology there is a need for increased training opportunities. It takes time for a person with vision loss to feel prepared and comfortable using assistive technology (Southall et al., 2008). A study by Gold, Zuvela, & Hodge (2006) revealed that only a small number of participants were trained in the use of assistive devices. Those who did receive training reported receiving only one or two brief sessions per assistive device. Furthermore, in most cases the limited numbers of training sessions were used to teach individuals how to use more than one device. In

addition to improving the confidence of users, research has demonstrated that as little as five training sessions can increase compliance with assistive technology use (Gold & Zuvela, 2005).

Identified Barriers to Vision Rehabilitation Services

For the purpose of this research, the term barrier refers to the factors that prevent a person from accessing or using vision rehabilitation services. Barriers can be external to the individual or they can be personal challenges that prevent a person from accessing and using vision rehabilitation services.

Inaccessibility of assistive technology demonstration centres and stores. The lack of access to assistive technology demonstration centres and stores selling assistive technology is a barrier that can prevent people from using necessary devices. Assistive technology is often limited to training facilities, which are in short supply, where the availability of devices may be inadequate (Muzychka, 2009).

In Newfoundland and Labrador, for example, there is an assistive technology centre located in the St. John's CNIB centre showcasing many of the latest high tech assistive devices. There is also a store on site where many low tech items can be sampled and purchased. However, the CNIB centres in Corner Brook and Grand Falls–Windsor have a very limited selection of high and low tech assistive devices available for

demonstration and no devices are available for sale. When assistive technology is not available in the local office clients have the options of waiting for a piece of assistive technology to be couriered from the St. John's office in order to try it or ordering a device not knowing if it will be appropriate to meet their needs. Gold et al. (2006) found that in many instances a person will choose to order a less effective device simply because it is available for demonstration or choose not to order any assistive technology.

Transportation. The challenge of Canada's climate and geography means limited access to services where people live. People residing in rural areas may need to travel outside their community to receive the services they require. Even in urban areas, people may believe that vision rehabilitation centres are too far away from where they live and that they are difficult to get to (Overbury et al., 2008; Pollard et al., 2003). Transportation is frequently noted as a barrier to vision rehabilitation services, especially in rural areas where public transportation can be limited or non-existent (CNIB 2005; Gold, Zuvela, & Shaw, 2008; Muzychka, 2009; Overbury et al., 2008; Pollard et al., 2003). Transportation can also be an issue for vision rehabilitation specialists because time spent travelling to rural areas to provide vision rehabilitation services can be substantial (Gold et al., 2008).

Even when public transportation is available people may be anxious about using it as a result of the onset of low vision. Gold et al. (2008) report that based on the 2001 Participation and Activity Limitation Survey (PALS) people with vision loss are more

likely than those with other disabilities to experience difficulty using public transportation. Over 80% of PALS respondents with vision loss reported having difficulty getting on and off public transportation; 40% had difficulty getting to bus stops (Gold et al., 2008).

Unequal access to vision rehabilitation services. According to Matti et al. (2010) the unequal distribution of services in rural and urban areas may be a barrier to vision rehabilitation services for some people. Newfoundland and Labrador is a large province with many people living outside of the capital region of St. John's. The majority of CNIB services are housed in the St. John's centre with vision rehabilitation specialists regularly travelling to other areas of the province to provide services. Muzychka (2009) recognized that CNIB services may not be universally available and equally accessible to all people with vision loss due to staffing and geographical challenges.

Inadequate promotion of vision rehabilitation centres. The lack of public knowledge of vision rehabilitation programs and services and those they may benefit is a barrier to people with all levels of vision loss accessing these services. According to Muzychka (2009) the public has little knowledge of available vision rehabilitation services (Muzychka, 2009). People with vision loss have expressed concern that publicity of vision rehabilitation centres is directed at people that are blind and not those with mild to moderate levels of vision loss. Much of the advertising depicts people with

white canes and guide dogs and people with low vision find these images difficult to relate to (Pollard et al., 2003). In order to help eliminate this barrier advertising needs to be more inclusive of all levels of vision loss.

Concerns have been raised by people with vision loss that organizations providing vision rehabilitation services self-promote to raise funds rather than raise awareness of the programs and services they provide (Pollard et al., 2003). This may be due to the fact that many of these organizations are non-profit and rely on private donors to assist in funding the provision of vision rehabilitation services. It is anticipated that if these organizations received more government funding they could focus on public education efforts to raise awareness of the vision rehabilitation programs and services they provide.

Patient perception. People's perceptions of the nature of their vision loss and/or their need for vision rehabilitation services can be a barrier to accessing and using these services. They may choose not to avail of vision rehabilitation services due to misconceptions about the services, inadequate understanding of their eye condition, lack of knowledge of the available services, waiting for eye treatments to be finished, transportation issues, and not considering themselves to have low vision (Matti et al., 2010; Overbury et al., 2008).

Research has reported conflicting information about the uptake levels for vision rehabilitation services. Overbury et al. (2008) reported that only 58.2% of their participants availed of vision rehabilitation services, while Matti et al. (2010) reported a

97% uptake of vision rehabilitation services among participants. The research by Matti and his colleagues appears to be the exception as research from Canada, Australia, and Britain has reported that low numbers of people are accessing any type of vision rehabilitation service (Gold & Zuvela, 2005; Overbury, et al., 2008; Pollard et al., 2003). Mattie et al. attribute the high rate of uptake in their study to the service delivery model used. All participants were contacted by the vision rehabilitation provider within one week of the referral being received with interpreters and volunteer drivers also being made available (p. 185).

Matti et al. (2010) found the biggest barrier to uptake of vision rehabilitation services was patient perception. Of those participating in the study, initially 27% did not believe they needed vision rehabilitation services and a further 10% did not believe that vision rehabilitation services would benefit them. This was supported in a study by Pollard et al. (2003) where almost 50% of participants did not consider themselves to have low vision and of the participants that did, many falsely believed that vision rehabilitation services could not assist them because their eye care practitioner told them that "nothing more can be done" (Pollard et al., 2003).

As previously discussed, people often have the misconception that low-vision services are for people with severe vision loss and are unaware that there is a range of vision rehabilitation services that may benefit people with varying levels of vision (Gold & Zuvela, 2005; Matti et al., 2010; Pollard et al., 2003). Related to the barrier created by

a misperception of the value of vision rehabilitation services, is a lack of understanding about the long term consequences of eye conditions that causes people to delay accessing vision rehabilitation services (Southall et al., 2008).

People may also choose not to use vision rehabilitation services because they are scared and confused at the time of their diagnosis and may go through a period of denial. It may be difficult for the person to consider availing of vision rehabilitation services if they are concerned about being labelled as 'blind' (Southall et al., 2008). This barrier may be particularly prominent among older adults who assume that vision loss is a natural part of aging and only seek services when their vision loss significantly interferes with their ability to complete everyday activities or when they realize their vision loss is increasing (Gold et al., 2006).

Concurrent health problems. Matti et al. (2010) cite the presence of concurrent major health problems as a further barrier to vision rehabilitation services. People with concurrent health problems may choose not to avail of vision rehabilitation services because they are hesitant about committing to the low vision assessment due to the fear of multiple appointments and additional testing (p. 185). Concurrent health problems may be a particular barrier for older adults.

Identified Pathways to Vision Rehabilitation Services

For the purpose of this research, the term pathway refers to factors that motivate or enable a person with vision loss to access and use vision rehabilitation services.

Initial contact. People report initially contacting and accessing vision rehabilitation centres to learn new skills and ways of managing tasks of everyday life (Scheiman, Scheiman, & Whittaker, 2007). This may include learning new ways to complete chores, select clothes, cook, and walk in the community. People may also want to learn ways to maximize their vision and improve their reading ability with devices or training (p. 62).

After initial contact vision rehabilitation training often includes accessing and using assistive technology. CNIB provides information about the availability, selection, use, and purchase of assistive technology. They are able to assist people in finding the best devices to meet their individual needs, through demonstration, assessment, training, and technical support (CNIB, 2010).

Other providers of vision rehabilitation services. Itinerant Teachers are employed in schools throughout Newfoundland and Labrador and provide important pathways for children and school aged youth with vision loss and their parents. Access to Itinerant Teachers is regulated by the Government of Newfoundland and Labrador. In order to receive support services from an Itinerant Teacher "a child must have a visual

acuity of 20/70 or less in the better eye with corrective lenses, or a child must have a visual field restriction of 20° or less" (Government of Newfoundland and Labrador, 2001, p. 2.2). In addition to the support provided to families, Itinerant Teachers also provide support to classroom teachers that work with children with vision loss. They encourage a realistic understanding of the child's needs and abilities with the aim of helping the child reach their highest potential (Government of Newfoundland and Labrador, 2001).

In partnership with CNIB, Itinerant Teachers provide training to students in the areas of Braille, orientation and mobility, language, social skills, independent living skills, use of low vision aids, listening skills, keyboarding skills, assertiveness training, organizational skills, visual efficiency and post-secondary counselling (Government of Newfoundland and Labrador, 2001). They also assist students in accessing assistive devices, teach them how to use and maintain the devices, and monitor the devices to ensure that they are working properly (p. 5.20).

The Hadley School for the Blind is helping to make vision rehabilitation services more accessible to people by offering distance education programs focusing on assistive technology, Braille, independent living skills, and other important areas. The school was founded in 1920 and today it is the largest educator in the world of people with vision loss and the largest educator of Braille. Each year they have more than 10,000 students located in 100 countries (The Hadley School for the Blind, 2011).

The mission of The Hadley School for the Blind is to "promote independent living through lifelong, distance education programs for individuals who are blind or visually impaired, their families and blindness service providers" (The Hadley School for the Blind, 2011, ¶ 1). The school provides distance education programs free of charge to individuals living with vision loss and their families. They also offer affordable tuition courses to professionals working within the field of vision loss. The school relies on assistance from individuals, foundations, and corporations to fund its programs (The Hadley School for the Blind, 2011).

Partnerships and collaboration. Partnerships between vision health professionals and related organizations are cited in the literature as having the potential to improve pathways to vision rehabilitation services for people living with vision loss if they unite around common goals (CNIB, 2008). This could include improved referral processes by eye care specialists, increased awareness of available services offered by CNIB and other vision rehabilitation professionals, and initial referrals being made at earlier stages of vision loss (Gold & Zuvela, 2005; Muzychka, 2009).

Public education. A lack of public knowledge of vision rehabilitation programs and services and their benefits was identified as a barrier. Thus it is clear that investment in education, awareness, and health promotion campaigns are potential pathways to the access and utilization of vision rehabilitation services (Muzychka, 2009). An increase in public education focusing on the terminology used when discussing vision loss and the

role and function of vision rehabilitation services in the lives of people with vision loss has the potential to increase public awareness and improve public attitudes about vision loss (Pollard et al., 2003). An increase in public awareness could result in an increased uptake of vision rehabilitation services as well as an increase in the social inclusion of those living with vision loss due to an increased understanding of the abilities of people with vision loss.

Summary

Research from within Canada and other countries identifies a number of needs, barriers, and pathways related to the accessibility and utilization of vision rehabilitation services for people with vision loss that can be generalized to people in Newfoundland and Labrador. These are the identified needs of professional awareness and referral, psychological and emotional support, assistive technology, and assistive technology funding and training. The barriers identified were inaccessibility of assistive technology demo centres and stores, inadequate promotion of vision rehabilitation centres, transportation, unequal access to vision rehabilitation services, patient perception, and concurrent health problems. The pathways identified were initial contact, other providers of vision rehabilitation services, partnerships and collaboration, and public education.

The goal of this research was to explore the experiences of accessing and using vision rehabilitation services of persons living with vision loss in Newfoundland and Labrador. The next chapter discusses the process used to carry out the research.

Chapter 3

Methods

Introduction

This chapter describes the methods used to explore the experience of sixteen individuals in accessing and using vision rehabilitation services in Newfoundland and Labrador. The chapter begins with a description of the study design and the sampling methods used to select participants. The chapter then goes on to discuss methods of data collection, the instruments used, and data analysis.

Study Design

The purpose of this research was to explore and describe the needs, barriers, and pathways to accessing and using vision rehabilitation services in the province of Newfoundland and Labrador.

Exploration of a topic is best accomplished using a qualitative research approach as a means of opening dialogue in which to examine issues because the primary aim of qualitative research is not to discover or verify commonalities across experiences but rather to explore each person's uniquely lived experiences (Piantanida & Garman, 1999). Furthermore, a qualitative approach is better suited than quantitative methods to examine issues that are poorly understood and research questions that consider the quality of

experiences rather than magnitude (Creswell 2007). This type of approach generates rich data allowing for depth of understanding (Hutchinson & Lee, 2004). The use of a semi-structured qualitative interview in this study captured the lived experiences of people with vision loss. This will provide the Vision Rehabilitation Committee with an in-depth understanding of participants' experiences and perspectives of vision rehabilitation services in the province.

The research question asked: what are the needs, barriers, and pathways to accessing and using vision rehabilitation services in the province of Newfoundland and Labrador? Project participants were asked to describe their experiences of access to and utilization of vision rehabilitation services and assistive technology in Newfoundland and Labrador.

Sampling

Sampling strategies in qualitative research differ from quantitative research as they are designed with the goal of studying a particular phenomenon in detail rather than for the purpose of statistical inference (Luborsky & Rubenstein, 1995). It is generally accepted that a minimum sample size of twelve interviews is sufficient to reach data saturation in qualitative research (Guest, Bunce, and Johnson, 2006). For this research

sixteen participants were selected for individual interviews using a combination of availability and purposive sampling.

Availability sampling is a sampling method that selects elements because they are readily available and convenient. This sampling method is commonly used in social work research because it is usually less expensive and more feasible than other methods of sampling (Rubin & Babbie, 2007).

Purposive sampling is common in qualitative research and involves selecting participants based on variables that are analytically and theoretically linked to the research question (Rubin & Babbie, 2007). Using the CNIB client list as the sampling frame, a purposive strategy was undertaken to consider specific categories of experience of vision rehabilitation services. Purposive sampling was used to select participants based on the experiences of the following groups:

Group 1: Parents or guardians of children with vision loss (Children ages 18 and under)

Group 2: Working age adults with vision loss (aged 19 – 65)

Group 3: Older adults with vision loss (aged 66+)

These experiential categories represent the main vision rehabilitation consumer groups in Newfoundland and Labrador.

Recruitment

The recruitment protocol was reviewed and approved by Memorial University's Interdisciplinary Committee on Ethics in Human Research (ICEHR) (see Appendix A for Letter of Ethical Approval and Appendix B for information about the Protection of Participants).

Participants were recruited using the CNIB client list. A CNIB representative contacted potential interview participants from each category to inform them of the research and ask if they would agree to receive additional information about the research including a follow up phone call from the researcher. A recruitment script was used to ensure that people understood that their participation was completely voluntary and would have no impact on their eligibility for CNIB programs and services (see Appendix C for Script for Telephone Contact with Individual Interview Candidates). A list of individuals that agreed to receive more information about the project was compiled using a standardized form (see Appendix D for Candidate Information List) and turned over to the researcher. The key informant from CNIB did not know which potential participants agreed to be interviewed. A Participant Profiles list provides more detail about the participants and can be found in Appendix I.

Individuals who agreed to receive more information were sent a letter and project information sheet which introduced the researcher, identified the purpose of the research, and informed them that the researcher would follow up with a phone call to answer

questions and provide more information as necessary (see Appendix E for Letter to Candidates and Appendix F for Project Information Sheet). This package also contained a consent form outlining the research conditions (see Appendix G for Consent Form). All materials sent to participants were developed following the guidelines for plain language and were available in alternative formats.

Data Collection and Instruments

Data was collected using telephone interviews. The interview guide was created in consultation with the CNIB Newfoundland and Labrador Vision Health and Rehabilitation Committee using the framework of needs, barriers, and pathways described in Chapter 1. The committee was provided with a draft copy of a preliminary interview guide and asked to provide feedback. Feedback was collected and utilized in the development of the final draft of the interview guide (See Appendix H for the Interview Guide).

Individual interviews were recorded and conducted via telephone. The consent form was read at the beginning of the interview and participants were asked to provide verbal consent to proceed before the interview commenced. The verbal permission of each participant was recorded and the researcher signed the consent form indicating that verbal permission had been granted. The interview guide consisted of open ended questions designed to encourage a full, meaningful answer using the participant's own

knowledge and feelings related to accessing and using vision rehabilitation services. The use of a semi-structured interview guide allowed for individualized discussion and questioning based on participants' answers to the preliminary questions.

Data Analysis

In qualitative research analysis a coding procedure is used to discern and organize patterns within data. The process of coding involves moving from raw data to a theoretical narrative in small steps, each new step building upon the previous one (Auerbach & Silverstein, 2003).

As part of the initial coding process the text from the individual interviews was reviewed and organized in the context of the research concerns of needs, barriers, and pathways. For each interview any reference made to needs, barriers, and pathways was identified as relevant text and copied into an electronic chart. Other information provided by participants that did not fit these categories but seemed to be relevant to the research was placed in the "other" category (see Appendix J for the Coding Chart). This made the text easier to work with. The relevant text was then examined for repeating ideas across individual interviews. Repeating ideas are the same or similar words and phrases used by participants to express the same idea (Auerbach & Silverstein, 2003). A new electronic document was created to compile the repeating ideas into themes. The themes were then

organized into categories based on the concepts of needs, barriers, and pathways. The identified themes were used to examine what was learned from the data about the research concerns.

Summary

This research utilized a qualitative research approach to explore the needs, barriers and pathways to accessing and using vision rehabilitation services in the province of Newfoundland and Labrador. A combination of availability and purposive sampling was used to select participants from three experiential categories representing the main consumer groups of vision rehabilitation services in Newfoundland and Labrador. Data was collected from individual phone interviews and recorded to ensure accuracy. Data obtained from the interviews was coded and organized according to their relevance as needs, barriers, and pathways. The resultant categories are described in the following chapter.

Chapter 4

Results

Introduction

This study aimed to explore a sample of individuals' experiences of vision rehabilitation services: their needs regarding access to services, the variables that can compound or complicate the process, and the pathways that facilitate access and utilization of vision rehabilitation services. The results of this study are organized according to this framework using needs, barriers, and pathways to vision rehabilitation services as the three main headings. Each heading contains a presentation of the findings as it relates to that specific concept.

Presentation of the Findings

Individual interviews were conducted with sixteen participants; four parents or guardians of children with vision loss, eight working age adults with vision loss, and four older adults with vision loss. The findings of the research are presented as they relate to the organizing framework of needs, barriers, and pathways. In some cases the findings corresponded with issues identified in the literature review. However, participant interviews also revealed subthemes that were unique to this research.

Needs Related to Vision Rehabilitation Services.

In this research I used the term 'need' to refer to the supports and services needed to enable a person to access and use vision rehabilitation services. Needs were identified by examining the experiences of people with vision loss in relation to using and accessing vision rehabilitation services.

Assistive technology training. Participants identified assistive technology training as a need and reported availing of training from a number of sources. Participants reported having received training in school, from CNIB, and being self taught. Most participants said that the assistive technology training provided by CNIB is relevant, beneficial, accurate, and relatively up to date. However, Joy said while the assistive technology training she received from CNIB has been beneficial it was "not always in depth as I would have liked it." She was often unsatisfied with the assistance provided by CNIB and would contact the manufacturer for further help.

Three participants received assistive technology training from CNIB via telephone but said this form of training was not helpful. Corey, a partially sighted man in Labrador, said he needed "hands on" training but CNIB was not able to provide it. CNIB attempted to provide training to him over the phone but "it wasn't beneficial." He went on to say "the hands on thing is the thing with the technology for people with vision loss because they can't see to operate it." He said he called for assistance but "[CNIB

Specialist, Assistive Technology] just couldn't leave and come up here to help me work it out."

Psychological and emotional support. The majority of participants discussed the need for professional counselling services as a part of the vision rehabilitation services offered by CNIB. Participants said professional counselling and emotional support is very important because people must adjust to their vision loss emotionally before they are open to accessing other vision rehabilitation services. Participants in each age category agreed that counselling is helpful throughout the life span not just for them but for their family members who also live with and are affected by vision loss.

Andrew spoke at length about the need for a professional counsellor at CNIB. He said "that's where your connection is between CNIB and the client, it's the counsellor." Andrew went on to say "every one of those, from kids right into the elders, they need someone to talk and it needs to be a professional counsellor." Participants pointed out that counselling services need to be provided by a professional counsellor, not someone that provides other vision rehabilitation services. Participants said counselling lets people know that CNIB cares in addition to providing people with a connection to the organization.

The need for emotional support was identified as particularly important by working age participants as they believed emotional support was not available to CNIB clients between the ages of 20 to 65. Andrew said "just the idea of dealing with vision

loss and the change it has in your life you need a little support." Frank said counselling services are needed and are very important for those in the workforce that begin losing their vision or experience changes in their vision. When speaking about counselling he says "...it is all intertwined. Issues come up all the time and how do you deal with these things? Even for me and I've been visually impaired for all my life."

Some working age participants stated that CNIB does not provide any type of support to them. Brenda said working age people with vision loss "have nothing." Four of the working age participants specifically expressed the need of some form of peer support. They believe this would provide CNIB clients with an opportunity to share information, provide support to each other, and interact socially. Brenda noted that older adults and children can have their peer support needs met outside of CNIB but working age clients are forgotten about. In general working age participants indicated they are feeling isolated and believe they need a group specifically for working age people because they have different needs and issues than older adults.

The Canadian Council for the Blind (CCB) is an organization that addresses the ongoing effects of blindness with programs designed to encourage active participation of people living with vision loss in local communities, education, sports and recreation, and employment. They have sixty-five chapters across Canada, including two in Newfoundland and Labrador. Some participants believe that this organization is meeting the emotional needs of people with vision loss. They believe CCB is providing the peer

support that CNIB is not. Andrew said the organization provides an opportunity for people to get to know themselves and become comfortable living with vision loss. He says "just to deal with the idea of having vision loss and the change in your life, you do need a little bit of extra help." He believes this extra help is being provided by CCB. However, Brenda, a working age person from Eastern Newfoundland, believes CCB is for older people with vision loss. She described attending CCB outings and feeling they did not have anything to offer to working age people. Once again, highlighting the expressed need for a peer support group specifically designed for working age people with vision loss.

The need for professional counselling was also noted in relation to the emotional distress associated with the loss of a Driver's License due to vision loss. When discussing the loss of his Driver's License, Eugene, an older adult in Central Newfoundland, said "that was the worst thing I found about it, the loss of my license. I was driving since I was 17."

Ongoing access to counselling was highlighted by participants to deal with fears of increased vision loss and the possibly of being blind. Erin, an older adult in Western Newfoundland that recently started experiencing vision loss, said she is worried about "what happens when I go in total darkness because I'm terrified of the dark. Counselling will be kinda late when I'm in the dark."

Emotional support was described as important to parents of children experiencing vision loss. Amy said "it's more than just the support of the child it's the whole emotional support as well" for her as well as her child. Parents said CNIB is able to provide recommendations when they feel "stuck," provide direction, and make referrals to other services when necessary. Parents also said that the support provided by CNIB at children's appointments with the eye care specialist is very important. Parents said CNIB specialists ask appropriate questions and assist during the appointment when it becomes overwhelming for them.

Increase in public and professional information. Participants believed there is a need for increased public and professional information about the programs and services offered by CNIB, the benefits of assistive technology, and the effects of vision loss. A number of participants believe CNIB should be publishing regular newsletters to keep clients, professionals, and the general public informed about the programs and services offered by the organization and highlight new assistive technology as it becomes available. Participants suggested that these newsletters should be shared with doctors, nurses, social workers, and other professionals, noting that front line workers, especially those visiting people's homes, need to be educated about vision loss and CNIB.

Eleven of the participants said CNIB should increase the number of public information sessions they offer. They believe these information sessions should be used to increase awareness of vision loss, what it is like to live with vision loss, the programs

and services provided by CNIB, and available assistive technology. Participants also pointed out the importance of promoting all public information sessions to ensure awareness amongst the general public and the client population. Frank suggested there be a trained volunteer in each community that can facilitate these sessions on a regular basis.

Participants believe assistive technology should be an important part of all public information sessions and low and high tech items should be available for demonstration. They said this would provide an opportunity for hands on experience with assistive devices. Brandon said there is a need to have an assistive technology tour every 6-12 months because these tours are very beneficial and provide clients with an opportunity to see items and try them first hand. This is very important because as previously mentioned people outside of St. John's do not have regular access to assistive technology demo items. Participants also said it may be beneficial to have information sessions for working age people that begin losing their vision to inform them about assistive technology and let them know there are ways for them to continue their employment.

Participants suggested two specific groups, employers and students, to which public information sessions should be targeted. Working age and older adult participants suggested information session for employers to increase opportunities for people with vision loss in the workplace. Joy suggested CNIB bring a person with vision loss that is currently employed to the session as a means of promoting the hiring of a person with

vision loss. Participants said businesses need to be more accessible to people with vision loss. Danielle noted that it is hard as a person with a disability to find employment in a small community.

A number of participants also expressed a need for information and issues related to vision loss to be taught in schools at all levels. They believe that in addition to a university course aimed at teaching professionals about the causes of vision loss, what it is like to live with vision loss, and how to interact with those living with vision loss, CNIB should conduct information sessions about vision loss with students at all levels of the education system.

Changing needs throughout the life span. Participants discussed the need for ongoing opportunities for vision rehabilitation training throughout the life span beyond initial contact or referral. This issue had not been revealed through the course of the literature review. Eight participants stated that as their vision changed so did their need for vision rehabilitation services and new assistive technology.

Carla is now blind but had partial vision as a child. She recently began independent living skills training to improve and redevelop skills she learned when she still retained partial vision. When speaking about the changing need for vision rehabilitation services throughout the life span, Carla said "it changes for sure because I mean you learn things as a child that you want to improve as an adult." Frank, a resident of Labrador who is now blind but had partial vision in the past, reinforced Carla's view

saying his vision rehabilitation needs have "significantly changed" over the years due to changes in his vision. Other participants discussed needing orientation and mobility training to learn new routes when they moved to new geographical areas. Joy, an older person who is blind, said she "…came to a new country… and wanted a bit of [orientation and mobility] as I wanted to start using routes because I came with a guide dog and just wanted a little bit of showing me routes and things like that."

Participants also discussed their changing needs in relation to assistive technology. They noted that devices need to be upgraded and changed as new technology becomes available and people experience changes in their vision. Devices need to be replaced as they become outdated and wear out due to usage. Frank explained the importance of assistive technology: "it doesn't just sit there. You use it."

Increased contact with CNIB. Participants reported a need for increased contact between CNIB and their clients. Nine participants said they have little contact with the organization. A particular concern raised was that CNIB does not keep them up to date on new information and assistive technology. This was a dominant theme amongst the working age participants. Andrew commented that CNIB needs to make a connection with their clients and go out and show people what is available. According to Andrew, a working age person that is partially sighted, this is especially true for new clients: "they just have no idea what's available."

Participants suggested that CNIB should hire a counsellor to maintain contact with clients and keep them informed. Parents of children and youth with vision loss indicated a need for someone to keep in contact with families and provide them with updates. Gillian commented that as their child has gotten older they have less and less contact from CNIB. Participants indicated that clients are losing contact with the organization and believe a counsellor could help prevent this from happening. Other participants said they take the initiative and contact CNIB for updates and to see what new assistive technologies are available for people with vision loss. CNIB services outside St. John's are irregular and infrequent given the demands on staff. Participants in these areas said they would like to be notified when CNIB specialists are visiting their area to maximize these opportunities.

Improved access to vision rehabilitation services. In general, participants outside of St. John's did not believe they were receiving the same level of service as those living in the city. Of the fourteen participants that lived outside of St. John's, seven said it is hard to access services where they live and the full range of vision rehabilitation services, such as Braille training, are not always available to them. Amy, who lives in Eastern Newfoundland, and Corey and Gillian who live in Labrador, said it is often difficult for vision rehabilitation specialists to travel to their areas due to weather, scheduling of extra time needed to travel, and the cost associated with travelling. Despite this they would like to see an increase in the number and regularity of visits they receive.

Lack of awareness about services is a further challenge to access. Brandon, a working age participant in Central Newfoundland, was unaware that low vision assessments were available to him in his community and said he would like this service to be more obtainable so that he could try new magnifiers as they became available.

Improved access to services such as orientation & mobility and assistive technology was cited as especially important when needed for work or when someone is living alone. The timeliness of access to services was also highlighted. Joy, now retired, and Frank, a working age client, both said that working age people need to be able to access services immediately in order to gain or keep employment and the urgency is not always met by CNIB.

Participants indicated they would like to see an increase in government funding to CNIB to aid in the hiring of additional vision rehabilitation specialists. They believed an increase in the number of vision rehabilitation specialists providing services could result in increased visits. Amy, the mother of a child with vision loss in Eastern Newfoundland, said her family is receiving one visit a month from both the orientation and mobility and early intervention specialists. When asked about her needs she said "more staff would greatly be appreciated." In reference to the services she received from the early intervention specialist she said: "there is a great need for more than one [visit per month]." Participants in other parts of the province indicated they also sometimes have to wait months for a visit from a vision rehabilitation specialist.

Gillian, the mother of a school aged child with vision loss, expressed a need for an Occupational Therapist in the school system. She said this service is available in school systems in other provinces and would like to see it offered to all students with disabilities in Newfoundland and Labrador.

Access to assistive technology demo centres and stores. Participants indicated the need for assistive technology demonstration centres and stores throughout the province. Participants reported problems with having to rely on the CNIB catalogue to view products such as magnifiers. Many participants reported that they did not have access to demo items in their area and some said they have to purchase items without knowing if they will be of benefit to them. They noted that having low vision assessments and assistive technology centres in their communities would enable them to see the items first hand before making a purchase. Fiona, a partially sighted woman in Western Newfoundland, said "you don't get access to [assistive devices] here in Newfoundland and Labrador anymore." Fiona described a situation where she needed to order a replacement magnifier but did not know the correct one to order from the CNIB catalogue. "Last time I had to order from the catalogue and there are so many magnifiers there I didn't know which one to get. So I don't really know if I did get the right magnifying glass." She said a demo centre would have helped with this because she could have visited the centre and tried the magnifiers before making a purchase.

Brandon, a participant from Central Newfoundland, also noted the importance of having access to demonstration devices. He was pleased that he did not have to spend money on assistive technology that did not work for him because he had the opportunity to demo the items before making a purchase. He said he tried magnifiers and assistive technology at his doctor's office and the CNIB office in Grand Falls-Windsor when it housed an assistive technology store. As a result he was able to identify the items that did not benefit him. "I was fortunate enough to get in a setting, like a doctor setting, like the CNIB… I actually had the hands on experience before I bought these things so I tried every one that was there… and nothing works. So I've never had to spend any money to say that was a waste of time."

Frank agreed that CNIB technology sales are crucial because devices are not available elsewhere in the community and points out that "these devices need to be readily available. You do need to have samples that are available for people to view when the situation arises."

CNIB promotes catalogue and web ordering but participants said this does not work for everyone. They said a lot of people are afraid to purchase items online or in the catalogue especially when they are unable to see them due to their level of vision loss. Frank points out that "for someone that has a significant vision impairment they can't really get an idea of what they're looking at on the web anyway."

Issues specific to Labrador. Labrador is a unique area of the province, due mainly to its geographical location and sparsely distributed population. In general, vision rehabilitation services are not as accessible in Labrador as they are in Newfoundland because all three of the CNIB centres are located on the island portion of the province. Participants in Labrador said CNIB is absent in their area and they often felt forgotten about. They indicated there is a lack of services and the ones that do exist are hard to access. Gillian was very specific about CNIB's lack of visibility in Labrador: "I know that here the CNIB is non-existent." Corey estimated "99%" of people living with vision loss in Labrador are not aware of CNIB or the services they provide.

Participants indicated the need for CNIB to have more of a presence in Labrador including the establishment of a CNIB office. They said there is a need for vision rehabilitation specialists based in Labrador so that people in that area of the province did not have to wait for Vision Rehabilitation Specialists to come from St. John's or Corner Brook. Participants believe services should be available when they are needed and an office in Labrador would be especially beneficial for low vision assessments. Low vision specialists currently carry low vision kits, containing a variety of magnifiers and other visual aids, when travelling to Labrador. The participants believe the low vision kits need to be updated but said this did not resolve the problem because specialists are only able to show a small selection of magnifiers using a mobile kit. Participants also said there are no assistive devices regularly available for demonstration in Labrador and it is not possible for visiting specialists to bring samples of all assistive technology

particularly of larger items, such as CCTVs. An assistive technology office with a demonstration centre is needed in Labrador because it is difficult for vision rehabilitation specialists to travel with these larger items due to their size and weight. It also takes time to set up these items for use.

In addition to access to demonstration devices, participants said there is a long wait time for services in Labrador and that the services they are receiving are not meeting their needs. Corey said he had to wait months for orientation and mobility training because CNIB could not immediately send someone to Labrador. Some clients said CNIB specialists did not have the time necessary to spend with individual clients when they travelled to Labrador resulting in limited training opportunities. CNIB specialists have a limited amount of time to provide vision rehabilitation training and support when visiting Labrador. When speaking about CNIB Gillian said "I'm sure they're doing the best possible job they can possibly do. It's unfortunate that that's the one you don't see as often as you should."

Frank observed that services that were available when he was living close to St. John's were not accessible when he moved to Labrador. Kathy an older adult in Labrador was learning Braille when she lived in St. John's but said she had to stop when she moved to Labrador because there was no one there to teach it. Gillian expressed a need for an Itinerant Teacher in Labrador as they have not had one for 5 years: "When we had an Itinerant Teacher here it was fabulous. The [Itinerant Teacher] was trained

and could do different activities with her [child with vision loss]." She indicated this is an essential service that is available to children in Newfoundland but not Labrador.

Not all participants were negative about the services they received. Although she missed her Braille training Kathy said CNIB visits once a year to just check in and have a chat. Her optimism may be related to the fact that she perceives her need for services as minimal noting that she does not receive any vision rehabilitation services when the specialists visit because she does not believe she requires any services.

Barriers to Vision Rehabilitation Services

I use the term 'barrier' in this research to describe the difficulties people have accessing and using vision rehabilitation services. Barriers were identified by exploring the variables that participants described that compound or complicate the process of accessing and using vision rehabilitation services.

Cost of assistive technology. The cost of assistive technology was the barrier most cited by participants. Some participants are doing without needed assistive technology because they cannot afford to purchase items. Seven of the participants, six of whom were of the working age category, spoke of the need for an assistive devices funding program. Some of these participants believe CNIB needs to lobby government to make an assistive devices funding program a reality.

Participants highlighted the benefits of assistive technology to underscore the need for an assistive devices funding program. They said assistive technology provides them with independence and is a means of communication that keeps them in touch with family, friends, and society. They said it is an essential part of life and they use it every day. Participants reported using assistive technology to access email, websites, read, write, watch TV, and play sports. Joy said assistive technology "opened up the whole world to me." Andrew said assistive devices reconnected him with society. He uses monocular glasses to play darts and says after five years of not being involved "it gives me that connection with society again. It's such a big thing just to make you feel a part of everyday society."

Funding was described as available to those in need of assistive technology to participate in an educational program or in the workforce. Participants said assistive technology is making it possible, or has made it possible, to get through school and graduate. Two of the youth had access to assistive devices that were provided by their school and one of the working age participants discussed how assistive technology had enabled her to be successful in school. When discussing assistive technology Carla said "without that I wouldn't have gotten through my schooling."

Working age participants said assistive technology enables them to actively participate in the workforce. Frank said that "the difference between having assistive technology and not having assistive technology is the difference between working and

not working." Iris was one of two working age participants who were employed. Her employer will provide her with assistive technology but the approval process proved troublesome for her. She requested a CCTV through her employer but the approval process was taking too long. She decided to request a much cheaper item instead. This item was approved very quickly. The cheaper item met her needs while using a computer but did not assist her with reading printed materials.

Some participants were able to afford to purchase assistive technology but they still said there is a need for funding for those that are less fortunate. Participants reported for example there are no funding programs available for those that need assistive technology in their home. Danielle, who participated as a parent of a child with vision loss and who is herself only partially sighted, uses her child's assistive devices that are provided by the school because she cannot afford to purchase her own items for home use. She said when her child leaves for university she will lose her access to most of the assistive devices: "He's going to take all the equipment with him and I'm going to need it."

Parents identified the gaps in access to assistive technology between home and school for youth as being an issue. Children and youth with vision loss have access to assistive technology at school but cannot always afford devices for home use. It is not always practical for them to carry devices between home and school.

Participants pointed out that funding is needed not only to purchase assistive technology but also for the replacement and upkeep of items. They said items become obsolete quickly and need to be updated or upgraded frequently. Some participants said they have purchased items which they cannot afford to repair or replace if they become damaged or give out.

Perception of individual vision loss and postponement in accessing vision rehabilitation services. Participants' perception of their vision loss may have been a barrier to accessing vision rehabilitation services and assistive technology. Not all participants were using vision rehabilitation services and some had chosen not to avail of any programs and services after their initial referral believing they did not require the assistance of CNIB even though a referral had been made. The reasons they gave for not accessing these services indicate a lack of understanding about their vision condition and about the benefits of vision rehabilitation.

Brenda, a working age person that began experiencing vision loss as a child, said she was not using vision rehabilitation services because she believed she did not require the services. Eugene, an older adult living in Central Newfoundland, said that he is currently not using any services because he is waiting for eye surgery and will assess his need for services when it is completed. Kathy, an older adult living in Labrador, said she was not using vision rehabilitation services because her perception is that losing her vision was just a part of getting older. When asked if she had any unmet vision

rehabilitation needs she said "well, what else can they do? I mean it's getting worse all the time. Quite quickly now I think but there's nothing to be done about Macular [Degeneration]. It's just a fact of life for us old people." In reality, vision rehabilitation services can benefit a person of any age.

Despite the many benefits of assistive technology six of the participants, two from each age category, said they did not use assistive devices. The parent and working age participants said assistive technology was not used because they believe it is not needed. The older adult participants had a misconception that they were too old to use it or were waiting to see if their vision improved.

Transportation. Transportation was cited as a barrier for a number of the participants especially in areas where there are no forms of public transportation available. People with vision loss do not have the option to drive and may have difficulty accessing and using public transportation due to the travel that may be required to get to transportation access points and knowing when they are at their desired destination. Participants reported having to rely on family and friends to bring them to appointments, grocery shopping, and other places outside of the home. Eugene voiced his own distress when his license was revoked and he suddenly had to rely on others: "That was the worst thing I found about it, the loss of my license. I was driving since I was 17." He now relies on his wife to drive him most places.

Danielle said there should be bus service to school available for children with disabilities. She reported that her child cannot use the bus service because the school says they live too close to the school but it is still too far for her child to walk. Danielle said she has to rely on other parents to drive her child because she does not drive due to her own vision condition.

Personal experiences of CNIB. Participant's perception of CNIB was identified as a barrier to accessing and utilizing vision rehabilitation services. They indicated they believe CNIB programs and services are not meeting the needs of those living with vision loss in the province. Corey noted that he suggested improvements to programs and services but nothing was ever done or changed. Brandon and Brenda reported the same. Andrew commented that a large number of people who are in need are not receiving vision rehabilitation services and therefore CNIB services and practices are not working and need to be changed. His perception is that this is true not just in Newfoundland and Labrador but across Canada.

Andrew further commented that CNIB is not keeping ahead of things. He does not believe the current vision rehabilitation service delivery model is effective, especially on the West Coast. He believes there needs to be more connection with clients and CNIB needs to be more proactive rather than responsive: "Instead they wait for someone to come to them. Instead of being proactive and going out there and showing people with vision loss what [CNIB] have."

Some participants recognized the financial constraints placed on CNIB and suggested that government should increase their funding to the organization so that they can focus on providing vision rehabilitation services. Corey was most candid commenting that he believes CNIB cares more about raising funds than they do about their clients.

Wait for services. Despite participants' general comments about a lack of access to programs and services in regions of the province outside of St. John's, the wait for access to vision rehabilitation services was described as a barrier only by those living in Labrador. The one exception was Joy, an older adult in Eastern Newfoundland, who tried to get someone from CNIB to come in and mark a new washer and dryer to make it accessible but was told there was not anyone that could come to her house to do it.

The most extreme wait for services was reported by Corey, a working age person in Labrador, who said he was 8-10 years without contact from CNIB following the submission of a CNIB referral form. He said CNIB did not call to discuss programs and services and therefore he was unaware of what was available to him. Years later he received a phone call about taking part in an Adjustment to Vision Loss group and found out about vision rehabilitation services as a result of participating in the group.

Eugene, an older adult living in Central Newfoundland, said he did not have to wait for services but did indicate there was some informational disconnect. His nephew went to CNIB and got him a white cane. He was told that the Orientation & Mobility

Specialist would visit to teach techniques for using the cane but he did not hear from CNIB for a number of months. He admitted that he had not called to follow-up as he believed he did not need the service.

Andrew indicated that services in the Western Region have changed in recent years due to staffing changes in the Corner Brook office of CNIB. He said there are currently no independent living skills, orientation & mobility, or assistive technology specialists in the area therefore clients have to wait for services from St. John's. He was unaware that there is a half-time assistive technology specialist working in the Corner Brook office of CNIB.

Pathways to Vision Rehabilitation Services

I use the term 'pathway' to describe the ways in which people find and use vision rehabilitation services. Pathways were identified by asking participants about the available resources that assist people in accessing and using vision rehabilitation services.

Source of referral to CNIB. Eye care specialists are an important pathway to vision rehabilitation services in Newfoundland and Labrador but one that could be improved. Contrary to the problems that emerged in the literature related to delayed or non-existent referral, the majority of participants interviewed had been referred to CNIB by an eye care specialist. They said their doctors discussed CNIB programs and services

with them but the information was often vague. Andrew said he raised the issue of CNIB to his doctor but even though a referral was made to CNIB on his behalf no information or reinforcement was provided by his doctor.

Eugene learned about CNIB when he went to an information session offered by the organization about different eye conditions. He found this very beneficial as he was able to talk to others with vision loss and professionals in the field. Corey found out about CNIB by means of the Mobile Eye Van that would visit Labrador. He was later referred to CNIB by a genetics researcher at Memorial University.

Other providers of vision rehabilitation services. Itinerant Teachers were identified as a pathway because they assisted students and families with accessing vision rehabilitation services and assistive technology while also providing basis training. With the exception of Labrador, all the parent participants had an Itinerant Teacher working with their child. They indicated that Itinerant Teachers provide a lot of assistance with obtaining assistive technology for their child, assistive technology training, and conducting information sessions in classrooms. Parents did express a concern that the number of hours their child works with an Itinerant Teacher had been reduced. Heather thought this was having a negative impact on her child's development.

The Hadley School for the Blind is also a pathway to vision rehabilitation services because it enables people to learn a selection of vision rehabilitation services in their home environments regardless of where they live. As mentioned earlier, The Hadley

School for the Blind promotes independent living through distance education programs for individuals who are blind or visually impaired, their families and professionals. Danielle said she is learning Braille through The Hadley School for the Blind via a distance education program. She chose this route because she did not believe Braille training was available to her through CNIB because of where she lives in the province.

Partnerships and collaboration. Participants identified increased partnerships and collaboration between organizations providing services to people with vision loss as a potential pathway. Participants believe there is currently a lack of communication and partnership between organizations, especially CNIB and CCB. Participants believe the level of service provided to people with vision loss in Newfoundland and Labrador would be improved if these organizations worked in partnership.

Initial contact. The theme of initial contact in an important element of vision rehabilitation pathways because it provides insight into the motivation of a person to seek out and use vision rehabilitation services. Upon referral participants identified a number of reasons for initially availing of CNIB vision rehabilitation services. The majority of participants needed some type of assistance and training related to day to day activities. This included needing assistance identifying money, completing household chores, accessing the CNIB library, assistance in school, and getting around at home and outside. Participants said vision rehabilitation services were a necessity. Danielle said her and her

son "would never be able to cope daily" without assistive technology and vision rehabilitation services.

Less tangible reasons for contacting CNIB included needing support and guidance, wanting to know what was available to people with vision loss, and a desire to connect with others experiencing vision loss.

Access to vision rehabilitation services in communities. Access to vision rehabilitation services in communities was identified as a pathway to meet the previously discussed need for improved access to vision rehabilitation services. Twelve of the participants reported receiving vision rehabilitation services in their home and/or community. Not only did this make services more accessible to participants it also gave them the opportunity to learn and practice their new skills in their home environment. Services received in homes and communities included low vision assessments, orientation and mobility training, independent living skills training, and early intervention. Participants noted that home visits were very helpful as items such as stoves, washers, and thermostats need to be marked in the home with high contrast tactile paint to assist with the accessibility of these items. Onsite orientation and mobility was also reported as beneficial. For example, many rural communities do not have sidewalks. Therefore, skills learned in larger centres would not translate easily to home communities.

Adjustment to vision loss groups. Adjustment to vision loss groups were identified as a pathway to vision rehabilitation services and assistive technology. Four of the adult participants, located in various areas of the province, had or were currently participating in an Adjustment to Vision Loss (AVL) group program. Eugene said the AVL group is very enjoyable noting that it provides an opportunity to learn from others of all ages. Other participants said AVL groups enabled people to make life long connections and form valuable friendships. Andrew said it brought people out of their shells, opened them up to opportunities, let people know that there are others living with vision loss, and that support is available. Corey said the group helped people gain confidence and was an opportunity to talk to different people about your problems. He said participants get the opportunity to relate to one another and know they are not alone.

Other participants commented that AVL groups enabled people to access programs and services internal and external to CNIB. Corey said the emotional and peer support offered by the Adjustment to Vision Loss group gave him the courage to seek out and use other vision rehabilitation services.

Andrew, Corey, and Brandon were unaware that AVL groups were still offered by CNIB and commented that it was a positive program and they were disappointed it was no longer available. Corey commented that the group was a wonderful program and he believed there should be 2-3 groups offered per week. This demonstrates the important

role CNIB has in making sure their clients are aware of the programs and services they offer to ensure the continuation of existing pathways to vision rehabilitation services.

Summary

Participant interviews identified a number of needs, barriers, and pathways related to accessing and using vision rehabilitation services in Newfoundland and Labrador. In terms of needs participants discussed the need for assistive technology training, psychological and emotional support, increase in public and professional information, and changing needs throughout a person's life. In addition to this they discussed the desire for increased contact with CNIB, the need for improved access to vision rehabilitation services, access to assistive technology demo centres and stores, and issues specific to Labrador.

The barriers discussed related to the cost of assistive technology and the postponement of vision rehabilitation training due to their personal perceptions or misperceptions of vision loss and the benefits of vision rehabilitation services and assistive technology. Other barriers identified were transportation, personal experiences of CNIB, and wait for services.

Participants also identified a number of existing or potential pathways to vision rehabilitation services. These included the source of their referral to CNIB, other providers of vision rehabilitation services, partnerships and collaboration, initial contact,

access to vision rehabilitation services in communities, and adjustment to vision loss groups.

Chapter 5

Discussion

Introduction

The purpose of this research was to identify the needs, barriers, and pathways to accessing and using vision rehabilitation services in the province of Newfoundland and Labrador. Although limited in scope, this study provides valuable insight into the challenges and benefits associated with accessing and using vision rehabilitation services in the province and will assist the CNIB Newfoundland and Labrador Vision Health and Rehabilitation Committee in the development of a vision health framework for the province.

Using the conceptual lens of social inclusion, this chapter discusses the findings as they relate to the goals of the CNIB Newfoundland and Labrador Vision Rehabilitation Committee. The discussion concludes with a summary of the limitations of the study and recommendations for social work practice, policy, and research.

Discussion

Participants agreed that vision rehabilitation services were a necessity even though they initially availed of vision rehabilitation services for different reasons ranging from practical goals, such as learning to complete household chores and mobility skills,

to more intangible needs such as support and guidance on issues related to the emotional impact of vision loss. The findings demonstrate that people experiencing vision loss in this province face a number of challenges related to the availability and accessibility of vision rehabilitation services and programs and that these challenges are exacerbated for those who are living in the province's more rural and remote regions. The findings also underscore that vision rehabilitation is a lifelong process.

The organizing framework of needs, barriers, and pathways did facilitate the analysis but it was also clear that the categories were not necessarily separate and distinct from each other. The next section of this chapter therefore summarizes in a more general way what we can learn from participants about vision rehabilitation services in this province.

Changing needs throughout the life span and continued contact with CNIB. A dominant theme throughout the participant interviews was the need for adaptation of vision rehabilitation training and services as vision needs change throughout the life span. If clients are engaged with vision rehabilitation organizations on an ongoing basis they will be more likely to contact them if they require additional services and supports. Half of the participants identified the need for additional vision rehabilitation training, emotional support, or new assistive devices as their vision changed. Participants reported they would like to see an increase in the amount of contact they have with CNIB and indicated they would like the organization to keep them informed about new assistive

devices and upcoming events. Continued contact with CNIB is a potential pathway to ensuring that people feel comfortable contacting the organization when, and if, their vision rehabilitation needs change.

The majority of literature reviewed focused on initial access as a pathway to vision rehabilitation services. There was a lack of information pertaining to the need for vision rehabilitation services throughout a person's life. This is an important insight in relation to the goals of the CNIB Newfoundland and Labrador Vision Health and Rehabilitation Committee framework. In order to facilitate the continual best quality of life for people with vision loss findings suggest vision rehabilitation services need to be accessible to people throughout their life span as they experience changes in vision and life circumstances. People may need to access additional vision rehabilitation training at several points in their life to adapt or develop skills to remain independent, care for others, and maintain a good quality of life.

Adaptation of vision rehabilitation training and services throughout the life span is also necessary to ensure the social inclusion of people with vision loss. Changes in vision may require access to new assistive technology and additional vision rehabilitation training to enable continued employment and sustain economic inclusion. These adaptations may include additional assistive technology training, orientation and mobility training related to the commute to work and safety within the work environment, and independent living skills training to assist with the completion of job tasks. Lifelong

access to vision rehabilitation services is also necessary to ensure the functional, participatory, and physical inclusion of people with vision loss. The findings suggest there is a need for organizations that provide vision rehabilitation services and programs to focus beyond the initial referral. Ongoing vision rehabilitation training may be necessary for people with vision loss to remain actively involved in their communities, access transportation and public places, and to contribute to their communities.

Source of referral to CNIB and increase in public and professional information. In the review of the literature it was noted that eye care professionals typically do not refer patients to vision rehabilitation services and most people are referred to services by a friend or family member. In contrast, this study identified this group of professionals as a pathway to vision rehabilitation services as the majority of participants in this study had been referred to CNIB by an eye care specialist.

The literature review also revealed that eye care specialists provide limited information about coping with vision loss and often wait until the end of treatment to suggest vision rehabilitation services. Participants in this study supported this notion, all but one reporting that while their doctors had discussed CNIB programs and services with them the information was sometimes vague. This suggests that there is a need for CNIB to work with eye care professionals to ensure they are knowledgeable about the vision rehabilitation programs and services offered by CNIB and equipped to provide detailed information to their patients and to answer questions about the organization.

Participant interviews did indicate a lack of referral among professionals other than eye care specialists. This could be due to be a lack of knowledge about CNIB among other professional groups or lack of awareness that they are able to make referrals to the organization. Knowledge of CNIB programs and services is especially important for professionals working at the community level because they often visit people in their own environments and are able to observe if a person is having difficulties with activities of daily living due to vision loss.

There is a need for CNIB to work with all professionals to increase knowledge of CNIB vision rehabilitation services, their benefit to people with vision loss especially in the early stages, and the referral process. It is anticipated this would increase the number of clients being referred to CNIB and improve the level of information provided to a patient when being referred to CNIB programs and services.

Public and professional education. Participant interviews supported the view that access and utilization of vision rehabilitation services would be improved by investing in education, awareness, and health promotion campaigns. Participants believed CNIB should increase the number of newsletters and public information sessions they provide. These initiatives should target specific audiences, such as doctors, social workers, nurses, and other professionals. Participants suggested this would improve awareness of vision rehabilitation services and access to vision rehabilitation services and assistive technology.

Participants also saw the benefit of conducting information sessions for employers and those in the work force experiencing vision loss. These sessions could help ensure the economic inclusion of people with vision loss because they could increase the likelihood of companies hiring a person with vision loss. Participants believed these sessions would be a way of promoting the abilities of people with vision loss and their capability of participating in the workforce. These sessions may also be a means of support for current and potential CNIB clients by letting them know they do not have to give up their employment just because they are experiencing vision loss.

Overall participants believed that CNIB needs to raise awareness of their programs and services, about the causes of vision loss, and what it is like to live with vision loss. Participants in Labrador also believed that CNIB needed to do a better job of raising awareness of the organization, especially the programs and services they offer, and making CNIB recognizable in that area of the province.

Public information sessions could help ensure the cultural and relational inclusion of people with vision loss as participants reported feeling marginalized because the general public does not understand vision loss and the abilities of those living with vision loss. There is a need for public information to increase knowledge about the abilities of people with vision loss and how to interact with the population. It is anticipated that such public information sessions could improve respect for people with vision loss, recognition of their abilities, and their contributions to society. The value of CNIB

information sessions and public events should not be overlooked as participants reported accessing CNIB programs and services after having attended such an event. These types of events introduce people to the organization and provide an opportunity for them to make further contact.

Referral to CNIB programs and services from all sources and increase in public and professional information is important. They help facilitate the best quality of life for people with vision loss by improving the likelihood of people accessing vision rehabilitation services and increasing the knowledge of the abilities of people with vision loss amongst the general public. An increase in public knowledge would result in improved interactions between people with vision loss and the general population. It would also help remove some of the stigma associated with vision loss.

Public education also has the potential to reduce the incidence of vision loss and blindness through early detection. Public education can be used as a platform to highlight the causes of vision loss and the need for regular eye exams. Regular eye exams are necessary for the early detection of eye diseases leading to vision loss and blindness. This is turn can reduce the occurrence of unnecessary vision loss.

Perception of individual vision loss and postponement in accessing vision rehabilitation services. Individual perception of vision loss may be a barrier to people accessing vision rehabilitation services and assistive technology. Those that chose not to avail of services or devices cited reasons that had been discussed in the literature such as

waiting for eye surgery to be completed in order to determine if services would still be required and believing that vision loss was a natural part of aging therefore little could be done to assist. Participants also were not convinced that assistive technology would be beneficial.

Participant interviews supported the idea that people with vision loss need to be made aware that vision rehabilitation services and assistive technology can benefit them at any stage of vision loss and at any age. In Newfoundland and Labrador as in the rest of Canada, people often have to wait extended periods of time for eye surgeries. This is time that could be spent participating in vision rehabilitation training. Although vision loss can be a result of the aging process older adults need to be made aware of the benefits of vision rehabilitation training and learn not to dismiss vision loss as a natural part of the aging process.

People with vision loss need access to assistive technology to understand the benefits of devices and the improvements they can make in their life. Access to assistive technology would enable people to try the devices and understand how they can contribute to their independence. Vision rehabilitation providers need to promote the benefits of vision rehabilitation services and assistive technology for all people with vision loss, regardless of age, level of vision, and the duration of vision loss.

The postponement of accessing vision rehabilitation services and assistive technology can have an impact on a person's quality of life and their inclusion in society.

People may experience economic hardships because they may unnecessarily give up their employment, believing they can no longer work when vision rehabilitation services and assistive devices may be able to assist them in performing their job. Delay in accessing vision rehabilitation services may also effect a person's functional and physical inclusion because they may not have the skills to remain active members of their communities, use transportation services, and access public places.

Improved access to vision rehabilitation services, assistive technology, and transportation. For people with vision loss to experience optimal quality of life they need to have access to vision rehabilitation services, assistive technology, and accessible transportation. Participant interviews supported reports that CNIB services may not be universally available and equally accessible to all people with vision loss due to staffing and geographical challenges (Muzychka, 2009) and there is an unequal distribution of vision rehabilitation services in rural and urban areas (Matti et al., 2010). Participants outside of St. John's, especially those in Labrador, did not believe they were receiving the same level of service as their counterparts in the capital region of the province and said it was difficult to access services where they live as services are not readily available to them.

Transportation was reported by most participants as a barrier to accessing vision rehabilitation services. For those living in rural areas of the province there is little, if any, public transportation available. Participants reported having to rely on family members

and friends to assist them with transportation to medical appointments, grocery shopping, and other daily activities outside of the home. Access to public transportation wherever possible is imperative to ensure independence and enable access to vision rehabilitation services, community resources, and businesses.

One way to meet the demand for services in all areas of the province is the hiring of additional vision rehabilitation specialists. The hiring of additional specialists would increase the number of professionals located throughout the province. It would also increase the number of professionals travelling to provide vision rehabilitation services increasing the number of visits received and the duration of visits. The amount of time spent travelling to rural areas in order to provide vision rehabilitation services can be problematic for specialists due to the geographical area that needs to be covered. Participants said the wait for vision rehabilitation specialist to visit their area can be lengthy and the specialists do not always have enough time to provide the level of service deemed necessary.

Another way to meet the demand for vision rehabilitation services is the opening of additional CNIB centres in various regions of the province. These centres could be located in areas of high demand and serve the outlying areas. The centres could also house assistive technology demo items, providing people with an opportunity to view and try various assistive devices.

A partnership with the four provincial health authorities, Eastern Regional Health, Central Regional Health, Western Regional Health, and Labrador/Grenfell Regional Health, could also provide an opportunity for people with vision loss to have improved access to vision rehabilitation services and assistive technology. Visiting vision rehabilitation specialists could provide service out of local health offices, reducing the need for travel within the region. This would also provide additional time for each client visit because specialists would not have to spend time setting up equipment for each session. The regional health authorities could also provide space for the housing of assistive technology demo items, providing people in the area an opportunity to view the items and try them to determine their effectiveness.

The implementation of these initiatives would improve access to vision rehabilitation services, assistive technology, and reduce transportation barriers for clients in all areas of Newfoundland and Labrador. This could facilitate the economic inclusion of people with vision loss enabling them to find employment or continue working as they would have timely access to the services and devices needed for successful employment. There is also the potential to improve functional, participatory, and physical inclusion as improved access to vision rehabilitation services and transportation would enable people to remain active in their communities and provide them with access to programs and services and public places. Furthermore there is an opportunity to improve the political and structural inclusion of people with vision loss by removing systematic barriers, improving community capacity building, and providing options for change. These

initiatives could change the current system of vision rehabilitation service delivery in Newfoundland and Labrador and improve the environment so that it is more accessible to people with vision loss.

There is also the potential to improve the public perception of vision loss in all areas of the province because residents would see people with vision loss living independent, active lives as a result of vision rehabilitation training and assistive technology. Community members would see people with vision loss travelling independently, completing daily tasks such as shopping, and being involved in sports and community groups.

Equal access to services is a significant issue for older persons given the statistics cited in the introduction that one in eight people in the province can expect to live with significant vision loss after the age of 75 (CNIB, 2008). It is also important to note that the majority of those living in rural locations will be older adults due to the continuous outmigration of youth in these areas (Economic and Statistics Branch Department of Finance, 2005).

Psychological and emotional support. Despite the fact that large numbers of people with vision loss experience depressive symptoms (Southall et al., 2008), psychological and emotional support is often overlooked in the current model of vision rehabilitation services. It is also known that psychological and emotional factors can be a barrier to people accessing vision rehabilitation services as people must deal with the

emotional and psychological impacts of vision loss in order to be comfortable fully availing of vision rehabilitation training. These issues were confirmed by participants in this study. There is a need for psychological and emotional support within the current model of vision rehabilitation services in Newfoundland and Labrador in the form of individual, family, and group counselling.

Individual and group counselling services are needed throughout a person's life as they adjust to their changing vision and its impact on life situations. Counselling also assists family members cope with the vision loss of a loved one. Vision loss affects not only the individual experiencing vision loss but also those closest to them. Family members need to be able to speak with a professional counsellor to discuss their own adjustment process and changing relationships. Participants stressed the importance of these services being provided by a trained professional counsellor.

Psychological and emotional support is an important aspect of social inclusion. People need to believe they are valued and respected in their homes, communities, and society in general. Psychological and emotional distress can cause people to become withdrawn from the friends, family, and society. They may choose to stop working, participating in groups, and availing of programs and services. Support is needed to ensure that people with vision loss do not experience unnecessary emotional hardships and that they retain the opportunity to be active members of society.

CNIB does provide some emotional support in the form of group programming and given the significance of psychological and emotional support they need to promote this program amongst their client base. Some participants were not aware of the Adjustment to Vision Loss group program and others who had already taken the course were not aware that it was still being offered to clients in Newfoundland and Labrador.

Psychological and emotional support is clearly an important pathway to people accessing vision rehabilitation services and a determinant of a person's quality of life. People may need the assistance of a professional counsellor to help them adjust to their vision loss and feel comfortable accessing vision rehabilitation services. Vision loss can also place a great deal of strain on personal relationships and a professional counsellor knowledgeable about vision loss could help couples and families overcome these issues.

Assistive technology demo centres and stores and assistive technology training. There is a need for access to assistive technology demo items and local stores to purchase devices. Assistive technology enables people with vision loss to experience the best quality of life possible. It is an important determinant of social inclusion as participants said it provided them with independence and enabled them to participate in school and the workforce. Assistive technology also makes it possible for people to stay in touch with friends and family, participate in society through information sharing and social networking, and improves access to public transportation and community

resources. Assistive technology assists a person with vision loss to read a bus schedule, read labels and price tags when shopping, and even play sports.

Assistive technology demo centres and stores are beneficial and needed throughout the province. These services enable users to try various assistive devices to determine which devices would best meet their needs and provides the opportunity to immediately purchase the device. This prevents participants from spending money on devices that would not benefit them and from having to wait for devices to be delivered. Participants expressed frustration when they did not have the opportunity to experiment with assistive devices before purchasing and ended up spending money on devices that were ineffective.

In this study, the majority of participants were not using any assistive devices which may support the literature that people choose not to use assistive devices because they are not able to view them before purchasing (Gold et al., 2006) and the view that assistive devices need to be available for demonstration and hands on experimentation to eliminate the barriers associated with accessing and using assistive technology. This is the only way people will know if a device is suitable and will meet their needs.

For those who do avail of assistive technology, training is essential and may result in an increase in compliance with the use of assistive technology (Gold & Zuvela, 2005). Participants in this study agreed there is a need for increased training opportunities from CNIB. Although CNIB provided most of the assistive technology used by participants,

many reported being self trained in the use of assistive devices or utilizing assistive technology training services outside of CNIB. Participants believe the assistive technology training provided by CNIB needs to be more in-depth and the services need to be improved for clients outside of St. John's.

The majority of assistive technology training provided to participants from CNIB was via telephone. Given that CNIB has only one full time and one part-time assistive technology specialist it is difficult for them to travel throughout the province to offer hands on training. This is not the preferred method of providing training as people often need hands on assistance learning how to use assistive technology. One way of providing this service to clients may be to have trained volunteers available in communities to provide individual training to those that require it.

Cost of assistive technology. Participants stressed the importance of assistive technology and the need for all people with vision loss to have access to devices at school, in the workforce, and at home. It is an integral part of life for people with vision loss and there is a need for equal access. The development of a provincial assistive devices program would be a pathway to ensuring that all people have equal access to assistive technology.

Research indicated the rising cost of assistive technology is significantly affecting the benefits of vision rehabilitation services for people with low or fixed incomes (Gold et al., 2006). The cost of assistive technology was identified as a significant barrier for

participants of this study. Participants confirmed that there is a lack of funding programs to assist people with acquiring assistive devices and they are unaware of the eligibility criteria for known funding programs. Participants reported doing without devices or settling for cheaper alternatives because they are not able to afford the assistive technology they require. People are not able to maximize their vision rehabilitation training if they do not have the assistive devices they require to aid them throughout daily life.

The cost of assistive technology has an impact on the economic, political, and structural inclusion of people with vision loss. In general, people do not have the income to purchase assistive technology that would aid them in meeting their basic needs and participating in society. The development of an assistive devices funding program would remove the systematic barriers involved with accessing assistive technology and bring about change. A provincial assistive devices program or subsidy would enable people with vision loss to increase their independence through access to devices that would be responsive to their individual needs. Assistive technology enables people with vision loss to participate fully in life and needs to be made available to all people regardless of their economic situation.

Limitations of the Study

Although the participants provided rich insight into the experience of accessing and using vision rehabilitation services, the small sample size limits the transferability of the findings to the overall population of people living with vision loss in Newfoundland and Labrador.

Time and cost barriers also caused limitations in this study. Time barriers were created by the fact the CNIB Newfoundland and Labrador Vision Health and Rehabilitation Committee had a timeframe in which the study needed to be completed in order to lobby government for the development of a vision health framework for Newfoundland and Labrador. These time constraints affected the number of participants that would be interviewed and the duration of interviews. The number of participants and the length of interviews had to be manageable to ensure that time lines were met and the study was within the breadth and depth expected for the Master of Social Work degree thesis.

The scope of the project was further limited because CNIB did not have the financial resources to complete a fully developed needs assessment and cost barriers affected the method used to conduct participant interviews. Face to face interviews were not feasible in this study due to the cost associated with travelling throughout the province of Newfoundland and Labrador to meet with participants.

Another limitation of this study, related to cost and time constraints, was the use of the CNIB client list to recruit participants. This sampling strategy excluded those that have not accessed or used vision rehabilitation services creating a clear bias in the findings. Access to this group of potential participants would have provided insight into the needs of those that have never accessed vision rehabilitation services and the barriers that have kept this population from accessing the services. The needs of this population and the barriers they experience may be very different from the sample used in this study. However, this was an exploratory study and an understanding of users' past and current experiences of using and accessing vision rehabilitation services provided important information about key directions in the development of a strategic provincial vision health plan.

The informed consent protocol appeared to be a further limitation of this study. A large number of potential participants were contacted and chose to not receive information about the study. In addition to this, a number of participants chose not to participate once they did receive the information. Discussions with older adults suggested they were intimidated by the process of informed consent and did not believe they were competent enough to agree to participate. Some older adults had agreed to participate but declined after having the consent form read saying they did not think they should continue without the advice of their children or another person. This did not appear to be a concern for participants from the categories of parents of children with vision loss and working age adults groups. The resistance of older adults to provide

informed consent seemed to be due to the length of the consent form. The need for the use of plain language to accommodate varying literacy levels resulted in a consent form that was four pages in length. In hindsight, the document could have been further condensed to help eliminate the concerns related to informed consent amongst older participants.

The literature review was limited due to the lack of research about vision rehabilitation services, especially in Newfoundland and Labrador. Much of the research related to vision rehabilitation services and program development is new and has not yet reached the evaluation stage.

My previous employment with CNIB, although beneficial to my knowledge of vision rehabilitation services, proved to be a limitation of this study. As the interviewer I was in a situation where I was conducting interviews with six participants I had a previous working relationship with. Participant interviews sometimes discussed programs that I had developed while employed at CNIB. Participants did not always discuss their experiences in detail and relied on me to understand their experiences based on our history. This may have also affected the integrity of the discussion because participants may not have wanted to disclose negative views of the programs. However, participants new to vision rehabilitation services discussed these programs openly, not knowing I had been involved in their development. This factor presented further challenges at times when I knew the information the participant was providing about

programs and services was incorrect. Despite my previous employment with CNIB I aimed to remain objective and unbiased while conducting participant interviews. In these instances I would continue with the interview as if I did not have any previous knowledge of CNIB but at the end of the interview I would provide them with the correct information. For example, one participant believed CNIB in Newfoundland and Labrador charged clients for white canes while other provinces provided them free of charge. I informed the client after the interview that this was incorrect and CNIB in Newfoundland and Labrador did in fact provide free white canes to clients.

The interview guide also proved to limit the research findings. As the interviews progressed it was discovered that the questions contained in the original interview guide were not gaining rich, descriptive information about the needs, barriers, and pathways related to vision rehabilitation services. For example, the questions "what assistive technology have you found the most beneficial? Least beneficial?" simply generated a list of assistive devices used by participants. It would have been more valuable to ask how the assistive technology benefited the person. For future research it would be important to determine with a pilot study if the questions contained in the interview guide would extract the breadth of information necessary to answer the research question.

Recommendations for Social Work Practice, Policy and Research

Social workers need to be aware of the profound impacts of vision loss on individuals, families, and communities as identified in the research. They need to be conscious of the psychological and emotional impacts of vision loss as the research confirms that the impacts of vision loss are not exclusively physical. In addition to this, they need be sensitive to the fact that a person with vision loss may be at an increased risk for depression. Social workers should also be attentive to how vision loss may be affecting family members because they too have to adjust to and live with vision loss.

Social workers, especially at the macro level, must help advocate for modifications and improvements to current policies and programs that impact people with vision loss. They must be involved in the development, implementation, and monitoring of a vision health strategy for the province to ensure the best quality of life for people living with vision loss in the province and reduce the incidence of vision loss and blindness through public education and early detection. Social workers have a specialized role to play in this initiative because they are able to identify social problems and are skilled at suggesting legislative and other solutions. They are also skilled in advocating for the rights of those living with disabilities and researching and analyzing policies, programs, and regulations.

Research is a crucial aspect of social work practice because it informs and shapes practice through the development of new interventions, and provides the opportunity for

critical analysis of current and proposed interventions. Research helps to ensure that the best method of intervention is used and most importantly that no unnecessary harm comes to clients.

There is an opportunity for further research into issues related to vision health and rehabilitation in Newfoundland and Labrador. Further research is needed to examine the barriers to vision rehabilitation services as they relate to those that have never accessed the services. There is also an opportunity for further research into the need for access to vision rehabilitation services throughout the life span. Present research focuses on the initial contact and referral but it is also beneficial to investigate if people are accessing and utilizing vision rehabilitation services when needed after the initial referral. Further research will help provide an evidence base for best practices related to the expansion of vision rehabilitation services in Newfoundland and Labrador.

This research has contributed to a better understanding of the needs, barriers, and pathways to vision rehabilitation services in Newfoundland and Labrador and the role social workers have in ensuring that people with vision loss have access to these services. Social workers may occupy a wide variety of roles in a vision rehabilitation model from direct counselling with individuals, families and groups, to advocating with and on behalf of people with vision loss, to shaping and developing vision health policies, and finally to research that informs and evaluates best practices.

Conclusions

The primary goal of this study was to explore the needs, barriers and pathways to accessing and using vision rehabilitation services in the province of Newfoundland and Labrador. A qualitative study was undertaken using individual interviews with CNIB clients from three client age groups and from each of the four provincial health authorities to ensure a cross sample of consumers were given a voice. Participants described their personal experience of the needs, barriers, and pathways to accessing and using vision rehabilitation services and the results chapter discussed the themes that emerged from these discussions.

In addition to what was learned from the literature about the general vision rehabilitation needs of persons with vision loss, several elements emerged that appear to be unique to the province of Newfoundland and Labrador. Participants discussed the need for vision rehabilitation services and new assistive technology throughout a person's life span due to changes in vision and life situations. The expansive and isolated geography of the province has an important influence on accessibility and awareness of vision rehabilitation services particularly for residents of Labrador. It also appears that there are a higher number of eye care specialists referring people to vision rehabilitation services in Newfoundland and Labrador than in other provinces and countries.

Participant interviews supported the call for improved access to assistive devices. An essential part of ensuring this happens is the development of an assistive devices

funding program. People with vision loss are doing without essential devices because they cannot afford them. These devices enable people to participate in school, the workforce, and their communities. They are also essential for ensuring independence in their homes.

As was noted in the introduction to this thesis, the impacts of vision loss to individuals and communities are profound and costly and will continue to grow in an aging society. At the same time, vision rehabilitation services and assistive technology have been identified as protective factors in the social and economic inclusion of persons with vision loss. Recognizing these realities the CNIB Newfoundland and Labrador Vision Rehabilitation Committee came together to propose a provincial vision health strategy. This study contributed to the goals of the committee by identifying the outstanding vision rehabilitation needs of a small sample of people with vision loss in the province and the barriers that are preventing them from fully accessing and utilizing programs and services. An exploration of pathways to vision rehabilitation services was also important because it identified the reasons people sought out and accessed vision rehabilitation services. This information can help improve the relevance and accessibility of vision rehabilitation services in Newfoundland and Labrador thus expanding opportunities for people with vision loss to participate fully in the life of their communities.

References

Access Economics Pty Limited. (2009). *The cost of vision loss in Canada: Summary report.* Toronto: COS & CNIB.

Auerbach, C. F., & Silverstein, L. B. (2003). *Qualitative data : An introduction to coding and analysis.* New York: New York University Press.

Burhmann, R., Fielden, M., & Hodge, W. (2007). *Forecasting the vision loss epidemic in Canada: Projections of cause specific blindness.* Abstract. Montreal: The Eye, the Brain and Low Vision.

CNIB. (2011a). *FAQ - About vision loss.* Retrieved from http://www.cnib.ca/en/faq/vision-loss/; accessed 18 June 2011.

CNIB. (2011b). *Assistive technology.* Retrieved from http://www.cnib.ca/en/services/products/assistive-tech/; accessed on 10 March 2011.

CNIB. (2010). *CNIB Newfoundland and Labrador vision health and rehabilitation committee.* Retrieved from http://www.cnib.ca/en/newfoundland/activities/vision_health_rehabilitation_committee/default.aspx; accessed on 20 April 2010.

CNIB. (2008). *The need for a provincial vision health strategy in Newfoundland and Labrador*. Unpublished paper.

CNIB. (2007). *Age-related macular degeneration (AMD): Take a closer look... before it's too late: A journalist's guide to AMD*. Retrieved from www.cnib.ca/en/about/media/.../Journalist_GuidetoAMDEN_FINAL.doc; accessed on 17 June 2011.

CNIB. (2005). *VOICE in health policy: The impact of health policy gaps on low vision services in Canada*. Toronto: CNIB.

Canadian Council for the Blind. (2011). *About us*. Retrieved from http://www.ccbnational.net/content/index.php?option=com_content&view=article&id=53&Itemid=54; accessed 09 April 2011.

Creswell, J. (2007). *Qualitative inquiry and research design: Choosing among five approaches*. Thousand Oaks, CA: Sage.

Department of Health and Community Services. (2007). *Provincial healthy aging: Policy framework*. Retrieved from http://www.health.gov.nl.ca/health/publications/ha_policy_framework.pdf; accessed on 19 October 2010.

Economics & Statistics Department of Finance. (2005). *Demographic change: Newfoundland and Labrador issues & implications*. St. John's, NL: Government of Newfoundland & Labrador

Federal/Provincial/Territorial Ministers Responsible for Seniors. (2007). *Working together for seniors: A toolkit to promote seniors' social integration in community services, programs and policies*. Retrieved from http://www.seniors.alberta.ca/Seniors/docs/WorkingTogetherForSeniors.pdf; accessed on 01 March 2011.

Frazee, C. (2003). *Thumbs up! Inclusion, rights and equality as experienced by youth with disabilities*. Toronto: The Laidlaw Foundation.

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods*, *18*(1), 59-82.

Gold, D., & Zuvela, B. (2005). *The impact of health policy gaps on low vision services in Canada*. Toronto: CNIB.

Gold, D., Zuvela, B., & Hodge, W.G. (2006). Perspectives on low vision service in Canada: A pilot study. *Canadian Journal of Ophthalmology*, *41*(3), 348-354.

Gold, D., Zuvela, B., & Shaw, A. (2008). Canadian seniors with vision loss: How are they faring? *Abstract book of Vision 2008 the 9th international conference on low vision*. Montreal: Canada.

Goss Gilroy. (2007). *HCS disability supports project*. Report to the Department of Health and Community Services. St. John's, NL: Unpublished.

Government of Newfoundland and Labrador. (2007). *Our blueprint for the future*. Retrieved from http://www.hrle.gov.nl.ca/hrle/disabilities/consultations.html; accessed on 19 October 2010.

Government of Newfoundland and Labrador. (2001). *Programming for individual needs: Teaching children who are blind or visually impaired*. Retrieved from http://www.ed.gov.nl.ca/edu/k12/studentsupportservices/publications/TeachingStudentsBlind.pdf; accessed on 04 February 2011.

Government of Ontario. (2010). *Assistive devices program*. Retrieved from http://www.health.gov.on.ca/english/public/program/adp/adp_mn.html; accessed 14 April 2010.

Hick, Steven (1998). *Canada's unique social history*. Retrieved from http://www.socialpolicy.ca/cush/m5/m5-+16.stm; accessed 07 April 2011.

Human Resources, Labour and Employment (2010). *Provincial government announces consultations to develop a strategy for the inclusion of persons with disabilities.* Retrieved from http://www.releases.gov.nl.ca/releases/2010/hrle/0902n01.htm; accessed 09 May 2011.

Hutchinson, A., & Lee, B. (2004). Exploring social inclusion in practice: Perspectives from the field. *Canadian Social Work Review, 21* (2), 119–136.

Industry Canada. (2010). *Assistive technology links.* Retrieved from http://www.at-links.gc.ca/zx10000E.asp; accessed 19 October 2010.

Jin, Y.P., & Wong, D.T. (2008). Self-reported visual impairment in elderly Canadians and its impact on health living. *Canadian Journal of Ophthalmology, 43*(4), 407-413.

Lighthouse International. (2010). *Rehabilitation services.* Retrieved from http://www.lighthouse.org/services-and-assistance/low-vision-clinical-services/rehabilitation-services/; accessed 02 March 2010.

Luborsky, M.R., & Rubinstein, R.L. (1995). Sampling in qualitative research: Rationale, issues, and methods. *Research on Aging, 17* (1), 89-113.

Matti, A.I., Pesudovs, K., Daly, A., Brown, M., & Chen, C.S. (2010). Access to low-vision rehabilitation services: barriers and enablers. *E-Journal of Clinical and Experimental Optometry,* 10.1111, 1-6. Retrieved from http://onlinelibrary.wiley.com.qe2a-proxy.mun.ca/doi/10.1111/j.1444-0938.2010.00556.x/full; accessed 07 February 2011.

Mackelprang, R.W., & Salsgiver, R.O. (1996). People with disabilities and social work: historical and contemporary issues. *Social Work*, *41*(1), 7-14. Retrieved from EBSCO*host*.

Muzychka, M. (2009). *Environmental scan of vision health and vision loss in the provinces and territories of Canada*, Report for the National Coalition for Vision Health.

Mwilambwe, M., Wittich W., & Freeman, E.E. (2009). Disparities in awareness and use of low-vision rehabilitation. *Canadian Journal of Ophthalmology*, *44* (6), 686-691.

National Eye Institute. (2010). *National plan for eye and vision research*. Retrieved from http://www.nei.nih.gov/strategicplanning/np_eyehealth.asp; accessed 17 February 2010.

Newcomb, R.D. (2006). *What do 20/60 vision and 20/10 vision mean?* Retrieved from http://www.netwellness.org/question.cfm/35956.htm; accessed 08 April 2011.

Overbury, O., Wittich, W., Ferraresi, P., & Southall, K. (2008). Barriers to rehabilitation: A new starting point. *Abstract book of Vision 2008 the 9th international conference on low vision*. Montreal: Canada.

Piantanida, M, & Garman, N.B. (1999). *The qualitative dissertation: A guideline for students and faculty*. Thousand Oaks, CA: Corwin Press Inc.

Pollard, T. L., Simpson, J.A., Lamoureux, E.L., & Keeffe, J.E. (2003). Barriers to accessing low vision services. *Ophthalmic & Physiological Optics: The Journal of the British College of Ophthalmic Opticians*, *23* (4), 321-327.

Rubin, A. & Babbie, E.R. (2007). *Research methods for social work* (6th ed.). Scarborough, ON: Nelson Education.

Saloojee, A. (2001). *Social inclusion, citizenship and diversity*. Toronto: The Laidlaw Foundation.

Scheiman, M., Scheiman, M., & Whittaker, S. G. (2007). *Low vision rehabilitation: A practical guide for occupational therapists*. Thorofare, NJ: SLACK Incorporated.

Shookner, M. (2002). *An inclusion lens: Workbook for looking at social and economic exclusion and inclusion*. Retrieved from http://www.phac-aspc.gc.ca/canada/regions/atlantic/Publications/Inclusion_lens/inclusion-eng.php; accessed 23 May 2010.

Social Workers Act, SNL2010 CHAPTER S-17.2. (2010). Retrieved from http://www.assembly.nl.ca/legislation/sr/statutes/s17-2.htm#2; accessed on 09 May 2011.

Southall, K., Wittich W., Overbury, O., & Ferraresi, P. (2008). Barriers to vision rehabilitation: A qualitative approach. *Abstract book of Vision 2008 the 9th international conference on low vision*. Vision 2008: Montreal.

Stanley, J. (2007). *The usefulness of social exclusion as a theoretical concept to inform social policy in transport*. Retrieved from http://www.thredbo.itls.usyd.edu.au/downloads/thredbo10_papers/thredbo10-themeD-Stanley.pdf; accessed 01 May 2010.

Statistics Canada. (2006). *Participation and activity limitation survey (PALS)*. Retrieved from http://www.statcan.gc.ca/cgibin/imdb/p2SV.pl?Function=getSurvey&SDDS=3251&lang=en&db=imdb&adm=8&dis=2; accessed 20 February 2010.

Temisjian, K., Wanet-Defalque, M.C., Gresset, J., Desrosiers, J., Rousseau, J., Dubois, M.F., Vincent, C., Carignan, M., Renaud, J., & Overbury, O. (2008). Waiting for services from a vision rehabilitation center: Are services related to the needs of elderly clients? *Abstract book of Vision 2008 the 9th international conference on low vision*. Vision 2008: Montreal.

The Chicago Lighthouse. (2011). *Because there is still hope for those with low vision...* Retrieved from http://chicagolighthouse.org/Because%20there%20is%20still%20hope%20for%20those%20with%20low%20vision...The%20Chicao%20Lighthouse; accessed 07 March 2011.

The Hadley School for the Blind. (2011). *About Hadley*. Retrieved from http://www.hadley.edu/1_a_AboutHadley.asp; accessed 04 February 2011.

The Roeher Institute. (2003). *Policy approaches to framing social inclusion and social exclusion: An overview*. Toronto, ON: The Roeher Institute.

World Health Organization. (2010). *Social determinants of health: Social exclusion.* Retrieved from http://www.who.int/social_determinants/themes/socialexclusion/en/index.html; accessed 01 March 2011.

Appendix A

Letter of Ethical Approval

July 14, 2010

ICEHR No. 2009/10-142-SW

Ms. Melinda Duggan
School of Social Work
Memorial University of Newfoundland

Dear Ms. Duggan:

Thank you for your e-mail correspondence of July 13, 2010 addressing the issues raised by the Interdisciplinary Committee on Ethics in Human Research (ICEHR) concerning your research project *"Vision rehabilitation services in Newfoundland and Labrador: identifying the needs, barriers, and pathways"*.

The ICEHR has re-examined the proposal with the clarification and revisions submitted and is satisfied that concerns raised by the Committee have been adequately addressed. In accordance with the *Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans (TCPS)*, the project has been granted *full ethics clearance* for one year from the date of this letter.

Also, ICEHR has reviewed your proposed amendment and is pleased to give clearance to you to conduct 16 interviews instead of 20, removal of the focus group, and a shortened question guide.

If you intend to make other changes during the course of the project which may give rise to ethical concerns, please forward a description of these changes to Mrs. Brenda Lye at blye@mun.ca for the Committee's consideration.

The *TCPS* requires that you submit an annual status report on your project to the ICEHR, should the research carry on beyond July 2011. Also to comply with the *TCPS*, please notify us upon completion on your project.

We wish you success with your research.

Yours sincerely,

Lawrence F. Felt, Ph.D.
Chair, Interdisciplinary Committee on
Ethics in Human Research

LF/en

copy: Supervisor – Dr. Gail Wideman, School of Social Work

Telephone: (709) 737 2561 / 737 2861 Fax: (709) 737 4612

Appendix B

Protection of Participants

There was no anticipated risk of harm to participants in this research project. However, the qualitative process tends to generate the articulation of personal, sometimes emotionally sensitive material. This may be especially true for people who are struggling to cope with vision loss. These concerns were addressed with the following measures:

1. The introductory information package contained specific information about the kinds of questions that would be covered in the interview guide to maximize informed consent to participation.
2. At the beginning of each individual interview session I reiterated the purpose of the research and outlined who would have access to the information as well as how the information would be stored.
3. Participants were informed as to exceptions to confidentiality, as in a case where a participant suggests there is risk of harm to him or herself or to another person.
4. In the event of an issue or problem being divulged that required intervention, a list of contact names and numbers would be provided of relevant supports and services in each community.

There were no immediate benefits identified with participants in this project other than the opportunity to express ideas and feelings.

The design and implementation of research tools including the information package and consent form accommodated low levels of literacy as well as vision impediments. The following measures further ensured informed and voluntary participation:

1. After the initial contact by the key informant (the CNIB representative), the key informants did not know who agreed to participate.
2. The information package provided to candidates contained the following information:

    - A brief description of the research study, and the value of the study to the social work and vision loss communities and to the participants.
    - An explanation as to how and/or why they were selected including a statement that their participation is completely voluntary.
    - A description of the procedures including:
        - Frequency with which the participants would be contacted.
        - Time commitment.
        - Location of participation.
        - Information that would be recorded and how it would be recorded.

            - An explanation of who would have access to the information.
            - A description of how the data would be made public.
            - An explanation of participants' rights:

- They may terminate or withdraw at any time.
- They may ask for clarification or more information throughout the study.
- They may contact the thesis supervisor if they have any questions about the study or process of the research.

The research participants for this project consisted of those that are legally competent and did not involve children or others whose competence to consent to participate may have been in question. All participants in this research project were of the age of legal consent which is 19 years of age in Newfoundland and Labrador.

As participants were users of vision rehabilitation services, they were recruited using the CNIB's client list. This form of recruitment was necessary as CNIB is the primary provider of vision rehabilitation services in Newfoundland and Labrador. A CNIB representative contacted potential participants to inform them of the research and asked them if they would agree to receive additional information about the research.

When consent for further contact was obtained, candidates received a letter and the project information sheet which introduced me as researcher, identified the purpose of the research, and extended an invitation to participate in an individual interview.

Information about the project was reviewed at the outset of each interview session and documented proof of consent was verbally collected and recorded prior to commencement.

Project participants were assured that confidentiality would be preserved to the extent possible and that they would not be named in the research report.

Appendix C

Script for Telephone Contact with Individual Interview Candidates

Good morning/afternoon/, my name is [name] and I am calling on behalf of Melinda Duggan, a Graduate student at the School of Social Work at Memorial University. As part of her degree Melinda is conducting a research project that looks at vision rehabilitation services in Newfoundland and Labrador. Vision rehabilitation services are services that help a person with vision loss live a better life. Most of these services are provided by CNIB. Melinda's research will look at the services that people with vision loss need, the ways in which they get to and use the services, and the way people find the services. She would like to talk with people that have used vision rehabilitation services and parents of children that have used vision rehabilitation services.

The reason for my phone call today is to ask if I can send you an information package about the project and have the researcher contact you with a follow up phone call. By agreeing to receive more information about the project you are under no commitment to take part. Only Melinda Duggan, as the researcher, will know who agreed to take part. Deciding not to take part will in no way impact the services provided to you and/or your child(ren) by CNIB.

If permission granted:

Thank you. You will receive an information package in the next few days. Melinda will follow up with a phone call next week to answer any questions and set up an interview time if you want to take part in the research.

Appendix D

Candidate Information List

Please record the name, address, and telephone number for persons who have agreed to be contacted by me for further information about the project. Please also ensure that each candidate understands that by agreeing to receive more information about the project they are under no obligation to participate. To ensure informed and voluntary participation it is essential that you also inform each candidate that only I, as researcher, will know who agreed to participate. Please note any special needs of participant, if known and if the person would prefer to be contacted at a particular time of day.

Contact Information			**Category of Participation**				
Name	**Address**	**Phone**	**Parent of Child**	**Working Age**	**Older Adult**	**Preferred Time of Contact**	**Large Print, Braille, or Audio/ Other Special Needs**

Appendix E

Letter to Candidates

Date [ ]

Re: Vision Rehabilitation Services in Newfoundland and Labrador: Identifying the Needs, Barriers, and Pathways

Researcher: Melinda Duggan, Graduate Student, School of Social Work, Memorial University, a message can be left at 709-737-8161

Research Supervisor: Dr. Gail Wideman, School of Social Work Memorial University, phone: 709-737-8161

Dear [ ]

As per your phone conversation with [person that made initial contact] on [date] I am sending you information about my research project which will study the needs, barriers, and pathways to accessing and using vision rehabilitation services in Newfoundland and Labrador. Vision rehabilitation services are services that help a person with vision loss live a better life. In Newfoundland and Labrador most of these services are provided by CNIB. Information gathered from this study will aid in the development of a provincial vision health strategy.

If you choose to participate in this research you will be asked to answer questions about experiences accessing and using vision rehabilitation services and to offer some personal insight into the needs, barriers, and pathways related to vision rehabilitation services in this province. Needs refer to the reasons why people use vision rehabilitation services; barriers refers to the difficulties people have accessing and using vision rehabilitation services; and pathways refers to the ways in which people find and use vision rehabilitation services. I am writing to ask for your participation in this research project. To adhere to ethical standards of research with human subjects, CNIB will not know who agreed to participate.

I will be conducting approximately 16 individual interviews with people living with vision loss in Newfoundland and Labrador. The groups will be categorized in the following way:

Group 1: Parents of children with vision loss
(Children aged 18 and under)

Group 2: Working age adults with vision loss (aged 19 – 65)

Group 3: Older adults with vision loss (aged 66+)

The individual interviews will consist of approximately 4 members in each of these categories representing various geographical regions of the province. Geographical regions will be determined based on the current regional health authority boundaries.

You will find a consent form included in this package. If you choose to participate please read this document very carefully. I will review this document with you at the beginning of the interview to ensure that you have a clear understanding of the research and what is being asked of you. You will be asked to give verbal consent before we begin.

I will be following up with you by phone in the next couple of days to discuss the research and answer any questions you may have and to confirm that you would like to be a participant in this research. I remind you that you do not have to participate and only I will know if you decide to participate or not.

If you have any further questions related to the research please feel free to contact myself or my thesis supervisor, Dr. Gail Wideman, for more information. Dr. Wideman can be reached at 709-737-8161. You may leave a message asking me to contact you at the same phone number.

The proposal for this research has been reviewed by the Interdisciplinary Committee on Ethics in Human Research and found to be in compliance with Memorial University's ethics policy. If you have ethical concerns about the research (such as the

way you have been treated or your rights as a participant), you may contact the Chairperson of the ICEHR at icehr@mun.ca or by telephone at (709) 737-2861.

Thank you in advance for considering this request.

Sincerely,

Melinda Duggan

Appendix F

Project Information Sheet

Title: Vision Rehabilitation Services in Newfoundland and Labrador: Identifying the Needs, Barriers, and Pathways

Researcher: Melinda Duggan, Graduate Student, School of Social Work, Memorial University

Supervisor: Dr. Gail Wideman, School of Social Work Memorial University

Project Information Sheet

- In Newfoundland and Labrador there are over 15,000 people living with vision loss; for people over the age of 75, one in eight people can expect to experience significant vision loss as they get older.
- The term vision rehabilitation refers to supports or services provided by CNIB including orientation and mobility training and assistive devices like magnifiers that help people with vision loss live and work in their homes and communities.
- However, we know that many people who have vision problems are not using vision rehabilitation supports or services. We want to understand why.

- The research question is: **What are the needs, barriers, and pathways to accessing and using vision rehabilitation services in the province of Newfoundland and Labrador?**

- Individuals will be asked to talk about this subject in a telephone interview with me. I will carry out the interviews over 4 – 6 weeks in the summer of 2010.
- I will be speaking with people who use vision rehabilitation services from each of the four groups listed below:
    - Group 1: Parents of children with vision loss (Children ages 18 and under)
    - Group 2: Working age adults with vision loss (aged 19 – 65)
    - Group 3: Older adults with vision loss (aged 65+)

The interviews will take place with four members in each of these groups and from the four health regions of the province.

Additional Information

- To be sure that information is recorded correctly the interview will be recorded.
- All names and other information that may be used to identify you will be removed. Only I, and my supervisor, will have access to the list of participants, the consent forms, and recordings. The recordings will become the property of the CNIB but will not contain any identifying information. All of us are bound by Memorial University's standards related to ensuring anonymity of research

participants and confidentiality of data. However, exceptions to confidentiality may be made if suggestion is made that anyone is at risk.

- Your rights as a participant include:
  - To end the interview at any time.
  - To have the audio recorder stopped at any time.
  - To refuse to answer any question.
  - To ask questions about the study at any time.

I am a graduate student at Memorial University. This research project is part of the requirements for my Masters degree. For more information about the study, you may leave a message for me at 709-737-8161. Dr. Gail Wideman is my thesis advisor and can also be reached at 709-737-8161.

The proposal for this research has been reviewed by the Interdisciplinary Committee on Ethics in Human Research and found to be in compliance with Memorial University's ethics policy. If you have ethical concerns about the research (such as the way you have been treated or your rights as a participant), you may contact the Chairperson of the ICEHR at icehr@mun.ca or by telephone at (709) 737-2861.

Appendix G

Consent Form

Title: Vision Rehabilitation Services in Newfoundland and Labrador: Identifying the Needs, Barriers, and Pathways

Researcher: Melinda Duggan, Graduate Student, School of Social Work, Memorial University

Supervisor: Dr. Gail Wideman, School of Social Work Memorial University,

Purpose of study:

You have been asked to take part in a research project entitled "*Vision Rehabilitation Services in Newfoundland and Labrador: Identifying the Needs, Barriers, and Pathways*."

The purpose of this research project is to learn about the vision rehabilitation services and supports needed by people living with vision loss in Newfoundland and Labrador.

This form is part of the process of informed consent. Along with the information sheet, it should give you the basic idea of what the research is about and what your participation will involve. If you would like more information about the research you should feel free to ask. Please take the time to read this carefully, or to have someone

read it to you. It is important that you understand any information given to you by the researcher. It is entirely up to you to decide whether or not to take part in this research. No one besides myself and my thesis supervisor will know who agreed to take part in the study.

What you will do in this study:

You will be interviewed by telephone and asked to describe your experiences of using vision rehabilitation supports or services and to give your opinions about what was helpful or not helpful to you. You will also be asked about your ideas about what can be done to make vision rehabilitation supports or services more helpful to you.

Length of time:

The telephone interview will take approximately twenty to thirty minutes to complete.

Benefits:

The only benefit to you will be the chance to tell us how you feel about the vision rehabilitation supports and services that you have found helpful, and about the supports and services you need but have not been able to find.

Risks:

There will be no risk to you from taking part in this research project.

Confidentiality:

We will do our best to make sure that your personal information will be kept private. However if you tell us something during the interview that makes us believe that you were at risk of harm to yourself, or of harming someone else, we would have to report this information to someone who could help.

Questions:

You are welcome to ask questions at any time during your participation in this research. If you would like more information about this study, please contact:

Researcher: Melinda Duggan, Graduate Student, School of Social Work, Memorial University. Message can be left at 709-737-8161 or email melinda.duggan@mun.ca.

or

Supervisor: Dr. Gail Wideman, School of Social Work Memorial University, Phone 709-737-8161 or email gwideman@mun.ca

Consent:

Your signature on this form means that:

- You have read the information about the research
- You have been able to ask questions about this study
- You are satisfied with the answers to all of your questions
- You understand what the study is about and what you will be doing
- You understand that you are free to withdraw from the study at any time, without having to give a reason, and that doing so will not affect you now or in the future.
- You understand that you are free to request that the audio recording be stopped at any time.

If you sign this form, you do not give up your legal rights, and do not release the researchers from their professional responsibilities.

Please keep a copy of this form for your records.

Your Signature:

_____ _____

Signature of participant Date

The proposal for this research has been reviewed by the Interdisciplinary Committee on Ethics in Human Research and found to be in compliance with Memorial University's ethics policy. If you have ethical concerns about the research (such as the

way you have been treated or your rights as a participant), you may contact the Chairperson of the ICEHR at icehr@mun.ca or by telephone at 737-2861.

Appendix H

Interview Guide

Research Project: Vision Rehabilitation Services in Newfoundland and Labrador: Identifying the Needs, Barriers, and Pathways

Researcher: Melinda Duggan, Graduate Student, School of Social Work, Memorial University

The ordering of questions in this guide is not indicative of the order that questions will be asked to participants. They are organized by theme to ensure that questions relate to the objectives of the research.

Interview Guide for Individual Interviews

Needs

- What made you (your child) decide to use vision rehabilitation services?
- What vision rehabilitation services have you found the most effective? Least effective?
- What assistive technology have you found the most beneficial? Least beneficial?
- After the assistive technology was provided to you did you receive further training and support? Do you feel it was adequate?

- Are there any needs related to vision rehabilitation or assistive technology that were not met?

Barriers

- Did you (your child) have to wait to receive any of the vision rehabilitation services you requested? If so, how long and what were the reasons for the delay?
- Is there any assistive technology that you (your child) need but can't access? (Probe: Funding/Demo Items/Training)

Public Education

- Did an eye care practitioner discuss vision rehabilitation services with you? If so, was the information helpful?
- Are there ways to increase awareness of assistive technology and new items that become available? (Probe: How do they learn about new assistive technology?)

Appendix I

Participant Profiles

Andrew	Andrew is a working age person in Western Newfoundland that started experiencing vision loss approximately 5 years ago. He is partially sighted and stopped working due to his vision loss.
Brandon	Brandon is a working age person in Central Newfoundland that started experiencing vision loss as a child. He is a small business owner that is blind.
Corey	Corey is a working age person in Labrador that started experiencing vision loss as a child. Has been a client of CNIB for over 10 years. He is not currently employed and is partially sighted.
Danny	Danny is a working age person in Central Newfoundland. He first experienced vision loss as a child. He is not currently employed and is partially sighted.
Eugene	Eugene is an older adult in Central Newfoundland. He recently began experiencing vision loss and is partially sighted.
Frank	Frank is a working age person in Labrador. He first began experiencing vision loss as a child and has been a client of CNIB for over 10 years. He is not currently employed and is blind.
Amy	Amy is the mother of a young child living in Eastern Newfoundland. Her child began experiencing vision loss before the age of 1. Her child is blind.
Brenda	Brenda is a working age person living in Eastern Newfoundland. She first experienced vision loss as a child and has been a client of CNIB for over 10 years. She is currently employed and is partially sighted.
Carla	Carla is a working age person living is Eastern Newfoundland. She began experiencing vision loss as a child

	and has been a client of CNIB for over 10 years. She is not currently employed and is blind.
Danielle	Danielle is the mother of youth in Central Newfoundland. She is also a working age person with vision loss. Her child began experiencing vision loss at the age of 4 and she has also been living with vision loss since she was a child. She is not employed and both she and her child are partially sighted.
Erin	Erin is an older adult is Western Newfoundland. She recently began experiencing vision loss and is partially sighted.
Fiona	Fiona is a working age person in Western Newfoundland. She first began experiencing vision loss as a young adult and has been a client of CNIB for over 10 years. She is not currently employed and is partially sighted.
Gillian	Gillian is the mother of school aged child in Labrador. Her child started experiencing vision loss before the age of 1 and is blind.
Heather	Heather is the guardian of a youth in Western Newfoundland. Her child started experiencing vision loss in elementary school and is partially sighted.
Iris	Iris is a working age person in Eastern Newfoundland. She started experiencing vision loss as a child and has been a client of CNIB for over 10 years. She is not currently employed and is blind.
Joy	Joy is an older adult living in Eastern Newfoundland. She has been living with vision loss for most of her life and has been a client of CNIB for over 10 years. She is blind.
Kathy	Kathy is an older adult living in Labrador. She recently began experiencing vision loss and is partially sighted.

Appendix J

Coding Chart

	Needs	Barriers	Pathways	Other
Code # **Pseudonym** **Age Group** **Region**				
Code # **Pseudonym** **Age Group** **Region**				
Code # **Pseudonym** **Age Group** **Region**				