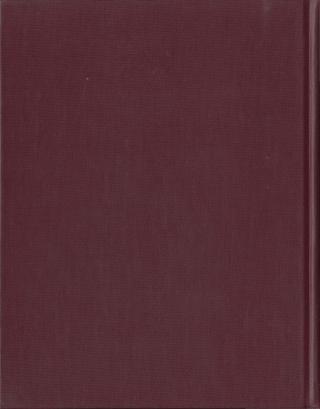
FACTORS INFLUENCING ACCESS TO HEALTH CARE SERVICES IN LABRADOR: A CASE STUDY OF TWO DISTINCT REGIONS

# GIOIA MONTEVECCHI









# FACTORS INFLUENCING ACCESS TO HEALTH CARE SERVICES IN

## LABRADOR: A CASE STUDY OF TWO DISTINCT REGIONS

by

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#### Abstract

This research explores the factors that influence access to health care services and addresses strategies for improvement in two distinct regions of Labrador. This qualitative project employed an interpretive epistemology and case study methodology. The environmental scan and interview analysis outlined the major challenges accessing health care and strategies to overcome them from the perspective of local healthcare administrators, providers, and community members. The findings identified thirteen factors that create challenges accessing health care associated with the physical environment, socio-cultural and political environment, gender, and continuity and comprehensiveness of care. These factors were considered in light of factors that influence access to health care in other rural regions of Canada. Despite the complexities encompassed within these factors, participants identified seven strategies to overcome the challenges accessing health care services, notably: Tele-health, bringing services to communities, recruitment and retention strategies, the Medical Transportation Assistance Program, navigation tools, the scheduled evacuation system, and the medical evacuation system.

#### Abstract

This research explores the factors that influence access to health care services and addresses strategies for improvement in two distinct regions of Labrador. This qualitative project employed an interpretive epistemology and case study methodology. The environmental scan and interview analysis outlined the major challenges accessing health care and strategies to overcome them from the perspective of local healthcare administrators, providers, and community members. The findings identified thirteen factors that create challenges accessing health care associated with the physical environment, socio-cultural and political environment, gender, and continuity and comprehensiveness of care. These factors were considered in light of factors that influence access to health care in other rural regions of Canada. Despite the complexities encompassed within these factors, participants identified seven strategies to overcome the challenges accessing health care services, notably; Tele-health, bringing services to communities, recruitment and retention strategies, the Medical Transportation Assistance Program, navigation tools, the scheduled evacuation system, and the medical evacuation system.

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#### Chapter 1: Introduction

In Labrador, you are physically isolated from service by geography... you can't change that. You have fly-in communities. You have no road access. You have weather... When I grew up in Labrador, there was very little access to anything... there's obviously been a great expansion of service, but the thing that changed is that we were just all from Labrador and now we are specific ethnic groups with our own health management... and what that does is it influences the access of anybody who physically lives in Labrador (Happy Valley-Goose Bay, April 14, 2011).

This quote introduces the complex realities that residents living in isolated Labrador face when accessing health care services. Labrador is made up of five distinct regions: Labrador West, Upper Lake Melville in central Labrador, the north coast, the south east coast and the Labrador straits. There are great differences among communities within and between these regions of Labrador (Our Labrador, 2004). Some Labradorians live in non-isolated communities of over 7000 members and others live in isolated communities of less than 200 above 60° latitude. In addition to geographic differences, Labradorians are culturally diverse. There are Innu, Nunatsiavul Inuit, Inuit-Metis and non-Aboriginal in Labrador. These geographic and cultural factors influence access to health care in Labrador.

## **Research Purpose and Objectives**

This research explored the factors that influence access to health care services and strategies for improving access in two diverse regions in Labrador: the five northern isolated communities within Nunatsiavut, the land claims region of the Labrador Inuit, and Happy Valley Goose Bay, a multi-cultural community in the Upper Lake Melville region of Labrador. This research investigated factors influencing access to health care services as reflected in the experiences of health care administrators, providers, and community members in two distinct regions of Labrador.

The research question was:

 What factors influence access to health care services in two geographically and culturally diverse regions of Labrador?

The study objectives were to:

- identify factors that influence access to health care services in Happy Valley-Goose Bay and Nunatsiavut, Labrador; and
- determine strategies recommended by community members, health care providers and administrators in Happy Valley-Goose Bay and Nunatsiavut to improve access to health care services in Labrador.

This chapter is organized as follows: first, I discuss the relevance of the research. Second, I provide a working definition of rural, northern, and isolated communities and the concept of access that will be applied throughout this thesis. Third, I describe Labrador's geography and social context, as well as my reasons for choosing Happy Valley-Goose Bay and Nunatsiavut for this research. Fourth, I offer a discussion of my place in the research by describing how my experiences influenced the approach and development of the research.

## **Research Relevance**

There is an identified need (Labrador Regional Council of the Rural Secretariat, 2009), but limited focus on the examination of factors that influence access to health care services in Labrador. Historical records show that Labradorians have been concerned about access to health care since the 1960s. Several reports over the last four decades have incorporated Labradorians concerns with health care in Labrador, including Labrador in the 70s, Labrador Conference Report (1970), Report on the Royal Commission of Labrador (1974), Report on the Adequacy of Health Care Services in Happy Valley-Goose Bay, Labrador (1979), and Labrador in the 90s Conference Report (1990).

In 1970, Dr. W.A. Paddon, Director of Medical Services for the International Grenfell Association, addressed delegates at the Labrador in the 70s conference in Happy Valley-Goose Bay, and spoke of the need to address issues Labradorians face when accessing health care (Labrador in the 70s, Labrador Conference Report, 1970). Paddon cited geography as the biggest challenge with delivering health care in the region, as it presented "considerable obstacles", but it was his view that "a basic minimum of medical services, regardless of economic or political considerations, must be given to the people" (p. 100).

In 1974, the Report of the Royal Commission on Labrador was released. The report was the product of over a year of community consultation and research in 36 Labrador communities that intended to influence broad policies surrounding every aspect of Labrador life. The broad conclusion of the report was that Labrador had been neglected for generations, but the implications of this neglect were not predictable or obvious (Snowden, 1974). Although the organizations providing health care services in Labrador had changed and 37 years had passed between 1974 and the time of interviews for this research, residents of Labrador expressed similar concerns with accessing health care. Similar concerns included cost of air transportation incurred by Labrador residents seeking care outside the region, available services in community clinics, maternal health care, nursing shortages, and training opportunities for health care professionals.

In 1979, a public meeting was held by the Health Care Improvement Committee for Happy Valley-Goose Bay to address the issues around health care improvement in Labrador. Five hundred residents were in attendance, making it the largest public gathering to ever be assembled in the community for addressing a community issue (Health Care Improvement Committee for Happy Valley-Goose Bay, 1979). The Report on the Adequacy of Health Care Services in Happy Valley-Goose Bay, Labrador incorporated information from community meetings, surveys to assess local perspectives, and written commends from the public regarding the state of health care in the region and produced 17 recommendations for improvement, several of which parallel recommendations outlined in the present research (Health Care Improvement Committee for Happy Valley-Goose Bay, 1979).

Past research investigating specific health issues in Labrador is summarized in Table 1. At the time this research was completed, there was a lack of research examining factors that influence access to health care and strategies to overcome them from the perspective of Labradorians.

Year	Author	Title	Area of Focus
1993	Didham	Labrador Health Care Comes Home	Recruitment and retention of nurses in Labrador and the challenges nurses and community members face providing and accessing health care in isolated communities.
1993	Zammit, Kaira, Nelson, Broadbent, and Hans	Growth patterns of Labrador Inuit youth	An analysis of height and weight of Labrador Inuit youth in 1991.
1996	Gaudette, Freitag, Dufour, Baikie, Gao and Wideman	Cancer in Circumpolar Inuit: Background information for cancer patterns in Canadian Inuit	Investigation of cancer patterns in Canadian Inuit through out the arctic, not specific to Labrador.
1998	Beach and Jong	Appropriate training for Northern Physicians	Physician recruitment, retention and training in the north.
2002	Hanrahan	Identifying the needs of Innu and Inuit patients in urban health settings in Newfoundland and Labrador	Identification of the needs of Innu and Inuit patients in urban health settings in Newfourdland and Labrador in response to anecdotal evidence of Aboriginal dissatisfaction with these services.
2008	Bull	Defining our 'Ethical Space': Labrador Innu, Inuit, and Inuit- Metis Perspectives on the Governance of Health Research	Innu, Inuit, and Inuit-Metis perspectives on the governance of health research and impacts on ethical principles of Aboriginal health research.
2008	Curran, Solberg, LeFort, Fleet and Hollett	A responsive evaluation of an Aboriginal nursing education access program	The investigation and evaluation of an integrated Aboriginal nursing access education program offered through Memorial University and the College of the North Atlantic
2008	Wilkins, Uppsal, Fines, Senecal, Guimond and	A review of Aboriginal infant mortality rates in Canada: striking	This article discusses the deficiencies in the quality of IMR data for Aboriginal populations in Canada and attempts to determine the most

Table 1: A selection of past research on health needs of Labradorians

		Aboriginal/non- Aboriginal inequities	First Nations, Inuit, and Métis populations at the national and provincial/territorial level, while evaluating the quality and coverage of available data.
2010	McDonald and Trenholm	Cancer-related health behaviors and health service use among Inuit and other residents of Canada's north	Investigation of cancer related health behaviors and health service use among Inuit cancer patients.
2010	Egeland, Nunatsiavut Steering Committee with contributions from CINE staff members and graduate students	Inuit Health Survey 2007-2008	The Inuit Health Survey is the first comprehensive look at the health of Inuit in Inuvialuit, Nunavut, and Nunatsiavut to improve health care planning, personal health, and community wellness. Nunatsiavut Government was a partner in the project and will determine policy and programming improvements based on the results of the study.
2012	Martin, Valcour, Bull, Graham, Paul, and Wall	NunatuKavut Community Health Needs Assessment, A Community- Based Research Project	An identification of health care service needs, current health services gaps, and recommendations to improve health services in NunatuKavut communities.

In 2007, the Government of Newfoundland and Labrador announced the five-year Northern Strategic Plan to enhance the health and wellbeing of Labradorians. To improve health services in Labrador, the government committed to provide greater assistance with the medical transportation reimbursement plan in Labrador, increase financial assistance for emergency response initiatives, enhance family resource planning, construct an administration building for Labrador Grenfell Regional Health Authority in Happy Valley-Goose Bay, provide picture archiving and communications systems for the hospitals, strengthen the Tele-health network and video conferencing capacity, enhance social work staffing, support services for persons with developmental disabilities, reduce wait times for lab tests and enhance care for surgery patients in western Labrador (Government of Newfoundland and Labrador, 2007). Increased resources and support for priorities that decrease poverty rates, increase employment and educational opportunities, improve transportation around the region and onto the island has significant potential to improve access to health services. In 2011, the provincial government demonstrated commitment in the Northern Strategic Plan to improve health care services in Labrador with the announcement of \$770.500 to be allocated to the Labrador Health Centre in Happy Valley-Goose Bay for the purchase of capital equipment including a microbiology analyzer machine, lab sterilizer, portable ultrasound, yttrium aluminum garnet laser for laser surgery, centrifuge and iodized triage unit, and a dialysis water treatment system (Government of Newfoundland and Labrador, 2011a).

Health system development and health improvement requires effective policy decisions based on sound research evidence (World Health Organization [WHO], 2009). This research fills a gap in the literature surrounding access to health care services across culturally and geographically distinct populations, identifies the main factors influencing access to health care services, outlines strategies to over come them, and stands to inform policies related to health care in Labrador.

## Defining Rural, Northern and Isolated Communities

Defining rural, northern and isolated communities is contentious as there is not a singular accepted definition of each. However, it is important that these terms be clearly defined for purposes of this research. In this section I present and justify my chosen definitions.

The definition of rurality is an element of rural research and therefore, an element

of the study design. Rural, as a term, implies different things to different people. Hart, Larson, and Lishner (2005) point out that rural can denote small communities, geographic isolation, rugged landscapes, and low population density. There is much variation between rural regions in Canada and within provinces. For instance, rural towns in close proximity to metropolitan areas may have more in common with metropolitan areas than smaller, isolated and remote towns within the same provincial borders. Research studies examining rurality that do not explicitly define the term or delineate the differences across and between rural and urban locales have reduced comparability, making it more difficult for policy decisions to identify distinct rural health care concerns and effective solutions to overcome those issues (Hart, Larson and Lishner, 2005; Muula, 2007).

There is significant literature examining the definition of "rural" and offering many competing and varying definitions of rural nationally and internationally (Vanderboom and Madigan, 2007). Unfortunately, most health services researchers use dichotomous classifications of urban and rural. Dichotomous classifications do not address the diversity within rural or urban populations, 'as there is often as much variation within the broad categories of rural and urban as between them' (Vanderboom and Madigan, 2007, p. 175). By using appropriate and consistent definitions, it is possible to discern differences in health care concerns and outcomes across rural areas and between rural and urban regions (Hart, Larson, and Lishner, 2005).

I decided to use the rural and small town classification system from du Plessis. Beshiri, Bollman, and Clemenson (2002) because it is the definition adopted by Health and Statistics Canada. Statistics Canada uses this delineation in each annual census, a widely recognized and reliable source of data about populations in Canada. I have used data from Statistics Canada 2011 to describe the context of health status in Labrador, so it makes sense to keep these data consistent with the definition throughout this thesis. Rural and small town refers to communities outside the commuting zones of larger urban centers with populations of at least 10,000 people.

Another facet of the Statistics Canada definition is commutability as a threshold for defining rural areas. Commutability influences access to centralized services, including health and education facilities, financial institutions, shopping centers, cultural centers and sports facilities (du Plessis et al., 2002). Rural and small towns are located outside of the commuting zone of communities of more than 10,000 people. The entirety of Labrador is not within commuting distance of a larger urban centre and therefore, can reasonably be considered rural under the Statistics Canada definition.

Statistics Canada expanded the rural and small town definition to further delineate regions according to the northern transition line that designates north and south regions of Canada by a set of complex indicators representing environmental, political, biotic, and human factors. The northern transition line runs along the 50<sup>th</sup> parallel in Newfoundland and Labrador. According to this definition, communities in Labrador are all located in northern regions (McNiven and Puderer, 2000; du Plessis et al. 2002).

The rural small town definition does not account for isolated communities. Therefore, Statistics Canada uses the definition for isolated communities adopted by the Public Health Agency of Canada (PHAC). According to the PHAC (2009), isolated communities are defined based on their lack of year round road access and limited telephone service. No roads travel north, so communities on the north coast of Labrador (the five communities of Nunatsiavut and Natuashish, the Mushuau Innu) do not have road access at any time of year. The Trans Labrador Highway, though serviced, is impassible during winter months in some regions on the south coast. Therefore, outside of Labrador West, Churchill Falls and the Upper Lake Melville Region (Happy Valley-Goose Bay, Sheshatshiu and North West River), Labrador is made up of sparsely populated isolated communities.

Based on the above criteria of rural, northern and isolated communities, Labrador can reasonably be defined as a rural, northern region with isolated communities. This means that all communities in the Nunatsiavut land claim area are isolated. See map in Appendix A.

#### Locating Labrador

Newfoundland and Labrador is the easternmost province in Canada. The Strait of Belle Isle separates the province into two geographical divisions, the island of Newfoundland, and Labrador, which is located on the mainland of Canada. The island of Newfoundland has an area of roughly 108,860 km<sup>2</sup>, extends between latitudes 46°36'N and 51°38'N and has a total population of 510,578 as of 2011 (Statistics Canada, 2012a). Labrador is geographically more than twice the size of the island portion of the province, comprising 294, 330 km<sup>2</sup> of diverse geography, 7886 km of which is coastal shoreline (Our Labrador, 2009). Labrador is located at 51°28'N and 60°22'N. Despite its size, Labrador makes up only 5% of the province's population, at 26,728 of 514,536 people (Statistics Canada, 2012a). Due to its rural reality, the population density in Labrador (0.1) is much lower than in Newfoundland (1.4) (Statistics Canada, 2012a). See Appendix A for a map of Labrador.

## Locating the Study

Several steps led up to the initiation of this research in Labrador. In early 2009, Lisa Densmore, Regional Partnership Planner with the Labrador Rural Secretariat in Happy Valley-Goose Bay, contacted Susan Hunt, Director of Business Development for Mitacs, Inc. at Memorial University to discuss the possibility of partnering with the Faculty of Medicine to undertake a research project to examine barriers to accessing health care in Labrador. The Rural Secretariat identified a lack of knowledge regarding access to health care throughout Labrador as an impediment to developing effective policy initiatives to ensure the many diverse regions in Labrador have reasonable access to quality health care. As part of their commitment to the rural inhabitants of the province, the Rural Secretariat aims to ensure that all policy advice submitted to the provincial government by Regional Councils is underpinned by current research (Labrador Regional Council of the Rural Secretariat, 2009). As part of this commitment, the Rural Secretariat pursued a partnership with community health researchers to initiate a research project examining the barriers to accessing health care from a Labradorian perspective.

With funding from Mitaes Accelerate Internship Program, Dr. Kris Aubrey of Family Medicine and Dr. Victor Maddalena of the Division of Community Health and Humanities in Memorial University's Faculty of Medicine united to lay the foundation for a graduate research project to explore the factors that influence access to health care in Labrador. In the fall of 2009, Dr. Diana Gustafson and I were brought into this project. I became the graduate student to carry out the research in Labrador as partial requirement of a Masters of Science in Medicine in Applied Health Services Research, and my committee was composed of co-supervisors Drs. Gustafson and Maddalena and committee member, Dr. Aubrey.

The research proposal was developed during May-August 2010 in Labrador under the guidance of the Labrador Aboriginal Health Research Committee, comprised of representatives of the Nunatsiavut Government, Innu Nation, NunatuKavut Community Council, Labrador Friendship Centre, Labrador Institute, Labrador Grenfell Regional Health Authority (Labrador Grenfell Health) and Health Canada, and through collaboration with my supervisory committee members. Ethics approval was granted from the Interdisciplinary Committee on Ethics in Human Research at Memorial University on August 27, 2010, Labrador Grenfell Health on November 2, 2010, and Nunatsiavut Government on November 29, 2010 (See Appendix B). Interviews were conducted between January and April 2011 with health care administrators, providers and community members from Happy Valley-Goose Bay and Nunatsiavut communities.

## Locating Myself

I have become increasingly interested in studying the health and well-being of rural populations. I have worked on projects related to bringing portable eye-screening resources and programs to rural Newfoundland, disseminating sign language curriculum to rural communities in southern Cambodia and improving food security for rice farming families in Takeo, Cambodia. These experiences have also influenced my desire to further research factors influencing access to appropriate health care services in diverse Aboriginal<sup>1</sup> areas of our province, especially Labrador where culture<sup>2</sup> and geography

<sup>&</sup>lt;sup>1</sup> The term Aboriginal people generally refers to the Indigenous inhabitants of Canada, including First Nations, Inuit and Metis peoples without regard to their separate origins and identifies. The Royal Commission on Aboriginal Peoples, Volume 3: Gathering Strength (1996) stresses that the term Aboriginal people "refers to organic politica and acutural entities that setm historically form the original

influence how residents access health care services. I believe understanding how individuals experience the factors that influence access to health care is integral for improving cultural safety.<sup>3</sup>

In May of 2010, I moved to Labrador to complete a practicum with the Rural Secretariat and to embark on this research project. In hindsight, I underestimated the enormity of the issues surrounding access to health care in Labrador and how long it would take to thoroughly examine how Labradorians think access to health care services could be improved. Ironically, from a Labradorian perspective, part of the answer is the need for policy and decision-makers of health care in the region to fully appreciate and recognize the complexities of the social, cultural, political, and geographical landscape of Labrador.

My first few months in Labrador consisted of a steep learning curve of the culture and the necessary establishment of my place as a researcher in the region. My initial proposal was refined in collaboration with key stakeholders, and incorporated the views of the Rural Secretariat, the Nunatsiavut Government's Department of Health and Social Development, Labrador Grenfell Health, and Memorial University. Once all parties approved the proposal, ethics applications were submitted to Memorial University, Labrador Grenfell Health and the Nunatsiavut Government. The ethics process was the

peoples of North America, rather than collections of individuals united by so called 'racial' characteristics. The term includes the Indian, Inuit and Métis peoples of Canada" (p. ii). Definitions for First Nations, Innu, and Inuit are offered in the Glossary of Terms.

<sup>&</sup>lt;sup>2</sup> For the purposes of this research, culture is defined as "the set of distinctive spiritual, material, intellectual and emotional features of society or a social group, that encompasses, in addition to art and literature, lifestyles, ways of living together, value systems, traditions and beliefs" (LNESCO, 2002, p. 1). Culture, as a factor influencing health care access in Lahandor will be discussed at length in fatter sections.

<sup>&</sup>lt;sup>3</sup> For purposes of this research, the concept cultural safety is used "to express an approach to heath care that recognizes contemporary conditions of Aboriginal people which result from their post-contact history" (Brascoupé and Waters, 2009, p. 7). Cultural safety will be discussed in greater depth in later sections of this thesis.

most challenging, humbling and lengthiest of all preparatory steps to my research, not finalized until December, 2010.

Living in Happy Valley-Goose Bay and North West River from 2010-2012 has allowed me to build a strong rapport with community members and to find a home in the community. I developed patience through this experience and I learned to have a more grounded appreciation and understanding of community-based research. By the time the data collection and analysis was complete, it became clear to me the interview findings were far richer than I could have ever imagined.

#### Research Scope, Assumptions, and Frameworks

My experience living and working in Labrador and first hand exposure to the political, cultural, and geographical complexities in the region has greatly informed my perspective on health and health care delivery in the region. My familiarity with the region, a detailed environmental scan on the context surrounding access to health care in Labrador, and rapport with community members allowed me to engage knowledgeable experts in the delivery and utilization of health care in Labrador. My personal experience enabled me to ask pointed and stimulating questions in interviews that revealed rich, personal accounts and detailed discussion around health care services in Labrador.

The purpose of this research is not to assert that improving access to health care services will improve health status in Labrador, but to explore and create awareness of the challenges and some solutions to improving access to health care services between and among communities in Labrador. While access to health care services in Labrador is the principal focus of the research, there is no direct correlation between access to health care and health status. An underlying premise of this research is that it could inform policies surrounding the improvement of access to health care services in Labrador. It does not assume that improving access will, in turn, improve health status in Labrador.

Research was my medium and my instrument in Labrador for learning and engaging in discussion around the factors that influence access to health care services for Labradorians in two diverse communities. This research focuses on highlighting the experiences of community members in Happy Valley-Goose Bay and Nunatsiavut as a way of demonstrating the complexities surrounding access to health care in Labrador. Therefore, this research is not meant to be representative or reflective of the sentiments of all residents in Happy Valley-Goose Bay and Nunatsiavut, or Labrador in general.

This research is viewed through a social justice lens. Beauchamp (1976) defined social justice as the fair and equitable distribution of society's benefits and burdens. Braveman and Gruskin (2003) clarified that equity focuses on distribution of resources and other processes that drive health inequality. Social justice frameworks can provide a blueprint of ways to think about and react to health issues among populations. This research was constructed within two established social justice frameworks: first, the social determinants of health and second, health as a human right as a means to examine the factors influencing access to health care.

The social determinants of health are relevant to the current project because the same factors that determine health status also influence how people access health care services (WHO, 2008). The social determinants can help illuminate inequities in health care access and utilization between segments of the same population. This perspective maintains that justice determines which social determinants of health are given precedence in society and which populations will be vulnerable. Another way to understand health and access to health care is to view it through the lens of human rights. The ultimate goal of the human rights approach to health is equitable health outcomes among populations. McGibbon, Etowa and McPherson (2008) contend that part of the human rights based approach is asking critical questions that direct our attention to how societies make policy decisions and which populations fall through the cracks. Attention to systemic structure is critical in human rights perspectives to health because injustice in health care systems is rooted in systemic power imbalances.

Since its incorporation in the Universal Declaration of Human Rights in 1948, health is recognized as an international human right (United Nations, 1948). The committee for the United Nation's International Covenant on Economic, Social, and Cultural Rights (ICESCR) recognized the relationship and dependency of the right to health on the right to other social determinants of health including food, housing, work, and education and means entitlement without discrimination to health services, goods, and facilities that are available, accessible, acceptable, and of good quality.

The International Covenant on Economic, Social, and Cultural Rights General Comment (2000) outlined four criteria for evaluating the right to health: availability, accessibility, acceptability, and quality. The accessibility criteria, pertinent to this research, included the four sub-criteria: non-discrimination, physical accessibility, economic accessibility, and information accessibility. Accessibility is one of the five cornerstone principals of the federal Canadian Health Act (1985) that sets criteria and standards of health care provision in Canada. In the context of the Canadian Health Act, accessibility means that Canadians must have "reasonable access" to insured services without charge or paying user fees. However, the federal government does not define

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what "reasonable access" means. Part of this research is discovering what Labradorians perceive as "reasonable access".

My understanding of reasonable access to health care encompasses several elements. First, access to health care is concerned with availability of health care services. If there is an adequate supply of health care services, then one could surmise that populations have access to health care. However, access to health care services does not depend solely on availability. Gaining access to services that stand to improve health outcomes is also dependent on the fit between a population's needs and available services. Factors that influence utilization of health care services, including affordability, physical accessibility, relevance and appropriateness of care can also influence the segments of population able to access health care services. Lastly, access to health services must also be assessed in the context of differing social and cultural realities and diverse perspectives on health present within populations. My understanding of the scope and characteristics of access to health care services is informed by several discussions on the definition of health care access (Carlton and Simmons, 2011; Gulliford et al., 2001; Hall, Lemak, Steingraber, and Shaffer, 2008; Jacobs, Ir, Bigdeli, Annear, and Van Damme, 2012; Penchansky and Thomas, 1981).

The social determinants of health and the health as a human right perspective are underpinned by social justice and recognize the influence of the determinants of health on an individual, family, and community's chance of living a healthy life. However, they differ in terms of ultimate goals. While social determinants of health frameworks can illustrate inequities in social, political, economic, and physical contexts between and among populations, human rights based approaches can hold governments accountable to integrating human rights principles in the design, implementation, and evaluation of policies and programs and can attend to and facilitate redress for vulnerable populations experiencing violations of the right to health (London, 2008). Therefore, I use the social determinants of health framework in the literature review to guide the description of the factors influencing access to health care services in Labrador and other rural and northern regions of Canada. I fuse health as a human right framework and the social determinants of health in the examination of recommendations for improving health care access in Labrador as it can shed light on policies and programming that do not allow all Labradorians equilable access to health care services.

## Thesis Outline

This chapter presented this study's relevance, main purpose and objectives. It also provided working definitions for rural, northern, and isolated communities adopted for this research. This chapter also located the study and provided a description of my place in the research.

The remainder of the thesis is organized as follows: Chapter 2 presents the relationship between improving access to health care services and health status, discusses the social determinants of health framework that is used to frame the discussion of factors influencing access to health care, and provides a review of literature examining major factors influencing access to health care services in rural and northern regions of Canada. Chapter 3 outlines the epistemological and methodological approach to the research and the specific tools (methods) I used to collect and analyze interview data. Chapter 4 presents an environmental scan of the context surrounding access to health care in Labrador. The purpose of the environmental scan is to offer the political, social. geographical and cultural context within which Labradorians accessed health services at the time of the research. Chapter 5 provides a description of the interview findings and explores the main themes creating challenges accessing health care services identified by health care administrators, providers, and community members and grounds them in previous research. Chapter 6 presents the data analysis of the interviews investigating strategies to overcome challenges accessing health care in Labrador and discusses them with reference to previous research. Chapter 7 presents the main recommendations flowing from this research through the Health as a Human Right framework and grounds them in the context of academic and grey literature. This final chapter concludes with a discussion of several theoretical and practical implications of the research and directions for future research.

#### **Chapter 2: Literature Review**

The objective of this research was to outline the factors that influence access to health care services in Labrador and compile a list of recommendations. There is a scarcity of literature examining access to health care services in Labrador. The literature review begins by discussion the perspective of Ivan Illich between health status and access to health care. It continues by presenting the social determinants of health framework and providing a demonstration of the complexities of influence of social determinants on accessing health care services. The chapter continues by presenting current literature that explores access to health care services in Labrador and other rural and northern regions of Canada.

#### Health Status and Health Care Access

Rural Canadians generally have lower health status than their urban counterparts (Kirby, 2002; Romanow, 2002; Public Health Agency of Canada [PHAC], 2006). Consequently, health status decreases with degree of community remoteness (CHH, 2006), so that Canadians in the most remote places are likely to have the lowest health status (Pong, 2007). Generally, rural Canadians are more likely to be in poorer socioeconomic conditions, to have lower educational attainment, to exhibit less healthy behaviours and to have higher overall mortality rates than urban residents. They are much more likely to die from chronic, circulatory and respiratory diseases, diabetes, injuries and suicide (DesMeules and Pong, 2006). Risk factors, such as smoking and obesity are reported more frequently among rural than urban residents, which may compound the risks of dying prematurely from circulatory disease. When compared to urban populations rural inhabitants also have less access to health services (Hutten-Czapski,

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2001).

Ivan Illich, a well-known challenger of medical institutions, contends, "the medical establishment has become a major threat to health" (Illich, 1975, p. 11). Illich's view is that dependence on the health care system results in a disconnection with our traditional capacity for self-care and resiliency, which causes a loss of self-determination, a resignation of responsibility, and a reliance on health care professionals to determine what constitutes illness, health and healing (Illich, 1975). In this regard, Illich specifically refers to social and cultural iatrogenesis.

Social iatrogenesis is a term that designates "impairments to health due to those socio-economic transformations which have been made attractive, possible, or necessary by the institutional shape health care has taken" (Illich, 1975, p. 40). Social iatrogenesis, as a process of medicalizing life, is at play when the medical system can be attributed with creating ill-health by accentuating stress, encouraging dependence, generating new needs, lowering levels of pain tolerance, and discouraging self-care.

Cultural iatrogenesis occurs when medical establishments undermine the ability and will of people to cope with their realities, express their values and accept irremediable pain, decline, and death. Illich (1975) defines culture as a system of meanings, and civilization as a system of techniques. According to this view, culture makes pain tolerable by integrating it into a meaningful setting, while civilization detaches pain from any subjective context with an ultimate goal of terminating it. Illich writes that the only cultures that survive are those able to embody a system of coping that is adapted to a group's genetic make-up, history, environment, and challenges. According to this line of thought, the medical enterprise is seen to undermine the continuation of traditional cultural healing traditions and prevents the emergence of new systems that encourage self-care and coping.

Although there is no demonstrated connection between improving access to health services and improving health status, access to health care is still a concern of rural Canadians (Browne, 2009; Romanow, 2002). There is common belief that inequities in access to health services in rural regions are a part of a system of social inequities between different communities. Examining the factors that determine health can highlight root causes of complex social inequities and are helpful in determining priority areas for improvement of social realities and community well-being.

## Social Determinants of Health

Health status is determined by the interplay of physical, social and economic factors, known as the social determinants of health. The World Health Organization (WHO) defines the social determinants of health as,

the conditions in which people are born, grow, live, work and age... shaped by the distribution of money, power and resources at global, national and local levels, which are themselves influenced by policy choices. The social determinants of health are mostly responsible for health inequities - the unfair and avoidable differences in health status seen within and between countries. (Commission on the Social Determinants of Health, 2008, p. 1)

The social determinants of health differ depending on the social, economic, political, cultural and physical climate within which they exist. According to the PHAC (2011), health determinants include social support networks, social environments, physical environments, income and social status, employment and working conditions. education and literacy, personal health practices and coping skills, healthy child development, biology and genetic endowment, health services, culture, and gender. Each of these factors impacts health and is interconnected with the other social determinants. Below I describe each social determinant of health outlined by the PHAC and discuss how they relate to one another in determining health.

First, the underlying premise of social support networks is that support from families, friends and communities is associated with better health (PHAC, 2011). Social environment as a determinant of health is reflected in institutions, organizations and societal practices that people create to build community. Understanding how social environment influences health is a step towards understanding health disparities across rural and urban populations (Ryan-Nicholls, 2004; Meadows, Lagendyk, Thurston, and Eisener, 2003).

Geography, population density, exposure to contaminants, housing and road infrastructure and travel to health services mean that physical environment can influence health. Distance from service, for example, is a factor determining how quickly one can access health care services and can compound the effect of income and place additional health burden on those with lower socio-economic status (Health Canada, 2007).

Generally, health improves at each step of the income and social hierarchy (PHAC, 2011). Socio-economic status influences living conditions, housing security, and ability to access health information, healthy foods, and higher education. Socioeconomic status varies widely between and within rural and urban regions and is an important factor in the health of rural communities (DesMeules and Pong, 2006).

Income-generating activities and working conditions vary between rural

communities, depending on geography, environment, climate, culture and other social factors. Unsafe and high stress working conditions are associated with poorer health (PHAC, 2011). Employment status also effects socio-economic status and therefore across populations, life expectancy rates are higher in communities with lower unemployment (Kirby, 2002). Regions closer to urban centers that rely on mixedeconomies tend to be more prosperous than isolated rural communities that are more likely to be dependent on a single industry such as agriculture, forestry, fishing, hunting, trapping, oil and gas, mining or tourism (MACRII, 2002).

Formal educational attainment and literacy rates are lower in rural Canada when compared with urban areas, but these rates also vary widely within and between rural regions (Kirby, 2002). Education and literacy influence socio-economic status, and health status is directly related to socio-economic factors. Life expectancy increases as education rates increase and unemployment rates decrease (Kirby, 2002).

The WHO and the PHAC consider culture a social determinant of health because certain individuals and populations belonging to a particular cultural group may face social exclusion. The premise of this argument is based on that fact that socio-economic environments are largely determined by dominant cultural values that can perpetuate stigmatization, marginalization, devaluation of language and culture and contribute to a lack of availability of culturally appropriate health care services for minority cultural communities (PHAC, 2011; WHO, 2008).

Some health issues in Canada can be attributed to gender-based social status or roles. Gender as a social determinant of health refers to the array of socially determined roles, personality traits, attitudes, behaviours, values, and relative power and influence that are ascribed to the two sexes on a differential basis (PHAC, 2011). The incorporation of gender into the social determinants of health emphasizes the social, political, and economic meanings attached to differences in reproductive capacities between women and men and how these meanings influence health and well-being. In societies where women's societal status is closer to men's, both women and men have better health (Doyal, 1994). A gendered approach to health means considering the way gender intersects with all other social determinants of health (Armstrong, Armstrong and Scott-Dixon, 2008). Since gender is related to power and relations within the health care system, it pervades health services as a social determinant of health. Gender is an important factor in the present research.

Personal health practices and coping skills are also considered a determinant of health (PHAC, 2011). This determinant refers to actions by which individuals can prevent disease and promote self-care, cope with challenges and develop independence and selfreliance to make choices that enhance health. Personal health practices and coping skills encompasses both individual choices and the social, economic, and environmental factors that influence the decisions people make about their health. Health practices factors into this discussion, as one of the ways this research examined access to health care is through the exploration of Labradorians experiences and critiques of available health care resources and services, including health education, awareness and promotion services.

Healthy child development and genetic endowment as social determinants of health are not explicitly linked to the present research, but are still two very important determinants of health. Healthy child development refers to the influence that early experiences on brain development have on health. These experiences are shaped, however, by many factors, including income, housing, neighborhood, parents' education, healthy food, and genetic endowment (PHAC, 2011). In Labrador, many people are concerned with the high costs associated with accessing pediatric care for children in isolated communities. Genetic inheritance can also predispose individuals to disease or health problems (PHAC, 2011). According to the present research, accessing specialist care for uncommon genetic disorders is often more challenging than in larger urban centers.

Health services, the twelfth determinant of health, are recognized internationally as one of the social determinants of health (Commission on the Social Determinants of Health, 2008). The WHO defines health services as: "...all services dealing with the diagnosis and treatment of disease, or the promotion, maintenance and restoration of health" (WHO, 2011, para. 1). According to WHO (2010), health services are the most visible part of the functions of a health system and are determined by how key resourcess (money, staff, equipment and medicine) are combined to deliver health care.

Charlotte Loppie Reading and Fred Wien (2009) offer a critique of the social determinants of health framework in studying the health of Aboriginal people in Canada, contending that Health Canada's approach to the social determinants of health excludes the holistic approach to health of Aboriginal cultures that encompasses physical, spiritual, emotional, and mental components. Although not recognized by the PHAC, the negative effects of colonization was recognized as a fundamental social determinant of health among all Aboriginal populations in the world at the WHO's International Symposium on the Social Determinants of Indigenous Health (CSDH, 2007). In Canada, colonization means the removal of Aboriginal people from their land and traditional lifestyle, cultural and linguistic suppression, forced assimilation into Canadian society, degradation of the environment and racism (CIHI, 2004; Loppie Reading and Wien, 2009; Smylie, 2009).

According to the WHO's Commission on Social Determinants of Health (2008): Colonization has de-territorialized and has imposed social, political, and economic structures upon Indigenous Peoples without their consultation, consent, or choice...Indigenous People continue to live on bourded, segregated lands and are often at the heart of jurisdiction divides between levels of government, particularly in areas concerning access to financial allocations, programs and services (p. 36).

The following section describes literature documenting the major social determinants of health influencing access to health care in both rural and Aboriginal regions of Canada and the complexities of their interactions on health.

### Access to Health Care in Rural and Northern Canada

Due to their heterogeneous nature, rural communities differ among themselves and from those of their urban counterparts in health and health care needs (Chenier, 2000; DesMeules and Pong, 2006). The Royal Commission on the Future of Health Care in Canada, led by Roy Romanow in 2002, found that the biggest concern of rural Canadians regarding the health care system was access to health care services. Rural regions face the most difficulties accessing health services in Canada (Hutten-Czapski, 2001). specifically, challenges related to geography, limited availability of services, lack of health care providers, and increased distance to services (Slifkin, 2002). Less access to prevention, early detection, treatment, and support services in rural areas may further exacerbate these factors, making good health status even more difficult to achieve (Browne, 2009; DesMeules and Pong, 2006; Kirby, 2002; Romanow, 2002).

Based on idiosyncrasies between rural communities, rural Canadians do not experience the effects of the social determinants equally (BC Centre for Excellence on Women's Health, 2004; DesMeules and Pong, 2006; Schement, 2001). There is a scarcity of research on factors influencing access to health care in rural and northern regions of Canada. This discussion explores available academic and grey literature that explores the factors influencing access to health care in rural areas of Canada and the intricate interactions between them.

The influence of several social determinants of health on access to health care has been studied in Canadian rural communities. These include the physical environment, availability of health services, and culture (Browne, 2009; Chenier, 2000; DesMeules and Pong, 2006; Kirby, 2002; Romanow, 2002). Several cross-cutting social determinant themes are present throughout the discussion, including gender, age, jurisdictional difference, and socio-economic status.

Physical environment. The relationship between health and place has been investigated in the literature (Bender, Clune, and Guruge, 2007; Wilson, 2003). Amy Bender and colleagues (2007) contend, "when a geographic location is assigned meaning, it becomes a place" (p. 21). The authors argue that place matters both as geographic location and also as experience, and geography includes social, cultural, historical, political, economic, and physical features that together create context. This context creates different life experiences that influence patient and health care provider relationships because individuals generally view health from very different places and perspectives (Bender, Clune, and Guruge, 2007). Kathleen Wilson (2003) investigated the relationship of Aboriginal people with the land and highlighted the complex link between spiritual and social aspects of place, land and health. Although there is evidence suggesting physical context attributes to health outcomes, the effect of these factors on ability to access health care services is less clear (Litaker, Koroukian, Siran, and Love, 2005). However, information on how place effects access to health care is necessary for effective health planning in rural areas (Hodgins and Wuest, 2007). In Labrador, the context of place influences the experiences of Labradorians living and accessing health care in diverse cultural and geographic communities.

Distance to health care services has been identified as a critical variable for studying health care utilization of people living in rural areas (Arcury et al., 2005), and is a central factor in rural residents' ability to access adequate and timely health services (CHII, 2006). A large proportion of rural communities face the added challenges of travel that go hand in hand with living in remote and isolated regions. Of the rural Aboriginal population in Canada, 22% live in remote and isolated communities with no road access (DesMeules and Pong, 2006).

Physical environment interacts with income, another social determinant of health to determine access to health care in rural areas. Financial burdens, for example, are intensified in situations where individuals have to travel from their home. This creates challenges for rural residents of Canada, because they are more likely to be in poorer socio-economic conditions and have lower education levels than their urban counterparts (DesMeules and Pong, 2006). Though provincial, territorial and federal governments may partially subsidize transportation costs for necessary health cars services, many rural Canadian residents are left to cover high costs of travel, child-care at home, accommodation, and food out-of-pocket (Chenier, 2000; DesMeules and Pong, 2006). Travel outside of the home community during a medical crisis can create emotional burden on individuals and families, and further exacerbate poor health outcomes (Sutherns, McPhedran, and Haworth-Brockman, 2004).

Physical environment and gender are intricately linked in determining access to health services in rural areas. Women face added emotional stressors in traveling away from rural communities because they are typically responsible for maintaining the home, caring for children and monitoring the emotional climate of the family (Sutherns, McPhedran, and Haworth-Brockman, 2004; Kornelsen and Grzybowski, 2010). However, there is limited research on the effects of geography on women's health (Leipert and Reutter, 2005). Kornelsen, Grzybowski, and Iglesias (2006) investigated the sustainability of maternal care in rural areas of the country. They documented most pregnant women who live in communities that lack hospital facilities have to relocate to urban centers several weeks before giving birth, yet women from rural areas that provide some level of maternal care services have better birth outcomes than women without access to local services (Kornelson, Grzybowski, and Iglesias, 2006).

In a cross-Canada study on rural, remote, and northern women's health, rural women across Canada described the health care system as unreliable and insufficient to meet their needs (Sutherns, McPhedran, and Haworth-Brockman, 2004). Not surprisingly, challenges created by geography were compounded by availability of women-centered care. The participants identified a lack of women-centered care in their communities. They described cutbacks in health services and health reform initiatives that led to more travel, often without improving access to transportation, higher stress. and less personalized care for northern residents. Many women reported rarely making appointments for preventative care and seeking medical attention only when they were very ill. Women in this study suggested several policy recommendations including more research on rural, remote and northern women that factors gender, culture and place into policy development, health programming and planning. They also discussed the need to address the effects of income security, social services and transportation on health, especially the ability of rural residents to cover costs related to traveling away from home for necessary care (Sutherns, McPhedran, and Haworth-Brockman, 2004).

Health care services. Rural Canadians often have difficulty accessing primary health care because health care infrastructure and providers are simply absent (Romanow, 2002). Many provincial and territorial governments began to take active steps to improve health care delivery and access in all regions in the 1990s when health care reform became a priority throughout the country (Kirby, 2002; Romanow, 2002). At this time, many services were centralized to larger urban centers, while outreach programs and delivery approaches, such as Tele-health, were implemented in rural regions in some provinces in Canada (Kirby, 2002; Romanow, 2002).

Critical shortages of physicians, nurses. and other health care providers in rural Canada influence access to health care services. Although almost a third of the Canadian population lives in rural areas, only 18% of registered nurses, 17% of physicians and 4% of specialists practiced in rural, remote and northern regions of Canada (Hutten-Czapski, 2001; Kirby, 2002; Ministerial Advisory Council on Rural Health, 2002; Romanow, 2002). In 2008, it was estimated that 14% of rural Canadians did not have a family doctor (Dumont, Zurn, Church, and Le Thi, 2008). In 2011, 45% of residents of the Labrador

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Grenfell Health's region did not have a family doctor, compared to a provincial rate of 12% (Statistics Canada, 2012b).

Continuity of care refers to "the ability of patients to access healthcare with and through the same professional care provider over time" (College of Family Physicians of Canada [CFPC], 2007). Comprehensiveness of care refers to the ability of patients to access a wide range of services to meet their diverse health care needs (CFPC, 2007). Although this has been identified as a concern in rural and urban regions in Canada, continuity and comprehensiveness of care factors influencing access to health care in northern rural regions are proliferated by lack of physicians in communities, increased trouble retaining health care providers, and mandatory travel to see general practitioners to get referrals (Jong, 2006).

Rural areas have difficulty attracting and retaining physicians. In northern communities, the situation worsens. Rarely do physicians live above 70 degrees north latitude, although 3300 people live above that latitude in Canada (Ng, Wilkins, and Adams, 1999). Because of the challenge attracting Canadian physicians in rural Canada, many positions are filled by trained immigrants (Basky, Mathews, Edwards, and Rourke, 2007). In 2005-2006, more than 22% of doctors in Canada were foreign trained and 37% were foreign born (Dumont, Zurn, Church, and Le Thi, 2008). Newfoundland and Labrador has provisional licensing, that allows foreign-trained doctors who do not have a full practicing license to practice in rural areas with the condition they earn their license in three years. Provisionally licensed international medical graduates made up a third of the physician workforce in Newfoundland and Labrador (Basky, Mathews, Edwards, and Rourke, 2007). In 2007, Newfoundland and Labrador and Saskatchewan had the highest

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proportion of internationally trained physicians in Canada, at 45% and 62% respectively. Studies have found, however, that most internationally trained medical graduates who enter Canada through the provisional licensing program leave rural communities after receiving their full license (Basky, Mathews, Edwards, and Rourke, 2007), not entirely eradicating the high turn-over rate of physicians in rural Canada. There has been little research looking at rural community integration and adaptation that could help to retain overseas physicians (Beaton and Walsh, 2010).

The limitation of medical school programs in Canada may compound the shortage of rural doctors (Canadian Council on Learning [CCL], 2008). Rural and Aboriginal people are under-represented in the Canadian medical school system (CCL, 2008). Canadian medical school training programs have been criticized for admitting the majority (90%) of their students from wealthy urban neighborhoods, promoting specialist care most suited to urban practice, and requiring students to live in an urban area for the entirety of their program (Society of Rural Physicians of Canada [SRPC], 2007). Therefore, medical students who complete their programs in urban areas (originating in rural or urban neighborhoods) do not have experience and knowledge adequate to address the health care needs of rural populations (SRPC, 2007).

The overall number of nurses practicing in rural areas has decreased over the last several decades (Canadian Health Services Research Foundation [CHSRF] 2004). Overall, most nurses in Canada work in acute-care settings in urban areas. However, a larger proportion of rural nurses are required to work in community-based settings (CHSRF, 2004). Most provincial nursing associations have adopted generic entry-level requirements that do not specifically address rural or remote nursing practice (CHSRF, 2004). Although having lower levels of formal education and clinical resources than their urban counterparts, rural registered nurses are responsible for a greater range of services. Turnover rates of both rural physicians and nurses are high and similar factors for leaving rural areas apply to both professions, such as higher perceived stress, no opportunities for spouses or children, a lack of social support, and a desire for higher education (CHSRF, 2004; SRPC, 2007).

There are well-established processes that enhance access to health services in rural Canada. Tele-health, one of the most endorsed health technologies in rural regions of the country, is defined as the use of information and communications technology (ICT) to deliver health services, expertise and information over distance, geography, time, and social and cultural barriers. Muttitt, Vigneault, and Loewen (2004) describe Tele-heath as a key mechanism for improving access to health services. Tele-health can reduce the time, cost, and strain of travel on patients, families and clinicians, improve health care delivery, and reduce professional isolation (Canada Health Infoway, 2010). For rural residents using Tele-health means less time away from home and work, fewer travel related expenses and access to health care in their home communities. Tele-health allows residents local access to specialists through video-conferencing, faster medical test response times, and allows residents to participate in consultations with specialists and community care providers simultaneously (Health Canada, 2005).

Culture. The United Nations Educational, Scientific and Cultural Organization's (UNESCO) Declaration on Cultural Diversity defines culture as "the set of distinctive spiritual, material, intellectual and emotional features of society or a social group, and that it encompasses, in addition to art and literature, lifestyles, ways of living together. value systems, traditions and beliefs" (2002, p. 1). The importance of culture in shaping healthy public policy is significant (Schimpf and Sereda, 2007). Strong cultural engagement can positively influence the cohesiveness of communities and create economic, social and environmental benefits (Prime Minister's External Advisory Committee on Cities and Communities, 2006).

Rural populations do not share a homogeneous culture. Canadian rural communities, for example, are located in agricultural regions, close to urban centers, in coastal regions and the most remote regions of the north. These different manifestations of rurality can influence cultural traditions (Ryan-Nicholls, 2004). As previously mentioned, place has a significant impact on health behaviors (Bender, Clune, and Guruge, 2007). Despite marked differences between them, however, rural communities share many common features. Strasser (2003) writes that rural residents share feelings of loyalty to their home communities, relationships are viewed as personal and durable and rural inhabitants embody self-sufficiency, self-reliance and ind-pendence.

Rural Aboriginal people have health cultures that differ from the health culture of their non-Aboriginal Canadian rural counterparts. In many Aboriginal communities, survival depends on collectivity, cooperation and sharing (Isaak and Marchessault, 2008). Holistic approaches to health support integrated approaches, such as the primary care model (complementary to the social determinants of health approach) to health and wellbeing that encompass the physical, mental, emotional, and spirilual dimensions and promote the eradication of "silo" approaches to health promotion and prevention (Isaak and Marchessault, 2008; Peiris, Brown and Cass, 2008).

The Eskasoni First Nation in Nova Scotia, for example, introduced a primary care

model in 1999. The Eskasoni Primary Care Project involved multi-sectorial collaboration between the Band Council. Health Canada's Health Transition Fund, the provincial government and Dalhousie. The Eskasoni Health Centre offers an integrated public health/primary care model with salaried physicians, as opposed to the more common rural clinics held on a fee-for-service basis. The team was expanded to include a primary care nurse, community health nurses, prenatal care coordinator, health education/nutritionist and pharmacist. An evaluation, completed one year after opening the health centre, found that between the years of 1997 and 2000, per-capita physician visits decreased from 11 to 4 per year, emergency visits at the regional hospital declined 40%, prenatal, delivery and post natal maternal care for women increased from 0% to 96%, the cost of prescribed items decreased by 7% despite a 10% growth in the population, physician referrals to the nutritionist for diabetic management and prenatal care increased 850%, the center saved of \$200,000 in the medical transportation budget due to increased availability of services, and 89% of patients surveyed believed that the quality of health services had improved (CIHI, 2004). Although this is just one example of introducing a primary care model on a First Nations community in Canada, its success makes it a practical example for the successes of integrating traditional and holistic approaches to care

The Aboriginal portion of the rural population face additional challenges accessing health care services. Access to culturally relevant care has been a major issue for all Aboriginal groups in Canada (Loppic Reading and Wien, 2009; Romanow, 2002). This includes adequate access to interpretation services, cultural and regional understandings within the health care system of unique cultures and needs within communities (First Nations Regional Longitudinal Health Survey, 2005).

For Indigenous people, access to health services is a substantial problem, and again, it is almost universal, though for widely different reasons. For communities in rural areas access is impeded by distance from facilities and the lack of trained staff to provide the service. Resources are concentrated on services for the better off. (International Symposium on Social Determinants of Indigenous Health Adelaide, 2007, p. 114)

The unique histories and cultures of Aboriginal people emphasize the importance of integrated approaches to problems that affect communities and reinforce the necessity of holistic approaches to life. Exploring the underlying reasons for health access inequities is paramount to improving the quality of health services in Aboriginal populations through appropriate policies and programs (First Nations and Inuit Health Branch, 2009).

The concept of cultural safety is used "to express an approach to heath care that recognizes contemporary conditions of Aboriginal people which result from their postcontact history" (Brascoupé and Waters, 2009, p. 7). Cultural safety developed in nursing practice in New Zealand in 1999 to provide more inclusive and respectful health care delivery for Maori people. The concept asserts that to provide quality care for people from diverse cultures, the care must be provided within the cultural values and norms of the patient (Brascoupé and Waters, 2009).

First Nations people in Canada identified several barriers to accessing culturally safe care in the First Nations Regional Longitudinal Health Survey (2005), including: difficulty getting traditional care so choosing not to see a health professional and inadequate health care services. The First Nations Centre (2005) identified a lack of culturally relevant care, including lacking interpretation services and cultural and regional understandings of different First Nations communities' health care needs, to be a barrier to accessing health care across all of Canada.

Inuit cultural safety means that providers recognize 1) Inuit health is a holistic concept, encompassing physical, emotional and mental well-being, 2) Inuit ways of thinking and being are important to the restoration of health, 3) Inuit mental health is maintained through interconnectedness with family and nature, 4) Inuit historical context influences health experiences, 5) health processes are different for different people, 6) rapport must be built between the health care provider and patient based on principles of cultural safety, and 7) respect for each other's strengths and abilities in helping (NAHO, 2008).

Hanrahan (2002) carried out a study that identified the health care needs of Innu and Inuit from the north coast of Labrador. Innu and Inuit reported feeling profound disorientation in airports, hospitals, and surrounding cities when they were referred to urban settings for health care services. Most participants reported cross-cultural communication issues associated with eye contact, hody language, the practice of asking questions, and difficulty conveying concepts that exist in one culture, but not the other, such as visiting hours.

Although both Innu and Inuit experienced disorientation, a lack of interpretation services, challenges with cross-cultural communications, inadequate accommodation, and barriers accessing food, the experience was different between the two Aboriginal groups (Hanrahan, 2002). For example, in communication with health care professionals, Innu expressed feeling disrespected, while Inuit felt misunderstood. A lack of interpretation services affected both Aboriginal groups in a similar way, with Innu feeling discriminated against, and Inuit felt misunderstood. Gender factored into experiences within both Aboriginal groups, albeit in different ways. Innu men, especially, experienced alienation associated with disorientation that influenced their decision to leave the setting. Conversely, Inuit women, especially, experienced fear and loneliness associated with disorientation that led to feelings of "freezing" (p. 151).

Using cultural safety as a lens in a broad context can allow richer critique of issues of institutional racism that shape the provision of health care in Aboriginal communities (Smye, Josewski, and Kendall, 2009) and help define the limitations of cultural competence among practitioners (Wasekeesikaw, 2009). For the purposes of this research, cultural competence refers to the skills, knowledge and attitude of practitioners (Wasekeesikaw, 2009). Whalen (1999), a Labradorian Inuit nurse practicing in an urban setting, wrote an article on her personal experience with the lack of cultural competence in the health care system.

First Nations and Inuit place high value on their elders, privacy, peace and respect. The First Nations people have several characteristics they value as showing respect, including: treating people as inherently worthy and equal; genuinely attempting to understand them and their unique situations; attempting to provide adequate explanations; and showing sincerity during interactions. Inuit have two values inherent in their culture that should be considered when implementing care -- respect for elders and the importance of relationships. (Whalen, 1999, p. 43) Whalen (1999) writes of two experiences witnessing racism against First Nations and Inuit individuals in the health care system and states there are three ways caregivers can improve their cultural competence in order to appropriately care for individuals with different values than their own. First, trans-cultural education can enable health care professionals to avoid racially discriminatory practices. Second, effective communication can be improved through provision of interpreters or non-verbal communication training. Lastly, respect was identified as the most forgotten and most important virtue of health care professionals. She asserts that respect is mandatory in relations with patients, regardless of race, culture, religion, or illness, because it helps the patient in coping with hospitalization to the best of their ability and improves their well-being (Whalen, 1999).

The National Aboriginal Health Organization (NAHO) conducted a needs assessment that explored models of quality maternity care in First Nations and Inuit communities in Canada in 2006. The needs assessment was based on a focus group discussion and questionnaires with ten Inuit women and nine telephone interviews with health care professionals from Nunavut, Nunavik, Inuvialuit, and Labrador. They documented that Inuit in Canada share a common cultural heritage and birthing tradition that covers a large geographic area and crosses jurisdictional boundaries. Participants identified a lack of coordinated maternity services throughout this region. Women also felt traditional Inuit birthing practices were disrupted when women had to leave their communities to give birth and warned that Inuit birthing culture was at risk of being replaced by western health care delivery in the north. Participants outlined many interacting factors that determine healthy childbirth in the north, including isolation, teen pregnancies, housing shortages, domestic violence. poor nutrition, high costs of living. persistent organic pollutants in country food and wild game, lack of knowledge of available services, and general insensitivity of the medical system to Inuit culture. Participants reported Inuit women to be at greater risk of complications during pregnancy, childbirth, and postpartum (NAHO. 2006). Unfortunately, health care planners, providers and administrators continue to rely on urben-focused approaches to health care delivery rather than designing strategies conducive to the distinct social and cultural contexts of rural communities (Ryan-Nicholls, 2004).

#### Summary

Increasing knowledge and awareness of the factors influencing access to health care services and how they interact can inform effective policy development and improve the accessibility of health care services that fit the needs of diverse Labrador communities. I used the social determinants of health framework to explore factors that influence access to health care services in rural and northern regions of the country, because in these regions, social determinants of health also influence access to health care services. In my literature review, I highlight physical environment, availability of health care services, gender, and culture. However, the social determinants of health interplay quite intricately to determine how individuals access health care in rural areas. These highlighted factors, as well as gender as a factor influencing access to health care, will be explored in the Labrador setting in my findings chapters, Chapter 4: Environmental Scan and Chapter 5: Interview Findings. In the following methodology chapter, I discuss the epistemological and methodological underpinnings of the present study, the ethical considerations necessary to carry out health research in diverse communities of Labrador, and the specific methods used to collect and analyze the data.

### Chapter 3: Methodology

The purpose of this research is to explore the factors that influence access to health care services in Labrador and to recommend strategies for improvement. This chapter presents the theoretical and methodological underpinnings and the specific methods I used to conduct my research. This chapter will introduce the study's epistemic stance that serves as a foundation for the methodology. Next, the chapter will introduce the study's methodology and how it ensures consistency across the research design from epistemic stance to methodological lenses, research question, methods for data collection and analysis. The specific methods used to collect and analyze the data will also be outlined. Finally, the ethical considerations of the research approach will be examined.

# Epistemology: Naturalistic Inquiry

Epistemology is the researcher's particular orientation to the world – their way of seeing and perceiving the world and the events and people within that world (Koetting, 1984). I chose naturalistic inquiry based in interpretivism as my epistemic stance. The ontology (nature of reality) of the interpretivist epistemology is a world made up of tangible and intangible, multi-faceted realities that are best studied as a unified whole (Koetting, 1984). It contends that an individual's reality does not exist in a vacuum, but is rather influenced by its social, cultural, and historical context (Holloway, 1997). Interpretive approaches seek to better understand the experiences of others and the meanings they assign to them within a given context (Grant and Giddings, 2002). Interpretive inquiries are axiological (Grant and Giddings, 2002; Koetting, 1984), meaning that the researcher's values influences choice of a research question and how the question is framed, the methodology and specific methods that facilitate investigation

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into the problem, and in the selection and interactions with study participants within the particular social and cultural context.

Consistent with the distinctive characteristics of interpretivism, naturalistic inquiry engages the researcher and their perceptions in all stages of the research process and focuses on creating an integrated mosaic of individual subjective realities (Erlandson, Harris, Skipper, and Allen, 1993; Lincoln and Guba, 1985; Polit and Beck, 2008). Lincoln and Guba (1985) define naturalistic inquiry as a non-manipulative study of a real-world situation that enables the researcher to study phenomena as it occurs in its natural environment (Lincoln and Guba, 1985).

Naturalistic inquiry findings, like the ones arising in this research, are typically grounded in real-life experiences of people with first hand knowledge of a phenomenon (Polit and Beek, 2008). Koetting (1984) writes that "to gain an understanding of an individual's perception of reality...the [interpretive] researcher must enter into a dialogic relationship with that individual" (p. 297).

Individuals and communities in Nunatsiavut and Happy Valley-Goose Bay have diverse and distinct constructions of reality that determine how they perceive access to health care in the area based on such things as personal history, culture, geographical location, and livelihood. My intention was to capture the rich and unique experiences of Labradorians accessing health care amid diverse geographical, cultural, and political contexts through face-to-face dialogue. Interviews with departmental level staff, health care professionals and community members allowed me to explore different perspectives on issues surrounding access to health care services in the regions.

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### **Research Design**

Trustworthiness of qualitative research encompasses different dimensions of qualitative data collection and analysis and must be addressed at the outset of this discussion on research design. Credibility (the extent that research methods engender confidence in the researchers' interpretations of the data), transferability (the extent to which findings can be transferred to other settings), confirmability (the degree to which study results are derived from participants and context, not from researcher bias), and dependability (consistent and stable data) are all very important aspects of qualitative research (Polit and Beck, 2008).

There were several ways I designed my research so that it was more likely to produce credible and trustworthy results. These steps included prolonged engagement, rapport development, reflexivity, triangulation, member checking and inter-rater reliability.

Corinne Glesne and Alan Peshkin (1992) state "time is a major factor in the acquisition of trustworthy data" (p. 146). She discusses how prolonged engagement within the research community can lead to the creation of productive relationships between the researcher, the participants and the research environment. Viewing phenomena in its natural environment is essential when a naturalistic approach to research is taken. It is my perspective that spending extended periods of time within a specific environment can lead to an informed understanding of how context can influence experiences, especially the relationship between participants and environment. In addition, time allows the researcher to test for misinformation and distortion, use directed questions and prompts in interviews to unearth deep description of phenomena and feel confident when they have reached saturation in an interview setting. Accordingly, the researcher interprets data in a more informed manner when they have a deeper understanding of the relationships between the participant and the context in which they live. One effective way to gain deeper insight into the factors that influence access to health care in Labrador was through direct and prolonged engagement with the environment and people of Labrador.

As the principal investigator of this project, I decided to move to Labrador for the completion of my research (2 years). I lived in Labrador for 8 months before beginning my interviews. This allowed me to bring an informed perspective to the data collection phase of the research. I then remained in Labrador for another year of data collection, analysis and writing my thesis. I intended to capture a broad scope of experiences accessing health care services in Labrador, and in this quest, it proved invaluable to spend two years living in the region.

It was equally important for me to build a strong rapport with community members of Labrador. Working with the Rural Secretariat and completing short contract appointments with several community organizations during the summer of 2010 introduced me to key stakeholders in the community and forged a place for me to begin my data collection. Second, my initial proposal was refined in collaboration with key stakeholders, and incorporated the views of the Rural Secretariat, the Nunatsiavut Government's Department of Health and Social Development, Labrador Grenfell Health, and the Labrador Institute and the Division of Community Health and Humanities of Memorial University. This ensured it was acceptable to all parties before the final proposal was submitted. Once all parties accepted the renewed proposal, ethics applications were submitted to Memorial University, Labrador Grenfell Health and the Nunatsiavut Government. These community agreements served as the primary means of clarifying and confirming mutual expectations and commitments between and among communities and myself.

Another way I ensured trustworthiness was through reflexivity. Reflexivity is defined as critical self-reflection about one's biases and preconceptions (Polit and Beck, 2008). Through the research process. I continually reflected on my influence on the research and the ways my relationship, respect, familiarity and knowledge of the research communities grew from beginning to end. "As [we] begin to interpret reality... processes of self-reflection and communication of internal processes need to be considered by the researcher" (Koetting, 1984, p. 297). Interpretivist research is axiological, meaning the values and perspectives of the researcher influence the research questions, the methodology, the way in which the methods are carried out, and the analysis of the interviews. The researcher's values are the filter through which all incoming stimuli and information gleaned from the research is interpreted, and they shape the overall are of the research story. Therefore, I was mindful and unreserved about documenting in a journal any biases I was bringing to the research to enhance the richness of my research study.

Triangulation is defined as the use of multiple methods to collect and interpret data so as to converge on an accurate representation of reality (Polit and Beck, 2008). I used triangulation of sources by developing a detailed environmental scan by researching local organizations, provincial and federal policies, and studying the physical, social and cultural context of Labrador. I used triangulation of methods by developing separate interview guides employing one-to-one and focus group interview techniques to gain the perspective of health care administrators, providers and community members. I also collaborated with stakeholders from different communities and organizations in Labrador and Memorial University through out the entire research process.

Another method used in the present study to improve trustworthiness of findings was through member checking and inter-rater reliability (Polit and Beck, 2008). Participants were given the option during the interview to review the interview transcripts once they were developed to ensure accuracy. During the initial phase of data analysis, members of my supervisory committee and I independently analyzed a sample of the interview data and held a lengthy group session one afternoon to review, discuss and agree on coding decisions. This process is outlined below in the data analysis section.

Using these tools influenced the way I engaged in my research, how I responded to the stories I was told, how I reacted and conversed with each of my research participants, and helped to produce interview findings far richer than I could have imagined.

# Methodology

Collective Case Study Approach. The collective case study methodology is the utilization of diverse data sources to holistically explore a phenomenon. Collective case studies allow for in-depth investigation into a particular case through the exploration of various dimensions of social phenomena surrounding that case (Gillham, 2000; Lincoln and Guba, 1985; Feagin, Orum and Sjoberg, 1991). Case studies encapsulate the principles of naturalistic inquiry based in interpretivism, by allowing the qualitative researcher to capture and offer rich descriptions of the complexities of interactions between individuals and their social and physical context (Yin, 1994). Although case studies are widely used to explore theoretical propositions, they are also useful when limited research is available on an issue (Brophy, 2008; Polit and Beck, 2008). Case studies can unearth preliminary information about phenomena that have not been rigorously researched. In-depth exploration can lead to insight of unexpected relationships and guide the development of subsequent research endeavors (Polit and Beck, 2008; Yin, 1994). The case study approach is suitable for studying complex social phenomena whose boundaries are not clearly defined, because the focus is on real-life context and evidence comes from multiple sources (Yin, 1994).

I chose the case study approach to explore concerns regarding access to health care services because research investigating access to health care in Labrador was in its exploratory stage and because I will be using data from a variety of perspectives from two regions in Labrador. Individuals at the administrative, provider, and community member level of Happy Valley-Goose Bay and Nunatsiavut were interviewed to explore the historical, cultural, physical, and social context surrounding access to health care in Labrador through a sample of unique perspectives.

## **Data Collection Methods**

My data collection methods of one-to-one and focus group interviews with health care administrators and providers and community members practicing and living in Happy Valley-Goose Bay and Nunatsiavut communities are consistent with my epistemic stance and the study's methodological framework. The purpose of interviews was to explore Labradorians' personal experiences accessing health care services through semistructured open-ended dialogue.

Justification of site selection. The purpose of this research was to highlight the factors that influence access to health care in Labrador by highlighting the diversity of factors that influence access to health care in two distinct regions. Initially, I selected Happy Valley-Goose Bay and Nain as the two communities of focus. These communities were selected for several reasons: First, the communities were expected to highlight differences and similarities in access to health care between isolated. Aboriginal communities and a non-isolated, multi-cultural community. Second, selecting communities that housed the headquarters of health care authorities governing health care in Labrador was important, as one-to-one interviews with administrators in Nunatsiavut's Department of Health and Social Development and Labrador Grenfell Health contributed significant and important knowledge to the comprehensive discussion of barriers to accessing health care in Labrador in this study. The suggestion from Nunatsiavut Government's Department of Health and Social Development was to conduct interviews with Nunatsiavut beneficiaries during their stay at the Labrador Friendship Centre<sup>4</sup> as the hostel that houses all Nunatsiavut community members while they are accessing health care services in Happy Valley-Goose Bay. Community members of four of the five isolated Nunatsiavut communities on the North coast were interviewed.

Happy Valley-Goose Bay is usually referred to as the "hub" of Labrador. It is the largest town in Labrador, with a population of 7552 people (Statistics Canada, 2012a) and is located in the south-east at the mouth of Lake Melville. The Canadian Forces Air

<sup>&</sup>lt;sup>4</sup> The Labrador Friendship Centre is a centre for cultural, traditional, social, educational and recreational activities and gatherings that promotes communication and understanding between Aboriginal people and activities and gatherings that promotes communication and understanding between Aboriginal people and acommunity service agencies, and also assists Aboriginal people of Labracor migraring to or living in the Happy Valley-Goose Bay area adapt to an urban evitoroument, find and maratin employment and housing, make personal, social, cultural and cross-cultural contacts. The centre also promotes and Aboriginal elevation and and perstation and perservistion of Aboriginal arts, centre, and and artifacts and operates a house! Labrador Friendshipt Centre, 2009.

Command operates a Canadian Forces Base for North Atlantic Treaty Organization (NATO) flight training in Happy Valley-Goose Bay. Over the last 6 decades, air forces of the United Kingdom, the Netherlands, Germany and Italy have used the base for flight training. At the time of this research, the base was serving as a Canadian military flighttraining program.

In terms of health care resources, Happy Valley-Goose Bay houses the main hospital in the region (the Labrador Health Centre) and the regional and provincial medical evacuation planes. Labrador's health care services, physicians, and secondary care services are also centralized in Happy Valley-Goose Bay.

Nunatsiavut is the Inuit land claim region located in northern Labrador. Nunatsiavut contains five northern, isolated, coastal communities (Rigolet, Postville, Makkovik, Hopedale, and Nain) and has a population of 2617 people (Statistics Canada, 2012a). All Nunatsiavut communities are fly-in communities, isolated from other communities in the region. The settlement area of Nunatsiavut is approximately 72,500 km<sup>2</sup> of land and an adjacent ocean zone of 48,600 km<sup>2</sup>. Of the entire settlement area, 15,800 km<sup>2</sup> are Inuit-owned lands, upon which Inuit are entitled to 25% of provincial revenues from future development. Labrador Inuit have co-management rights in the remaining area of land and ocean in the settlement area upon which they are entitled to 5% of provincial revenues from future development (Nunatsiavut Government, 2011). All Nunatsiavut communities have community clinics with primary care provided by nurses and community health nurses and 24-hour observation capabilities.

Nain is the administration capital for the Nunatsiavut region and, therefore, houses the main administration buildings for Nunatsiavut Government's Department of Health and Social Development. Nain is the northern most coastal community in Labrador, located 230 air miles north of Happy Valley-Goose Bay (Our Labrador, 2009), and the largest of the Nunatsiavut communities, with a population of 1188 (Statistics Canada, 2012a). Residents of Nunatsiavut communities are employed with Nunatsiavut Government departments in the five communities and in the education system. Tourism is also increasing as an employer, especially since the establishment of the Torngat National Park in 2008, when the Nunavik Inuit Land Claims Agreement came into legal effect (Parks Canada, 2012). In the spring and summer months, Nunatsiavut residents fish most notably for trout, salmon, crab, char, and scallop for personal consumption. Hunters also engage in subsistence hunting of ducks and geese in the fall, fox and wolf in the winter, caribou in the spring, and seals vear round (Our Labrador, 2009).

Environmental sean. Before and during my stay in Labrador, I conducted a detailed environmental scan of the context surrounding access to health care in Labrador at the time of the research. For purposes of this research, I define this environmental scan as comprehensive overview of facts that relate to accessing health care in Labrador. Websites and government and non-government reports and literature were primary resources. However, I also gleaned information from "on-the-ground" research that came in the form of local knowledge and information. This scan highlighted the geographic, political, cultural, and social context within which Labradorians access health care. This scan allowed me to gain the knowledge necessary to create pointed interview guides that were directed at the issues surrounding access to health care in Labrador. The environmental scan is presented in Chapter 4.

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Interviews. One-to-one and focus group interviews were conducted between February and April 2011 in Happy Valley-Goose Bay. Health care administrator and providers were interviewed individually. My decision to use the one-to-one interview method with these participants was based on the specific knowledge of departmental level staff in the health care authorities in Labrador. Health care administrators and providers can provide insight into the nature of an issue from a broad spectrum of informed perspectives and opinions (Marshall, 1996). The principle advantage of one-toone interviews relates to the quality of information that can be obtained in a relatively short time period (Lincoln and Guba, 1985). Consistent with the collective case study approach and the research question, my intention of using one-to-one interviews us to explore a blend of diverse perspectives of individuals with varying experience. perspectives and roles in the health care system in Labrador.

I initially intended to carry out focus group interviews with community members of Happy Valley-Goose Bay and Nunatsiavut. Unfortunately, time and scheduling did not allow for the organization of focus groups with Nunatsiavut community members. These participants were interviewed during short stays at the Labrador Friendship Center hostel while they were accessing health care in Happy Valley-Goose Bay, and therefore, it proved impossible to organize a set time for focus groups that worked for participants. The community member interview script was used to conduct these in-depth, semistructured, one-to-one interviews with two male and two female Nunatsiavut community members. During interviews, individuals did not speak on behalf of their communities, rather they gave their individual experience and perspective on access to health care within their communities. One-to-one interviews are not considered the optimal method

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for carrying out interviews in Inuit communities as knowledge is often shared through talking circles and social gatherings (Status of Women Canada, 2006).

Focus groups are a qualitative research method in which the researcher can explore specific questions about a topic in a small group discussion (Onwuegbuzie, Dickinson, Leech, Zoran, 2009). Krueger (1994) describes a focus group as a "carefully planned discussion designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment" (p. 6). Focus groups are especially useful if one is exploring a new area of research, as they can highlight participants' perspectives on the reasons why something is occurring as it is (Litosseliti, 2003; Onwuegbuzie, Dickinson, Leech and Zoran, 2009; Wong, 2008). My decision to use the focus group interview method for community members was to provide an added dimension that oneto-one interviews can not encompass - the power of group interaction (Wong, 2008). Sharing experiences with a group of similar people can facilitate feelings of validation, security, comfort of expression, and group cohesion among research participants, which can encourage expression and elicit greater depth of discussion (Onwuegbuzie, Dickinson, Leech and Zoran, 2009). Focus group interviews were appropriate for this naturalistic inquiry with a case study methodology because they examined the diverse experiences of multiple Labradorians to gain insight into personal accounts of shared challenges accessing health care in Labrador and strategies used to overcome reported challenges.

Participant Recruitment and Sample. Purposeful sampling, defined by Polit and Beek (2008) as a selection method based on personal judgment about which participants would be most informative, was used to recruit health care providers and administrators for one-to-one interviews. Labrador Grenfell Health and Nunatsiavut Government's Department of Health and Social Development provide health care services in Happy Valley-Goose Bay and Nain. Participants in both organizations were selected based on experience, role, and knowledge regarding health care delivery. The Labrador Aboriginal Health Research Committee helped me to select individuals for these interviews. Recruitment took place in February 2011. An email script was sent to participants from the Labrador regional partnership planner with the Rural Secretariat. The recruitment script included information regarding the research objectives. Once participants expressed interest in the study, they were contacted to determine whether they desired any more information regarding the study. See Appendix C for the health care administrator and provider email recruitment script.

Due to limited human resources in each organization, individuals often filled more than one professional role. Administrator and provider interviews were held with two individuals working with Nunatsiavut Government's Department of Health and Social Development and three individuals working with Labrador Grenfell Health.

For the Happy Valley-Goose Bay focus groups, a notice of recruitment was sent out to community members via the CET Network list serve, a public community events email network. Due to the unity of the community, information about the focus groups was also communicated by word of mouth. A copy of the recruitment script is attached in Appendix D.

Since gender can influence group dynamics and freedom of expression (Khan et al., 1991), and I wanted to elucidate female and male-specific patterns of accessing health care, focus groups were segmented by gender. Focus group recruitment was more

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successful for women than men. Within two hours, fifteen women offered to participate in a focus group. Men were purposively selected based on community affiliation and experience with accessing health care services in the last year. Although four females and four males confirmed attendance at each focus group, only three female community members were present and two male community members present during focus group sessions. There was representation in both focus groups of nor-Aboriginal and Inuit Happy Valley-Goose Bay community members.

The hostel coordinator at the Labrador Friendship Centre recruited Nunatsiavut community members residing at the hostel while accessing health care in Happy Valley-Goose Bay. This help was invaluable, as the coordinator was personally acquainted with the recruited community members and served as a liaison between the participants and myself. Nunatsiavut participants were from Postville, Makkovik, Hopedale and Nain and were fluent in English, though the second language of several of the participants was Inuktitut. Participants noted that translation of consent forms was not necessary.

The only criteria for inclusion was that participants were members of the selected communities and had experience accessing health care in the region. Consultation with the Labrador Aboriginal Health Research Committee and Nunetsiavut representatives shed light on strategies to include a broad selection of key individuals who had experience accessing health care and to share information in a manner conducive to the participants' culture and background. This is in accordance with Section 9C, Article 9.13 of the Tri-Council Policy Statement<sup>6</sup> (Canadian Institute for Health Research [CHIR]. Natural Science and Engineering Research Council [NSERC] and Social Sciences and

<sup>&</sup>lt;sup>5</sup> The Tri-Council Policy Statement (TCPS) 2, now in effect, was released in 2010, after completion of data collection for this research.

Humanities Research Council [SSHIRC], 2009). In line with section 4B, article 4.1 of the Tri-Council Policy Statement (2009), participants were not excluded based on ethnicity, race, culture, sexual orientation, age, linguistic proficiency, race, or religion. Children were not excluded and although none were in attendance, several participants discussed accessing health care for their children.

Interview Process. Two focus groups and nine interviews were carried out with fourteen participants. Interviews with health care administrators and providers were indepth and semi-structured and were conducted within a time frame of 35 and 87 minutes. Interview guides were developed to explore challenges accessing health care services in Labrador and strategies to overcome them from the perspective of health care providers and administrators. All administrators and providers lived in Labrador and spoke from the experience of being departmental level staff and as community members accessing health care in the region. The health care administrator and provider interview guide is in Appendix E.

The community member interviews were semi-structured. The female focus group in Happy Valley-Goose Bay was one hour and 49 minutes and the male focus group was 37 minutes. Discussion in the female focus group surrounded issues and experiences associated with female specific health care, with which several members had emotionally challenging experiences. Expansion of personal experiences and stories increased the comfort level of the group and influenced the length of the interview. In contrast, the male focus group did not entail elaborate discussion around personal experiences and the interview took less time.

As facilitator, I encouraged focus group members to express their views and for

everyone to play a cooperative role in sharing experiences and refrain from dominating discussion. If someone were interrupted, I would politely bring the conversation back to the individual to finish his or her point. If conversation moved off topic, I would politely steer the discussion back to the topic of focus.

Nunatsiavut community member one-to-one interviews were carried out using the same interview guide. Each individual discussed their experiences accessing health care services in their communities, in Happy Valley-Goose Bay and in larger urban referral centers. These four interviews took between 34 minutes 58 minutes. The community member interview guide can be found in Appendix F.

### Data Analysis

My approach to analysis of interview transcripts was based on an approach used and refined by Natasha Mauthner and Andrea Doucet (1998) called the voice-centered relational method. Mauthner and Doucet outlined a qualitative data analysis method in a clear, step-by-step manner due partly to the lack of attention that has been paid to issues of power, voice, and authority in the data analysis stage of research and the difficulty of articulating the implicit, thick, subjective, and sometimes uncomfortable process of qualitative data analysis in a logical, sequential, and linear fashion (Mauthner and Doucet, 1998).

I used the first stage of their analysis method, entitled: Stage One – The voicecentered relational method of data analysis: four readings, case studies and group work. This voice-centered relational method has foundations in relational ontology that postulates individuals do not exist as independent entities, rather in an intricate web of social relations (Gilligan, 1982). Mauthner and Doucet's voice-centered relational method represents their attempt to translate a relational ontology into concrete methodological steps of data analysis by exploring participant transcripts in terms of relationships to themselves, to people around them, and to the broader social, structural, and cultural contexts within which they exist.

The method entails four different transcript readings for relationships, the development of participant case studies from the findings, and comparison of findings across a team of researchers to highlight similarities and differences in findings (Mauthner and Doucet, 1998). This team approach to analysis is beneficial because others are able to point out important issues or significant passages the primary researcher may have missed in the interview transcripts. Working as a team can also create awareness of power and personal biases influencing the selection of particular passages and the ignorance of others (Mauthner and Doucet, 1998).

Two interview transcripts were selected for initial readings and independent coding by me and my co-supervisors. These transcripts were chosen because they were rich with descriptions of the major players in the administration, delivery, and encompassed many issues surrounding access to health care services in Labrador. The intimate knowledge of the two selected participants (from growing up and working in health care provision and administration in diverse communities in Labrador) gave the transcripts distinction and worthiness in the discussion of health care in Labrador. Both participants were women, native to Labrador and spoke from the perspective of all three levels of the health care system: users, providers, and administrators. According to Mauthner and Doucet (1998), the first reading has two main objectives. First, to outline the overall plot and story of the interview transcript: What are the main events? Who are the protagonists? What are the subplots? The second objective is the reader-response element of the first reading, in which the researcher reads for how they related to the respondent socially, emotionally, and intellectually to gain some comprehension over the not-so-clear boundaries between the narrative and our interpretation of the narrative. Mauthner and Doucet (1998) write that being reflexive about interpretations of data involves locating ourselves socially in relation to the interviewee, observing our emotional responses to the interviewee, examining how we make interpretations of the transcript, and documenting these processes for others and ourselves. I had a direct relationship with these women due to my experiences dealing with bureaueracy of the health care system and accessing health care as a woman in Labrador. During this first reading, I explicitly described how I related to the transcripts in my notes. This reading allowed me to examine the influence of my personal assumptions and views had on my interpretations of the transcripts and to lay out these assumptions for others on my supervisory committee to see during the group analysis session.

The second reading involves reading for the voice of 'I', focusing on the ways participants feel and speak and express ideas about themselves. I used a marker to highlight where the participants used personal pronouns, I, we, or you, in talking about themselves. This reading focused my attention on the person telling the story and helped me recognize when participants struggled to articulate experiences or became emotionally charged. It also helped me identify places where 'I' might change to 'we' or 'we' might change to 'you', which indicated a change in how participants perceived themselves. By reading in this way, I could actively listen to participants' descriptions of their social location to people and the world around them and their stories in their own terms. One participant used the term 'I' to refer to herself as a user of the system, and 'they' to refer to service providers. When she referred to decisions and policies of the health care organization at which she is an administrator, she used the word 'we'. When she spoke of challenges Labradorians faced accessing health care, she used the term 'we'. It was noteworthy to document how she related to herself as a community member health care user, provider, and administrator, as if she had three inter-related selves and how each of these experiences influenced her personal health decisions.

The third reading was to identify how participants spoke about relationships, i.e., how they interact and perceive relationships with family, children, and broader social networks where they live. I used a different color marker to highlight passages where participants discussed their relations to those around them and where they saw themselves in this complex social web. Since both selected transcripts were from respondents who were administrators, providers, women, and mothers using the health care system, they spoke of their relationships with other health care administrators and providers as women accessing health care. They also spoke about Labrador women as primary care givers and their role of guiding children and elders through the health care system. I highlighted passages in which positive and challenging relationships were discussed. This reading allowed me to trace fluctuating relationships through the experiences of the participants with the health care system, which allowed deeper insight into the narratives.

Mauthner and Doucet (1998) contend that the fourth reading focuses on such social structures as gender, class, nation, region, ethnicity, age and sexuality and social institutions such as state, work and family that form social realities for people. The fourth reading placed participants within the larger cultural, political, and social structures of society. It involved attending to respondents' recognition and discussion of social factors, which can allow the researcher to locate the respondent within their social context and networks. In my own research, I attended to how respondents perceived societal influence and whether they felt these influences were facilitative, authoritative, or limiting. By reading from this perspective, I picked up on some unexpected findings that contradicted my assumptions about accessing care in Labrador.

From this analysis, a case study was drawn up for each participant and major themes and sub-themes in the discussion around the factors that influence access to health care in Labrador were generated. Major themes were discussed in a group session with the three members of my supervisory committee, who had generated their own themes from the selected interviews. This inter-rater reliability was a method I used to ensure credibility and trustworthiness in my data analysis. As a group, we addressed and analyzed everyone's identified themes and drew up a refined list of what we perceived as the most significant themes. These themes were used as a base for further analysis of the remaining interviews. All remaining transcripts were read four times and expected and unexpected themes were identified.

After all transcripts were analyzed, I organized passages into similar thematic categories, which allowed me to generate clear names for themes sub-themes that became the identified factors influencing access to health care in Labrador and the strategies to overcome the challenges created by them. I then provided a Labrador context for each factor, selected the most compelling passages to include in my analysis chapter.

A journal and a collection of notes recorded throughout the research process and

interviews helped me to keep track of my thoughts and reflections as I created categories for major concepts arising in interviews. Qualitative researchers use their own judgment when determining the importance of each theme (Braun and Clarke, 2006). Keeping personal reflections through the research process was invaluable during data analysis. My journal also allowed me to document my reactions during interviews and general observations on my research topic while living, working, researching and generally experiencing local life in the selected communities. The process of analysis was informed through revisiting and studying past journal entries from the two years I was conducting research in Labrador. These entries helped me to identify and tease out significant, common and uncommon experiences of community members during my analysis. Ultimately, I produced a data analysis story that deeply explored the perceived factors creating challenges accessing health care services in Labrador and strategies that help Labradorians overcome these challenges, thereby improving access to health care services.

One drawback of the voice-centered relational approach to data analysis is the great deal of time and effort it requires from a research team (Mauthner and Doucet, 1998). Given time and resource restrictions, it was impossible for me to use this approach for all 11 one-to-one and focus group interviews. Mauthner and Doucet (1998) write that carrying out this process on a sample of interviews enables the researcher(s) to 'tune their ear'. Focusing intently on two selected interview transcripts allowed me to actively listen for critical issues identified in the sample interviews and new issues addressed in the remaining nine interviews. Moving from slow deliberation on individual transcripts to the brisk process of reading through transcripts can cause the researcher to selectively focus in on certain issues while shutting out others (Mauthner and Doucet, 1998). I placed significance on issues that were addressed by several participants, but also on data that was contrary to other findings to explore the complexities of experiencing the health care system in Labrador from perspectives of community members from diverse cultural and social backgrounds.

## Ethical Considerations

Ethics approval was sought after the initial research proposal was developed in conjunction with the Labrador Aboriginal Health Research Committee. Ethics approval was obtained through the Interdisciplinary Committee on Ethics in Human Research ethics board at Memorial University in August 2010, Labrador-Grenfell Regional Health Authority and the Nunatsiavut Government in November 2010. The agreements addressed the ethical protections that apply in gaining individual informed consent, specify commitments regarding collective community participation, decision making and consent, set out the purpose of the research, and detailed mutual responsibilities in project design, data collection, management, analysis and interpretation, production of reports and dissemination of results (Section 9C, Article 9.11, TCPS; CHIR, NSERC, SSHRC, 2009).

Information regarding the research objectives, process, risks, benefits, and dissemination strategies relevant to free and informed consent was fully disclosed to participants before focus group and one-to-one interviews were conducted. On commencement of interviews, participants were given time to read a detailed consent form and the option to go through the consent form with me. Participants were given the opportunity to raise any concerns or questions regarding the research process and their

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participation in it as is described in Section 3A, Article 3.2 of the TCPS (CIHR, NSERC, SSHRC, 2009). Once the participant finished with the consent form, I summarized the information and ensured they understood and felt comfortable with their participation. In situations of low literacy, I read through the consent form in its entirety with the participant. Participants were told they could withdraw themselves or their information from the study at any point they felt appropriate or necessary. Participants were given a written copy of the consent form to keep with contact numbers in case they had concerns after the interview was completed. Consent was documented by signing the consent form. The consent form can be viewed in Appendix G.

Some Aboriginal groups in Canada perceive written signatures as binding, coercive, an attempt to legalize the consent process, and a violation of trust (Liamputtong, 2007). Therefore, a separate section for those who wished to give verbal consent, which could be documented by the researcher in writing, was on the form. If a participant was not able to give written signature due to language or literacy challenges, they could have given consent by an intermediary external to the research project and proficient in the researchers and participants chosen languages. This is in line with the TCPS as it is outlined in Section 2A, Article 2.1 (CIHR, NSERC & SSHRC, 2009).

All participants spoke English as a first language or were bilingual in English and Inuktitut and were willing to give written consent. The process used for gaining informed consent from participants is in line with Section 3A, Article 3.3 of the Tri-Council Policy Statement (CHR, NSERC and SSHRC, 2009). A copy of the consent form is in Appendix F. All information and data collected through these interviews was kept secure and confidential in password-protected files on the researcher's personal computer. Direct identifiers of individuals, such as their names, address, telephone number, etc. were not essential research information and were not recorded in transcripts or findings. Identifying information was masked as much as possible using a standardized protocol in line with Section 5C, Articles 5.3 and 5.4 of the TCPS (CIHR, NSERC & SSHRC, 2009), which states the importance of keeping information integral for research, but masking information that may identify individuals. In the data analysis, job titles and other personal identifiers are not used to protect the identity of interview respondents in the small communities of Labrador.

To ensure security of the interview content, the interviews were recorded in an MP3 file on a voice recorder memory card. Once transferred to the researcher's computer, the MP3 file on the memory card was erased. The audio and textual data was kept secure during transcription in password-protected files. The files were backed up to protect against loss and damage in password-protected files on a flash drive. All MP3 files and transcribed interviews were transferred to locations where they were analyzed and are stored securely for future consultation in Victor Maddalena's office in the Division of Community Health and Humanities in the Faculty of Medicine on the Memorial University premises. These practices are in line with Section 5C Articles 5.3 and 5.4 of the TCPS (CIHR, NSERC & SSHRC, 2009), that requires researchers to ensure data obtained are stored with all appropriate precautions.

#### Summary

This chapter discussed my application of complimentary epistemological and methodological frameworks and method techniques. The following chapter presents an environmental scan on Labrador's context that will help to provide a context for the

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# discussion of experienced challenges accessing health care services in Labrador and strategies to overcome them.

#### **Chapter 4: Environmental Scan**

The information presented in this environmental scan is a compilation of historical and contemporary information to provide a context for examining the factors influencing access to health care services in Labrador. Labrador's people, health context, jurisdictions, organizations and services, modes of travel, and strategies used to improve access to health care services for Labradorians will be documented in this chapter.

## Labrador's People

Labrador is home to three Aboriginal groups, the Innu, the Inuit, and the Inuit-Metis. In 2006, Innu, Inuit and Inuit-Metis comprised approximately 30% of Labrador's population, at 10,560 (Statistics Canada, 2008), and non-Aboriginal multi-cultural Labradorians.

Innu. The Innu are a First Nations<sup>6</sup>. First Nations are Status and Non-Status "Indian" people in Canada. Detailed definitions of First Nations and Innu are offered in the Glossary of Terms. There are currently 615 First Nation communities in Canada representing more than 50 cultural groups and languages (Indian and Northern Affairs Canada [INAC], 2008. First Nations are recognized under the Canadian Indian Act and are eligible for federal coverage for social and health programs (INAC, 2008).

At the time of this research, there were approximately 2200 Innu of two Innu First Nations in Labrador: the Mushuau Innu, located in Natuashish Innu First Nation on the north coast of Labrador and the Sheshatshiu Innu, located on the Sheshatshiu Innu First Nation in central Labrador. The Labrador Innu were not recognized under the Indian Act

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<sup>&</sup>lt;sup>6</sup> First Nation has been adopted by some Indian communities to replace the term Indian hand. A hand is defined as a body of Indians for whose collective use and benefit lands have been set apart or money is held by the Crown, or declared to be a band for the purposes of the Indian Act. Many Indian bands started to replace the word band in their mane with First Nation in the 1980s (INAC, 2005).

until 2000 (INAC, 2008). These communities were recognized as reserve lands in 2003 and 2006 respectively (Higgins, 2008a). The language of the Labrador Innu is Innuaimun, and it is still practiced as a first language in Sheshatshiu and Natuashish, though the communities have different dialects (Matthews, 1998).

Archaeological evidence has found the Innu people have inhabited Labrador for over 7,000 years. The Innu name for their homeland is Nitassinan. Traditionally a nomadic people, the Innu of Labrador traveled the interior of Labrador and Quebec in the winter to hunt caribou, and spent summer months on the coast to fish (Matthews, 1998). When Newfoundland and Labrador joined confederation in 1949, neither the federal government nor the provincial government extended the Indian Act to the Aboriginal people in Labrador. In lieu of the Indian Act, the Canadian government transferred financial support to the province to deliver health, education and other social services. During this time, the province built houses and schools in Sheshatshiu and Davis Inlet (Higgins, 2008a; Tanner, 1999).

Sheshatshiu was established as a permanent settlement in the 1950s. The Mushuau Innu lived in Davis Inlet, established in the 1960s (Higgins, 2008a; Matthews, 1998). Residents of Davis Inlet chose to relocate to Natuashish in the early 2000s. At this time, the community became the focus of international media attention for its poor living conditions and social problems, stemming mainly from a community settled in an unsuitable location with inadequate water supply, on an island with limited access to the mainland for hunting (Tanner, 1999).

It was mandatory for Innu children to attend school and families whose children did not attend school were threatened with termination of social assistance and family allowance payments (Higgins, 2008a). The education system laught children about North America society, and the young generation were alienated from their cultural traditions (Higgins, 2008a). Because of mandatory attendance in school, many Innu were forced to settle in communities for most of the year, which threatened their migratory way of life and connection to nutshimut, the country (Higgins, 2008a). The Innu also became threatened with forestry, mining and resource development occurring on Innu land without Innu permission or consultation. The Innu joined the Native Association of Newfoundland and Labrador in 1973 with the Mi'kmaq and Inuit. The Innu split from the association in 1976 and formed the Naskapi Montagnais Innu Association, which became Innu Nation in 1990 (Higgins, 2008a).

Inuit. Since this research focuses mainly on the Labrador Inuit, the present section will offer a more detailed historical and social context description. Inuit<sup>7</sup> are the Aboriginal people of Arctic and Sub-Arctic Canada. A more detailed definition of Inuit is available in the Glossary of Terms. There are currently 53 Inuit communities, classified by region, tribe, and culture in Canada (CIHI, 2004). Four regions in Canada have settled Inuit land claims: Nunatsiavut (Labrador), Nunavik (Quebec), Nunavut and the Inuvialut Settlement Region of the Northwest Territories. At the time of interviews, there were approximately 2500 Inuit living in five coastal communities in Nunatsiavut on the north coast of Labrador: Rigolet, Postville, Makkovik, Hopedale, and Nain, and approximately 2000 living in the Upper Lake Melville region (Government of Newfoundland and

<sup>&</sup>lt;sup>1</sup>Inuit are the Aboriginal people of Adrecic Canada, Junei, Tiky perimarity in N mayut, the Northwest Territories and northern people of Adrecic Canada, Loneit, Tiky have traditionally fived above the tree line in the area bordrered by the Mackenzie Delta in the vest, the Labrador coast in the cast, the southern point of Hudson Bay in the south, and the High Artice issuids, in the north. Inuit are not evered by the Indian Act, Housever, in 1939 the Supreme Coart interpreted the federal government's pover to make laws affecting "Indians, and Labate" servered for the Indian's a testening in Unit (MAC, 2005).

Labrador, 2002), accounting for 84% of the population in the region (Statistics Canada, 2008).

Inuit are the direct descendents of the prehistoric Thule people who hunted from Alaska across the circumpolar regions of Canada and Greenland. The Thule people are thought to have first moved to Labrador as a result of a decrease in access to European metal following the collapse of the Norse colonies in Greenland (Rankin, 2009). Although there is no agreed upon date of the Thule expansion into Labrador, two possible dates have arisen from archaeological evidence in the region. Evidence dating between AD1296-1466 suggests Thule occupation in Nunaingok, on the northern tip of Labrador (Rankin, 2009) and other archaeological evidence in Ikkusik on Rose Island in Saglek Bay dates in the probable range of AD 1475-1674 (Rankin, 2009). Thule/Inuit southern expansion in Labrador has been debated for several decades, though it is generally accepted that the Thule arrived in northern Labrador and expanded south to Hebron, and perhaps Okak or Nain prior to contact with Europeans. Occupation of more southerly areas, such as Hamilton Inlet and farther south is generally accepted as being post-European contact (Rankin, 2009). European presence in southern Labrador increased in the 16th century, which prompted further southward movement of some communities. Excavations in Red Bay in southern Labrador that uncovered Thule material, for example, indicate that Thule contact with Europeans commonly occurred in the 16th century. Evidence also suggests further southern expansion of winter settlements at Okak, Nain, Hopedale, and finally Hamilton Inlet into the 17th century (Rankin, 2009). This evidence suggests that Inuit had limited, perhaps seasonal, contact with Europeans, who settled further south where the climate was more hospitable and the landscape more

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desirable.

Since contact with Europeans, the Inuit have faced a long history of colonialism, resettlement, and dislocation from traditions (Nunatsiavut Government, 2011). In 1831, a Moravian mission was founded in Hebron, the northernmost community in Labrador that offered limited medical services. The community had a history of residential schools, religious conversion, physical, sexual, drug and alcohol abuse. The mission disbanded in 1959, ten years after confederation, when a member of the Int:rnational Grenfell Mission (British medical mission led by Sir Wilfred Grenfell in northern Newfoundland and Labrador) reported to the provincial government on the cramped living conditions in the region that led to a tuberculosis outbreak. Not long after, the government cut off services to the region and uprooted the entire community, segregating them into five communities along the North coast, now known as Nunatsiavut (Garth Taylor, 1998).

The Labrador Inuit Association was formed in 1973 to promote Inuit culture, improve health and well-being, protect constitutional and human rights and advance Inuit claims to land and to self-government (Nunatsiavut Government, 2011). The Inuit submitted its land elaim to the provincial and federal governments in 1977. It was settled in 2005 and the Nunatsiavut Government was formed, making it the first Inuit region to reclaim self-government in Atlantic Canada (Nunatsiavut Government, 2009). The Nunatsiavut Government is a regional Inuit government within the Province of Newfoundland and Labrador. Nunatsiavut, which means 'our beautiful land' in Inutitut, is the homeland of Labrador Inuit.

The Nunatsiavut Government was designed to operate at both the regional (departmental) level and the community level. The departmental level government is located in Happy Valley-Goose Bay. The community level of Nunatsiavut Government is comprised of five Inuit Community Governments representing the Inuit communities of Nain, Hopedale, Postville, Makkovik and Rigolet. Currently there are also two Inuit Community Corporations within the Nunatsiavut Government: the NunaKatiget Inuit Community Corporation serving beneficiaries residing in Happy Valley-Goose Bay and Mud Lake; and the Sivunivut Inuit Community Corporation serving beneficiaries residing in North West River and Sheshatshiu. A final constituency, the Canada constituency, enables Labrador Inuit living outside of Labrador to be represented by an elected member in the Nunatsiavut Assembly.

The Nunatsiavut Government has many of the responsibilities and rights of other governments, such as planning for sustainable economic development, protecting and preserving Labrador Inuit Culture and traditions, and implementing social programs on behalf of beneficiaries of the Labrador Inuit Land Claims Agreement. There are seven departments, each reflecting the unique principles of the Labrador Inuit Constitution. The departments are: Nunatsiavut Sceretariat; Nunatsiavut Affairs; Finance and Human Resources; Health and Social Development; Education and Economic Development; Lands and Natural Resources; and Culture, Recreation and Tourism.

Inuit-Metis<sup>8</sup>, Formerly the Labrador Metis Nation, the NunatuKavut Community Council (NCC) was formed in 1998 to represent people of European and Inuit descent not recognized by the Labrador Inuit Association. The NCC is an affiliate of the Congress of Aboriginal Peoples, the national Aboriginal representative body. Although the NCC members have asserted Aboriginal rights in Labrador, because they are not recognized

<sup>&</sup>lt;sup>8</sup> The NunatuKavut Community Council (NCC) refer to its members as Southern Inuit. However, at the time of this research the NCC referred to its membership as Inuit-Metis, and therefore, this term is used through out this thesis.

under the Indian Act, the NCC members are not cligible for certain programs related to health care services such as the Non-Insured Health Benefits Program (NIHB) (INAC, 2010). In 2010, the NCC formally submitted new documentation in support of its land claim to the federal and provincial governments in a report entitled "Unveiling NunatuKavut". The NCC represents approximately 6,000 members. At the time of this research, resident membership was primarily concentrated in Upper Lake Melville and the southeast coast of Labrador (Government of Newfoundlard and Labrador, 2002; NunatuKavut Community Council, 2012). Because Inuit-Metis people in Labrador are not recognized under the Indian Act, they do not receive federal health and social services coverage available to both the Nunatsiavut Inuit and the Sheshatshiu and Mushuau Innu. The challenges this creates for the Inuit-Metis in Labrador accessing health care will be outlined in later sections that discuss jurisdictional differences in Labrador.

Non-Aboriginal. The remainder of the population of Labrador is non-Aboriginal, living in diverse communities dispersed over the large geographic expanse. Europeans began settling Labrador in the 16<sup>th</sup> century to engage in the transatlantic cod fishery and whaling. Jurisdiction over the area was passed between France and Britain (British colony of Newfoundland) for the following three centuries. As a result, most inhabitants in Labrador have English, French, or Irish ancestry. Christian missionaries and commercial trading companies interacted with Aboriginal groups in Labrador after the mid 1700s in a mainly hostile and politically and economically oppressive manner. The commercial fur trading company, Hudson Bay Company was established in 1831 and interacted mainly with the Innu in central Labrador (Higgins, 2008b). Moravian, and later Roman Catholic, mission stations were established throughout Labrador in the 18<sup>th</sup> and 19<sup>th</sup> centuries. These institutions promoted Christian ideals that undermined Innu and Inuit beliefs.

During the early days of settlement, communities in Newfoundland and Labrador were established based on proximity to resources: shelter, fresh water, access to the fishery, or access to fur trading sites in Labrador (Butt, 1998). Communities in the Straits and on the south coast were settled in the 17<sup>th</sup> and 18<sup>th</sup> centuries. A military base was created in Happy Valley-Goose Bay in Central Labrador in the early 1940s and mining towns centered around emerging mining activity in Labrador City and Wabush in the 1960s. These events increased the number of non-Aboriginal people living throughout all regions in Labrador. Today, multi-cultural, non-Aboriginal populations are the majority population in the mining communities in Labrador City, Wabush and Churchill Falls and Happy Valley-Goose Bay.

## Labrador's Health Context

The Labrador-Grenfell Health Region comprises the area north of Bartlett's Harbour on the northern peninsula of New foundland and all of Labrador, and mirrors the national pattern of inequity on a smaller scale (Statistics Canada, 2012b). In Labrador, for example, 71% of people reported having contact with a medical doctor in the last 12 months versus 81% in the entire province, and only 55% of Labradorians reported having a regular family doctor compared to 88% in the entire province (Statistics Canada, 2012b).

Labrador has higher rates of daily smoking and alcohol consumption than the provincial average, and lower fruit and vegetable consumption (Statistics Canada, 2012b). In Labrador, the long-term unemployment rate is 16% compared to an 11% provincial average (Statistics Canada, 2012b). According to Statistics Canada (2012b), 79% of Labradorians surveyed between 25 to 29 years graduated high school, compared to 86% in the province as a whole. Labrador has double the number of injuries causing hospitalization per 100,000 people compared to provincial numbers, higher suicide rates, at 28 per 100,000 people in Labrador, compared to 8 per 100,000 people in the entire province (Statistics Canada, 2012b). Infant mortality is higher and life expectancy is lower by 2 years. Percentage of deaths due to circulatory dise as and cancer are higher in Labrador than the province. Mental illness hospitalization rates in Labrador are 821 per 100,000 people, compared to 391 per 100,000 people in the entire province (Statistics Canada, 2012b). Due to the health profile of the region, access to appropriate and relevant health care services in Labrador should remain a priority of the provincial government and health care authorities in the region.

#### Jurisdictional Differences in Health Care Coverage

Political divisions arising between different cultural groups in Labrador has resulted in jurisdictional differences in health care coverage for residents of Labrador. In addition, historical legislation resulted in Aboriginal health care in Canada a responsibility of the Canadian government while non-Aboriginal health care remained under jurisdiction of provincial governments. The differences in health care coverage between different cultural communities in Labrador will be outlined in this section.

There are four political organizations representing Labradorians that add complexity to accessing health care services in Labrador; the Government of Newfoundland and Labrador representing all people in Labrador, and the three 75

Aboriginal political organizations: Nunatsiavut Government representing the Inuit, Innu Nation representing the Innu, and the NunatuKavut Community Council representing the Inuit-Metis. Aboriginal cultural and political populations cross geographical boundaries in Labrador so individuals identify with their larger cultural community as well as their geographical community. Some Aboriginal groups in Labrador are fighting for land claim rights (Innu Nation and NunatuKavut), while others (Nunatsiavut) have established selfgovernment. Each organization vies for access to federal programs and financial resources and often boundaries and hostilities are created between different cultural groups sharing the land. This shapes the political and social context and structure of health care services available in individual communities.

Jurisdictional differences between the Labrador Innu, self-governing Inuit and Inuit-Metis populations create three different health coverage agreements for the Aboriginal population in Labrador. Services (health and other housing and recreation programs) for the Innu and Inuit are the responsibility of the First Nations and Inuit Health Branch through the Non-Insured Health Benefits Program (NIHB) (Health Canada, 2003).

The NIHB provides coverage for specified health services and equipment if they are not insured through provincial, territorial, or private insurance coverage. In order to be eligible to receive NIHB services, one must be a registered Indian according to the Indian Act, an Innu member of one of the two Innu communities in Labrador, an Inuk recognized by one of the Inuit Land Claim organizations or an infant under the age of one whose parent is an eligible recipient (Health Canada, 2003). The Labrador Innu have a direct relationship with this federal program. The self-governing Labrador Inuit receive health services and programs through provincial Medical Care Program (MCP) and Nunatsiavut government, who allocate funding from the NIHB. This has resulted in the development of Inuit community-based health promotion, public health, addictions prevention, healing and home care for Inuit populations (Nunatsiavut Government, 2009). Metis communities are not recognized under the federal or provincial government, so are entitled to the same services as any non-Aboriginal resident of the province. Provincially funded services through Human Resources Labour and Employment are available to those residents on income supplement in Labrador. Residents who are working, non-Aboriginal, and do not have access to private insurance, are restricted to the provincial MCP. Each group has the entitlement to private health insurance – personal or work coverage.

However, covered services are not consistent between these jurisdictions. First Nations and Inuit Health Branch and Nunatsiavut cover travel, accommodation, and food costs for their beneficiary<sup>9</sup> residents, Innu and Inuit respectively. Innu, Inuit, and income support residents requiring assistance with daily living tasks when outside of Labrador are also eligible for financial support to be accompanied by an escort.

In Labrador, residents restricted to MCP accessed the Medical Transportation Assistance Program (MTAP) of the provincial government to help cover a portion of the costs of travel to access medically necessary, physician related services outside of the region. The MTAP is a provincial government program that provides financial assistance to residents who avail of MCP and incur substantial out-of-pocket travel costs to reach

<sup>&</sup>lt;sup>9</sup> For the purposes of this thesis, a beneficiary is a person who receives financial support for costs associated with accessing health care services through a particular government department. Innu and Inuit are beneficiaries of the First Nations and Inuit Health Branch. Numatisant Government redistributes funding from FNIIB for Labrador Inuit. In this thesis, any Inuit receiving Iunding for health care is a Numatisant beneficiary.

medically necessary insured health care services (Government of Newfoundland and Labrador, 2011b). It is available to all residents of the province who are referred out of their community by a physician and meet the criteria for distance traveled. MTAP applies specific criteria to Labradorians due to distance and methods of travel between the region and referral centers in larger cities, most notably St. John's or Halifax, Nova Scotia. At the time of interviews, MTAP provided Labradorians with \$1000 for their first return flight in a 12-month period and cost shared the balance of remaining air travel expenditures at 50% (Government of Newfoundland and Labrador, 2011b). If residents drove to services, they were reimbursed \$0.16/km if they traveled in excess of 2500 km in a 12-month period. If a resident was receiving private insurance benefits, the insurance provider assessed MTAP claims and eligible expenses were reduced by the amount paid by private insurance. This balance was assessed based on the guidelines of MTAP (Government of Newfoundland and Labrador, 2011b). There is no provision for the related costs for patients with extraordinary hardships, such as diseases requiring considerable travel.

A maximum of \$125 is provided for utilizing registered accommodations providers and these patients can claim up to \$29/day in province and \$43 out of province for food. Patients medically required to remain in the referral region while receiving treatment or awaiting transplant, can claim up to a maximum of \$1500 for accommodation and a maximum of \$700 for food per month. If a resident requires an escort while temporarily residing in another region, the escort is expected to pay his or her own travel costs, share accommodation and is provided a maximum meal allowance of up to \$700/month. Costs for escort travel/accommodation/food costs for shorter trips are not covered by MTAP (Government of Newfoundland and Labrador, 2011b). The Newfoundland and Labrador provincial government's MTAP subsidizes a portion of travel costs for those living in rural areas who do not receive coverage through the First Nations and Inuit Health Branch (Innu people in Sheshatshiu and Natuashish) or Nunatsiavut Government (Inuit). The MTAP was implemented in 1998 to assist Newfoundlander and Labradorians who incur significant travel costs accessing insured health services not available in their region. However, MTAP only covers "medically necessary" health services, or those outlined under MCP. This has been confusing for some residents of Labrador as travel for dental, eye care, and para-services such as physiotherapy, speech language pathology, and allergy tests, are not services covered under the program. In addition, MTAP does not offset the costs for escorts to travel with patients or for procurement of medical equipment once back in their communities.

Significant changes were made to the MTAP in the 2011 provincial budget. Prior to these changes, the MTAP funded the first \$1000 of expenses in any 12-month period from the date of initial travel with remaining claimable expenses cost-shared at 50%. Claimable expenses in excess of \$5000 during a 12-month period were cost shared at 65% (Government of Newfoundland and Labrador, 2007). Residents were required to pay up front costs and apply for reimbursement of expenses. This was a concern of Labradorians people who could not afford costs associated with travel. In addition, Labradorians were not covered for fuel costs unless they drove at least 5000 kilometers in a year. This meant residents who did not have air travel as an option, were left paying significant out-of-pocket fuel costs (Canadian Broadcasting Corporation [CBC], 2010). In the 2011 provincial budget, the Province amounced it was enhancing the MTAP by changing reimbursement of 50% to the prepayment of 50% of the cost of airfare for residents. In addition, allocation of \$700,000 to the MTAP in the 2011 budget reduces the private vehicle expense threshold from 5000 to 2500 km for those traveling to access insured medical services. This change was retroactive to October 1, 2010 (Labrador-Grenfell Regional Health Authority [LGRHA], 2011). At the time of interviews, this policy was yet to be implemented.

## Modes of Travel in Labrador

Labrador has the highest percentage of people seeking medical care outside of their regional area in the province of Newfoundland and Labrador (Newfoundland and Labrador Centre for Health Information [NLCHI], 2007). A brief discussion on travel in Labrador is necessary as one of the ways this research explored access to health care in Labrador was by examining factors related to the physical environment.

At the time of this research, residents relied heavily on air travel, so access to timely health care is subject to the natural elements: geography, daylight hours and weather. There are three domestic airports located at Happy Valley-Goose Bay, Churchill Falls and Wabush in Western Labrador. Small Twin Otter planes service coastal, remote, and isolated communities on the north and south coasts of Labrador, as larger planes are unable to land on the small gravel runways. Travel from northern, isolated coastal communities is contingent on: access to flights, weather conditions, financial costs, familial responsibility, emotional factors, and gender issues. It is difficult to impossible to travel out of north coast communities when there are high winds, fog and winter storms. In addition, planes do not visit isolated communities after dark as there are no lights on the gravel runways, there are mountainous regions surrounding northerm communities. especially Nain, and the planes are not equipped with GPS or radar.

Patients who required immediate attention of an emergency physician or equipment unavailable at the local clinic, such as surgery, maternal and specialist care, were required to travel out of their community to access care. Since all necessary health services were not available at the Labrador Health Center in Happy Valley-Goose Bay. Labradorians who needed services beyond what was locally available were referred outside of the Labrador region to the nearest suitable facility. If weather conditions, daylight hours, and/or the location and status of the Medevac plane restrict emergency medical evacuation, this situation increases physical and mental risk to the patient.

The Labrador Grenfell Regional Health Authority runs a scheduled evacuation plane (Schedevac) that services the six northern communities twice a day, three times a week (Monday, Wednesday, and Friday) to transport residents who have been referred by the nurse in their community clinic to the hospital in Happy Valley-Goose Bay. The Labrador Grenfell medical evacuation plane (Medevac) serviced emergency situations in Labrador that required patients to be transferred to hospital services in Happy Valley-Goose Bay or beyond. The Medevac plane embarked with nurses and/or a physician depending on severity of the emergency, and equipment to provide on the spot care and monitoring while in transit to a suitable health care facility.

The Provincial Air Ambulance Service was moved to Happy Valley-Goose Bay from St. Anthony, on the Northern Peninsula of the island in 2010 to improve access to emergency services from the hospital in Labrador West and in Happy Valley-Goose Bay to the island or onward depending on the nearest suitable health care facility (Dodge, 2010). Because the Air Ambulance is a large aircraft (King Air), it is limited in terms of where it can land. The Twin Otter Medevac must shuttle patients from north and south coast communities to Happy Valley-Goose Bay before they can board the provincial Air Ambulance (Dodge, 2010).

Residents of Labrador who lived on the Trans-Labrador Highway were able to drive to access non-emergent health care services in Happy Valley-Goose Bay or in Newfoundland, The Trans-Labrador Highway connects the west, central, south-east, and southern points in Labrador, including Labrador City/Wabush, Churchill Falls, the Upper Lake Melville Region, and communities on the south coast of Labrador connected to the highway by road. The Trans-Labrador highway connects with Fermont, Quebec west of Labrador City and the Lower North Shore of Ouebec south of the Labrador Straits. The highway is a seasonal gravel road, and is, at times, impassable during the winter months. Although it has improved access to Happy Valley-Goose Bay for individuals on the south coast, the road conditions are often poor, there are no service stops or cell phone reception, weather conditions are inconsistent and there is little traffic (aside from large transport trucks) on the 488 km of dirt road between Happy Valley-Goose Bay and Port Hope Simpson. The Blanc Sablon Ferry to Newfoundland is 137 km past Port Hope Simpson (Department of Transportation and Works, 2012). Please see Appendix A for a map of Labrador.

Residents can also travel via boat from coastal communities and onward to Newfoundland. A daily ferry service runs throughout the spring/summer/fall months between Blane Sablon on the Quebec-Labrador border and St. Barbe on the Northern Peninsula of Newfoundland. This section of the Strait of Belle Isle is generally impassable during winter and some spring months due to the break up of ice that can block the Strait. The ferry that ran year round between Happy Valley-Goose Bay and Lewisporte on the north coast of Newfoundland was cancelled when the south coast road opened in 2010. Therefore, it is no longer possible to travel diractly from Happy Valley-Goose Bay to the island by ferry (Government of Newfoundlard and Labrador, 2010). There are three Labrador ferry services that run from June to November along the east coast of Labrador. The northbound ferry services ports in Rigolet, Makkovik, Postville, Hopedale, Natuashish, and Nain from Happy Valley-Goose Bay. The southbound ferry services ports in Rigolet, Cartwright and Black. Tickle ports from Happy Valley-Goose Bay, Lastly, a ferry connects the communities of Charlottetown, Norman Bay, Pinsent's Arm, Williams Harbour and Port Hope Simpson on the south-east coast of Labrador (Government of Newfoundland and Labrador, 2010).

Labradorians were not receiving equivalent financial support for travel, accommodations, food or per diems when they were referred cutside of their home community or the Labrador region to seek health care at the time of interviews. This study investigated how residents of Labrador coped with travel limitations when accessing health care in and outside of Labrador.

## Health Care Organizations and Facilities

Many organizations are directly or indirectly involved in the study of health and health service delivery in Labrador, including the Labrador Aboriginal Health Research Committee, the Labrador Institute and the Division of Community Health and Humanities of Memorial University, Dalhousic University, Labrador-Grenfell Regional Health Authority, the Nunatsiavut Government, the Mushuau and Sheshatshiu Innu Nation, the NunatuKavut Community Council and other Labrador non-governmental organizations.

The Labrador-Grenfell Regional Health Authority provides the majority of health services in Labrador. They are responsible for a population of just less than 37,000 in 81 communities in the area north of Bartlett's Harbour on the Northern Peninsula and all of Labrador (LGRHA, 2007). The services are delivered through 22 facilities, including 3 hospitals, 3 community health centers, 14 community clinics/nursing stations, and 3 longterm care facilities (LGRHA, 2007). The corporate headquarters for Labrador-Grenfell Regional Health Authority are in Happy Valley-Goose Bay.

Hospitals servicing Labrador are the Labrador Health Center in Happy Valley-Goose Bay, the Captain William Jackman Memorial Hospital in Labrador West, and the Charles S. Curtis Hospital in St. Anthony on the Northern Peninsula.

The Labrador Health Center in Happy Valley-Goose Bay is a 25-bed facility with a 24-hour emergency department and outpatient clinics staffed by family physicians. Each physician is responsible for the medical care of a coastal community. General practitioners trained in specialist areas deliver specialty care and visiting specialists provide services at the center on a regular basis every one to three months or once a year (LGRHA, 2007). Specialist area includes general surgery, an anesthetics and an obstetrics/gynecology. The hospital offers full diagnostic (CT scans, radiology, mammography and laboratory) and rehabilitation (physiotherapy, occupational therapy, and speech-language pathology) services. Interpretation services are available in Inuktitut from 8am-8pm and Innu Emun from 9am-5pm (LGRHA, 2007).

The Captain William Jackman Memorial Hospital in Labrador City has 20 beds, of which six are designated for long-term care. Inpatient units provide medical, major and minor surgery, obstetrics, pediatrics, respite, palliative and intensive care. The hospital employs six family physicians, a general surgeon, an anesthesiologist, and three dentists.

The Charles S. Curtis Memorial Hospital is located in St. Anthony and is a 50-bed facility. It services the people of the Northern Peninsula, the southern coast of Labrador and a large number of residents of the Quebec Lower North Shore, most likely due to the ferry route that travels from Blanc Sablon to St. Barbe. The hospital offers specialty services including anaesthesia, dentistry, family practice, general surgery, internal medicine, obstetrics/gynecology, ophthalmology, orthopedies, pathology, pediatrics, radiology, urology, and psychiatry.

In addition to the hospitals, there are 14 community clinics with primary care and 24-hour observation capabilities in Labrador. Specifically, there are six located in the six northern coastal communities, Nain, Natuashish, Postville, Hopedale Makkovik and Rigolet, six on the south coast in Cartwright, Black Tickle, Charlottetown, Port Hope Simpson, St. Lewis and Mary's Harbour, one servicing North West River and Sheshashiu 35km outside of Happy Valley-Goose Bay, and one servicing Churchill Falls in central Labrador (Government of Newfoundland and Labrador, 2002). These community clinics are staffed with nurse practitioners. Physicians visit once a month for regularly scheduled visits.

## Facilitators of Access to Health Care Services in Labrador

Two historically important strategies for improving access to health care services in Labrador were recruitment and retention strategies and Tele-health.

Recruitment and Retention. One of the first efforts to recruit physicians and nurses in the province of Newfoundland and Labrador began in nursing stations in

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Labrador in 1892 and was led by Sir Wilfred Grenfell, a British Medical Missionary, who took it upon himself to raise money to establish regular health care services in Labrador after traveling there to investigate living conditions among local fishermen. He established the Grenfell Mission, which later became the International Grenfell Association. In 1981, the International Grenfell Association sold their medical services to the provincial government for \$1 (Higgins, 2008b).

Physicians at the Labrador Health Centre in Happy Valley-Goose Bay were trained in general specialist services such as internal medicine, obstetrics, gynecology, psychiatry, and surgical care, but specialists were historically not present. The Government of Newfoundland and Labrador has several incentives in place to encourage health care professionals to work in rural regions of the province, including a resident and medical student practice initiative that provides financial support to students and residents who commit to practicing in areas of need in the province, a rural bursary for nursing students to complete a rural practicum, and a dentistry bursary program which requires recipients to fulfill a practice commitment in a rural area determined by the province (Government of Newfoundland and Labrador, 2012).

Several other initiatives in Labrador have been implemented to improve recruitment and retention for nurses and physicians. The first is the Northern Family Medicine Program (NorFam) program, offered through Memorial University's Faculty of Medicine Family Medicine program developed to train physicians in rural practice. NorFam's 16-week rural family medicine rotation gives physicians valuable experience in rural practice settings. This program is intended to introduce students to northern lifestyle and medical practice and to increase physician recruitment and retention to the Labrador region (Memorial University, 2008).

In Happy Valley-Goose Bay, finding appropriate and adequate housing has been a challenge for many health care professionals, as well as other community members. Labrador Grenfell Health sought to remedy this situation by offering new working professionals housing units or at least three months to find a divelling. However, many people have been forced to leave the community due to the high demand and limited availability of housing. In 2011, the provincial government announced it would allocate \$650,000 for repairs and renovations to housing units used by visiting health care professionals (Government of Newfoundland and Labrador, 2011a).

Tele-Health. Tele-health is a video-conferencing system that uses information and communication technology to improve access to health services. Health Canada views Tele-health as the bridge to accessing health care across this geographical gap, as it allows patients and providers to talk as if they were sitting across from one another (Health Canada, 2011). Jong (2004) found Tele-health use in Labrador saved residents and physicians time and money associated with travel and allowed people to stay in their community to access care. Tele-health initiatives in Labrador have helped residents without access to primary care physicians or specialists to consult with physicians outside of their region.

The Labrador region was linked with the Smart Community project, a federal project to increase technological capacity in rural areas in the late 1990s (Peddle, 2007). SmartLabrador began as the Smart Communities Demonstration Project for Newfoundland and Labrador in 1997 to help ensure that information technologies were being used effectively for business, human resources and economic development in Labrador (SmartLabrador, 2007). SmartLabrador installed Tele-health sites throughout all regions of Labrador including three communities in the central region, six on the north coast, seven on the south coast, four in the Labrador Straits and three in the western region. This initiative made Labrador one of the most connected areas in the country (SmartLabrador, 2007).

In 2005, a pan-provincial Tele-health project was initiated between the Government of Newfoundland and Labrador, Canada Health Infoway (funded by the federal government), the Newfoundland and Labrador Centre for Health Information, and the Regional Health Authorities in the province. Since its inception, the Newfoundland and Labrador government and Canada Health Infoway have invested approximately \$6 million into infrastructure, equipment and project support throughout the province and patient consultations have increased provincially from 66 per month in 2005 to 482 per month in 2010. There were more than 50 functional Tele-health locations throughout the province, 19 of them located in Labrador (Canada Health Infoway, 2010). Tele-health has been improving in recent years with the addition of new applications for use in rural communities. With the addition of new applications comes access to specialists that community members would otherwise have to travel long distances to access.

## Summary

My experiences living in Labrador for two years gave me first-hand experience with the factors that influence access to health care services in Labrador. My in-depth research examining local organizations, provincial and federal policies, and the physical, social and cultural context of Labrador helped me to situate my research within the context of historical and contemporary information. This chapter helps frame the

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following data analysis chapters by demonstrating how the cultural and geographic diversity of Labrador, coupled with the small and dispersed population over a large landmass, creates a complexity of factors influencing access to health care services for Labradorians. The following chapter outlines the interview findings highlighting the major challenges accessing health care services in Labrador from the perspective of respondents.

## Chapter 5: Data Analysis - Major Challenges Accessing Health Care in Labrador

This chapter presents findings related to challenges accessing health care services in Labrador from the data analysis of nine one-to-one interviews and two focus groups with health care providers, administrators, and community members of Happy Valley-Goose Bay and Nunatsiavut communities. From the 11 transcripts, I identified the main themes and associated factors creating challenges and strategies to overcome them in Labrador. Specifically, 13 factors were categorized into four overarching themes that created challenges accessing health care services in Labrador. This chapter also offers a discussion on each factor by linking the findings to available literature. The four themes and associated factors that influence access to health care services in Labrador, mapped in Table 2 are physical environment (distance to service, weather, geographical landscape), political and socio-cultural environment (cultural landscape, jurisdictional coverage, historical/social context, cultural safety), gender (maternal care, differential service usage, seasonal work, family needs), and continuity and comprehensiveness of care (provider shortages, fit between community needs and services).

The data analysis focused on the transcripts of the respondents involved in this research, representing a small sample of Labradorians. Note that the transcripts are individual perspectives, and do not represent the perspective of all health care administrators, providers, or residents of Happy Valley-Goose Bay and Nunatsiavut, or reflect the sentiment of all Labradorians. These findings are meant to highlight diverse perspectives to illustrate the complexities surrounding access to health care services in Labrador, but cannot be generalized to all Labradorians' experiences accessing health care.

Broad Themes	Associated Factors
I. Physical environment	Distance to service Weather Geographic landscape
II. Socio-cultural and political environment	Cultural landscape Jurisdictional coverage Historical/social context Cultural safety
II. Gender	Maternal care Differential service usage Seasonal work Family needs
IV. Continuity and Comprehensiveness of Care	Health care provider shortage Fit between community and service

Table 2: Identified themes and associated factors influencing access to health care services in Labrador

## Physical Environment

Where we are born, where we live, and where we work directly influence our physical and mental health. The ways health is affected by physical environment are directly relevant to health policy (Dummer, 2008). The identified factors associated with physical environment significantly influence access to health care services in Labrador, mirroring a national pattern of barriers to accessing health care created by the physical environment in other rural and northern areas of Canada (Browne, 2009). A common theme that arose from the interviews was the precarious nature of living in isolated Labrador communities:

In Labrador, you are physically isolated from service by geography. So you have geography, you can't change that. You have fly-in communities. You have no road access. You have weather. And weather is a constant factor. Today the weather's good, the planes are flying. Friday the weather was bad, the planes didn't fly. Since Labradorians rely mainly on air transportation to access specialist, emergency, secondary or tertiary care in Happy Valley-Goose Bay and larger centers outside the region, factor such as weather, geography, and distance to services were addressed in most interviews.

Weather. A health care provider practicing in the region for over 30 years described how weather and seasons affect the ability of Nain (and other Nunatsiavut) residents to travel outside of their community.

Because of its location, Nain is very weather dependent.... For emergency care, the plane can usually only get in on daylight hours.... So it could be only a window of maximum six hours during the winter months, which means the other 18 hours, there is no way in or out ... In terms of access to care, it's much more challenging in the north... the more remote a person is, the harder it is to access health care.

In Labrador, weather usually creates the most challenges for air travel twice a year, during "freeze up" in December/January, and "break up", March/April, when ice starts to break up and move through the Labrador Strait and winter storms, high winds, and fog are common.

Usually at the change [beginning and end] of the [winter] season... there's a couple weeks where you cannot get a plane into these communities. It's the freezing rain and the fog and just the winter storm that comes in.

Tarlier, Browne, and Johnson (2007) found a similar pattern in northern British Columbia, where residents faced challenges accessing health care during freeze-up and break-up seasons in the fall and spring, when storms and fog prevent flights from landing and taking off, and ice is too thick to allow boat traffic.

Participants made it clear that weather not only posed a threat to accessing emergency medical attention, but to specialist services in Happy Valley-Goose Bay or outside the region. One participant discussed how missing a specialist appointment affected the well-being of Labradorians.

You're already booked off from your place of employment, have someone lined up to look after your kids... and then the weather's down, you have to cancel all of that. Hopefully you'll have it rescheduled, and you don't know how long that will take... the specialist may not come back until next year... You're not getting that diagnosis... and who knows what the problem is, maybe something that needs to be treated urgently.

Geography. The geographic location of communities in Labrador affects how residents access health care services. Because many communities in Labrador are isolated and fly-in only, geography may create challenges accessing health care when weather makes air travel impossible. In Nain, mountainous regions around the community create difficulty taking off and landing, especially during high winds and low visibility. Residents faced additional challenges accessing health care because Nain is the northermmost and farthest community from Happy Valley-Goose Bay and has the shortest daylight hours in Labrador. One participant described several other factors that create difficulty for air travel:

It's the only community on the coast that doesn't have the airstrip lights... because of the large hills that surround the community of Nain, they can only fly when there's day light. Because we don't have air traffic control on the coast of Labrador, the pilots on the planes, they talk to each other, when they are approaching, landing, or departing... And it's all gravel dirt runways as well.

Distance to Services. Residents of Labrador must travel long distances to access health care within and outside of the region. "If a patient in Nain has to seek a service that cannot be provided locally, it's a long way to travel for them... Access to care outside Nain is time consuming and costly."

Great hardships resulted for families left behind and for patients who were isolated from their communities while away.

[A] challenge would be the *time* away. The other is being away in a strange environment, where things are very different. For someone who had never been to Goose Bay, to go from Nain to St. John's is quite scary.

A pregnant Inuit woman from Nain who traveled alone to Happy Valley-Goose Bay four weeks before she gave birth acknowledged her feelings of isolation. "It is a long time to be away, for a month. I can't wait to go back... I just miss being home."

An Inuit community member of Happy Valley-Goose Bay anticipated stress associated with traveling long distances while in recovery: "Having to get on the plane not feeling well and get home – that's stressful. And not knowing what the future's going to bring. I can only imagine if I lived on the coast." Some Labradorians made decisions between treating life-threatening illnesses away from home and spending remaining days in their home communities with family.

I'm going to live for a year if I take the treatment, but I'm from Nain. I want to stay home now with my family instead of doing six trips to St. John's. You understand what I'm saying? A conscious decision on what priorities are.

## Socio-Cultural and Political Environment

Although Labrador has always been a culturally diverse place, feelings of segregation in cultural heritage have arisen in the last several decades due to political divisions.

When I grew up in Labrador, there was very little access to anything. There was one doctor in Northwest River, one hospital. We went to the nursing clinic here in Happy Valley if we got sick... there's obviously been a great expansion of service, but the other thing that changed since I was a child is that we were just all from Labrador and now we are specific ethnic groups with our own health management... Politically, we have a bit of a blend, and what that does is it influences the access of anybody who physically lives in Labrador.

Factors of the socio-political and cultural environment identified in interviews were: cultural landscape, jurisdictional differences, historical/social context, cultural safety, and institutional racism.

Cultural landscape. Communities are not only culturally, but geographically distinct and factors influence access to health care services in different ways depending on the specific location of communities. There are distinct differences present between and among the five Inuit communities, two Innu communities, each of the Inuit-Metis communities, and the multi-cultural communities of Labrador.

According to participants, some policies work on a region-wide scale or in communities of the same culture, but most health policies need to be adapted to the distinct health needs and unique characteristics of specific communities. Despite significant differences in cultural practices, histories, lifestyles and social contexts of Nunatsiavut Inuit and Labrador Innu, some Nunatsiavut administrators reported that policies handed down from the federal government often lump together these two culturally distinct groups. "We struggle with a lot of what Health Canada produces, they think in our best interest, but it's all First Nation.... I will go to my grave telling Health Canada, "We're not First Nations!" So, it's at every level."

Participants reported great differences among each of the five Nunatsiavut communities and discussed the importance of adapting policies and programs to each community depending on its needs.

You can't compare any of our communities... I think that probably Nunatsiavut Government and us in Health and Social Development are much more conscious of the need to not try and have one size fits all, cause it doesn't work... We do try very hard through our regional health plan and our community health plans to tailor what we're doing in our communities specifically.

Jurisdictional differences. Political divisions mean different cultural communities in Labrador have different sources of funding for social services. Although all Labradorians access the same health care system, the ways in which they do so is influenced significantly by their cultural heritage. In interviews, jurisdictional differences in health care coverage were identified as the most significant factor creating inequity in access to health care coverage in Labrador. It was reported that external health benefits, available to some communities and not available to others, further segregate the different Aboriginal communities and non-Aboriginal communities in the Labrador health care system.

Politically, what you have is services that are funded by the federal government,

that are available to First Nations and Inuit, but not available to the NunatuKavut. So in fact, what you have is a 'have' and 'have-not' within a 'have-not' situation. It makes it very difficult for health care providers to make decisions around care.

Nunatsiavut Government covers travel to MCP insured services and uninsured services such as dental, optometry, audiology, and rehabilitation for their beneficiaries. Participants identified individuals who slip through the cracks of the bureaucracy in the provisional coverage of health care services.

For the First Nations and the Inuit, we have the Non-Insured Health Benefits system, and with that system, your medications are paid for, your glasses are paid for, your dental is paid for up to a point. Your medical transportation... your accommodation... your meals... If you need a walker, you have a walker.... For the non-Inuit and non-Innu people living in Labrador in these communities, they don't have the same coverage, unless they're income supplement... HRLE [Human Resources Labour and Employment<sup>10</sup>]. But if you're Joe Blow and you're working and you're white and you're living in these communities and you may or may not be on good income, *then* there's the struggle.

Due to different jurisdictional coverage of health care services, some rural Canadians face greater out-of-pocket costs of travel to health care services than others. In Labrador, low-income residents who depended solely on the provincial MCP were limited in terms of services they could access without incurring out-of-pocket costs.

MCP doesn't cover optometry, because that's not a physician provided service. It doesn't cover dental. If you have to go to St. John's for an abortion, that's not an

<sup>&</sup>lt;sup>10</sup> Human Resources Labour and Employment (HRLE) – now the Department of Advanced Education and Skills, is the NL provincial government department responsible for delivering income support payments.

MCP covered service. So, all of these things... doesn't cover physiotherapy, or any of these other modalities... It only covers physician service.

Rural residents who do not receive adequate travel funding have been found to have low utilization rates of provincially covered health care services (Pong, 2007). Rural residents show even lower utilization of services not covered under provincial jurisdictions, such as dentistry, optometry, and rehabilitation services, as provincial programs are unlikely to cover travel costs to access uninsured services (Pong, 2007). Residents limited to MCP accessed financial support to travel long distances through the MTAP. Participants said that MTAP financial support was insufficient and therefore residents limited to MCP faced greater financial challenges traveling long distances than Labradorians who received full travel coverage. Travel out of Labrador, accommodation, food and other incidental health-related costs can be very expensive... 'If you don't have non-insured health benefits or another type of insurance it's very expensive.... Cost is enormous and a lot of people here, because of the economy, they don't have a lot of money.'' Another participant echoed this sentiment:

We forget that some people... don't have the ability to just slap the Visa on the counter and get your flight... a trip to St. John's for some people can be thousands, particularly if you're Mede-vaced... you're paying for the ambulances, you're paying for the nurse escort, you have to pay your accommodation in St. John's. If you're the person going with the person who's admitted, you gotta bring yourselves back.

Some community members sold personal assets to pay for their health care.

I decided to sell my home - I've been a home owner for 20 years... You're

talking \$1600 for two tickets... and ten days staying in a hotel – all at our own cost... But, I'm not waiting, cause I'll lose my appointment. So, what if some people don't have the [financial] ability? I made a conscious decision. I can't wait, I'm selling my house... and we'll use it to fix my health.

As discussed in the environmental scan, Innu, Inuit, or income support residents requiring assistance with daily living tasks when outside of Labrador, were able to bring an escort (family member or friend), but residents restricted to MCP were not. "The least thing that you should be worrying about at that time is how the hell you are going to get home... the government should allow you to have your main focus on your family member."

There was a common sentiment among community merabers that financial inequities in access to health care existed between different cultural communities of Labrador that left many people financially drained, mentally stressed, and in some cases, led them to disregard their health because it was too expensive to leave the region to gain access to required services. There was common hesitancy to speak out about discrepancies in jurisdictional differences. One participant offered her perspective on the NIHB, which is available to Innu and Inuit in Labrador.

It's so hard to talk about this because you just sound like a racist, but that's not true. Inuit and Innu are covered for astronomically large amounts of stuff, and when you talk to people that are 'the others', who would be settlers, Métis, and people who are just here and not too wealthy, it's a different story. There's an appearance of 'Oh that crowd in Labrador, they get all that Aboriginal money.' But for those people I mentioned, it's not a level playing field. They're below the level of support. So the rising tide does not rise all ships. There are people who sink, and it's *really* unfair.

Jurisdictional differences in health care coverage mean that certain cultures in Labrador suffer greater vulnerability to financial barriers to health care services than do others. According to participants, Labradorians limited to MCP coverage faced the most significant financial barriers to accessing provincially insured and uninsured health care services created by jurisdictional differences.

Historical/social context. Health is influenced by the social and historical realities facing Labrador Inuit communities. The following is a passage from an interview with an Inuit community member recollecting the relocation of Inuit from Hebron highlights the historical effects of colonization on the traditional way of life and wellbeing of Labrador Inuit culture.

When they moved us out of Hebron, they segregated us in all the communities along the coast, so there would be one end of town- the Hebron side. When they took us from there, separated us, well that's when it all started to happen ch. That's when the lnuit lost their spirit. Yeah, spirit I guess you call it ch. And unhealthy behaviors started after that, from being helpless, you know? People drank to escape the reality of what was happening to them and they started eating food out of the stores right? Cause they weren't going out on the land. And we weren't used to that food ch. We had no control anymore. Our culture was dying. Anyway, that's when it happened. That's when we lost it. There was no color any more.

Participants noted that historical effects of colonization are proliferated by other

social realities including the effects of climate change on traditional ways of life, incoming mining and mineral exploration companies in the Nunatsiavut land claim area, food insecurity, and housing instability.

In addition to everything that's normally going on in Nunatsiavut, you've got elimate change that's really impacting on everything. It's impacting on food security. It's impacting on mental wellness. It's impacting on medical transportation. And everyone wants to consult, because you're told that's what you must do and people are consulted to death. And it's right that there should be input, but *boy*. Right now, it's a bit of overkill. You've got uranium people coming in and telling you it'll be okay to mine uranium in Postville. Then you've got the gas and oil people coming in and they want to talk about some of the implications of that in Nain.

The social determinants of health need to be addressed in Labrador communities due to its lower health status when compared to the remainder of the province (Statistics Canada, 2012b). Addressing the root causes of lower heath status, however, is a longterm process. In the meantime, it is equally important to ensure equitable access to needed health care services so that the most vulnerable rural residents receive the interventions they need to access health care (Pong, 2007).

Cultural safety. Cultural safety is an important aspect of health care delivery, research, and policy development across diverse populations and is particularly applicable in areas of Aboriginal health because of the historical, social, and political contexts that impact on how individuals access health care (Strye, Josewski, and Kendall, 2009).

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Participants addressed cultural challenges with health policies, programs, services, and providers in Labrador and centers in Newfoundland and other provinces. "The [Innu and Inuit] beneficiaries might have the financial coverage, but... for the majority of the people that live in Labrador... cultural needs are not met, whatever they are."

Lack of cultural safety in the health care system in Labrador was attributed to several factors. The first was inadequate cultural competence of health care professionals. Labrador Grenfell Health provides cultural orientation to new physicians practicing in Labrador. Although orientation is meant to introduce them to the Labrador wilderness and the different Aboriginal cultural traditions, several participants expressed concern that cultural orientation programs for new physicians lacked lnuit representation. Other community members felt cultural orientation programs further promoted stereotypes of Aboriginal cultures, instead of directing attention to the cultural and social contexts of vulnerable Labrador Aboriginal populations. According to one participant:

When you look at the orientation, cultural awareness for all the new medical staff, they go off in the country.... It's actually a holiday where people go off and ski and do all the fun things, and it's the stereotypical people.... You're promoting the stereotypes and you're really not getting at the local stuff...

Second, lack of cultural safety in the health care system was attributed to high turn-over rates and long working hours of health care professionals in Labrador. Several participants felt creating appropriate cultural orientation for health care professionals was important to improve cultural competence, but equally important was ensuring staff had the time to complete them and recruiting and retaining staff that were able to make long term commitments to living in Labrador. As one participant noted:

There's a lot of work that could be done around improving cultural safety. You can create all the cultural competency packages that you want to help people understand the Inuit, nobody's got the time to do them.... Turnover is so great that you are always faced with this dilemma of the revolving door.

Third, there was concern that cultural education programs were restricted to physicians. "It needs to be that way for all health professionals, especially social workers, because they get brought here and they get sent to an Aboriginal community."

Fourth, participants identified a lack of support provided to Labrador residents in referral centers outside of St. John's. At the time of interviews, Nunatsiavut was providing ground transport, translation services, accommodations and navigational support through the Native Friendship Centre and other supports in St. John's.

Our guideline under Non-Insured [Health Benefits Program] is the person goes to wherever is closest. But... because the difference in cost in going to St. John's and going to St. Anthony is not that great, and because... of the need for additional accommodation costs and road transportation, because we don't have our own system in St. Anthony, it's just as cost-effective and certainly more culturally supportive to have the client go to St. John's.

Non-Aboriginal Labradorians also felt their rural culture was disregarded in the health care system outside of Labrador. Participants were concerned that cultural supports available to lnuit and First Nations people were not available to non-Aboriginal or lnuit-Metis residents of Labrador, although they come from distinct communities as well. Without navigational and cultural supports in new urban centers, participants said they felt scared, abandoned, confused and disregarded in the health care system outside of Labrador.

There's no patient navigator to help patients of any race, any nationality to navigate through the system. Even something as simple as 'Where do I go for accommodations?' or 'Where do I go to access food?'... there should be someone out there.... So that at least there's someone in the crowd looking out for your best interests.

All participants discussed the need for mental health and addictions programs and support in their communities and in the entire region of Labrador and identified these services as severely lacking. Most believed mental health counseling and other programs would be more effective were they run by community members aware of the cultural, historical, and social context of the community. Drug and alcohol rehabilitation programs were highlighted several times as not being grounded in the principles of cultural safety. Two Inuit men discussed the lack of support in their communities for alcoholism and drug abuse. One Nunatsiavut participant described how he was unable to access longterm counseling because there were no counselors in his community and the rehabilitation program for Aboriginal adults which incorporated traditional healing practices was discontinued in Labrador. Instead he had to travel to Happy Valley-Goose Bay and see different providers for one week counseling sessions every few months, which he felt was ineffective for his condition.

According to participants, there is not a true and comprehensive understanding and appreciation for Aboriginal cultures within health care institutions within and outside of Labrador. Aboriginal and non-Aboriginal community members living in Happy

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Valley-Goose Bay and Nunatsiavut communities spoke to the need for more culturally safe health services and programs within and outside of Labrador for Inuit residents. According to a report from NAHO (2008), one way to improve cultural safety in the health workforce is by raising organizational awareness of historical context, the diversity of First Nations, Inuit, and Metis communities, health care provider-patient power relations, and how these factors are manifested in the context of the Canadian health care system.

Institutional racism. McGibbon and Etowa (2009) argue that all forms of oppression, such as racism, sexism, and ageism, are structural, meaning they are embedded in social institutions such as the health care system. Several community members perceived there was institutional racism in the health care system in Labrador and offered several specific examples of its occurrence. Residents of Nunatsiavut voiced their concern about racism toward Inuit.

It's important for the staff not to put pressure on our people, especially when it comes to stress.... They don't want to tolerate stuff like that, especially elders. They should not have to be pressured in any way, shape or form. They should care for the elders with more respect.

Traditionally, Inuit elders are highly respected members of communities. Several participants felt this was a clear example of condescension and disregard of Inuit culture in the health care system in Happy Valley-Goose Bay. According to one participant, experiences of racism had left elders from Nunatsiavut communities over-stressed and distraught when accessing health care outside of their communities, producing risks to their already vulnerable health. One elderly [Inuit] man went up to the hospital here and he was sitting down for more than 6 hours before anybody seen him. I heard of another... Inuit elder as well, he was waiting for 12 hours before somebody seen him. Every time someone comes up, there's always a story...We respect our elders, we try to do everything we can for them. Especially when they're older, stress can kill. That's the scary part of it. I've had Inuit elderly women come to me crying because of certain situations.... It's happening, it's just that a lot of people that work within the system turn a deaf ear to it.... They more or less don't want to deal with you, so they neglect you.

Inuit participants described first hand experiences with racism in the health care system outside of Labrador. One participant attributed his removal from an alcohol rehabilitation program to racism engrained in western policies that did not fit with lnuit ways of healing and rehabilitation.

I was in there for two weeks and their rules were just, they were too strict. You get three strikes in the program or you're booted out. They gave me a strike one time because I wanted to leave the room because I was too hot. I'm Inuit... I like the cold right? They told me no, so they gave me the first strike because I left for 15 minutes. The second time they gave me another strike was when I was in a session and I had some flash backs and amongst the group I felt a little uncomfortable and I wanted to get away for maybe 15 minutes and when I asked, they said 'No, you're doing it too much. You say you're too hot and now you're having flashbacks.' They gave me two strikes. And the third one, same thing happened again. I was so hot, I wanted to go outside and cool off, so they wanted me to ask the counselors if I could go out. They told me, "You're doing it too much. You're out of here." Just like that, I was out of the program.

These stories are reminiscent of Whalen's experiences witnessing racism to Inuit in the health care system outside of Labrador (Whalen, 1999), and demonstrate the importance of improving cultural competence among practitioners caring for Aboriginal residents of Labrador. Whalen (1999) writes that Inuit have two inherent values in their culture that need to be considered in health care interactions: respect for elders and the importance of relationships. Peiris, Brown and Cass (2008) write that distrust and power imbalances in health care interactions that do not address the continuing impact of colonization can contribute to high levels of stress among Aboriginal people that has been linked to adverse health outcomes.

## Gender

Gender and geography are increasingly being interlinked as central in understanding rural health all over Canada (Leipert and George, 2008; Leipert and Reutter, 2005). Labrador is no different. Gender was one of the most referenced themes relevant to accessing health care in Labrador. Residents discussed gender by speaking out about issues associated with maternal care for Nunatsiavut residents, seasonal employment and hunting and trapping patterns of Labrador men, and family needs and deep rooted gendered responsibilities of most Labrador families.

Maternal care. The availability of suitable maternal care has been linked to the sustainability of communities (Miewald et al., 2011). Research in Northern British Columbia found that residents felt a lack of maternal care could negatively effect the recruitment of young families to the region. Miewald et al. (2011) write that a loss of control over where women give birth may have significant effects on perceptions and feelings toward giving birth. Rural women participants thought the ability to give birth in their community could create positive bonds between community and health care providers, enhancing the overall social fabric of the community (Miewald et al., 2011).

Continuity of larger system supports throughout pregnancy, such as pre and postnatal care, important to the health of mother and baby, is lacking in communities where women have to travel away from home to give birth (Miewald et al., 2011). In Labrador, some nurses provide strong pre and post-natal care, but midwives are not found in every community. As one participant said:

Long ago, people had their babies in their communities. Now you've got to come out to Goose Bay almost a month before your delivery date. That puts a lot of hardship on the families.... There are still some regional nurses, who happen to be midwives,<sup>11</sup> They're able to provide really good prenatal care to their clients and the breastfeeding support.... but midwifery is not practiced.

In Labrador, pregnant women of coastal communities are required to leave their communities to give birth in Happy Valley-Goose Bay at the Labrador Health Centre. Women travel twice throughout pregnancy for ultrasounds and are required to remain in Happy Valley-Goose Bay for three weeks (four if the woman is from Nain) before and a week after delivery. Administrators and health care providers in the region were firm in the belief that women had to come to Happy Valley-Goose Bay to deliver babies, since the resources to aid in emergency situations during childbirth were unavailable in isolated

<sup>&</sup>lt;sup>11</sup> The participant was referring to British midwives who came to Labrador with the International Genefield Association. According to several participants, the Grentfel nurses who remain in Labrador have extensive midwifery knowledge, and this improves access to pre- and post-natal care for mothers who live in communities lacking maternal care.

communities.

What enormous stress for a mom and a haby if you opt to deliver in the community and something were to go wrong. I mean, I know that it means coming away from your community for several weeks, but imagine the loss and the suffering you would feel if you didn't do that and you delivered and something happened. I mean, you're talking about a lifetime then.

Although maternal care decisions need to be made based on safety or resources and financial constraints (Miewald et al., 2011), Labradorians felt it was equally important these decisions be made with an appreciation of cultural and community sustainability. Two pregnant lnuit participants expressed their desire for birthing stations staffed by lnuit nurses and midwives in their communities. The first said "If nurses were trained from Nain, it would be good to have them there. I want a birthing station in Nain, so we can give birth in Nain. Women want their babies born in Nain and raised in Nain." The second woman expressed tension between wanting to stay in her community for cultural support and knowing the materials were lacking. "Certain equipment is missing in Hopedale, [so] it's better to come here... People are scared back home, where it's so small..., but there should be more equipment for people that have babies that didn't know they were...due."

Traditionally, Inuit women gave birth where they were on the land and were surrounding by grandmothers, mothers, sisters, and aunts to help with delivery. At the time of interviews, if women chose to remain in their communities, they were required to sign a form that transferred all responsibility of the health of woman and baby to the woman. Women were able to bring an escort. Both pregnant women interviewed had partners who were unable to leave work, and were in Happy Valley-Goose Bay alone. Participants said although most women choose the baby's father to accompany them, the choice caused stress for the pregnant woman as mothers generally desire to be present. In Nunavut, it has been found that forcing Inuit women to leave home can disjoint the family unit and put undue pressure on the pregnant woman (Purdon, 2008).

Family needs. Interviews with Labrador women revealed they were generally the primary caregivers of the family. Although it is stressful for families left behind when women are away seeking care for themselves or accompanying a sick loved one, participants said women bore the brunt of the stress.

It really puts a hardship on the family, so your mom is out here. Is Dad feeding the kids right? Are they being looked after? Are they being cleaned? Are they being kept for? Are they going to school on time? Are they doing their homework?"

At the time of interviews, deep-rooted gendered family care-giving responsibilities were differentially impacting women of Labrador. "A breastfeeding mum who has to bring the other child, to bring the baby and the child... It's just that added piece. The man can get on the plane... That's the way it is. That's never going to change."

Stress was two-fold for employed Labrador women leaving their communities for health care services, because they were still expected to fulfill their traditional role as primary caregiver. "More and more women are being employed, so you've got that double whammy of your job, your family, you gotta come out and the minimum you're out is 3 days." This finding is not unique to Labrador. Women employed outside the home in rural Nova Scotia reported being overschelmed by feelings that family caregiving was their fundamental role and they were increasingly burdened by dependent family members with declining health (Harold and Jackson, 2011).

Seasonal employment and hunting/trapping patterns. In coastal communities, many Labradorians, mainly men, work seasonally. In Nunatsiavut, some men spend extended periods of time throughout the year hunting and trapping on the land. These months of work were reported as critical for families relying or seasonal employment and/or hunting and trapping. This factor appeared more prominently in interviews with residents outside of Happy Valley-Goose Bay.

A lot of people here in Goose Bay tend to have more of a yearly income... they don't seem to be as financially burdened as someone who works seasonally. And our history has been the fishery, of course, so our employment has been during those peak summer time periods and the rest of the year you're getting just a small fraction of this money through employment insurance.... They don't want to leave home because they don't want to miss out... and so they're putting off' their health care because of that.

Participants said there was a drop off in the rate of men accessing health care services while they are working seasonally. Seasonal workers' disconnected from personal health circumstances while working because their families relied on Employment Insurance during the off-season. "If you look at our medical transportation statistics... you'll see the fall-off in the seasonal employment. People have to be pretty sick to miss work when they're counting on it for their stamps."<sup>12</sup>

<sup>&</sup>lt;sup>12</sup> Historically in Newfoundland and Labrador, weeks worked for unemployment insurance purposes were recorded by pasting stamps in a record book.

Participants noticed similar patterns in the rates of men traveling out of Nunatsiavut communities during peak hunting and trapping times. Men who hunt and trap rely on these limited time periods to procure meat and sustain the diet of their families and communities throughout the year. The situation has become dire in recent years because climate change has caused changes in caribou migration and sea ice patterns and, as some participants noted, hunters were uncertain they would obtain enough food for their families. In families that rely on country foods as part of their subsistence, men were said to prioritize between their personal health and providing food for their families. According to these participants, if a health care issue could be postponed, it would not be addressed until after hunting/trapping seasons.

There is a paucity of research surrounding the effects of seasonal work and hunting/trapping patterns on access to health care services in Canada, but according to participants in this research it as a significant factor influencing access to health care services for men in Labrador.

# Continuity and Comprehensiveness of Health Care Services

Continuity of care implies there is consistency and predictability in the way patients' access and receive health care services. Comprehensiveness of care implies a physician's ability to respond to the variety of health care needs during a patient's lifetime. According to this perspective, true continuity and comprehensiveness of care requires access to human resources other than physicians, such as nurses, dicticians, social workers, and other health care professionals (CFPC, 2007). At the time of interviews, continuity and comprehensiveness of health care did not exist in Labrador.

The identified factors and sub-factors of continuity and comprehensiveness of

care are provider shortages (access to specialists and retention and recruitment challenges) and fit between communities needs and services (models of health care delivery, dissatisfaction with physicians, long wait times).

Provider shortages. As reported in Statistics Canada's community health profiles (2011), 65% of Labradorians do not have a family doctor, compared to 12% of the province as a whole. Most Labradorians felt they were unable to access physician care in a timely manner and reported seeing a different physician each time they went to the hospital. "We get a lot of doctors that come for short periods of time... and that gets hard because... three, four months down the road... they're gone." Farticipants attributed this to high turnover rates of physicians. "The physicians are changing like socks and from the primary eare perspective, it's a very frustrating place to live. And I can speak to that as someone who lives here. Very, very difficult." Due to high turnover rates, some participants felt physicians were unaware of personal health histories of patients, so could not advocate for them in the health care system. Some participants add they felt personally responsible for themselves when it came to seeking appropriate care. "You really do need to look after yourself. Not knowing what doctor you are going to get the next time you have to go up is really hard."

Access to specialist care. At the time of interviews, there were no specialists practicing in Happy Valley-Goose Bay. A provider described the state of specialist care in Labrador, saying "the biggest challenge in Goose Bay would be access of some specialty services... most of us are trained to a sufficient level that we can provide a lot of the generalist specialty services.... it's the sub-specialties that are missing." For community members who required ongoing specialist services for chronic conditions, the

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lack of specialty services was challenging. "There's not very many specialists in Labrador, there's none actually that I know of... so people with arthritis or autistic kids or hearing problems or other disabilities, you have to travel." As mentioned already, weather is a significant factor in whether or not a resident is able to travel by air to the specialist appointment. Many individuals with chronic conditions decided to move to larger urban centers to save on costs associated with frequent travel to and from Labrador.

Wait times. In Labrador, wait times are prolonged due to weather or other geographic factors that impede travel to referral centers. According to participants, the booking system procedure at the Labrador Health Centre, residents of Happy Valley-Goose Bay could schedule an appointment no less than a month in advance with a general practitioner at the hospital. "Talk about access to health care. You cannot book an appointment any more than a month ahead and that's if you can get through." At the time of interviews, participants reported that having a family doctor did not mean faster access, which left some Labradorians fearing for their health.

Their caseload is full, you can't get in to see them.... If you are on their caseload, you're waiting a good month, month and a half to get a doctor's appointment. My husband's a heart patient. Waiting... could kill him.

There was agreement among health care administrators and providers that first contact with a health care provider such as a nurse is faster in Nain than Happy Valley-Goose Bay.

I don't know why they can't fix the system here. They have physicians working in outpatients and you can't see them for a month. Well if you're in Nain, you might have to wait a day or so [to see a nurse]... the care in Nain is actually better from a routine, day-to-day, primary care provision, than it is here in Happy Valley-Goose Bay.

Participants reported that a consequence of long wait tirres to see general practitioners meant that the emergency department in Happy Valley-Goose Bay was used for non-emergent health care problems, such as medication refills, because residents had no other choice if they could not wait a month to see a physician. "Chances are if I'm really, really sick, I'll have to go to the emergency department and, you know, that's not the best use of service really."

Overuse of emergency departments is reported more in rural than urban areas of Canada (Sherman et al., 2010). Hodgins and Wuest (2007) conducted a study investigating emergency department use for less urgent problems in rural and urban areas of New Brunswick and found that rural residents without a family doctor viewed the emergency department as their only venue for obtaining routine care. They also found that the use of the emergency department for referrals, prescription refills, and follow-up care was more common in rural than urban areas (Hodgins and Wuest, 2007).

Recruitment and retention challenges. Labrador, like many northern, rural regions of Canada, faces challenges recruiting and retaining health care professionals (Curran, Bornstein, Jong and Fleet, 2004). One participant describes the challenge faced in Labrador: "Recruitment and retention is an issue in Labrador... There's a tendency for people to leave and work in the bigger, urban centers. It's always difficult to recruit anyone, not just health care professionals, to rural and remote locations."

Buxton et al. (2007) write that the more a physician is a part of the community,

the greater likelihood they will stay and create positive community bonds and interventions. Participants in the present study recognized burn out in health care professionals, especially nurses, in Nunatsiavut communities and attributed it to a lack of community support networks and long working hours in high stress environments without professional support.

There's a lack of resources for them, they may be the only health professional in their field covering a community, covering three or four communities, their work loads increase because they have a higher number of clients and sometimes they're the first health professional coming in, with nobody having been there for a long time... there's no back up for them... They're kind of on their own. Due to high turn over rates. Nunatsiavut community members reported being left without continuity in health care professionals. "We only have one nurse in our community and every time we get a nurse... they are overworked, overtired, and they usually end up leaving."

One of the most often discussed issues associated with retaining health care professionals was the lack of opportunities for spouses and children. "The biggest issue [is] employment for spouses. If the spouse has no prospect for employment, why come here?" One participant felt recruiters need to think holistically about families in order to retain health care professionals. "The family will evolve and the person will have children... the spouse may find they want to work and are they satisfied with the work environment... very important to address if you are going to address retention." This finding is common across rural and northern regions in Canada (Curran, Bornstein, Jong and Fleet, 2004). Rourke, Rourke, and Belle Brown (1996) reported that family concerns had a stronger influence on female rather than male physicians and the chief factor affecting female physician's decision to practice in rural areas might be the presence or absence of employment for spouse and ability to spend time with children.

At the time of interviews, another challenge was recruiting health care professionals with the broad set of skills necessary for providing care in isolated communities, not typical of new graduates. According to a participant:

People who work in rural areas need to be very well trained and broadly skilled... If you put a new grad in remote communities and expect them to work without being trained to work in that environment, they won't stay.

This has been a documented finding among rural physicians across Canada. Curran, Bornstein, Jong, and Fleet (2004) write: "In an isolated setting a physician carries greater responsibility and must use a wider variety of medical skills." (p. 5). According to participants, more experienced nurses nearing the end of their careers were typically the ones that stayed in the communities for longer periods because they had the skills to deal with the broad range of issues. "We're finding the nurses that are coming and staying permanently seem to be the older nurses that are at that stage in their life."

Fit between community needs and services. Participants felt services available in communities did not fit the needs of the community. According to one participant, it is not only access to health care services, equipment and providers that is needed in Labrador communities. This participant felt health promotion activities needed to fit the specific needs of their communities:

We need to spend more money on health promotion, but we need to understand each community. They are all different and... because of the different value systems, different ethnic groups, we need to understand how [health promotion] works for each.

A health care provider discusses how the deleterious effects of colonization differentially affect Nunatsiavut communities and impede health promotion and self-care activities.

There's a lot of issues. You've got the food security issue. You've got the housing overcrowding. You've got all of the factors that impact on people through colonization, residential schools, TB. You have communities that are more in crisis than others and you've got people who are very much into survival mode and you aren't going to be able to do any of this self-care with people in survival mode.

In British Columbia, Aboriginal community members discussed the need for health care professionals to think beyond the medical model and consider and address health care needs, especially mental health needs, from a social determinants of health perspective (Buxton et al., 2007). The need for access to appropriate mental health and addictions services in Labrador was one of the most significantly discussed issues when it came to fit between community needs and services. One participant described the situation in Happy Valley-Goose Bay. "The services to support people with multiple and complex needs are not here... there's no psychiatris, secure facility ... The services for mental health are not here... there's no psychiatrist." At the time of interviews, Labrador Grenfell Health was recruiting a psychiatrist, but due to the absence of this specialist care, social work counselors were filling the role for mental health care services in the region. Although residents described mental health counseling services in Happy ValleyGoose Bay as lacking, the community was the primary referral center for Labradorians with mental health and addictions needs.

Participants said Nunatsiavut communities faced the added factor of widespread addiction issues surrounding drug and alcohol consumption and acknowledged the inadequacy of available counseling services. "In Nain... they don't have social worker counselors. They have community health workers, who don't have a social work degree, so their focus is more along community support, group support. Not one-to-one in-depth counseling." A Nunatsiavut participant accessing counseling services in Happy Valley-Goose Bay for an alcohol addiction said services in his community could not handle the severity of the problem.

Small community, lots of alcoholic... But nobody goes there [to do counseling]. It's hard, but they don't treat it. They don't pay no attention to it. There's so much drinking going on... There's a support group, but they can't handle the people... they're really alcoholic. Heavy, heavy, heavy drinkers.

Similar sentiments flowed from community members of other Nunatsiavut communities. "Over the years, especially when it comes to counseling... [we are] completely left in the dark... Right now there are no counselors, there's no one I can go to sit down with."

Nunatsiavut residents seeking addictions counseling in Happy Valley-Goose Bay, discussed social workers' lack of experience with social, cultural and historical contexts of Inuit in Labrador and the need for counselors with expertise in counseling who are from Labrador. "I would like to see counselors from along the coast who already experienced some stuff, who are older than us. There are lots of teens who are young parents, that needs counseling, but they can't get it proper sometimes." The culturally based adult rehabilitation program that operated out of North West River, Labrador had been closed, which meant lnuit residents had to leave the region to access drug and alcohol rehabilitation programs. A Nunatsiavut participant remembered the program as being more culturally rich than the counseling services he was receiving during the time of his interview.

They closed down... Used to go out camping and stay out for the night.... Used to go fishing....They were good too... they were all from Northwest River, the counselors ... They do different way than other outsiders. If I could stay there, I would stay there."

At the time of interviews, the province and Labrador Grenfell Health were recruiting mental health and addictions counselors in all communities in Nunatsiavut. "By having these professionals in the community, it will reduce the number of people coming down... the service would be located in the community, people wouldn't have to be away from their family for five days to get counseling."

Inappropriate models of care for isolated northern communities. According to participants, models of health care in Labrador were inappropriate for isolated northern communities. Administrators recognized one path to improving access to health care is by introducing primary care models in Nunatsiavut. Primary care delivery is based on a holistic approach that takes into account the cultural, physical and social environment and treats mental and emotional as well as physical well-being. This is in line with Inuit ideologies and culture of health. Primary care models also emphasize the importance of continuity and comprehensiveness of health care (CFPC, 2007). The Newfoundland and Labrador health care system compensates general practitioners based on a fee structure, within which consultations are coded and compensation is allotted for different tasks. In Labrador participants said that physicians were not offering health promotion, self-care and counseling because there is no compensation for these services.

MCP doesn't compensate a physician to spend time with the client helping them with self-care. Each visit is coded and it's just not in there, this counseling piece, this promotion-It's not in their funding, so why should they do it? So if they can't, well there needs to be other people that can here. And this is where that whole multi-disciplinary, true primary care model should come in.

Community members in three rural Aboriginal communities in British Columbia identified a need for physicians to expand their scope of practice to include prevention and proactive care rather than curative and reactive services, ensure continuity of care through long-term commitments and to maintain partnerships with communities to build public health (Buxton et al., 2007). Similar concerns around the limited scope of physician practice were being raised in Labrador and participants believed they should be able to access a broader scope of care in their communities without having to seek referrals from physicians. This perspective is illustrated by the following comment: "There is still opposition by physicians to the other professionals having the same scope of practice... there still isn't that full team recognition approach of the other providers who can provide the corollary service." Participants felt Labradorians faecd added challenges seeking referrals because most did not have family doctors and had to travel or wait upwards of 6 weeks to receive a referral. Participants felt if primary care models

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were available in isolated communities in Labrador, residents would not have to travel outside of their communities so frequently for referrals from physicians to access other modalities of health care.

Dissatisfaction with physician care. Community members identified a lack of rapport with physicians caused by high turnover rates, heavy workloads, and limited access to family doctors, which left them dissatisfied with physician care. A Nunatsiavut community member voiced his reluctance to be treated by over-worked physicians and how it has led him to avoid dealing with his health, saying he had "seen staff upset, irritable, and annoyed... I've been referred out for check-ups and I've turned it down because I think, 'Well this person will be too difficult.'' An Inuit community member of Happy Valley-Goose Bay echoed this sentiment:

I'd rather see a resident, because they actually take the time... and they look at your personal history... and the [nurse practitioners] that work out of Goose Bay and North West River, they're better than half the doctors up there... They take more of the time needed to figure things out.

One participant discussed residents' reservation to access mental health care providers because of their lack of knowledge on the social, cultural and historical realities that impact Labradorians' mental wellness. Mental health inequities in Aboriginal communities in Canada cannot be addressed in isolation of the background of colonization that continue to shape access to health care, health care experiences and mental health outcomes (Browne, Smye and Varcoe, 2005).

This is saying nothing of the people in that division in Labrador Grenfell Health, but they are not trusted.... This is why Nunatsiavut have their own mental health division, and people who are in that division have not got the training... So you've got the people who have not got the real connections, even though they think they do, who are in the offices with the big salaries, and you've got the people who run the job with the Aboriginal organization who have some of the passion, but not necessarily the skills they need.

Peiris, Brown, and Cass (2008) write that when care providers promote trust, reciprocity, effective communication, and shared decision-making with Aboriginal patients, they can promote respectful relationships with patients which can encourage positive health outcomes.

#### Summary

The interviews conducted with community members, health care providers and administrators in Labrador were rich with data as everyone had a very important story to tell. The diversity and enormity of factors influencing to access health care in the region arise from the physical, socio-cultural and political environments, as well as gendered responsibilities and continuity and comprehensiveness of health care. In my data analysis, I selected pertinent passages from interview with community members to highlight the identified challenges Labradorians face accessing health care in Labrador. Promisingly, all participants identified existing and novel strategies to overcome these challenges. Each identified strategy can overcome more than one of the identified challenges accessing health care in Labrador. The following chapter discusses the identified strategies.

# Chapter 6: Data Analysis - Major Strategies to Overcome Challenges to Accessing Health Care in Labrador

This chapter outlines the main strategies to overcome challenges accessing health care in Labrador discussed in interviews and highlighted through data analysis. Participants identified seven strategies to help overcome the challenges to accessing health care created by the above factors. These strategies are: Tele-health, bringing services to communities, the scheduled evacuation system (Schedevac), the medical evacuation system (Medevac), the MTAP, recruitment and retention strategies, and tools for navigating the health care system. Passages from study participants are used through out the data analysis to support the discussion of the major factors that influence access to health care services in Labrador. Table 3 presents the seven strategies that help overcome the four broad themed challenges accessing health care discussed in the previous chapter.

	Physical environment	Socio-cultural and political environment	Gender	Continuity and Comprehensiveness of Care
Tele-health	X	X	X	X
Bringing services to communities	x	x	x	x
Recruitment/ retention	x	x		x
MTAP	X	X		X
Patient Navigation tools		x		
Medevac	X			X
Schedevac	X			

Table 3: Strategies that help overcome challenges accessing health care in Labrador

### Tele-Health

Participants identified Tele-health as the most cost-effective and efficient tool to overcome the barriers to accessing health care in Labrador created by physical, sociocultural and political environment, gender, and ensure continuity and comprehensiveness of care. Tele-health allows residents to access health care in their home community. One participant expressed how Tele-health helps overcome the challenges of traveling long distances: "I don't want to fly to St. John's..., for something that's going to take ten minutes. We have to get to that place where people don't need to leave. Tele-health is the answer." An identified benefit of Tele-health use for specialists was that it decreased waitlists for face-to-face appointments as they could conduct consultations via video conference. In the past, "They'd... fly up here, do a clinic, be away from their home and their families, which made it difficult for them... They just did it because the waitlists are long and that impacts their lives as well."

Participants identified Tele-health as a strategy to overcome barriers created by the socio-cultural and political environment such as the lack of culturally safe services in referral centers, as Nunatsiavut residents can attend consultations and appointments at home, accompanied by family or a friend if they are in need of cultural, translational and emotional support.

Tele-health was also identified as a strategy to overcome barriers to access related to gender. Participants said it could improve access to pre and post-natal care services and decrease stress on mother and baby in isolated communities in Labrador in two ways. First, if Tele-health services were broadened, women could access consultations with midwives in other regions of Labrador or on the island. Second, if video-conferencing were equipped with ultrasound capabilities, pregnant mothers would not have to leave their communities twice during pregnancy for ultrasounds in Happy Valley-Goose Bay. Participants thought Tele-health could help decrease stress on women primary caregivers if women could deal with some of their health care needs through video-conferencing with physicians or specialists in other regions. Tele-health was also identified as a strategy that could help men access health care during seasonal work or peak hunting/trapping seasons. If residents could consult with a physician in Happy Valley-Goose Bay via Tele-health for non-emergent conditions from home, they would not have to give up working.

Tele-health can be used as a strategy to overcome the barriers to health care access created by a lack of continuity and comprehensiveness of care. Participants felt recruitment of specialists who fit the needs of the community to use Tele-health technologies and to travel to communities was important.

[Tele-health] accessories that could be useful, like the ultrasound... diabetic services... pediatricians... so you wouldn't have to wait so long... We got a large, young population in Nain and Northern Labrador - a lot of kids would benefit from the service. Psychiatry as well... from a community needs perspective, these are the kinds of services we really need.

Participants were especially concerned with the lack of mental health and addictions services in communities and felt Tele-health was one way to improve access to counseling services. Labrador Grenfell Health and Nunatsiavut launched a Tele-Psychiatry pilot project to address the mental health needs in Nunatsiavut communities in 2003. The project connected Nain residents at risk of suicide to a psychiatrist in St. John's for mental health assessment. Seventy one patients were able to remain in their community for assessment. A study conducted after the project concluded found the use of Tele-health for psychiatric assessment saved the provincial government \$140,088 and patients and health care providers were satisfied with the service (Jong, 2004).

Suggested Improvements. According to participants, improving Tele-health infrastructure would create large cost-savings to Nunatsiavut Government and improve access to health care for residents of remote and northern communities in Labrador. Despite the apparent appropriateness of Tele-health to Labrador's geography and dispersed population, Labradorians offered several explanations as to why Tele-health had not become every day practice in Labrador. "Some of the issues are big, they're system issues, and some of the issues are at the health authority level, and some at the community level. And everything needs to be coming together to improve the access."

First, few service providers in the province had found a way to make a profit or recover the costs of providing Tele-health service. The provincial government decides which physician tasks are compensated. The province does not supply financial incentive to health eare service providers for Tele-health use, thereby lowering it on the priority list of most health eare providers in the region. Participants suggested the provincial government provide incentive to use the system to encourage Tele-health use among physicians.

Second, at the time of interviews, there was no capacity for additional high-speed internet connections in Labrador, so access to Tele-health use throughout Labrador was limited. Additional bandwidth was needed in the region to improve capabilities and add new applications that would allow more specialists to access and use the Tele-health system. Health care providers postulated that since the federal government assumed the costs associated with travel for health care services for most residents of northern Labrador's isolated communities through First Nations and Inuit Health Branch, the provincial government has not made increasing bandwidth a priority in the region:

There has to be political will that recognizes that one of the most essential parts of improving access to service is going to be improving infrastructure for Telehealth... You save a lot of money... You can't even put a cost on it!... Part of the reason the province doesn't have the strength of the political will is because the federal government is paying for the Innu and the Inuit. If [the provincial government] had to assume the costs, they might be singing out of a different hvmn-book. They aren't seeing what we're spending.

#### Bringing Services to Communities

Another identified strategy to overcome challenges accessing health care in Labrador was to physically bring services to communities. Participants believed there were several benefits associated with bringing services to isolated communities, rather than bringing residents to services outside of Labrador.

If more services were available in communities, Nunatsiavut Government would undergo enormous cost savings associated with covering associated travel costs for all Nunatsiavut residents. Two successful examples of overcoming physical environment challenges by bringing services to communities in Labrador were discussed in interviews. The inception of traveling dental clinics in Happy Valley-Goose Bay, for example, improved access to dental treatment for Nunatsiavut residents ravel to Happy Valley-Goose travel for dental care. In Nain, a high volume of residents travel to Happy Valley-Goose Bay every year for x-rays due to a history of tuberculosis. A traveling x-ray clinic was brought to the community and patients were able to stay home. As one administrator explained, it was a successful example of adapting services to community needs through collaboration:

It was one of the only examples in the country where you had industry, health authority, province, Nunatsiavut, community working together to create one opportunity in a remote community that meant 163 people didn't have to come to Goose Bay.

Bringing needed specialist care to the hospital in Happy Valley-Goose Bay was identified as the second best option for patients in isolated communities in Labrador. "It's not in the community, but... Goose Bay is the next best thing. The closer you bring the service, the better."

Bringing services to communities was also recognized as a strategy to overcome challenges associated with socio-cultural and political factors. Visiting health care providers are able to learn about how social, cultural and historical context of communities effect health behaviors of residents. In addition, health care professionals are required to work as a team, so visiting providers learn how to deliver health knowledge in culturally safe ways, clinic nurses gain confidence in referring and diagnosing patients, and clinic staff broaden their skill set of specific health conditions. One participant spoke to this: "Specialists... get to understand the culture.... There's the learning piece for [staff]... If that could even be happening once a year, it would have a tremendous impact on the knowledge level, cultural safety, and [number of] people you see." Increasing the number of physicians and specialists that visit Nunatsiavut communities can help residents overcome challenges accessing health care associated with gender in similar ways as Tele-health. Participants felt that being able to access some health care services in the community would allow greater access to care for pregnant mothers, primary caregiving, and seasonal working men.

Bringing services to communities was also identified as a way to improve continuity and comprehensiveness of health services in communities. The employment of services and health care professionals that filled a need would mean community members could access appropriate services. A step forward in this direction was the announcement in the Government of Newfoundland and Labrador's 2011 budget to direct funding toward recruiting mental health and addictions counselors in all Nunatsiavut communities. Training opportunities in communities was also identified as a way to ensure needed services were available in communities. Participants identified technical health aide training, such as physiotherapy and speech pathology aides, and Inuit midwifery training in Nunatsiavut communities. For example, in Nunavut, efforts have been made to record elders' experiences with traditional birthing practices to preserve and share lnuit midwifery knowledge within communities (Purdon, 2008). A viable option identified in Nunatsiavut communities was to have lnuit elders hold midwifery workshops with public health nurses and residents at community elinies.

Suggested improvements. At the time of interviews, the provincial government did not offer financial or other incentives to health care professionals to encourage travel to Labrador. Nunatsiavut's Department of Health and Social Development works with specialists to bring them to communities but participants noted that many specialists simply do not want to leave their home if they are not gaining adequate remuneration from the provincial government for their efforts.

# **Recruitment and Retention Strategies**

Improving recruitment and retention strategies was also identified as a strategy to help overcome challenges associated with the physical environment, socio-cultural and political environment, and continuity and comprehensiveness of care. In Labrador at the time of interviews, these strategies included: off-ring orientation programs, recruiting and building capacity within communities, training professionals in specific areas of practice, addressing family and spousal issues, overseas recruitment, and incentives.

One administrator said rural Canadian medical students are twice as likely to return to a rural area to practice, but most of them stay in urban areas once they have been trained in that environment. This administrator felt it essential to train medical staff in the location they will practice. Memorial University's NorFam allows medical residents of the general practice stream from across Canada to train in Labrador and enhance skills in rural and northern medicine. At the time of interviews, the program was seen as very successful in Labrador.

The training needs to be done in the rural location where you want them to practice. [Through NorFam], almost all of the physicians here did their training here and 90% of the trainees are working in rural settings across Canada. At the time of interviews, orientation programs were offered to students in the NorFam program to help introduce them to the geographical and cultural landscapes in Labrador. Students go out on the country and we show them what it's all about... but that's

not sufficient because when that is over, they still need to make the connection.

Again, it's how to maintain that interest in Labrador lifestyle, which is great if you know how to appreciate it, but some people need to be exposed to it.

There is also a cross Canada recruitment program for foreign physicians, called the Clinical Skills Assessment Test (CSAT) program, which recruits foreign trained doctors. According to one administrator, this program is not as successful as the NorFam program has been in Labrador.

We usually have a couple of CSATs at one time here.... They usually stay. They have to sign on... I think it's a two year [contract] that they have to sign on for in order to go through the training, but they tend to leave then.

Nunatsiavut Government partnered with the Faculty of Nursing at Memorial University to offer the Integrated Nursing Access Program (a post-secondary program for Inuit nurses) in response to challenges recruiting and retaining nurses in Nunatsiavut communities. This three-year program offered at the College of the North Atlantic in Happy Valley-Goose Bay, incorporates the completion of Adult Basic Education and the first year of Memorial University's Bachelor of Nursing (BN) Program. Integrating traditional indigenous knowledge and methodologies in university-level program activities, it prepares Labrador Inuit students for successful completion of a BN. The program was viewed as very successful in the region and at the time of interviews, there were several Inuit nurses working in Nunatsiavut communities who had completed the program. Labrador Grenfell Health had their own system for training nurses to prepare them for the broad range of responsibilities they faced in isolated communities in Labrador, which also involved training the nurse in the location of practice. As one participant described: "Generally, they come and spend a week here in Goose Bay with me, and then they'll spend anywhere from 2-3 weeks job shadowing with another nurse in [the community] clinic..."

Because it is hard to fill all nursing positions with Canadians, Labrador Grenfell Health also recruits nurses and physicians overseas. "Last year the nurse recruiter went to India and tried to recruit nurses... That's where we're having to go look for staff, and if you don't have the staff there to offer the service that certainly effects access."

Another strategy used by the provincial government and Labrador Grenfell Health at the time of interviews to improve retention was through financial incentive for new health care professionals. Labrador Grenfell Health has several incentives to attract health care professionals. They provide retention incentives for social workers and nurses, signing bonuses to specialists, physiotherapists, pharmacists, nurses, social workers and speech language pathologists and bursaries for hard-to-fill positions in Labrador (Government of Newfoundland and Labrador. 2012). One participant discussed incentives for physicians: "[Physicians] don't have to pay tax on their property for three years, so this can encourage people to buy something... if you buy something, you are more likely to stay on." Another participant discussed incentives provided to nurses: "There's a Labrador travel allowance, a food allowance, a survival clothing allowance.... It's rent free when you live in any of our accommodations.... if you come as a casual, you get 20% in lieu of benefits."

Retention and recruitment can help residents overcome barriers to health care created by the physical environment by employing more health care professionals and making services available in Labrador so that residents do not have to travel long distances.

Recruitment and retention of health care professionals from within communities in Labrador was identified as a strategy to overcome challenges accessing culturally safe health care in the region and increasing Labradorian health care providers. Education initiatives were identified as sustainable ways to recruit and retain health care professionals from Labrador, provide culturally safe care, and allow Nunatsiavut community members access to health care professionals who share similar historical, cultural and social roots. As one participant commented:

We need to grow more [health care providers]... so they go back to their communities. The way to improve it is as Memorial is doing, to really work on the recruiting of Aboriginal people into medicine. Nursing-wise we're doing quite well. Programs, when you do them specifically for that population [Inuit], are expensive but we would continue to do it through our post-secondary program, to support and encourage.

Recruitment and retention of health care professionals from Labrador to return and work in Labrador communities was identified a sustainable solution to challenges associated with continuity and comprehensiveness of care, including high turn-over rates. In addition, recruiting Labradorians means a better fit between community needs and services, as residents of these communities have experienced similar social, cultural and historical factors.

Suggested improvements. Participants identified several ways recruitment and retention strategies could be improved. According to one participant one route to developing a sustainable solution to recruitment and retention challenges is to put more focus on developing the capacity and independence of community workers, such as the public health nurses in Nunatsiavut clinics. "The more empowered our community health aides... workers that we have, the better, because they are the sustainable part of the health care. They live there, they're staying and there needs to be investment in them." Second, participants suggested orientation programs be guided and implemented by community and cultural organizations, rather than the health authority, and that Labrador Grenfell Health make cultural orientation a mandatory part of training for all health care professionals. Third, to address family issues that determine whether health care professionals stays in Labrador, one participant suggested hiring a coordinator to oversee these issues. "I'm trying to recruit someone to help me as a coordinator to try to understand the family issues."

# Medical Transportation Assistance Program (MTAP)

The MTAP introduced in the environmental scan, was identified as a strategy that could be improved to help Labradorians overcome challenges accessing health care associated with the physical environment and socio-cultural and political environment by allowing residents limited to MCP coverage to access the same financial coverage as Labradorians covered under other jurisdictions received.

Labradorians identified several problems with the program that needed to be remedied before MTAP became a viable strategy for accessing health care in Labrador. First, participants said insufficient MTAP financial assistance and the requirement that residents pay up-front for travel-related costs left residents overburdened with high outof-pocket costs. The most adversely affected residents were low-income families who did not have the financial means to pay up-front costs to access health care outside of their communities. As one participant commented: Coming up with 1500 dollars in a month or two is not feasible... If you are on social assistance, they will pay your way in and back... I can't say I'm the working poor, but I'm close enough to it."

At the time of interviews, residents who did not have the finances to pay for up front costs of travel were borrowing money, selling personal assets, mortgaging homes, holding community fundraisers, or going without needed health care services. Some individuals with chronic conditions required to travel out of Labrador several times per year found it so financially challenging to access health care in Labrador they migrated to larger centers. Pong (2007) writes that provincial strategies to help improve access to health services for rural residents tend to be generic in nature and do not address special needs of the rural poor. He contends that targeting this population with specific policies to improve access to health care is justifiable if it can be demonstrated the generic provincial program has failed to reach them. Participants reported that the most vulnerable population resides mainly in south coast communities where economies were struggling and in Happy Valley-Goose Bay.

Participants identified the second issue with MTAP was no available financial assistance for escort support. Caretakers who accompanied elders, children, and patients who needed assistance with daily functioning were responsible for paying their own travel expenses and meal costs. For most residents, producing up front airfare costs from Labrador for two people, even when cost shared at 50%, was a big challenge.

Table 4 provides an example of the out-of-pocket costs of a resident limited to MCP coverage referred from the south coast community of Cartwright, Labrador to St. John's for a common health problem.

Service	Cost	MTAP Reimbursement	Running Tally
Round-trip flight Cartwright to Happy Valley- Goose Bay	-\$600	\$0	-\$600
2 nights accommodation and food in Happy Valley-Goose Bay	-\$365	\$0	-\$965
Round-trip airfare Happy Valley- Goose Bay to St. John's	-\$800-\$1000	+\$1000 on first flight in 12 months, \$500 on subsequent flights	-\$965 for 1st flight or -\$1465 for subsequent
3 nights accommodation and food in St. John's	-\$465	+\$465	-\$965 or -\$1465
Ground transport	-\$90	\$0	-\$1075 or -\$1575
Escort related costs if required (flights, food)	-\$2130	\$0	\$-3205 or \$-3705

Table 4: Estimated out-of-pocket costs of a resident limited to Medical Transportation Assistance Program for travel

A third issue surrounded emergency evacuation out of the region. When Labradorians were flown out of Labrador on the provincial air ambulance, they paid a user fee of \$130 (Government of Newfoundland and Labrador, 2011c). Although the Department of Health and Community Services covered road ambulances to and from the air ambulance, costs were still high for individuals who were limited to MCP coverage. At the time of interviews, Labradorians reported being stranded in other regions of the province or out of province, because return travel airfare after an emergency evacuation out of Labrador was an excessive out-of-pocket cost. For example, one participant accompanied her spouse on emergency evacuation to St. John's, where they were unable to cover the costs of returning to Happy Valley-Goose Bay. Since MTAP did not cover costs associated with accommodation, food, or local travel for stranded Labradorians, this couple felt abandoned by the government. They were at risk of losing employment and forced to leave their children in the care of relatives until they were able to raise enough money for airfare.

Suggested improvements. Community members suggested the provincial government provide upfront coverage rather than reimbursement through MTAP. "If the government [MTAP] can even...put \$1000 towards you and your child's travel... Right on. \$600 is doable. \$1600 ain't." In the 2011 Government of Newfoundland and Labrador Budget, it was announced that the government will be enhancing MTAP by providing the prepayment of 50% of the costs of airfare for rural residents of the province. At the time of this research, however, the implementation of this policy was yet to materialize. Even with the implementation of this policy, residents still face challenges producing the other 50% of travel costs associated with airfare, accommodation, and food.

# **Patient Navigation Tools**

Patient navigation tools were identified as useful strategies to help Labradorians overcome barriers to health care access created by the socio-cultural and political environment. Although there is not a standard definition for patient navigation, a barrierfocused definition developed by Dohan and Schrag (2004) after an extensive literature review denotes patient navigation as the provision of particular services or set of services to patients that specifically address barriers to care. For the purposes of this research, a navigation tool refers to systemic, technological and human resources that help residents navigate the health care system. According to a non-Aboriginal Happy Valley-Goose Bay resident, the lack of navigation support in Labrador was especially hard for vulnerable sections of society who were under informed or had low literacy. "One of the biggest things is navigating through the bureaucracy, knowing who to talk to and what questions to ask.... How do people with low literacy rates, or who don't understand government, how do they work through the system?"

Participants identified the Aboriginal Patient Navigator Program in St. John's as an effective navigation tool. Two Aboriginal Patient Navigators, employed by Eastern Health, provide navigation assistance in the health care system, hospital, the city, and finding accommodations, meals and social support services for Aboriginal individuals accessing health care in St. John's. According to Nunatsiavut participants, these navigators are a useful resource for lnuit residents who are aware of the program. However, participants identified a lack of awareness of the program in Nunatsiavut communities that created a barrier to accessing the health care service. One Inuit woman in Happy Valley-Goose Bay said, "Not a lot of people know about that program. I only know by pure fluke.... I met the Aboriginal Patient Navigator [at the Native Friendship Center in St. John's]... and she told me all about the program." Most participants were confident patients would feel more comfortable being referred to St. John's for care if they were initially aware of the program and knew they would have an advocate and supporter when they arrived in the city.

Non-Aboriginal participants acknowledged feeling vulnerable, lost, intimidated, confused, and unprepared for dealing with new surroundings as they were going through detrimental health situations in foreign eities. According to one participant, "a patient navigator [is needed].... then you have a contact person.... At least that person knows you are there and knows a little bit about why. Right? Rather than just going out there blind." Some participants felt self-advocacy was a skill only some people in the community had, and there were a lot of people who did not have the skill to work their way through the system. "The loud mouth and the squeaky wheel are those, educated or not, who are able to work the system."

Suggested improvements. The general consensus in interviews was that non-Aboriginal Labradorians should be able to access similar peer navigational support as Aboriginal Labradorians in referral centers.

A second suggestion from participants was for the implementation of a wellness list serve or online network to allow residents of Labrador to share stories, experiences and advice around how to navigate the health care system in and outside of Labrador. One participant stated:

It should be community based where services are seen through an advocacy lens and a curiosity lens to say 'I'm a patient, a resident of this community. What are the services, when this happens to me?' And some kind of easy to read, clear language version of: If this, then that.

According to participants, a website would be useful because word of mouth was the main communication medium and way to share knowledge in Labrador. Participants believed that a community network of support would decrease stress for residents accessing care outside the region and would ensure residents could seek important health care information in a non-intimidating environment. Participants suggested the network provide information such as: lists and locations of specialists in the province, description of MCP insured services, and an outline of criteria for MTAP reimbursement. Participants liked the idea that health care providers, as community members, could interact and share knowledge and advice with other community members on navigating the health care system outside of the region.

One participant addressed the 50+ Group initiative at the Labrador Friendship Centre, that helped Labradorians 50 years and older to navigate the health care system. "One of the projects was to develop a buddy system, so that there could be some process for advocacy."

# Schedevac

The Schedevac system was said to help overcome challenges accessing health care associated with the physical environment, by providing scheduled air over long distances from isolated communities three days a week, and continuity and comprehensiveness of care, by allowing residents to access a broader scope of services in referral centers. According to participants, the Schedevac system was running effectively given limited resources. Labrador Grenfell Health subsidized the majority of the flight cost, so residents were required to pay \$40 for travel to health care services in Happy Valley-Goose Bay. Administrators believed it offset expensive travel costs of flying in Labrador. "Rather than \$800, you are only paying \$40 dollars return to come out for services here in Goose Bay." At the time of interviews, Nunatsiavut and Innu Nation members did not have to cover the \$40 portion of the Schedevac as it was covered by non-insured health benefits. Participants believed this helped inuit patients overcome financial barriers associated with air travel. "As Inuit, we are all living in isolated communities that are fly in only ... within the four regions of Canada that are Inuit, we have, by far, the better system [Schedevac] and they would gladly have what we have."

Another way Schedevac had improved access to health care in Labrador is through accommodating for seasonal changes in daylight hours and weather. During the winter, the Schedevac traveled to the northernmost communities first. "If we leave it too late in the day we won't get in because darkness is starting to set in. So in the winter months, we tend to go to Nain first."

Suggested Improvements. Non-Aboriginal and Inuit-Metis patients limited to MTAP for travel coverage faced hardships coming up with \$40 to cover the cost of the flight to Happy Valley-Goose Bay. "On the south-east coast of Labrador there's people with no income now and just getting \$40 to pay for the ticket to get from the coast to Goose Bay is a lot of money." It was suggested that all Labradorians living in isolated communities receive travel coverage for flights to the main hospital in Happy Valley-Goose Bay.

## Medevac

The Medevac system was identified as a strategy to help overcome challenges associated with the physical environment. Medevac was reported to be working well as the primary mode of emergency evacuation in Labrador's isolated communities given limited resources, unpredictable weather conditions and staff shortages. Several back-up supports from other systems were available in case the primary emergency evacuation plane was unable to travel, which helped the system work efficiently. The Schedevac plane could transform into a second Medevac. "If you have an [emergency] when that plane is in the air doing it's business on Monday. Wednesday, or Friday, it just gets rerouted." Also, a physician could communicate with clinic staff through Tele-health as a final option in emergency situations. "Tele-heath helps us with a lot of those situations

where we cannot get in."

Suggested improvements. One identified problem in providing timely medical evacuation is the scheduling system for nurses on Medevae flights. At the time of interviews, nurses were volunteering and self-scheduling to go on Medevae flights on their days off. With nursing shortages, it was difficult to find staff if no one was scheduled for the flight. According to participants, this took unnecessary time and delayed emergency services to the coast. One administrator said "The Medevae system could improve in that you have assigned nursing staff..., if you don't have anybody to volunteer..., you're doing a lot of calling to find a nurse and that's a delay in access." Summary

Investigating access to health care in northern, isolated. Aboriginal regions requires examination of many interacting factors. In Labrador, this deliberation requires incorporation of the thirteen factors generated by this research. From the interviews, it was apparent that to improve Labradorians' access to health care in the region, creative solutions and strategies must be employed. Several of these strategies were in place or under way at the time of the interviews. Other strategies were proposed. The final chapter will offer recommendations to provincial and regional health care authorities to inform policies and programs related to improving access to health care for Labradorians through a human rights and social determinants of health framework, discuss theoretical implications of this research, and suggest areas for future research.

### Chapter 7: Discussion of Recommendations

In the two previous chapters, I discussed thirteen factors that create challenges accessing health care services in Labrador, encompassed within four themes (Table 2), and seven identified strategies to overcome challenges accessing health care services in Labrador (Table 3). Identified themes that influence access to health care in Labrador are consistent with those in other rural and northern regions of Canada. Litaker, Koroukian, Siran, and Love (2005) documented that despite accumulating evidence of contextual factors as determinants of a variety of health outcomes, the effect of contextual factors on the ability to access health care services is less known but necessary for effective health care planning and development.

In this final chapter, I consider the identified challenges to accessing health care, potential strategies to overcome barriers in the development of recommendations to the provincial government and regional health authorities to inform policy development aimed at the delivery of health care services in Labrador. The recommendations flow mainly from participants' suggestions, so therefore, some focus specifically on Labrador Inuit and others focus on all Aboriginal people and Labradorians in general.

Recommendations are directed at the provincial government, regional health authorities, and community organizations in relation to the improvement of access to health care in Labrador. Recommendations to improve access to health care for Labradorians revolve around the identified themes arising from the data analysis that create the challenges accessing health care services in Labrador; physical environment, socio-cultural and political environment, gender, and continuity and comprehensiveness of care. In the later part of this chapter I will discuss the theoretical implications of this

research and suggest areas for further investigation.

I begin by framing the recommendations within a social justice lens using health as a human right and the social determinants of health. A human rights-based approach in the health care system "means making principles of human rights integral to the design, implementation, and evaluation of policies and programs. And it means assessing the human rights implication of health policy, programs, and legislation" (Rioux, 2010, p. 93). Capturing health within a human rights perspective can focus attention on vulnerable populations whose needs are not being met, diagnose the effectiveness of policies and develop new approaches, and provide a framework for addressing unfair access to health services (McGibbon and Etowa, 2009). Using a human rights perspective for the following recommendations allows the questions: If Canadians have the right to health care as outlined in the Canadian Health Act, why do inequities in access continue to persist in rural and northern regions of the country? What are the additional costs of health care for rural families in Labrador and how does this cost affect health outcomes in families who have chronic illnesses?

By fusing the health as a human right perspective with the social determinants of health framework, this discussion has other benefits. First, it highlights contextual factors that help to illustrate inequities in social, political, economic, and physical contexts between and among populations in Labrador, an objective of the social determinants of health. Second, the recommendations hold government and health authorities and institutions accountable for integrating human rights principles in the design, implementation, and evaluation of policies and programs for vulnerable populations experiencing violations of the right to health in Labrador, an objective of the human rights approach to health (London, 2008).

## Recommendations

Recommendations associated with the physical environment. The challenges created by the physical environment were identified as weather, geography, and distance to service. Suggested strategies to improve access to health care services by addressing challenges associated with the physical environment are: Tele-health, bringing services to communities, Medevae, Schedevae, the MTAP, and recruitment and retention. Most recommendations are directed at the provincial government, as they are the governing body responsible for the provision of health care services and resources in the Labrador region. These recommendations seek to remedy policies that could improve access to health care for Labradorians in the face of physical environment challenges. Some recommendations respond to more than one issue. These recommendations will be noted in appropriate sections, but not repeated.

Recommendation 1. That the provincial government provide financial incentive for physicians and specialists to provide Tele-health consultations and follow-up appointments in Labrador. Video-conferencing by physicians and specialists in the region was seen as a cost-effective solution to overcome challenges created by the physical environment. Although administrators and providers saw many benefits to Telehealth use and it has been proven to provide costs-savings to government and to have high consumer satisfaction in northern Inuit communities in Labrador (Jong, 2004), physicians and specialists did not receive any incentive to use the Tele-health system at the time of interviews from the provincial government. Providing incentive to health care professionals will result in decreased wait times for Labradorians, enormous cost savings for government and patients, and improved access to physician and specialist related health care for individuals in isolated communities in Labrador.

Recommendation 2. That the provincial government improve infrastructure in the region to expand Tele-health use by health care providers and broaden the scope of services available to residents of Labrador. Increasing bandwidth in the region will allow Tele-health to serve as a viable solution to improving access to otherwise time consuming and expensive travel to specialist health care services for residents of isolated communities in Labrador.

Recommendation 3. That the provincial government provide incentives for specialists and other health care providers to bring clinics to northern and remote communities. Visiting specialists in isolated communities allow rural inhabitants to access a broader range of health care services and allow them to remain in their home community to access specialist care (Drew, Cashman, Savageau, and Stenger, 2006). According to participants, access to dental health was generally poor in Inuit communities of Labrador and access to dentists was not covered under non-insured health benefits. When Nunatsiavut Government was formed in 2005, their Department of Health and Social Development covered costs to bring a dental clinic to communities. Participants reported that because of the visiting dentist, access to dental care and dental health has improved. Currently, the provincial government does not provide incentives for specialists in the province of Newfoundland and Labrador and elsewhere to travel to Labrador. If more specialists held clinics in remote communities of northern Labrador, cost-savings would result for Nunatsiavut Government in associated with travel-costs for Inuit residents attending medically necessary specialist appointments outside of the

region and for residents limited to MCP who were reported to receive insufficient travel funding through the MTAP.

Recommendation 4. That Labrador Grenfell Health work with nurses to ensure there is adequate staffing on the Medevac flights to the coast, thereby avoiding delays in emergency evacuation. Assigning nurses to emergency evacuation shifts, so that a Medevac team is ready for departure when emergencies arise in isolated communities will ensure more efficient departure and treatment for residents waiting for swift evacuation due to health emergency situations.

Recommendation 5. That the provincial government implement its commitment to prepaying 50% of travel costs through MTAP as soon as possible. Residents who are limited to MCP face significant out-of-pocket costs associated with long distance travel to access needed health care services. Participants noted that many low-income residents of Labrador limited to MTAP for travel coverage could not afford the upfront costs necessary to travel outside of Labrador. Covering 50% of airfare still leaves Labradorians with significant out-of-pocket costs for accessing health care services.

Recommendation 6. That the provincial government provide cash advances to Labradorians through MTAP based on the interaction of a resident's income, health care costs, and health care needs. Provincial programs that intend to improve access to health care for rural residents have been found to be generic in nature and to not address the needs of the rural poor (Pong. 2007). In Labrador, the MTAP does not account for differences in income, health care costs, or specific health care needs, rather it requires Labradorians limited to MCP for health care coverage to pay upfront costs of travel, regardless of circumstance. Labradorians have a range of incomes and health care needs

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and therefore, face varying out-of-pocket costs. Out-of-pocket costs are dependent on health condition, number of trips out of Labrador per year, referral center, type of health care service, follow-up services and equipment for residents returning to Labrador. Therefore, a one-size-fits-all policy is not appropriate in Labrador. Distribution of financial assistance through MTAP should take into account the above factors in order to equitably distribute resources and improve access to health care outside of Labrador.

Recommendation 7. That the provincial government provide financial assistance to escorts for Labrador youth up to the age of 16, and for residents who require an escort to perform basic living tasks while seeking health care outside of Labrador. At the time of interviews, parents and caretakers who needed to accompany children and other family members and friends out of Labrador to aid with daily functioning and tasks were personally responsible for funding their own travel, a great burden and significant barrier to accessing timely medical care for many residents. Participants noted jurisdictional differences between communities in Labrador, so that Inuit and Innu patients received financial coverage for the accompaniment of a caretaker if needed. However, certain populations, most notably, low-income non-Aboriginal and Inuit-Metis residents limited to MCP coverage did not receive comparable funding and faced financial hardship coming up with the up-front costs of ravel for two poople. Participants said children, elderly, and those too sick to travel alone should be entitled to coverage for the travel costs of an accompanying caretaker.

Recommendation 8. That the provincial government provide financial assistance associated with the costs of return airfare for those individuals evacuated by air ambulance out of Labrador. Residents evacuated by emergency air ambulance out of Labrador reported being unprepared to cover the costs of airfare to return home to Labrador. Many of these residents were left stranded without financial assistance from the province for costs associated with accommodation or food to stay in the referral centre or travel to return home.

Recommendation 9. That the provincial government provide assistance to Labradorians requiring medical follow-up care and equipment on return to Labrador. As an isolated region, residents of Labrador face heightened challenges accessing medical equipment and follow-up care due to such things as provider shortages and limited availability of services. Individuals limited to MCP coverage did not receive any supports for follow-up care or equipment. It is essential that the provincial government take into account the factors that create challenges accessing health care services in Labrador for residents limited to MCP coverage.

Recommendations associated with the socio-cultural and political environment. The challenges created by the socio-cultural and political environment were identified as cultural landscape, jurisdictional coverage, historical and social context, cultural safety, and institutional racism. Analysis of suggested strategies to improve access to health care, determined to be the main strategies to be: Tele-health, bringing services to communities, the MTAP, and recruitment and retention and navigation tools to overcome challenges associated with the socio-cultural and political environment.

# See recommendations 1-3, 5, 6.

Recommendation 10. That Labrador Grenfell Health, Nunatsiavut Government and the College of the North Atlantic collaborate to implement short-term technical programs to recruit and train health care aides from Nunatsiavut. Participants raised concern that certain modalities of care, especially rehabilitation services were not offered on Nunatsiavut communities, and community members were required to travel for these services. Participants felt training should be offered for physiotherapy and rehabilitation aides, speech-language pathology aides, mental health care counselors, and midwifery and pre and post-natal maternal care aides that would decrease the number of residents leaving their communities to access follow-up care and consultations. Nunatsiavut participants felt that having more health care professionals from Nunatsiavut would improve access to needed health care services that were culturally safe and delivered by professionals who shared similar social, historical, and cultural roots as patients. This was especially pertinent to women who felt there was a severe lack of pre- and post-natal care available in their communities.

Recommendation 11. That Labrador Grenfell Health create a working group of Inuit, Innu, and Inuit-Metis Aboriginal and non-Aboriginal representatives from across Labrador to create and provide a mandatory cultural orientation program to all health care professionals that encompasses the historical, social, and cultural contexts that different communities face in the region. Participants reported that orientation programs for new working professionals in Labrador were inadequate and served to perpetuate stereotypes of Aboriginal communities. Some participants felt there was a lack of representation of all Aboriginal groups in orientation, which decreased cultural safety for Inuit patients accessing health care in Labrador and discouraged many Inuit residents from seeking medical care through the health care system. There was concern that cultural orientation was not offered to all health care professionals, but limited to physicians, so cultural competence among health care professionals was lacking in Labrador. Participants also felt it necessary that all new health care professionals were given ample time to complete the cultural orientation process.

Recommendation 12. That Labrador Grenfell Health, partner with Labrador Aboriginal organizations to re-establish an alcohol and drug treatment and rehabilitation center for Aboriginal adults grounded in traditional cultural healing practices. Inuit residents reported drug and alcohol rehabilitation and counseling services in Labrador and outside the region to be inadequate in addressing the complex needs of Inuit in Labrador tied to a history of colonization, social realities and traditional healing practices. Culturally safe programs available in the region that encompass traditional healing and cultural practices of Labrador's Aboriginal populations will ensure residents will have better access to more effective and that programs are compatible with the many diverse cultures in the region.

Recommendation 13. That Labrador Grenfell Health provide navigational support and connections for residents traveling outside of Labrador to access health care. Regional health authorities should create patient navigator positions to provide navigational support for all rural residents of the province. Although there are Aboriginal Patient Navigators available to help Inuit, Innu, and Inuit-Metis residents of Labrador in St. John's, participants highlighted the lack of navigation support for non-Aboriginal Labradorians accessing health care in referral centers outside of Labrador. Non-Aboriginal Labradorians discussed their distinct rural cultures and a lack of exposure to urban areas that leave them feeling confused, disoriented and lost. Participants suggested that patient navigators in referral centers should be available to help all residents of rural communities, regardless of cultural affiliation. Recommendation 14. That Labrador Grenfell Health in collaboration with the Labrador Friendship Centre create an interactive website thai enables residents and health care providers of Labrador to share experiences and advice on accessing health care within and outside Labrador. As documented in Chapter 6, participants felt there should be a community-run on-line navigational tool that enabled Labrador residents to communicate with each other, offer support and encouragement, and provide advice on specific health care services available in and outside of Labrador. Participants specifically mentioned that a list of specialist services covered under MCP should be available on the website and that the site provide an interface for residents to connect and seek advice from health care providers in the region.

Recommendations associated with gender. Gender-related challenges to accessing health care in Labrador included maternal health, seasonal hunting/trapping patterns, and family needs. The main strategies to overcome challenges accessing care associated with gender were identified as Tele-health and bringing services to communities.

# See recommendations 1-3.

Recommendation 15. That Labrador Grenfell Health and Nunatsiavat Government implement ultra-sound applications on video-conferencing units in Nunatsiavat communities. Traditionally, births in lnuit culture were a collective process of family units. In Labrador, women are required to leave their community three times during pregnancy which disrupts the family unit. Inuit participants felt strongly about being able to access maternal care at home. If these capabilities were present, pregnant mothers would not have to leave their communities twice during pregnancy to have routine ultra-sounds in Happy Valley-Goose Bay, thus decreasing stress to mother and baby and costs to Nunatsiavut Government.

Recommendation 16. That Nunatsiavu Government partner with community clinics to offer traditional Inuit midwifery training workshops with elders and midwives in communities for public health nurses and interested residents of Nunatsiavut communities. This initiative will ensure lnuit midwifery traditions are preserved and passed down through lnuit mothers and caregivers. One way to initiate midwifery knowledge sharing is to record experiences and stories of elder lnuit women who are experienced in the traditional midwifery practices. This initiative has taken place in lnuit communities in Nunavut and could be used as a practical example that guides the development of a similar initiative in Labrador.

Recommendation 17. That Labrador Grenfell Health, Nunatsiavut Government's Department of Health and Social Development and Memorial University's Labrador Institute collaborate/partner to investigate the effects of seasonal work and hunting/trapping patterns on health care utilization in Labrador. There is paueity in available literature looking at the influence on health care utilization during peak hunting/trapping seasons and periods of seasonal employment for men of Labrador. Research into this issue could stand to inform health care delivery and provision policies in Labrador.

Recommendations associated with continuity and comprehensiveness of care. Challenges accessing health care in Labrador created by continuity and comprehensiveness of care were identified as health care provider shortages and fit between community needs and services. Analysis of suggested strategies to improve access to health care, determined to be the main strategies to overcome challenges accessing care associated with continuity and comprehensiveness of care to be Telehealth, bringing services to communities, and recruitment and retention strategies.

### Recommendations 1-3, 10-16

Recommendation 18. That Labrador Grenfell Health employ a coordinator to compile issues faced by families of new health care professionals in Labrador and provide support in their achievement of optimum well-being in Labrador communities. Opportunities for spouses and families were seen as a central factor determining retention of health care professionals in Labrador. This finding is consistent with those faced in a lot of rural and northern regions (Curran, Bornstein, Jong and Fleet, 2004). One potential strategy to addressing some of the spousal and family issues faced by physicians in the region was identified by a participant as hiring a coordinator who dealt directly with physicians families. Considering the high turn-over rates of most health care professionals in the region, it is recommended that this coordinator work with all health care professionals as similar issues were identified from both the nursing, social work, and physician perspective in this study. This coordinator could liaise between community organizations and Labrador Grenfell Health and work on the development of community initiatives to help retain health care professionals in Labrador communities. This would improve continuity of care as residents would be able to access the same health care professionals and comprehensiveness of care as a broader scope of services would be available in isolated communities in Labrador.

Recommendation 19. That Nunatsiavut Government's Department of Health and Social Development, the College of the North Atlantic in Happy Valley-Goose Bay and the special advisor for Aboriginal affairs at Memorial University support and encourage more initiatives for Aboriginal and non-Aboriginal Labradorian students to pursue careers in medicine, nursing, social work and other health care professions. At the time of interviews, Memorial University held two seats for Aboriginal students in their medicine program. The Integrated Nursing Access Program was also identified as a strategy to encourage Inuit nurses to pursue careers in nursing. The Inuit Bachelor of Social Work program has also been successful with 18 Inuit students scheduled to graduate in May 2013. Initiatives for Labradorian students to pursue health care careers encouraging Innu, Inuit-Metis and non-Aboriginal students could stand to improve continuity and comprehensiveness of care in the region.

Recommendation 20. That Labrador Grenfell Health dedicate two physicians to the emergency department after 5 PM to ensure residents can access timely medical care. Participants identified challenges accessing emergency care after working hours because there was only one emergency physician working after 5PM in the emergency department, responsible for all patients in the Upper Lake Melville region and in isolated and south coast communities in Labrador. Participants believed this could decrease wait times for patients and stress levels of emergency physicians, thereby improving access to timely emergency care for Labradorians.

Recommendation 21. That Labrador Grenfell Health and Nunatsiavut Government work together to identify specific community needs in Labradorian communities and strategies to recruit specialists to conduct consultations and clinics with residents via Tele-health that fit the needs of the communities. Participants discussed the need for services that suit the specific needs of different communities in the region. Participants discussed how the Nunatsiavut Government's Department of Health and Social Development is cognizant of the differences between communities when implementing health care policies and programs in Nunatsiavut. Recruiting services through Tele-health is a cost-effective solution to improving the fit between needs and services in communities related to continuity and comprehensiveness of health care.

## Theoretical Implications

Although this research focuses on specific recommendations for the development policy and programming, there are also several theoretical implications that deserve discussion. First, I will expand on how mental health and addictions issues relate to perceived institutional racism in the Canadian health care. Second, I will address the issue of the improvement of access to health care services and the improvement of health status in Labrador.

The health care system, a central institution in society, has helped to shape colonialist relations in Canada (Smye and Browne, 2002). Aboriginal people face a history of forced dependency on western medicine that began during early contact with non-Aboriginal settlers who brought foreign epidemics that threatened the survival of some communities. Leaders were often offered medicine to treat diseases in their communities in exchange for religious conversion (Smye, Browne and Josewski, 2010). Smye, Browne and Josewski (2009) argue that the Indian Act of 1876 is the fundamental cause of tensions between Aboriginal people and the health system in Canada and that health needs of Metis and non-status First Nations people often go unaddressed. The breakdown of communities in terms of social, cultural and political structures can be linked directly to assimilation interventions and government control established by the

Indian Act. Smye, Browne and Josewski (2010) write "colonization, systematic oppression and neo-colonial forces of discrimination and institutional racism have threatened almost every aspect of Aboriginal identity – individually, as well as collectively" (p. 8).

Mental health and addictions problems are a long-standing issue among First Nations, Inuit and Metis communities across Canada (Canadian Institute for Health Information, 2004). Kirmayer, Fletcher, and Watt (2009) consider the Indian Act to be the paramount cause of high rates of suicide, depression, anxiety, and substance abuse in Aboriginal populations in Canada. Under the Act, nations were forced to abandon traditional lands and self-government and ceremonial and traditional practices integral to Aboriginal cultural and social life were prohibited (Kirmayer, Fletcher, and Watt, 2009). Aboriginal cultural and social life were prohibited (Kirmayer, Fletcher, and Watt, 2009). Aboriginal children were forced away from their families into residential schools and subjected to an institutional Christian regime that suppressed and punished expressions of Aboriginal culture including the right to speak their native language. Many survivors of residential schools have reported a high prevalence of emotional, sexual, and physical abuse in these institutions (Smye, Browne, and Josewski, 2010).

Profound changes in traditional lifestyle, such as the settlement of nomadic groups of people into a territory, are another important historical factor that influences mental health of Aboriginal people, Samson (2009) notes "Innu who were settled in the Labrador villages have suffered extremely high rates of suicide, alcohol abuse, solvent abuse and sexual abuse". Kirmayer, Fletcher and Watt (2009) report that Inuit have experienced similar changes in lifestyle over two generations including mandatory residential schools and social housing regimes that severely disrupted family cohesion. Institutional racism is often highlighted in regions where various cultural communities access the same social system (McGibbon and Etowa, 2009). A core foundation of institutional racism in the health care system surrounds the centrality of biomedical dominance (McGibbon and Etowa, 2009). In Labrador, diverse cultural communities access the same health care system and participarts discussed racism present in health care policies and programs within this system. Although other factors produce inequity in access to health services in Labrador, the role of biomedicine and allopathic treatments need scrutiny. As mentioned in the literature review, Ivan Illich (1975) discusses the notion of medically-induced illness caused by a dependency on the health care system, which he termed social iatrogenesis.

Health care professionals are accustomed to learning complex theories and concepts within the biomedical sciences. However, they have far less exposure to complexities of perspectives in health beyond the biomedical viewpoint that encompass core theoretical concepts necessary for anti-racist practices, such as the human rights perspective (MeGibbon and Etowa, 2009). In order for anti-racist health care practice to develop, health care institutions must embrace larger contexts that surround health and bring them into practice arenas and institutional policies.

Much has been lost in the dismissal of Indigenous... knowledge and the privileging of the biomedical model over all other forms of knowing about health in Canada. We begin to see what we have lost when we consider the sophistication of Indigenous healing patterns and rituals when compared to Western intervention for traumatic stress. (McGibbon and Etowa, 2009, p. 108) There was significant concern for the lack of effective mental health and addictions services in Labrador and Nunatsiavut communities at the time of interviews. One factor that sustains inequities in mental health of Aboriginal people in Canada is the disconnection between Aboriginal understandings of mental health that incorporate mental, physical, and emotional factors and biomedical approaches to mental health care that respond primarily to individuals and physical bodies (Smyc, 2004).

Mainstream mental health services and programs are recognized as ineffective and inaccessible to Aboriginal people in Canada (Canadian Institute for Health Information, 2004). Participants in the present research identified the need for culturally safe mental health services and also discussed how mental distress arose through experiencing racism in the health care system in Labrador. If biomedical frameworks are used to assess and intervene in cases of mental distress, most physicians use a clinical checklist for assessment, which requires objectivity and dispassion and attributes mental illness to individual problems with individualized solutions rather than systemic problems requiring system wide adjustments. Mental distress associated with racism is identified as an individual psychiatric disorder and the paramount solution for treatment is prescribed through psychotropic medication. Identifying institutionalized racism embedded in the bio-medical framework is the first step to overcoming mental distress.

A second theoretical implication arising from this research is the link (or lack there of) between improving access to health care services and improving health status. Illich (1975) contends that dependence on the bio-medical system as the only way to improve health deters individuals from integrating traditional healing systems into modern practices of coping and healing.

Social justice frameworks provided a blueprint of ways to think about and react to

health issues among populations in Labrador. For example, participants spoke of the many challenges they face accessing the health care system. However, participants also felt there was too much focus on health care services as a way to improve health, rather than addressing deeper societal, cultural and historical factors in Labrador that influence health in some communities. Implicit within these discussions was the notion that many communities in the region are in "survival-mode" due to centuries of oppression, colonization, and racism. Many participants felt full financial coverage for health care was creating an even greater dependency on the health care system in Nunatsiavut communities in Labrador.

This research does not contend that improving access to health care services improves health status in Labrador. Intentions to improve health status require thorough investigation into cultural, social, and historical contexts of human health in Labrador. However, social justice approaches to health that contend society's benefits should be shared equally among populations, demonstrate it is equally important that residents of Labrador are able to access timely medical interventions when needed. This research seeks to inform policies and programs that can improve access to health care services for all communities in Labrador.

# Conclusion

This research project fills a gap in available knowledge surrounding access to health care in Labrador and other isolated and Aboriginal communities of Canada's north by exploring health care access concerns of two diverse communities as a way of highlighting the common and distinct issues influencing access to health services throughout Labrador. It lays a foundation upon which further research examining the

many complex factors influencing access to health care services in the diverse Aboriginal and non-Aboriginal communities in Labrador can be constructed and explored.

Chapter 1 introduces my understanding of reasonable access to health care services. This research reaffirmed the complexity of factors that surround access to health care services, and enhanced my understanding of what access to health care services means in the Labrador context. In interviews, participants identified 13 challenges accessing health care related to the physical environment, socio-cultural and political environment, gender, and continuity and comprehensiveness of care. Results of this study indicated several notable findings: First, differences in jurisdictional coverage between cultural communities in Labrador meant some residents faced significant out-of-pocket costs associated with traveling to reach needed health care services. Participants identified the need for the expansion of the MTAP to specifically address the needs of low-income individuals who face significant financial barriers to accessing necessary health care. Second, Aboriginal and non-Aboriginal Labradorians expressed a significant need for cultural safety within the health care system in Labrador and outside the region. There was recurrent mention of lacking mental health and addictions services for individuals with multiple and complex needs. Examining the barriers to accessing health care in Labrador through a social justice lens can help illustrate areas of injustice in the health care system and inform the development of socially just health care delivery and provision in the region that may improve access to health care services for all Labradorians

Participants identified several effective strategies to overcome challenges accessing health care in Labrador. The most notable strategies to improve access to health care services in Labrador were Tele-health, bringing services to communities, recruitment and retention, navigation tools, the MTAP, Medevac and Schedevac. Tele-health and bringing services to communities were the two strategies that prevail the challenges accessing health care in Labrador created by all four themes outlined in this research and deserve priority.

The 21 recommendations address inequities in health care access for Labradorians and provide suggestions for improvement at both the regional level through community organizations, health authorities, training institutes, universities and the provincial level through the Government of Newfoundland and Labrador. The recommendations can be used to inform the development and implementation of health policies and programming in the area of health care delivery and provision in Labrador and other rural and northern regions of Canada. My findings suggest that access to health care services in Labrador can be improved if the diverse cultural, social, political, physical, gender, and systemic realities of Labrador communities are appreciated and strategies are adapted to the identified needs of rural residents living in the diverse communities of Labrador.

## Limitations

There are a few limitations in the research design that should be considered when applying the findings to inform policy related to health services access and provision in Labrador. First, Happy Valley-Goose Bay residents were able to speak with me in the comfort of their home community. Interviews with Nunatsiavut members, however, were conducted outside of their communities while they were in Happy Valley-Goose Bay accessing health care and residing at the Labrador Friendship Center hostel. Interviews were conducted in shared hostel rooms and although I was alone with each interviewe for the duration of the interview, participants may have limited the information they revealed due to fear of being overheard by other residents or by hostel staff who were affiliated with the health care system. Second, due to the nature of recruitment, I was able to organize Happy Valley-Goose Bay community member interviews in focus groups. I was unable to do the same for Nunatsiavut community members, so interviews were conducted on an individual basis, which may have influenced the comfort level of participants and the quality of the data generated. Third, I was only able to interview community members from Happy Valley-Goose Bay and four of five communities in Nunatsiavut due to financial costs and timing constraints of my masters project. Although this study addressed the experiences of many Labradorians, the research findings are specific to the selected communities and research participants. As with other qualitative research, the findings are context specific recommendations should be applied with caution to other similar communities in Labrador.

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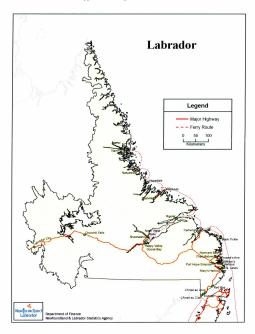
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Appendix A: Map of Labrador

#### ACCESS TO HEALTH CARE SERVICES IN LABRADOR

#### Appendix B: Labrador Grenfell Health, Nunatsiavut Government, and ICEHR Research Review Approval

2 November 2010

Gioia Montevecchi Division of Community Health and Humanities Faculty of Medicine Memorial University of Newfoundland St. John's NL

### Dear Ms. Montevecchi,

The Labrador-Grenfell Health Research Review Committee has reviewed your application for a study on 'Factors Influencing Access to Health Care Services in Labrador and has approved the portion of the study to be conducted in Happy Valley-Goose Bay. We are aware that you are awaiting response from the Nunatisarut Government's Research Review Committee on your aim to conduct interviews in the community of Nain for a comparative basis for your study.

I regret to inform you that information from community needs assessments conducted this year and in 2005 by the Labrador-Grenfall Health Authority was primarily intended as a reference for its Board in developing a strategic plan for health services and consequently is not available for public use. Most of the information is qualitative and must be interpreted in the context of community and regional operations.

When your study is completed, please forward a report of the results in an electronic PDF format to me for dissemination within the organization. Best wishes for success with the project.

Sincerely,

Carol Brice-Bennett Director, Aboriginal Health Programs & Research Labrador Grenfell Health Authority P.O. Box 7000 Stn C Happy Valley-Goose Bay, NL, A0P 1C0 carol brice-bennet@glehealth ca



Nunamik amma Nunamiutanik

Lands and Resources

19th November 2010

Gioia Montevecchi, BSc, MSc Med AHSR (c) No Address Provided MUN (709)899-2636 gioia.montevecchi@mun.ca

#### Re: Research Proposal - Factors Influencing Access to Health Care Services in Labrador.

Dear Ms. Gioia Montevecchi, BSc, MSc Med AHSR (c):

As stated in the Research Process a review to your proposal was initiated, involving appropriate Inuit Community Government(s) and NG staff ensuring for a comprehensive review.

Please accept this letter as confirmation of the Nunatsiavut Government's support for the above research project as outlined in your application, subject to the following suggestions:

- Thank you for the unsigned e-copy of the ethical approval letter. Please provide a scanned ecopy of the signed ethical approval letter from the Interdisciplinary Committee on Ethics in Human Research (ICEHR) and the Labrador -Gernfell (LG) Health for this project.
- As per the meeting between Gioia Montevecchi and the Department of Health and Social Development (DHSD). The project is supported based on adherence to the following conditions:
- Key informant interviews with departmental staff of DHSD will be undertaken with the assistance of the Researcher/Evaluator of the Department to assist with making the appropriate connections.
- b) Key informant interviews with individuals from the community will be conducted by informing beneficiaries who are traveling through Happy Valley - Goose Bay, who are staying at the Labrador Friendship Centre, of the study. Anyone wishing to participate in the survey will be able to contact the Researcher.
- c) Materials prepared for the interviews will be translated to Inuktitut if needed (e.g. Consent form, questionnaire, etc.) and if an individual identifies that a translator is required, one will be made available prior to the interview.
- Please provide copies of any reports, journal articles, papers, posters or other publications related to this project to the Nunatisavul Intuit Research Advisor and the Director of Health and Social Development, Nunatisavul Government and the Inuit Community GovernmentScorporations of Nain and Happy Valley Goose Bay upon completion of your work.

A plain language summary detailing the work, translated into Nunatsiavut Inuktitut should also be provided.

NG would appreciate copies of any photographs that you acquire during your research in the Nunatsiavut area as Nunatsiavut Government is developing a digital database of regional photos. Recognition will always be diven to the photographer.

Please note that if you are going to make any changes to your proposal, any such changes must be considered and supported by the NGRAC before they are implemented.

We thank you for considering our feedback on your work and look forward to more collaboration.

Sincerely,

John Lampe Chair, Nundstavut Government Research Advisory Committee Nundstävut Government 25 Ikajuktauvik Road P. O. Box 70 P. O. Box 70 Nain, NL, Canada A0P 1L0 Tel: (709) 922-2942 Ext. 235 Fax (709) 922-2942 Ext. 235

#### 17 Sandbanks Road, PO Box 70, Nain, NL, Canada AOP 1L0 ) Tel: 709.922.2942 Fax: 709.922.2931 ) Email: nain\_reception@nunatsiavut.com

Makkovik PO Box 92 Makkovik, NL AOP 1,0 Tet, 709,923,2365 Fax: 709,923,2365	Hopedale PO Box 91 Hopedale, NL, ADP 100 Tet: 709,933,3777 Fax: 709,933,3746	Higolet PO Box 47 Repolet, NL: AGP 100 Tel: 709.947.3383 Fue: 709.947.3371	Postville Gervral Delivery Proteille, Nr. ACP 1005 Tel: 710 179,9890 Fax: 710 179,9991	Happy Valley - Goose Bay SA Heorist Pool. PO Box 500, Str. 12 Happy Varity - Goose Bay, NL, ARP 160 Happy Varity - Goose Bay, NL, ARP 160 For 700, 806, 2510 Fax: 700, 806, 2510	North West River 2-13 River Roat, PO Ber 234 North West River, NJ, AOP 550 Tell, 728-077,0200 Fax, 709-097,0311
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www.nunatsiavut.com

August 27. 2010

#### ICEHR No. 2009/10-190-ME

Ms. Gioia Montevecchi Division of Community Health and Humanities Faculty of Medicine Memorial University of Newfoundland

Dear Ms. Montevecchi:

Thank you for your submission to the Interdisciplinary Committee on Ethics in Human Research (ICEHR) entitled "Factors influencing access to health care services in Labrador".

The Committee has reviewed the proposal and appreciates the care and diligence with which you have prepared your application. We agree that the proposed project is consistent with the guidelines of the Tri-Council Policy Statement on Editical Conduct for Research Involving Humanu (TCPS). Full ethics clearance is granted for que greag from the date of this letter.

Although ethics clearance has been grateful we would like to point out that there is an inconstruction; in the promise of ancorporty under the rections of "Confidentiality" vancomputy" and "Annovputy". The Communice magnets that you should not promise complete ancomputy under "Confidentiality vs. Annovputy" since there is a "possibility that is now protricements new to identifyible on the basis of employment position or community involvement. As little identifying information as possible..." (see "Annovputy")

If you intend to make 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 <u>Hyer/Intua.ca</u> for the Committee's consideration.

The TCPS requires that you submit an annual status report on your project to ICEHR, should the research cany on beyond August 2011. Also, to comply with the TCPS, please notify us upon completion of 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/bl

cc: Supervisors – Dr. Victor Maddalena, Division of Community Health and Humanities Dr. Diana Gustafson, Division of Community Health and Humanities

Telephone: (709) 864 2561 / 864 2861

Fax: (709) 864 4612

## Appendix C: Health Care Administrator and Provider Email Recruitment Script

Dear Participant;

## Invitation to take part in research looking at factors influencing access to

## health care in Labrador

You are invited to participate in a research study that intends to explore the factors that influence access to health care in two diverse communities in Labrador – Nunatsiavut and Happy Valley-Goose Bay. If you would like to participate, you will partake in a face to face interview of approximately 45-90 minutes with the researcher that will explore your experience with the factors that influence health care access in your community.

Interviews and all data associated with them will be kept strictly confidential and you will not be identifiable in any way. Your participation is completely voluntary and no negative impacts will occur if you choose not to participate in this study.

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. The proposal has also been reviewed and approved by the Labrador-Grenfell Regional Health Authority.

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/amun.ca or by telephone at 709-737-2861.

If you are interested in participating, would like further information about this research and/or would like to organize an interview, please contact:

Gioia Montevecchi: Principal Researcher, MSc. Med. (Health Services Research) candidate

Phone: (709) 899-2636

Email: gioia.montevecchi@mun.ca

Sincerely,

Lisa Densmore

Regional Partnership Planner for the Executive Council of the Rural Secretariat

## Appendix D: Focus Group Email Recruitment Script for Happy Valley-Goose Bay Community Members

## Invitation to Participate in a Focus Group to Discuss Factors that Influence Health Care Access in Happy Valley-Goose Bay

You are invited to participate in a research study that intends to explore the factors that influence access to health care in Happy Valley-Goose Bay. Have you recently accessed health care in Happy Valley-Goose Bay? Are you living with a chronic condition? Have you recently been referred out of the region to access specialist care or emergency care?

If you are a resident of Happy Valley-Goose Bay, answer yes to any of the above questions and would like to participate, you will partake in a focus group interview (a small group discussion of approximately 45-90 minutes) in your community with three other participants of the same gender. The focus group discussion will explore your experience with the factors that influence health care access in your community. Data and time will be determined based on convenience of participants.

This research is funded by the Rural Secretariat and the Atlantic Aboriginal Health Research Program. It has been approved by the Interdisciplinary Committee on Ethics in Human Research at Memorial University, the Labrador-Grenfell Regional Health Authority, and the Nunatsiavut Government. Interviews and all data associated with them will be kept strictly confidential and you will not be identifiable in any way. Your participation is completely voluntary and no negative impacts will occur if you choose not to participate in this study. You will receive \$30 in remuneration for your participation in this research.

If you would like more details about this research, please contact:

# Gioia Montevecchi: MSc. Medicine (candidate), Faculty of Medicine, Division of Community Health and Humanities, Memorial University

Phone: (709) 899-2636, Email: gioia.montevecchi@mun.ca

Sincerely,

Lisa Densmore: Regional Partnership Planner for the Executive Council of the Rural Secretariat

Appendix E: Health Care Administrator and Provider Interview Guide

Because Labrador is a geographically diverse place, do people in different geographic regions experience differential access to health care services? Which regions face the most challenges accessing health care services?

Labrador is also a culturally diverse region. Are factors influencing access to health care services experienced similarly between cultures in Labrador? How do jurisdictional differences in health care provision effect the accessibility of health care services in Labrador?

What are the most significant challenges Labradorians face when accessing health care services within their communities? What are the most significant challenges when they travel outside of their community?

probe for: geography, weather, availability of services, finances, cultural/language barriers - how do they impact access

We know that one of the biggest challenges facing rural Canadians when accessing health care is the shortage of health professionals. What challenges do health professionals face in Labrador? Are there health care positions here that are untilled? What recruitment strategies are in place?

Women generally have more frequent and intimate contact with the health care system. What challenges do women face in accessing maternal care in Labrador?

What challenges do men face when accessing health care?

What helps residents access health care? How can these factors be acted upon to improve access to health care? How can these services better accommodate Labradorians specifically?

How can these services be utilized to improve access to health care services?

What programs or services help residents in Labrador access health care outside of their communities? How do they operate effectively, given limited resources?

probe for: Tele-health, Schedevac, Medevac

What cultural or language programs are in place to help residents of Nunatsiavut communities?

In your opinion, which programs/services need to be implemented or improved to make health care services more accessible throughout Labrador?

## Appendix F: Community Member Interview Script

Do you feel you have all the health care services you need in this community? If not, what resources are missing?

When a resident needs to travel outside the community to access health care services, what are the challenges they face? How does this impact:

..finances: What costs do community members face when traveling outside of this community? How do community members cope with these costs?

...sense of well-being. Do you feel confident that you will receive the health care services you need when you need them?

..ties to your community. What kinds of supports do you receive from the community? Fundraisers, child-care, emotional..

Do community members seeking health care services generally travel in families or alone?

Do you feel respected when you access care elsewhere? Are your cultural needs met?

What supports do you receive in larger centres? How does this impact your choice to access health care services outside of your community?

Do you feel every community in Labrador has equal access to health care? If not, who do you think has the least access? Who do you think has the best access?

If you had the chance to talk to government about your concerns with accessing health care services in Labrador, what would you say to them

## ACCESS TO HEALTH CARE SERVICES IN LABRADOR

## Appendix G: Consent Form



## Faculty of Medicine, Division of Community Health and Humanities

Consent to Take Part in Health Research

Factors Influencing Access to Health Care Services in Labrador

searcher(s): Gioia Montevecchi, Memorial University, Faculty of Medicine (709) 899-2636, gioia.montevecchi@mun.ca

pervisor(s): Dr. Victor Maddalena, Memorial University, Division of Community Health and Humanities, Faculty of Medicine, <u>victor.maddalena@med.mun.ca</u> Dr. Diana Gustafson, Memorial University, Division of Community Health and Humanities, Faculty of Medicine, <u>diana.gustafson@med.mun.ca</u>

You are invited to take part in a research project entitled "Factors Influencing Access to Health Care Services in Labrador".

This form is part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. It also describes your right to withdraw from the study at any time. In order to decide whether you wish to participate in this research study, you should understand enough about its risks and benefits to be able to make an informed decision. This is the informed consent process. Take time to read this carefully and to understand the information given to you. Please contact the researcher, Gioia Montevecchi, if you have any questions about the study or for more information not included here before you consent.

It is entirely up to you to decide whether to take part in this research. If you choose not to take part in this research or if you decide to withdraw from the research once it has started, there will be no negative consequences for you, now or in the future.

## Introduction

This research is being conducted by Gioia Montevecchi under the supervision of Dr. Victor Maddaten and Dr. Dinan Gustafson in the Division of Community Health and Humanities at Memorial University. Financial support for this research has come from the Executive Council of the Kural Secretariat of the NewYoundland and Labrador government and the Mitas Accelerate Porgram. The study is briegine conducted to fulfill the requirements of a Master's in Science in Medicine in Applied Health Services Research (AHSR) through the Atlantic Regional Training Centre.

The aim of this project is to inform policy on access to health services in Labrador. It will to examine the factors influencing access to health care services from the perspective of health care providers and health care users throughout the region.

le:

The goal of the research is to explore how and how well individuals living in two different communities in Labrador access health care services. Two distinct communities (Nain, an Inuit, northern, isolated, coastal community and Happy Valley-Goose Bay, a multi-cultural, non-isolated community were selected to highlight the diversity of factors accessing health care issues in Labrador. The information generated from this project will be helpful to residents of Labrador who use health care services within and outside of the region, providers of health care services, health researchers in Labrador, and government departments responsible for health care services.

This research will create a report that will be submitted to the appropriate government offices from the Rural Secretariat to inform policy on health care delivery and accessibility in Labrador.

#### Purpose of study:

The purpose of this study is to:

1) outline factors that effect access to health care services from a Labradorian point of view,

2) lay a base for future health research,

3) add to the current knowledge on Labradorians' experiences with accessing health care in the region for health care organizations, providers, and community members, and 4) inform the development of health and community services policies and programming in the area of health care delivery and access in a report from the Rural Secretariat to the provincial government, the Nunatsiavut Government and the Labrador-Grenfell Regional Health Authority.

## What you will do in this study:

You, as a participant, will be interviewed about your experiences with accessing health care services within or outside of Labrador. Interviews will be held at a time and place convenient to you. Interviews with stakeholders and providers will be individual face to face interviews. Interviews with community members will be small (4 people and the researcher) group discussions about accessing health care within the community. The interviews will be taped and transcribed to text.

You will have the opportunity to read through the text of your interview after it has been transcribed if you wish to do so. You will not be required to participate in anything after the interview if you do not want to.

## Length of time:

Interviews are expected to take between 45 and 90 minutes.

## Withdrawal from the study:

Your participation in the research will pose no harm to you and is entirely voluntary. You can stop your participation in the research at any time, with no prejudice or penalty. If you decide you would like to remove your participation after completion of the interview, you can do so up until the data has been de-identified and combined with the other interview data. All your information will remain completely confidential and anonymous. You will not be able to be personally identified by any of your responses. When data-analysis is complete, the audio portion of your interview will be destroyed. Only Gioia Montevecchi, Dr. Victor Maddalena and Dr. Diana Gustafson will have access to the data from this research project. All data will be retained for a period of five years in a locked and protected location in Dr. Victor Maddalena's office, and will then be destroyed.

## **Possible benefits:**

It is not known whether this research will be of direct benefit to you, but you may find it helpful to share and discuss your experiences regarding the access of health care throughout Labrador and involvement in a project that will allow you to take social action and influence positive community development.

This research will add to the knowledge base of health care providers and organizations and encourage further research into the factors that influence health care access in Labrador. It has the capacity to inform the development of health and community services policies and programs within the federal, provincial, and regional governments and the Labrador-Grenfell Regional Health Authority.

## Possible risks:

This research does not involve more than minimal risk to you. There is a possibility, however, that you may choose to discuss an emotionally disturbing event or experience. If you become upset during the interview, we can take a break or turn off the audio recorder and talk through it, or stop the interview and reschedule it at a later time. If you are in need of emotional support, a member of the Rural Secretariat regional council will help you find counseling support.

## Confidentiality vs. Anonymity

All your information will remain completely confidential and anonymous. You will not be able to be personally identified by any of your responses. When data-analysis is complete, the audio portion of your interview will be destroyed. Only Gioia Montevecchi, Dr. Victor Maddalena and Dr. Diana Gustafson will have access to the data from this research project. All data will be retained for a period of five years in a locked and protected location in Dr. Victor Maddalena's office, and will then be destroyed.

## Confidentiality and Storage of Data:

- a. The data will be kept completely confidential. Your name will not be included on the transcript of the interview. The researcher will review the transcript to ensure there is no information that may identify you or your role in the community.
- b. The audio-recordings of the interviews will be stored on a computer in Victor Maddalena's office where they will be password protected and where the researcher will transcribe them into text and then destroy them. Only the researcher (Gioia Montevecchi) and her supervisors (Dr. Victor Maddalena and Dr. Diana Gusafson) will have access to the transcripts. The researcher will keep a list of the participants in the study, but this list

will be kept in a password protected file separate from the transcripts.

The transcripts (for research purposes) will be kept with the researcher, Gioia Montevecchi, in password-protected files until the completion of her Master's thesis. After completion of her thesis, the files will be kept in a password-protected file on Dr. Maddalena's computer at Memorial University for five years and then destroyed.

#### Anonymity:

Every reasonable effort will be taken to make sure you remain anonymous. You will not be identified in the thesis, or any reports and publications arising from this research. Since this research is taking place in small communities, there is possibility that some participants may be identifiable on the basis of employment position or community involvement. As little identifying information as possible will be included in final reports and publications. You will be given the opportunity to review the transcription to make sure you are comfortable with the way in which information is disclosed.

#### Recording of Data:

To ensure security of the interview content, the interviews will be recorded as an audio file on a voice recorder. All audio files pertaining to these interviews will be password protected. All audio files and transcribed interviews will be transferred to a computer in Dr Maddalena's office on the Memorial University premises where they will be analyzed and stored securely. The audio files will be destroyed after interviews are transcribed. The transcribed interviews will be kept securely for future consultation for five years at which point they will be destroyed.

## **Reporting of Results:**

Results will be used for academic purposes (at local and national conferences, and in academic journals), presentations and reports to researched communities, and submission of a report to the appropriate government offices and departments.

## 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:

Gioia Montevecchi, MSc. student (709)899-2636 gioia.montevecchi@mun.ca

or

Victor Maddalena, BN, MHSA, PhD (709) 777-8539 <u>Victor.maddalena@med.mun.ca</u>

The proposal for this research has been reviewed and approved by the Labrador Grenfell Regional Health Authority and the Nunatsiavut Government in Labrador and was found to be in compliance with Memorial University's ethics policy by the Interdisciplinary Committee on Ethics in Human Research. 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/amunca or by telephone at 709-737-2861.

## 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 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.

If you sign this form or give consent verbally and the researcher documents this on your form, you do not give up your legal rights and do not release the researchers from their professional responsibilities.

## Your signature or verbal consent:

I have read and understood what this study is about and appreciate the risks and benefits. I have had adequate time to think about this and had the opportunity to ask questions and my questions have been answered.

- I consent to participate in the research project understanding that my participation is voluntary and that I may end my participation (withdraw) at any time.
- Any data collected from me up to the point of my withdrawal from the study should be destroyed
- Any data collected from me up to the point of my withdrawal from the study may be retained for use in the research study
  - I agree to be audio-recorded during the interview/focus group
  - I agree to be quoted

A copy of this Informed Consent Form has been given to me for my records.

Signature of participant

Date

In case of unwillingness to give written consent, verbal consent will be documented by the researcher.

In addition to the above, I agree to allow the researcher to document my verbal consent in writing.

Signature of researcher on behalf of participant

## **Researcher's Signature:**

These explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

Signature of Principal Investigator

Date

