

**Self-Determination in Health Care:  
A Multiple Case Study of  
Four First Nations Communities in Canada**

by

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for the degree of Doctor of Philosophy

Dalla Lana School of Public Health  
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## Abstract

The perceived level of self-determination in health care in four First Nations communities in Canada is examined through a multiple case study approach. Twenty-three participants from federal, provincial and First Nations governments as well as health care professionals in the communities of Blood Tribe, Lac La Ronge, Garden Hill and Wasagamack First Nations provided insight into the diversity of perception of self-determination in First Nations health care. The difference in definition between Aboriginal and the federal and provincial governments is a factor in the varying perceptions of the level of control First Nations communities have over their health care system. Participants from the four First Nations communities perceived their level of self-determination over their health care system to be much lower than the level perceived by provincial and federal government participants. The organization and delivery of health care is based on the location of the community, the availability of the human resources, the level of communication, the amount of community resources, and the ability to self-manage. The socio-political history including impact of contact, residential schools, and integration of Aboriginal worldview are factors in the organization and delivery of health care as well as the perceived level of self-determination that the community sees. The duration and intensity of contact influences how health care is organized as the communities become more familiarized with the biomedical model that most Canadians use.

Having a holistic health care system that includes acknowledging the socio-political history, culture, language, worldview and traditional medicines is important to the four First Nations communities, but this has not been fully embraced in any of the communities. Despite their differences, all four communities are working toward self-determination that hopefully would result in an ‘ideal’ First Nations health care system which is holistic, cultural, spiritual, and interdisciplinary and ultimately lead to full management of the health care system.

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# Chapter 1

## Defining the Problem of First Nations Health Care

### 1.1 Introduction

There is growing evidence that First Nations people living on reserves in Canada have poorer health compared to other Canadians (Waldram, Herring, & Young, 2006). There is a higher prevalence of diabetes and other chronic diseases that put an excessive burden on the health care system due to the increased risk of further complications.

Health care for First Nations people in Canada is severely tested in dealing with the emergence of “new” diseases such as diabetes. Diabetes in First Nations communities is a modern issue, but dealing with the health of First Nations people began prior to Confederation. With the enactment of the *British North America Act* in 1867, provinces were given the responsibility of education and health care, while the federal government was given the responsibility of ‘Indians and their lands’ (Boyer, 2003). This has created jurisdictional confusion and uncertainty that has prevailed to the present day. For Canadians in the “mainstream”, health care has evolved since Confederation. Today, under the *Canada Health Act*, health care is funded under a complex federal-provincial formula and is provided to all citizens at no direct cost. However, First Nations people are subject to the federal government’s health and health care policies that are uniquely tied to history, treaties, nation-building, and a colonial policy of assimilation (Borrows, 2010). First Nations people were not consulted or advised regarding policy development or legislation. The early relationship between the federal government and First Nations was characterized by the government’s perception that First Nations people were ‘savages’ in need of ‘civilizing’. Over the past three decades, many First Nations communities have worked with the federal government to transfer health services to community control. However, some provinces and territories are uncertain of their role in First Nations health care. Jurisdictional issues occur in every province and territory across Canada where First Nations affairs are concerned, especially in the area of health care policy.

Primary health care provided to First Nations people living on reserve varies based on a number of factors (i.e. funding, population size, location of community, access to community, relationship with governments and other health stakeholders, etc.). However the Indian Health Policy of 1979 (Crombie, 1979), which now serves as the basis for policy and decision making within Health

Canada's First Nations and Inuit Health Branch (FNIH), stated that the federal government is to assist First Nations and Inuit communities to achieve more control of their health care. Thus First Nations communities should be, according to the federal government reports and policies, moving toward self-determination and self-governance.

Through the enactment of the *British North America Act*, 'Indians' became wards of the state with limited rights and freedoms (Borrows, 1994; J. Miller, 1990). Many other policies and legislations, such as the *Indian Act* of 1876 and the White Paper of 1969, have created tension in the relationship between Aboriginal people and the federal government. Due to this tension and the First Nations (the current term used for 'Indians') belief that they have an inherent right of sovereignty, they continue to strive for self-determination with the freedom to choose how to express "their identity, their sense of themselves and the character of their relations with others" (Royal Commission on Aboriginal Peoples, 1996b, p. 108). Returning to being self-determining and self-governing will assist with revitalizing and reclaiming their cultural identity, which has been shown to be a protective factor for health (Chandler & Lalonde, 1998; Warray, 1998, 2007). Therefore reclaiming cultural identity can assist First Nations people and communities may promote self-determination in their health care systems and may ultimately improve their health.

Both the federal government and First Nations communities believe that they have been working toward self-determination in health care, with the idea that this would lead to improved health of their population. As will be discussed in Chapter 2, the very definition of self-determination is in question and may reflect the ambivalence First Nations experience when dealing with the federal government in an attempt to attain 'control' of their health care system. The Harvard Project on American Indian Economic Development (n.d.) found that the Choctaw Nation did improve the health of their citizens after taking control of their health care system, and similar observations have been made in other American Indian tribes also.

According to Indigenous scholars (Buchan, 2003; Prince & Abele, 2003; Royal Commission on Aboriginal Peoples, 1996d) and for the purposes of this study, self-determination is the ability of an individual, family and/or community to have more than administrative control over their health care and health services, which are culturally relevant and empathetic to the socio-political history that First Nations people have endured.

With the increasing incidence rates of chronic diseases, access to health care in First Nations communities has gained importance. Self-determination in health may hold the key to providing culturally sensitive health services to match evolving health care needs of First Nations communities. This self-determination in health care may be the catalyst that could promote self-governance in other aspects of First Nations communities such as education, community development, cultural traditions and policy development (J. Graham & Wilson, 2004).

In order to improve First Nations health care, it is necessary to understand the potential organization and delivery structures that correspond to different levels of self-determination. Using an Indigenous methodology (the Medicine Wheel framework shown in Chapter 3), this study looks at four First Nations communities in western Canada, in three provinces and from three treaty areas, to ascertain what some First Nations health care systems look like, the level of self-determination that the three levels of governments (federal, provincial and First Nations) perceive exists, and some key factors that are connected to self-determination in health care.

Some scholars (Lavoie, 2011; Romanow, 2002; Royal Commission on Aboriginal Peoples, 1996d) stress that certain factors are required for self-determining First Nations health care systems, such as strong and open communications, adequate funding, and leadership capacity. Health Canada (2004a) and First Nations Healing (2010) state that these factors can move First Nations communities toward an ideal First Nations health care system that is culturally and linguistically responsive and provides communities with increasing self-determination. The structure or organization and delivery of health care in First Nations communities are not well documented in the literature. Warry (1998) argues that it would be difficult to examine how self-determination influences health care as there are many variables that can influence the level of self-determination that communities have or strive to achieve. Lavoie (2011) acknowledges that there is a patchwork of policies and programs to meet the health care needs of First Nations people, but does not provide any details about the organization of First Nations health care systems. Health Canada (2004a) released the Handbook on Health Transfer, which vaguely outlined the necessary components of a First Nations health system that are required to enter into a health transfer policy. Blood Tribe in Alberta, Lac La Ronge Indian Band (LLRIB) in Saskatchewan, Garden Hill and Wasagamack First Nations in Manitoba have all entered into health transfer agreements with First Nations and Inuit Health Branch (FNIH) of Health Canada. Each of these four communities has followed the mandatory steps to enter into a health transfer

agreement and is working toward further self-determination, and aspires to self-government. These four First Nations communities are the basis for this study.

## 1.2 Situating Myself

In my previous educational studies, I was situated within the social sciences, specifically in sociology. As social scientists, we are trained to situate ourselves in our work so that there is no misinterpretation about researcher bias or the lens the researcher uses for interpretation. Wilson (2008) states that it is necessary to follow the relationship protocol of introducing oneself when Indigenous research is conducted by Indigenous researchers. This includes the relationship to family and the land, which is the way that Indigenous people introduce themselves within Indigenous communities. Therefore, I wish to situate myself within this research.

Kwe, kwe, nurturuwins Ageeshegeshik. In English: Hello, my Algonquin name is Ageeshegeshik, or Eagle that Cradles Spirit. I am an urban Algonquin woman, who has lived in Toronto, but spent considerable time in my traditional territories of Timiskaming First Nation in northern Quebec. As an urban Aboriginal person, I have experienced and dealt with similar socio-political issues from our collective history as many of my relations have done while living on reserves. However, I have not experienced living on the land in remote parts of the country, nor have I shared the experience many First Nations people living in such environments had in accessing modern health care. I do believe that my worldview is grounded in Aboriginal culture and traditions, but mixed with a western worldview. Cardinal (1969) argued that an Aboriginal worldview, culture and language can be incorporated into modern Canadian life. Although I have always resided in an urban area, I have knowledge and experience of my Indigenous culture, language and traditional teachings.

For ten years I worked at Health Canada and the Public Health Agency of Canada, where I began to notice that policies and programming were created and administered differently depending on where First Nations people reside. This was intriguing and troublesome to me. I returned to graduate studies to further explore why Aboriginal issues persist and how I might be able to assist all Aboriginal people in achieving better health care regardless of their residence or status. During my work in community-based social programs, I learned the importance of the social determinants of health for vulnerable populations, especially First Nations people living on reserve. This awareness and knowledge compelled me to learn more about Aboriginal health systems, and hence the desire to complete this dissertation.



Through my studies in sociology, I have developed an affinity to Marxism and postcolonial theories. Marxism provides a social and economic lens for looking at First Nations issues, whereas postcolonial theory provides a way of decolonizing and allowing the voice of the oppressed to come through in the research. Marxism assumes that the proletariat wants to gain control and change the status quo, which is how I believe First Nations people see their current situation with the federal government. “[T]he issues of indigeneity – the difference that came from being a colonized people – would eventually rise up and become an obstacle in the path of cooperation” (Menzies, 2010, p. 5). From a Marxist perspective, Aboriginal people are the political underclass working toward ‘overthrowing’ the ruling political parties (the federal government) to regain their inherent right to self-governance, which will benefit all aspects of their lives. Critical social theory builds upon Marxism by examining the structures of domination and the resources required to change the social systems (Getty, 2010; Sinnerbrink & Smith, 2006). Using the critical social theory perspective has allowed me to critically examine the political, social and communication structures that are involved in the organization and delivery of health care to First Nations people. It is these structures that have kept control of health care from First Nations governments taking full control and assuring that the ideal First Nations health care system is created.

In postcolonial theory, the ‘othered’, who are usually those being researched, have the opportunity to use the research to decolonize and provide their worldview and knowledge into the research. The postcolonial theory works from a specific cultural identity (First Nations) in a colonized society (Canada) and uses the colonizer’s language to give voice to issues from the colonized group (Spivak, 1988). Building upon the work of D. Turner (2006), which promotes the need for ‘word warriors’ in the Indigenous communities to speak on behalf of Indigenous people in research, I have used all three of these theories to guide my research and to assist me in designing, conducting and analyzing this research by highlighting what Aboriginal people have stated are concerns and issues within their communities. My Aboriginality influences my work, but being an ‘outsider’ with ‘insider’ knowledge of culture and worldview compels me to be cognizant of Aboriginal communities’ needs, knowledge, culture, language and traditions. This study attempts to decolonize, to a certain extent, and inform policy makers, First Nations leaders, and scholars about the complexity of issues that surround First Nations health care systems, and First Nations communities’ ability and desire to gain self-determination in health.

The idea for this research study came as I completed my qualifying exam for my doctoral studies. I was recruited as a senior research fellow for a project looking at the Aboriginal Diabetes Initiative funded by Health Canada's First Nations and Inuit Health Branch. This project is known as the Expanding the CIRCLE Study. Through visits to the study sites in four First Nations communities, I learned first-hand how diabetes care was provided in these communities, what diabetes meant to the people, and how the social determinants of health appear to influence their lives. One observation that particularly interested me was the variation in the organization and delivery of health care in general, and diabetes care in particular. Each community organized their health care and diabetes care based on funding, community involvement and needs, health human resources, and collaboration/partnership with federal and provincial governments. I found four different health care systems in these four First Nations communities, which were influenced by the extent of their control or self-determination. The jurisdictional issues that are a part of the First Nations health care and policy became more noticeable when I was in Alberta, Manitoba and Saskatchewan. From my public service work and as a senior research fellow, I could see issues of self-determination emerge. It is with this knowledge and bias that I have undertaken the research in this dissertation; to provide an Indigenous voice regarding the inequalities in First Nations health care.

### 1.3 Research Question and Scope

First Nations health care systems in Canada have not been examined in any detail to determine how they function or how they are organized. Badgley (1973) provided an initial look at the First Nations health care system and provided some insight into the organization of care and who was entitled to such care. There has been much change since that time. T. K. Young (1984) looked at the socio-political history of Indian health services in Canada, but there does not appear to be any significant follow up from this study to determine how First Nations health care is today. Warry (1998) found that community healing required First Nations communities to have control in the governance of health care. Kluge (1999) and Romanow (2002) have reviewed the general Canadian health care system and provide limited information about the dire conditions in Aboriginal health care. As Chair of the Commission to examine the future of Canada's health care system, Romanow (2002) expressed the urgency in developing a new way of addressing First Nations health care, but the federal government has not moved forward by adopting the Commission's recommendations. Therefore there is still a need to conduct a study which examines the organization, delivery and

structure of First Nations health care in Canada, and how the level of self-determination influences health care systems on reserves.

There has been some research surrounding the Health Transfer Policy and various agreements that were established in the past twenty years. Lavoie (2005) argues that the agreements are not providing adequate latitude for communities to change programs and services based on community needs. Other studies (Jacklin & Warry, 2004) have also examined the Health Transfer Policy and health care in specific Aboriginal communities. Warry (1998) and Cornell, Curtis, and Jorgensen (2003) argue that self-determination is important to health care to ensure a culturally appropriate system that meets the local needs of the First Nations community. However, there has not been a comprehensive review of the First Nations health care systems' organization and delivery in Canada since Badgley (1973). There appears to be limited research that looks at self-determination, the organization and funding of First Nations health care, and the extent of collaboration between First Nations, provincial and federal government organizations with regards to health care for on reserve First Nations people. This creates a unique opportunity for a study to determine how different First Nations communities arrange and negotiate their health care. This study will build upon the literature that exists and develop a current snapshot of First Nations health care organization and delivery through an Indigenous voice. Indigenous perspectives are just beginning to reach the academic literature. Therefore my study will provide a much needed Indigenous perspective of First Nations self-determination in health care organization and delivery that has not been previously provided.

I believe that self-determination in the organization and delivery of health care to First Nations communities are vitally important to improving the overall health and well-being of First Nations communities as was stated in the Royal Commission on Aboriginal Peoples (1996c) report. Chandler (2008), Lavoie (2005), and Waldram et al. (2006) argued that self-determination in health is the first step toward improving the health of First Nations people. The primary intent of this study was to discover the organization and delivery of health care in First Nations communities, the perceived level of self-determination in health through the three levels of government (federal, provincial and First Nations), and what factors may connect self-determination to the organization and delivery of health care. My research question and objectives will be further discussed in Chapter 3.

Qualitative methods were chosen for this study to discover the organization and delivery of health care in First Nations communities. First Nations health care is complex and there are many different

variables that must be considered in the analysis and reporting of the findings. Kovach (2009) states that qualitative research is inclusive and “honours multiple truths” (p.27) and has a “strong narrative component as part of its method and presentation of [the] findings” (p. 35). Additionally, qualitative research allows for different views to be heard, which can be decolonizing and healing for Indigenous peoples (Kovach, 2009). A case study design provides answers to hypotheses that are seeking either how or why questions (Yin, 1999). A multiple case study was undertaken in four First Nations communities (Blood Tribe, Wasagamack and Garden Hill First Nations, and Lac La Ronge Indian Band). This dissertation research builds upon the work I did for the Expanding the CIRCLE study (principal investigators: Dr. Stewart Harris and Dr. Onil Bhattacharya) that was conducted in the same four communities in 2009-2010. In addition, interviews were conducted for this dissertation study with federal, provincial and First Nations government staff in the summer of 2011. My notes and the interviews related to the Expanding the CIRCLE study were re-analyzed for this current study.

Wilson (2008) argues that to truly conduct Indigenous research, an indigenous methodology must be used. H. Graham and Leeseberg Stamler (2010) found that using an indigenous conceptual framework that is not linear and allows for a story to develop also assists with decolonization. For this study, I have developed both an Indigenous conceptual framework based on the Medicine Wheel that highlights how interconnected the findings can be. In addition, I have also developed a ‘western’ or more linear conceptual framework that shows the same variables with direct connections. These conceptual frameworks will be fully discussed in Chapter 3.

Some of the key themes that emerged from the Expanding the CIRCLE study were jurisdictional issues, provincial government involvement, human resources and the effects of residential schools on health care needs. However other themes emerged in this dissertation study and will be discussed in later chapters. As will be discussed in the Methodology chapter, the four communities selected were those that I had access to from my participation in the Expanding the CIRCLE study and they represent a cross-section of different First Nations communities that had participated in previous diabetes studies. The study highlights a range of possible levels of self-determination in the organization of health services and provides some recommendations to improve First Nations health care systems.

In this dissertation, the focus in the discussion of the organization and delivery of health care services includes public health. In the Health Transfer agreements that each of the studied communities has with First Nations and Inuit Health, Health Canada, they are required to provide mandatory public health programs and services. However some public health programs and services remain the responsibility of external agencies such as regional health authorities, provincial ministries of health and the Public Health Agency of Canada.

## 1.4 Organization of Dissertation

The purpose of my dissertation is to document and analyze the typologies of primary health care, the perceived level of self-determination, and factors connected to these typologies in the four First Nations communities; Blood Tribe, Lac La Ronge, Wasagamack, and Garden Hill.

### **Chapter Two**

To fully understand the issue of self-determination in First Nations health care, it is necessary to explain the terminology from both a western and First Nations perspective as there are clearly differences in definitions. This chapter situates the differences in definitions and provides context to be used throughout the thesis. It is necessary to provide a socio-political history using a First Nations voice, when possible, to put context on why self-determination may in fact influence diabetes care and health care in general. This chapter will situate the study in the literature and show the gaps that the study is intended to fill.

### **Chapter Three**

Chapter 3 provides a comprehensive description of the theories and methodologies. This dissertation uses a multiple case study methodology that is informed by postcolonial theory, Marxism, and critical social theory. Marx argued that there would be a class struggle because those people living in poverty and without input and power would resist continuing in poverty. Building upon Marxism, critical social theory focuses on the analysis of the structures of domination and the resources required in changing the social systems (Sinnerbrink & Smith, 2006). Finally, postcolonial theory was created to examine the impact and continuing legacy of European domination over non-European peoples, lands and cultures (Browne, Smye, & Varcoe, 2005).

The four First Nations communities studied in this dissertation are located in three provinces; Alberta, Saskatchewan, and Manitoba. These First Nations communities represent three treaty areas and are considered semi-isolated and remote. The communities were chosen by the Expanding the CIRCLE study and the communities agreed to participate in this study and allow the data from the previous study to be used in this dissertation. These communities will be introduced in Chapter 3. The data collection was completed by document review, interviews, personal observations and secondary data analysis of the Expanding the CIRCLE data.

## **Chapter Four**

Chapter 4 will focus on the factors of self-determination in the four First Nations health care systems. The socio-political history, education issues, Aboriginal worldview and holistic approach to health care are discussed in detail to highlight the way in which these factors influence the organization and delivery of health care in First Nations communities and may influence the perceived level of self-determination in the health care systems.

## **Chapter Five**

Chapter 5 focuses on the perceived level of self-determination in the First Nations communities through the interviews with stakeholders at different levels of government. The perception of self-determination varies depending on where the participant is situated; federal, provincial or First Nations governments and health care professional. The participants' responses will provide insight into why there are different perceptions of self-determination that builds upon the knowledge provided in Chapter 4.

## **Chapter Six**

Chapter 6 focuses on analysis, looking for ways the health system typologies and self-determination perceptions connect to derive lessons. Geography, the health transfer agreements, federal-provincial involvement in First Nations health care, leadership capacity, and community involvement are reviewed before turning to look at the overall organization and delivery of First Nations health care.

## **Chapter Seven**

Chapter 7 discusses the main issues brought forward in Chapters 4, 5 and 6, and the interconnectedness of factors. The chapter also provides recommendations, discusses policy implications and recommends future research. The findings are informed by the literature and guided by the conceptual frameworks outlined in Chapter 3. The connection of socio-political history to concepts of self-determination and organization of health care is very important to this dissertation.

## Chapter 2 Acknowledge the Past

“To be forced to live a life that is totally out of one’s own control is a source of constant stress, and leads to weakness and demoralization of individuals and entire communities. We as Indian people have been forced into coerced dependence upon paternalistic and ever-shifting federal policies and this situation has contributed to a great extent to the manifestations of social ill health now seen among us, including alcohol and drug abuse, family breakdown, suicides, accidents, and violent deaths. There is increasing evidence that the stress of dependence and uncertainty leads to physical sickness and disease as well,” Noel Starblanket, National Indian Brotherhood (1979).

### 2.1 Introduction

The literature review for this dissertation covers the published and grey literature, official documents, videos, community and government websites regarding the four participating First Nations communities, First Nations health and health care, and government agencies. I conducted searches of University of Toronto Libraries online catalogue, Scholars Portal, Google and Google Scholar, which encompassed a wide range of relevant disciplines including the health sciences, government policies, social sciences, and Indigenous studies. The following keywords were used: First Nations, Aboriginal, Indigenous, Métis, Indian, self-determination, self-governance, health policy, health care policy, Canada, health care, traditional healing, traditional medicine, government relations, Indian-government relations, and social or political history. An initial review was conducted in September 2009, and further searches were conducted in August 2010 and January 2011. Titles and abstracts were screened and eligible articles were retrieved. Exclusion criteria were: i) the population was not First Nations, ii) the study was not conducted in Canada, iii) the study was specifically addressing a health issue other than diabetes, iv) the study was not in English, or v) the study was published prior to 1970. These criteria significantly reduced the number of potential articles and books used in this dissertation (n=232).

To understand why the level of perceived control or self-determination differs at each level of government, I found it necessary to reflect on the past socio-political history, ensuring that I looked



at terminology from both an Indigenous and western perspective. Terminology about First Nations people and communities is provided to define the people involved in this study. There are clear differences in how First Nations and government bureaucrats define and conceive of health and self-determination.

There are two conceptual frameworks used in this dissertation by design; the Medicine Wheel and a western framework. These conceptual frameworks use the same variables, but the Medicine Wheel framework has additional traditional teachings associated with the four directions and the overall belief that everything is interdependent and interconnected. In the Medicine Wheel framework, there are concentric circles that are embedded, or stacked, with the variables in each circle being interconnected and interdependent on the other variables – no variable is independent and all of the other variables are related. However, in the western conceptual framework, the socio-political history appears as an overarching set of variables that have influenced the Aboriginal worldview and self-determination, which influence the health care system on reserve. The western framework is much more linear than the Medicine Wheel framework, but the socio-political history that Aboriginal people in Canada have endured forms a part of their worldview, and may have influenced the level of self-determination that First Nations communities have in health care. In addition, the difference in worldview and language is important to understanding health and how health care is organized and delivered, which is connected to self-determination amongst First Nations communities.

## 2.2 First Nations People, Communities and Governments

The terms ‘Indigenous’ and ‘Aboriginal’ are often used interchangeably to describe all Indigenous groups in Canada, who were the original inhabitants in this country (Borrows, 1994; Posluns, 2007; L. T. Smith, 1999). Aboriginal people in Canada are comprised of three main groups: First Nations, Métis and Inuit peoples. The term ‘Aboriginal’ will be used when referring to all three groups together as this is the terminology used in the *Constitution Act* of 1982, the *Charter of Rights and Freedoms*, and by many federal government departments (Borrows, 1994; Posluns, 2007). The term ‘Indigenous’ will be used when referring to Indigenous people internationally.

This paper will focus on First Nations people, which is the modern term for Indians with less negative connotations (Gibson, 2009). ‘First Nations’ is a self-designated term used in the official names of communities, and regional and national organizations such as the Assembly of First Nations. The *Indian Act* defines who is eligible for status or registration among First Nations people

with all others being considered non-status. This definition means that some First Nations people and all Métis people are not eligible for certain rights and privileges contained in the treaties and *Indian Act* (Borrows, 1994; Posluns, 2007).

Identity and status are important issues in First Nations health care policy development. Identity and the legal rights associated with registration and status are unique to First Nations people in Canada. Upon the passage of the *Indian Act* in 1876, Indian agents were sent out to register those people deemed to be 'Indian'. This judgment was often based solely on visual criteria, meaning that some were not originally registered because they did not 'look Indian enough' (Gibson, 2009; Posluns, 2007). This has had a direct effect on who may register today and the special privileges received by those people able to register. By defining eligibility for registration, the government 'managed' the number of registered First Nations people, which decreased the economic impact on the federal budget and continued to 'cap' expenditures based on population size (Boldt, 2000; B. G. Miller, 2006; Weaver, 1981). The restriction of non-insured health benefits to only those having status as defined by the *Indian Act* thus has important financial implications for the government's budget. As First Nations represent a small portion of the total Canadian population, they have also had few opportunities for voicing their own health care policy solutions (Adelson, 2005; Lavoie & Forget, 2008; B. G. Miller, 2006; Surtees, 1982; Weaver, 1981).

The process of identification and the determination of status can place First Nations people at a disadvantage in its unique power relationship with the Canadian government (Alfred, 2009). Anderson, Smylie, Anderson, Sinclair, and Crengle (2006) argue that not being able to identify the three Aboriginal groups in health care databases leads to inadequate culturally sensitive health care and affects the ability to use health data as tools in health care planning. Registration under the *Indian Act* legally separates First Nations people from the general Canadian population. Their residence in remote reserves often limits them from access to health care services enjoyed by many other Canadians such as dentistry, optometry, and medical specialist services (Corenblum, 1996; Mishibinijima, 2004; Posluns, 2007). Conversely, if an Aboriginal person does not have status, they will not have access to culturally appropriate programs, services and other funding afforded to status First Nations people, especially those living on reserves (Alfred, 2009; Borrows, 1994; Kulchyski, 2003).

The defining of a status First Nations person has had a negative effect on health status in a variety of ways (Adelson, 2005). First, individuals who consider themselves to be First Nations, but are not legally recognized as such through the *Indian Act*, may feel less like they belong. Therefore it will lower their self-esteem, which will affect their education, employment, and social and physical environments because their sense of being will be out of balance (Mishibinijima, 2004). Secondly, the government has provided free health care and programs for reimbursement of prescription drugs and medical devices as per treaty rights (Mishibinijima, 2004). Therefore if an Aboriginal person is not considered as a status First Nations person, they will not be eligible for these paid services as originally defined in the treaty rights, and this will directly affect health status and quality of life (Adelson, 2005; Alfred, 2009; Mishibinijima, 2004). Lastly, Aboriginal people without status lack access to strong advocacy groups who work to attain health benefits and beneficial policy development (J. Miller, 1991; D. Smith, Edwards, Martens, Varcoe, & Dawies, 2008; Wellstead & Rayner, 2009).

In 1985, Bill C31 amended the *Indian Act* to include First Nations people who previously lost their status as a result of interracial marriage and enfranchisement (Borrows, 1994). Now the McIvor case ("McIvor v. The Registrar, Indian and Northern Affairs Canada," 2007) is changing eligibility requirements again, which will increase the number of status First Nations people in Canada. Bill C-3, the implementation of the McIvor decision, will allow as many as 200,000 people to apply for registration as the criteria in the *Indian Act* have been modified to include different familial relations as eligible for status (Gibson, 2009). Aboriginal people, who have not previously been eligible for status or did not meet the two-generation rule for registration, may be considered eligible for registration under the *Indian Act* because of Bill C-3. This eligibility change will provide for posthumous registrations that may allow for families to 're-enter' the registry. The number of registered First Nations people will likely increase dramatically. This will have an effect on First Nations community budgets, as these newly registered people can decide to live on reserve or ask for funding for post-secondary education or health services from the band that they belong to.

These changes will also have an effect on the federal government budgets. Prior to the eligibility changes for Bill C-3, Pohar and Johnson (2007) noted that "[c]rude per capita health care costs for registered Indians with diabetes were \$ 3,622" (p. 131). With an increase in the registered First Nations population, the budget will also need to be increased. The increase in Non-Insured Health Benefits (NIHB) serving an increasing population of registered First Nations will put a strain on an

already tight federal health budget situation. These new budget pressures could have an effect on policy for First Nations people in general, and non-insured health benefits in particular. Many different scenarios will need to be reviewed as the costs begin to increase for the federal government. These court decisions have legislative and policy implications for all Aboriginal people, especially currently non-status First Nations people. For the purposes of this dissertation, unless otherwise specified, I will focus primarily on First Nations people with status living on reserve. Where appropriate, comparisons will be made to First Nations people not on reserve to highlight the context and rationale of specific policies.

One factor that appears to increase the cost of NIHB and health care in First Nations people is the location of the community. First Nations people live in distinct communities across Canada. Their current location generally reflects their ancestral homelands. Different groups of First Nations people populated much of North America prior to contact. The *Indian Act* and other policies forced First Nations people who resided near the European settlers to be pushed further and further away (J. Miller, 1991). The population size prior to contact has been contested as some scholars estimate the number being between two million and seventeen million Indigenous people (Jones, 2006; Waldram et al., 2006). The disputed population size does contribute to the argument that with more Indigenous people at contact, the impact of colonization was much greater than if the initial number of Indigenous people was smaller.

Reserves were created by the British and Canadian governments to provide a protected area for First Nations to practice their culture and traditions without outside influence. Reserves are often referred to as First Nations communities in the current literature, including by the Canadian government, and this term will be used throughout this dissertation. There are 627 First Nations communities and 53 Inuit communities in Canada (Health Canada, 2009). According to Health Canada (2009), 57% of First Nations and 38% of Inuit communities have a population under 500 people. The locations of the four First Nations communities in my study are shown in Chapter 3.

Some scholars (Alfred, 2009; Borrows, 2005) argue that reserves have kept First Nations people from being included in Canadian society and this has had a detrimental effect on their economic development, but allowed for a reasonable amount of continuity in culture, language and traditions. It is clear that since their establishment, most First Nations communities have had some external influences on the daily lives of their community members. All four of the communities in this study

have websites and other social media (Facebook pages, YouTube videos, Twitter accounts) to assist in promoting the community and their people and bringing contact with outside influences.

There is no consensus as to what a First Nations government is. There are First Nations governments that were created by the federal government under the *Indian Act*. While many people in government and academics agree that the *Indian Act* is reprehensibly out-of-date, it is the main piece of legislation that rules over First Nations people and their communities (Alfred, 2009; Assembly of First Nations, 2001; Borrows, 2010; Gibson, 2009; Stonechild, 2006). Chief and band council were created under the *Indian Act* and have displaced the traditional forms of governance for many First Nations communities. Chiefs are elected by members of the community by majority vote. This is similar to the democratic election system that Canada uses. The Band Council is similarly elected. During the 1950s, the federal government started to ‘force’ all communities to give up traditional chiefdoms for an ‘elected’ Chief and council model. Some view this as an attempt by the federal government to have more control over the First Nations (Alfred, 2009; Royal Commission on Aboriginal Peoples, 1996b; D. Turner, 2006). Today, in some communities, elected and traditional hereditary Chiefs coexist, but the latter do not have political or administrative control over the affairs of the First Nation.

For the purposes of this study, the elected Chief and Band Council, determined according to Indian and Northern Affairs Canada voting regulations, will be the First Nations government spoken about. Some of these governments have grouped themselves into tribal councils and may operate regional health authorities that cover one or more communities. For example, the Garden Hill, Wasagamack, St Therese, and Red Sucker Lake First Nations in Manitoba constitute the Island Lake Tribal Council and have created the Four Arrows Health Authority to manage their health services in all four communities.

## 2.3 Different Perspectives on Self-Determination

The Royal Commission on Aboriginal Peoples (1996b) stated that:

“[a]s an inherent human quality, sovereignty finds its natural expression in the principle of self-determination. Self-determining peoples have the freedom to choose

the pathways that best express their identity, their sense of themselves and the character of their relations with others. Self-determination is the power of choice in action,” (p. 108).

There is considerable literature on self-determination and self-government for Aboriginal people in Canada (Borrows, 2001; Boyer, 2003; Buchan, 2003; Ladner, 2009; Prince & Abele, 2003; Royal Commission on Aboriginal Peoples, 1996a; VandenBurg, 2009). All people living in a democracy are believed to have self-determination over their lives, which is the power of choice in all aspects of their lives (Buchan, 2003; Royal Commission on Aboriginal Peoples, 1996a). This definition goes beyond just administrative or bureaucratic control to truly having control of decisions as they affect First Nations peoples and communities (Borrows, 2001; Buchan, 2003; Napoleon, 2005). Chief S. Atleo and Assembly of First Nations (2011) stated:

“First Nations themselves through individual and regional dialogue, respectful of their local and regional circumstances must have the full opportunity to consider options, to design and ultimately to build self-determination reflective of their own vision, rights and responsibilities. At the same time, through organizing this work, we can clarify the ways in which we can and must work together in support of one another’s efforts,” (p. 15).

Power and control over one’s life is a “core legal principle of international law”(Macklem, 2001, p. 34) and has been the struggle of First Nations people in Canada. However, some scholars (Borrows, 2001; Boyer, 2003; Buchan, 2003; Cornthassel, 2008; Royal Commission on Aboriginal Peoples, 1996a) argue that Aboriginal people have experienced a limited amount of self-determination as a result of assimilation policies and legislation. In fact, the Berger (1980) Report and the Penner (1983) Report also found that First Nations people have been subjected to assimilationist policies (i.e. Indian Residential School, reserves, Sixties Scoop), and this has contributed to racism and discrimination. Furthermore, the Royal Commission on Aboriginal Peoples (1996a) found many First Nations people have hid, renounced, or feared acknowledging their ethnicity, culture, language and traditions. Napoleon (2005) argues that self-determination is a political concept and becomes articulated differently depending on the political ideologies of the governing party.

Indigenous scholars (Alfred, 2009; Borrows, 2010; Gkisedtanamoogk, 2010) state that self-determination is an inherent right that is necessary in all aspects of Indigenous life to decolonize and

heal from the oppressive and colonial policies of the past two hundred years in health care. Self-determination is the ability of a community to have full control of the health care system including when, where, who and how the health care system can be used; it is beyond administrative control to truly being able to make decisions about health care (Prince & Abele, 2003; Royal Commission on Aboriginal Peoples, 1996a; Warry, 1998). Taking control of health care could be a first step as Penner (1983), Berger (1980) and the Royal Commission on Aboriginal Peoples (1996a) reports state.

In Canada, the federal government has sent mixed messages about self-determination. In many government reports and documents (e.g. Health Transfer Program Handbook, 2004; First Nations Self-Government Act, 1995), the federal government uses the term self-governance in a manner consistent with what Indigenous scholars term self-determination. Cornell (as cited in S. Atleo & Assembly of First Nations, 2011, p. 10) states “the definition of governance is how you translate the will of the Nation into sustained, organized action.” This statement is taken from an Indigenous document about self-determination (S. Atleo & Assembly of First Nations, 2011) and is similar to the definition of self-determination provided by Indigenous scholars like Alfred (2009), Borrows (2010), and Prince and Abele (2003). The difference in the lexicon used has further implications for this research, and future policy and research directions.

The courts and the *Constitution Act* of 1982 recognize the nation-to-nation relationship implicit in the treaties, but the federal government believes it controls when and how self-determination may be granted to First Nations people (A. Roy, 2001). The government of Canada has supported

“the recognition of the inherent right of self-government, Aboriginal title, and Aboriginal and treaty rights under section 35 of the Constitution Act, 1982.

Furthermore, in the international context, Canada supports the recognition of a right to self-determination for indigenous peoples which respects the political, constitutional, and territorial integrity of democratic states,” (A. Roy, 2001, p. 84).

However, without legal recognition of Aboriginal self-determination, the federal government can continue its policy of assimilation and Aboriginal people will not have the same choices and freedoms as other Canadians (Borrows, 2001; Cornell & Kalt, 1998; Dalton, 2006). According to the literature provided by the federal government, there is tremendous support for First Nations people to become self-determining and in the future self-governing (Indian and Northern Affairs Canada,

2010; A. Roy, 2001). Indian and Northern Affairs Canada (2010) stated, when trying to have the *First Nations Self Governance Act* approved in 2001, “[a]s Aboriginal governments and institutions exercise jurisdiction or authority and assume control over decision-making that affects their communities, they will also assume greater responsibilities for the exercise of those powers. As a result, Crown responsibilities will lessen.” (p. 2). However, Boyer (2003) argues that the federal government has not acknowledged the impact on health by providing self-government to First Nations communities. There will need to be further discussions and research in this area.

According to Corntassel (2008), there are four ways that Aboriginal self-determination has been framed by states and global organizations. By separating the discussions surrounding homelands and natural resources from Aboriginal powers of self-determination, governments can limit Aboriginal autonomy as there is no land base or resources to which Aboriginal people are entitled. For many countries with Indigenous peoples, the governments argue that the Indigenous people are minorities within their boundaries and thus do not require self-determination as all people have this right (Corntassel, 2008). Using the dominant political and legal systems, governments can argue that Indigenous cultures, languages and worldviews are upheld within the designated spaces made available to Indigenous populations (Corntassel, 2008). Therefore, there is no need to provide further political or legal rights for self-determination. “Finally, the rights discourse has limited the applicability of decolonization and restoration frameworks for indigenous peoples by establishing ad hoc restrictions” (Corntassel, 2008, p. 108). Thus, the political and legal systems have further oppressed Indigenous people within the existing rights of the country as legal assignment of Indigenous community-based powers are not viewed as necessary because Indigenous people are covered by other rights based legislation (Corntassel, 2008). However, collective rights within the dominant political and legal systems do not sufficiently reflect Aboriginal individual rights as culture, language and worldview of the first group in Canada are not respected (Martin, 2007).

Self-determination is the holism and interconnectedness that includes social, political, cultural, and economic aspects of life that perpetuates a First Nations culture, values and worldview (Buchan, 2003; Royal Commission on Aboriginal Peoples, 1996a). Self-determination is apparent in First Nations communities as they choose pathways to reach their goals to improve access to primary care and health services that are culturally appropriate and holistic. All the communities in this study possess these qualities. It is the degree of self-determination that varies among the communities. According to Indigenous scholars (Buchan, 2003; Prince & Abele, 2003; Royal Commission on



Aboriginal Peoples, 1996a) and for the purposes of this study, self-determination is more than administrative or bureaucratic control of health care in that it provides the ability of community to collectively determine control when, where, who and how health care is provided, which are culturally relevant and empathetic to the socio-political history that First Nations people have endured.

Self-determination is also something that the federal government purports to support and promote. However, the definition and how the federal government bureaucrats implement self-determination in health appear to be different. Health Canada (1996) has advocated for First Nations to build capacity in their leadership in order to have leaders that are knowledgeable about health and health care. Similarly, E. Peters (1992) argued that First Nations communities, on or off reserve, require a high level of leadership capacity for successfully improving the health care system. Adelson (2000) and Cornthassel (2008) argue that community leadership must envision methods of incorporating culture, language and worldview in the health system of their community. In the Health Transfer Program, the federal government see self-determination as:

“[e]ach community differs as to when it will take control and responsibility for its health programs and services. Communities take control and responsibility for health services at a pace determined by their interest, needs, and management capacity,”  
(Health Canada, 2004a, p. 4).

There is no specific definition of self-determination, but the statement above notes that First Nations communities must have the interest, need and management capacity in order to take increasing levels of self-determination or control. As was noted in the previous section, the federal government defines self-government in a manner similar to how Indigenous scholars define self-determination. Therefore there is a need to look at how this may influence government bureaucrats at all levels and their perceptions of the level of self-determination in First Nations health care.

It is important to distinguish self-determination from self-administration. Cornell et al. (2003) describe self-government in a manner similar to the way Indigenous scholars describe self-determination. In this study, self-determination and self-government will be used interchangeably as these labels have been similarly used by the federal government and Indigenous scholars. Cornell et al. (2003) describe self-determination as a First Nation community’s ability to perform “a variety of functions through the institutions of their own design” with accountability to the community instead

of funders and are considered partners with other governments (p. 13). “[S]elf-administration is a model in which Indigenous government is designed by someone else, funding comes from someone else, accountability is to someone else, and programs are designed and evaluated by someone else,” (Rae, 2009, p. 8). **Error! Reference source not found.** below shows the key differences between self-administration compared to that of self-determination (self-governance). Cornell et al. (2003) illustrate that there are a number of differences between self-administration of a program like health care services versus self-government of health care services.

**Table 1 Self-Administration Compared to Self-Government**

	<b>Self-Administration</b>	<b>Self-Government</b>
Jurisdiction	Vested in First Nations but limited to narrow policy domains and subject to federal or provincial veto	Vested in First Nations, tribes, or other associates of First Nations and covering a wide array of policy domains
Governing institutions	Designed largely by outsiders, usually the federal government (i.e. the <i>Indian Act</i> )	Designed by First Nations, tribes, or other associations of First Nations
Core functions of First Nations’ governments, perhaps in cooperation with other governments	<ul style="list-style-type: none"> <li>• Administer programs</li> <li>• Distribute resources such as jobs, money, services</li> <li>• Manage the internal affairs of the nation to the extent allowed by Canadian or provincial law</li> </ul>	<ul style="list-style-type: none"> <li>• Establish a constitutional foundation</li> <li>• Make and enforce laws</li> <li>• Make and implement decisions</li> <li>• Provide for the fair and non-political resolution of disputes</li> <li>• Administer programs</li> <li>• Manage the internal and external affairs of the nation as allowed by First Nations law</li> </ul>
Revenue	Largely from federal government, First Nations’ efforts to increase revenues focus largely on grantsmanship and lobbying for increased federal funding	From diverse sources, including but not limited to federal funds; First Nations’ efforts to increase revenues focus on enterprise development and other revenue-generation options
Accountability	Typically unidirectional, having to do largely with First Nations’ accountability to funders, especially the federal government, for how funds are used	Multi-directional, having to do with (1) First Nations’ accountability to their own citizens for governing well, (2) First Nations’ accountability to funders for use of funds, and (3) federal accountability to First Nations for policy decisions
Intergovernmental decision-making processes	Consultation (other governments “consult” with First Nations, then decide what to do); the assumption is that other governments know what’s best for First Nations but should at least talk to them about it	Partnership (decisions are made jointly where substantive First Nation interests are involved); the assumption is that First Nations and other governments can work together to determine what’s best for both

Adapted from Cornell, S.; Curtis, C.; Jorgensen, M. (2003). The Concept of Governance and Its Implications for First Nations. Joint Occasional Papers on Native Affairs, No. 2004-02; p. 30-31.

## 2.4 Self-Determination and Health Care

First Nations health care has been chronically underfunded to fully meet the needs of the community (Berger, 1980; Kulig, MacLeod, & Lavoie, 2007; Lavoie, 2005; Royal Commission on Aboriginal Peoples, 1996a). Funding is crucial to increasing the level of self-determination in health care (Warry, 1998). Without adequate funding, First Nations communities struggle with recruiting and retaining qualified staff, managing the resources available, and planning for future needs (Lavoie, 2005, 2011). Warry (1998) argues that land and finances are central to self-determination and self-government as self-determination often leads to self-government. Thus not having control of the funding will always be problematic for First Nations communities to truly achieve self-determination.

Kulig et al. (2007) also noted that there are four different models of funding, shown in Table 2 below. The Health Transfer, Integrated, and Self-Government models of funding are only available to First Nations south of the 60<sup>th</sup> parallel, whereas any community can apply for separate contribution agreement programs (Kulig et al., 2007). All of these models allow First Nations communities to take on responsibility for the delivery of social and health programming, which also allows them to provide input into future strategic directions, goals and objectives (M. Atleo, 2008; Knopf, 2008).

**Table 2 Models of First Nations Health Funding**

<b>Separate Contribution Agreements Model</b>	<b>Integrated Agreement Model</b>	<b>Health Transfer Model</b>	<b>Self-Government Model</b>
<ul style="list-style-type: none"> <li>• In communities that <b>have not</b> signed an integrated health transfer or self-government agreement.</li> <li>• FNIH defines programs and delivered by the community.</li> <li>• Each program is funded under a separate contribution agreement, some yearly and some multi-year depending on the program.</li> </ul>	<ul style="list-style-type: none"> <li>• Community undertakes a planning process to identify needs and services.</li> <li>• Community controls specific aspects of community health services.</li> <li>• ‘Laddered’ with intention to prepare for the transfer process and to facilitate capacity building.</li> </ul>	<ul style="list-style-type: none"> <li>• Community has flexibility in designing health programs and services, and resource allocation.</li> <li>• Allows for community-designed programs and capacity building, but ensures mandatory programs are delivered.</li> </ul>	<ul style="list-style-type: none"> <li>• Highest level of local management.</li> <li>• Treaty and Aboriginal rights can be exercised within the constitutional framework.</li> <li>• Responsibility falls under INAC.</li> </ul>

Adapted from: Lavoie, J. (2011). Looking for Aboriginal Health in Legislation and Policies, 1970 to 2008: The Policy Synthesis Project. British Columbia: National Collaborating Centre for Aboriginal Health.

First Nations health care, in general, is very prescriptive as it is either wholly provided by FNIH or at least funded through Health Transfer Agreements (HTA) from FNIH (Lavoie, 2005). First Nations health authorities can determine what programs, services, and professionals are provided to a community if they have signed a Health Transfer Agreement (Lavoie, 2005). However, this ‘flexibility’ is limited as a five year plan must be developed prior to the flow of funds, which limits the ability to make changes when the community sees new emerging issues (Lavoie, 2005; Quinonez & Lavoie, 2009).

Diabetes care is funded through separate and specific contribution agreement funding from First Nations and Inuit Health (FNIH), Health Canada. The program requires fund recipients to provide preventive and promotion activities and treatment for diabetes. The activities provided are not dictated or prescriptive; thus allowing First Nations health authorities to manage and choose how the funding and programming looks for their community (Expanding the CIRCLE, forthcoming). This could be considered a first step toward self-governance.

Dalton (2006) argues that the majority of Aboriginal people envision self-determination as a “reinstatement of autonomy over ‘political, social and cultural development’ *within* Canada and

freedom from state interference in order to allow the preservation and transmission of cultures to future generations” (p. 13). According to Reading, Kmetz, and Gideon (2007) when “people from the lower socio-economic class have less opportunity and training to influence the events that impinge on their lives” (p. 14), they will lack influence over their health care system. In this study, First Nations leaders and health directors, provincial and federal government staff were asked about the level of perceived control that First Nations governments and health authorities have over their health care, the different perceptions of the level of influence or control by First Nations will be identified.

As health care of First Nations communities must be responsive to their community members, culture, language and worldview must be integrated into the system (Ladner, 2009; Lavoie, 2011). Self-determination and self-governance provide First Nations communities with the opportunity to embed their culture, language, and knowledge into the dominant society’s structures (Martin, 2007). Self-determination is one critical determinant of self-government, thus it is important to embed culture, language and worldview into self-determination and self-government separately. “Aboriginal knowledge, heritage, language, and law in turn define how Aboriginal peoples will achieve self-determination and coexist within constitutional democracy,” (Martin, 2007, p. 95). Many scholars (Ball, 2004; Berger, 1980; Lavoie, 2005, 2011; Reading et al., 2007; T. K. Young, 1994) argue that health self-governance can have a positive preventative and curative effect for First Nations people. In addition, self-governance might allow First Nations communities to integrate their social and health services, which could further improve health status amongst the community members (M. Atleo, 2008). Therefore self-governance is an important factor in First Nations health and health care.

Some scholars (Ross, 2002; A. Young, Russell, & Powers, 2004) have found that a sense of community belonging is associated with positive self-perceived health including better physical and mental health, lower stress, and better social support. “As a cultural element, belonging relates to the psychosocial environment and the relationships among individuals and their community. Sense of belonging can be health promoting in communities that offer social support (Berkman, 1995)” (Hill, 2006, p. 210). Further, Chandler and Lalonde (1998) found that cultural continuity encourages traditional intergenerational connectedness that is associated with interdependence and interrelatedness of all things in Creation. Thus having a positive sense of belonging to traditional

culture and community can have a positive effect on individual, family and community health, which can come from having control of the health care system.

Jurisdictional issues have plagued First Nations policy and service delivery organizational systems as health care leaders and government bureaucrats are unsure of who is responsible for what portions of the system. Napoleon (2005) argued that clear boundaries must be established for the legal, political and policy realms. Nieguth (2009) found that if the boundaries are unclear and two levels of government can pass responsibility back and forth, First Nations communities will lose control and ability to implement self-determination, and eventually self-government. There is a need for clear boundaries so First Nations governments can understand their position and be clear in their future directions. “The federal system of health care delivery for status First Nations people resembles a collage of public health programs with limited accountability, fragmented delivery and jurisdictional ambiguity” (Loppie & Wien, 2009, p. 15).

To improve upon the issue of jurisdictional ambiguity, the Royal Commission on Aboriginal Peoples (1996a) report recommended that all First Nations organizations (health, social, band, legal, etc.) work together to improve conditions in First Nations communities. Romanow (2002) further argued that Aboriginal health partnerships would bring together the federal, provincial and First Nations governments to ensure accountability, transparency and capacity with regards to providing improved health care to status First Nations people. However, Prince and Abele (2003) found that First Nations communities required clear and frequent communications with the federal and provincial governments in order to improve their leadership and exchange knowledge among the various institutions on the reserve.

Self-determination is an inherent right of all people, but First Nations people are limited by legal issues (Boyer, 2003). Whereas it has been asserted that First Nations self-governance in health is necessary to improve the health of First Nations people (Estey, Kmetz, & Reading, 2007; Lavoie, 2011). Self-governance must be entrenched in the *Constitution Act* to ensure that First Nations people can move toward including their worldview, culture and language into their communities without external influence and input (Lévesque, 2006). However, self-determination should be inherent and already exist for all First Nations people and their communities. Although self-governance in First Nations health can occur through funding agreements with the federal

government, the goals and objectives of the funding must be in alignment with the needs of the community for it to be true self-governance (Lavoie, 2011; VandenBurg, 2009).

## 2.4 First Nations' Concepts of Health and Health Care

“[T]he meaning of health and its application in everyday-life is dependent on the culture and worldview of the population being served” (Colomeda & Wenzel, 2000, p. 244).

Health has different definitions depending on one's worldview, culture, language, and knowledge. The World Health Organization (WHO) has defined health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (World Health Organization, 1978, p. Preamble). This definition is widely accepted and has been ‘borrowed’ by many countries as they develop their own definition of health including Canada. *A New Perspective of the Health of Canadians: A Working Document* was tabled in the House of Commons on April 1, 1974 (Health Canada, 2011a) and was ground breaking by stating health is more than the biomedical absence of disease and must include lifestyle and environmental components.

The *Canada Health Act*'s primary objective is “to protect, promote and restore the physical and mental well-being of residents of Canada and to facilitate reasonable access to health services without financial or other barriers” (as quoted by Health Canada, 2009). Aboriginal people view health in a holistic way and believe that health encompasses physical, spiritual, emotional, and mental well-being, not just at the individual level, but also including others around them as well as the environment (Adelson, 2005; Smylie & Anderson, 2006). Some First Nations peoples have developed a collective worldview that includes the entire community from individual to nation as well as the ecosystem where they live (Adelson, 2005; Stephens, Nettleton, Porter, Willis, & Clark, 2005). Many Aboriginal scholars have defined health as “a state of physical, mental, emotional and spiritual wellness”, and many definitions include a component about being self-determining that would allow for balance among the four aspects of self, family, community and nation (H. Graham & Leeseberg Stamler, 2010; Lavoie, 2011; Waldram et al., 2006).

Health Canada continued to work toward a health promotion perspective after the 1974 working document, and developed the “*Taking the Population Health Approach*” in 1998 (Health Canada, 2011a), which provides twelve social determinants of health (see Table 3). In the early 2000s, the National Aboriginal Health Organization developed an alternative model of Aboriginal social determinants of health (see Table 4). In addition to the twelve determinants listed by Health Canada, the NAHO model adds another eight determinants that are specific to Aboriginal people (National Aboriginal Health Organization, 2006).

**Table 3 Key Social Determinants of Health**

- |  |
|--|
| 1. Income and Social Status                  |
| 2. Social Support Networks                   |
| 3. Education and Literacy                    |
| 4. Employment/Working Conditions             |
| 5. Social Environments                       |
| 6. Physical Environments                     |
| 7. Personal Health Practices & Coping Skills |
| 8. Healthy Child Development                 |
| 9. Biology and Genetic Endowment             |
| 10. Health Services                          |
| 11. Gender                                   |
| 12. Culture                                  |

Adapted from: Health Canada. (1998). *Taking the Population Health Approach*. Ottawa, Ontario.

**Table 4 Aboriginal Social Determinants of Health**

- |  |
|--|
| 1. The twelve Social Determinants of Health from Health Canada |
| 2. Colonization  |
| 3. Globalization   |
| 4. Migration   |
| 5. Cultural continuity   |
| 6. Access  |
| 7. Territory   |
| 8. Poverty   |
| 9. Self-determination  |

Adapted from: National Aboriginal Health Organization. (2006). Presentation to the Senate of Canada.



The First Nations definition of health is important as it will change how health care should be provided to First Nations peoples to improve health status. Under this worldview, First Nations communities will want to heal the environment, community and the individual simultaneously (Adelson, 2005; Anderson et al., 2006; Waldram et al., 2006). Health care is only one determinant affecting the health and well-being of all Canadians including First Nations people. Primary health care, according to WHO, must reflect access, equity, multisectoral collaboration, appropriate technology, and community involvement and empowerment (Thomas-MacLean, Tarlier, Ackroyd-Stolarz, Fortin, & Stewart, 2003). Throughout this paper, my focus will be on health care services, which include the full spectrum of curative, preventive and rehabilitative health services. In this dissertation, I will be using the Indigenous definition of health interspersed with the population health perspective as these two concepts are not mutually exclusive and the combination provides a wide view of health and health care. Diabetes care in First Nations communities reflects a spectrum of health beliefs from Canadian/Western to Indigenous to a range of combinations.

The Alma-Ata Declaration on Primary Health Care outlined the four basic principles, which are universal access, equity, intersectoral collaboration, and community and individual participation in planning and implementation of health care services (World Health Organization, 1978). Starfield (1998) explains that primary care is a “level of a health service system that provides entry into the system for all new needs and problems, provides person-focused (not disease-oriented) care over time, provides care for all but very uncommon or unusual conditions, and co-ordinates or integrates care provided elsewhere by others” (p. 8-9). Primary health care is more comprehensive, as Mable and Mariott (2002) state, it “recognizes the broader determinants of health and includes coordinating, integrating, and expanding systems and services to provide more population health, sickness prevention, and health promotion, not necessarily just by doctors. It encourages the best use of all health providers to maximize the potential of all health resources,” (p. 1). Recently, scholars and bureaucrats, including Health Canada, have added to the list with the addition of incorporation of the social determinants of health; health prevention and promotion in an upstream manner; interdisciplinary health care teams; and electronic information sharing (i.e. electronic medical records) (Health Canada, 1996; Health Council of Canada, 2008; Kirby, 2002; Mable & Mariott, 2002; Raphael, Curry-Stevens, & Bryant, 2008; Romanow, 2002).

Although there have been many changes to health and health care in Canada, First Nations communities, organizations and academic scholars have argued that a holistic First Nations health

care system is required. Such a system should be locally operated, open and available seven days a week with an interdisciplinary team of health professionals that includes both traditional Aboriginal and western practices of medicine that are devoted to creating an interconnected and holistic system working from individual, family and community perspectives (First Nations Healing, 2010). In this system, the community and health professionals would work together to use the best medicines available locally and through pharmaceutical means (First Nations Healing, 2010; Warry, 1998). The interdisciplinary team would encourage people to use the local land, game, herbs and medicines to assist in the holistic healing of illness and as a preventative measure. With strong leaders in the community and the goal of self-governance, the community would work toward interlacing all social activities (i.e. education, community development, economic development) into all aspects of health and well-being (First Nations Healing, 2010; First Nations Health Managers, 2009; Loppie & Wien, 2009).

Self-determination in health care involves local control of one or more components of the health care system, such as human resources, location, funding, policy development, health promotion and prevention programs and services, and leadership (Deber, 2008). The James Bay agreement in northern Quebec is unique and may be an example of the ideal First Nations health care system in that it is co-funded by both the federal and provincial governments, managed by local Aboriginal authorities and has close linkages to the provincial health care system (Lavoie, 2011). However, scholars (Jacklin & Warry, 2004; Lavoie, Forget, & Browne, 2010; Waldram et al., 2006) state that Aboriginal people, regardless of residency, wish to have a health care system that is empathetic to their socio-political history, allows for individual empowerment, and encourages self-determination and self-government. The ideal First Nations health care system must also balance overlapping jurisdictions, encourage capacity development, create partnership arrangements, and introduce an integrated method of providing traditional healing (Lemchuk-Favel, 1999b).

“Culture is a dynamic lived process that is inclusive of beliefs, practices, and values. Culture, however, is more than beliefs, practices and values that can be reduced to a list of personal characteristics. Culture is not homogenous or static and is not a single variable. Rather, culture comprises multiple variables and affects all aspects of experience; it is inseparable from historical, economic, political, gender, religious, psychological, and biological conditions.” (Kleinman & Benson, 2006 as cited in Gregory & Hart, 2009; p.20)

With strong leaders in the community and the goal of self-governance, the community would work toward interlacing all social activities (i.e. education, community development, economic development) into all aspects of health and well-being (First Nations Healing, 2009; First Nations Health Managers, 2009; Loppie & Wien, 2009). First Nations communities begin with self-determination in their health care system, which will allow them to make choices and provide input. The community leaders can then assist the community to work toward full self-governance in their health care system.

A holistic health care system must take culture and spirituality into consideration (Gregory & Hart, 2009). Therefore a brief understanding of Aboriginal culture and spirituality is necessary to understand how health care may be perceived by First Nations people. Turton (1997) argues that Aboriginal people have a health culture that is unique and emerges from their worldview. Aboriginal worldview is determined by experiences, family teachings, knowledge, culture and language, thus having an understanding of an Aboriginal worldview will further illustrate how First Nations people view health and health care. Many scholars (Adelson, 2005; Duran, Firehammer, & Gonzalez, 2008; Kovach, 2009; Lane, Bopp, Bopp, & Brown, 1984; Ten Fingers, 2005) have reported that First Nations cultures see all things (animate or inanimate) as connected and interdependent. Lane et al. (1984) have explained that the Medicine Wheel teachings, that many First Nations people receive and ascribe to, are focused on balancing the four aspects of life or self; physical, spiritual, emotional, and mental. Balancing all of these areas of a person's life is considered by many First Nations cultures as the 'good path' or 'balanced' way of life. Adelson (2000) found that Cree people tried to find and maintain balance in these four directions of self in order to achieve good health and well-being.

The interconnectedness pervades all aspects of Aboriginal peoples' lives and is instilled in traditional teachings, ceremonies, songs, stories, and social events (Ermine, 2007; Lane et al., 1984; L. T. Smith, 1999). The balance of the four aspects of self can only be achieved if an individual is aware when they are out of balance in one direction or more (Lemchuk-Favel, 1999b). However, to achieve physical, emotional, mental and spiritual health, Aboriginal people are aware that balance, communication, organization, and support are necessary (Duran, 2006; Gone, 2007; Stewart, 2008; Turton, 1997). Health in the Aboriginal worldview is not just the absence of disease, but how a person lives within the complexities of the world around them while maintaining connection to all things and balance in the four aspects of self.

The social determinants of health, noted in Table 3, established key factors that seem to determine health status; for example education, environment, physical health, health services, and social support (Adelson, 2005; Allec, 2005; Health Canada, 1998). The socio-economic conditions of most First Nations people are vastly different from those experienced by the mainstream population. Many First Nations communities have poor and substandard housing, lack of employment, poverty, substance abuse, domestic violence and child welfare concerns (Allec, 2005; Boyer, 2003; Brede, 2008; National Aboriginal Health Organization, 2004). Additionally, some First Nations communities do not have running water or have been on boil water advisories for many years (Brede, 2008; Stastna, 2011).

“Faced with enormous hurdles, First Nations peoples have, and continue to survive despite profound lower levels of income and employment, lack of access to health care services and poor community infrastructure, often including substandard housing, lack of potable water and other essentials which determine optimal health and well-being of any community” (Reading et al., 2007, p. 9).

Incorporating culture and language into health care can assist First Nations people with feeling welcome, and decreases the barriers that may inhibit their uptake of health advice (Chandler, 2008; Chino & DeBruyn, 2006). However, the holistic worldview of Aboriginal people is complex “especially to individuals who are not enculturated or familiar with an indigenous language or worldview” (McIvor, Napoleon, & Dickie, 2009, p. 13). Furthermore, culture and language lead to a stronger sense of identity and this can lead to improved health and wellness (McIvor et al., 2009). Culture, language and worldview are considered by many scholars as one of the key determinants to good health for First Nations people (Chino & DeBruyn, 2006; Lavoie, 2005; McIvor et al., 2009).

Traditional healing is comprised of the “practices, designed to promote mental, physical and spiritual well-being that are based on beliefs dating back to the time before the spread of western ‘scientific’ bio-medicine” (Allec, 2005, p. 57). Traditional medicine is used by Elders and healers, and it is “the sum of all the knowledge and practices, whether explicable or not, used in diagnosis, prevention and elimination of physical, mental or social imbalance, and relying on practical experience and observation handed down from generation to generation, whether verbally or in writing” (Allec, 2005, p. 57). Lemchuk-Favel (1999b) recommended that social services funding be combined with health funding to create a seamless system that is more Indigenous in nature.

“For Aboriginal people, holistic healing which interrelates physical, mental, emotional and spiritual elements, will restore not only wellness to individuals, but also renew their capacity to exercise collective responsibility and build caring, inclusive communities” (Lemchuk-Favel, 1999b, p. 24).

The funding of First Nations health care has been used to encourage institutional assimilation (Neu, 2006), which has further repressed the health care available on First Nations reserves (Lavoie, 2005, 2011). Rae (2009) argues that the funding provided to First Nations communities as part of devolution of responsibility is essentially downloading of administrative control, as the program’s structure, reporting requirements and partnerships are already established and ‘forced’ upon First Nations communities that chose to participate. In fact, devolution itself is problematic as it can be viewed as a ‘take it or leave it’ approach to assimilation and integration (Rae, 2009). The federal and provincial governments pass on “bits and pieces of the administrative apparatus but continue to block Aboriginal nations from assuming the broad powers of governance” (Royal Commission on Aboriginal Peoples, 1996a, p. 7), which would come with adequate funding and support to assist First Nations communities in their health care endeavors.

The *Canada Health Act* outlines what is required to be provided to Canadians for their health. Although the western bio-medical system is most interested in the absence of physical and mental illness, there has been a shift towards a more holistic model in the past thirty years (Health Canada, 1998; Lalonde, 1974; Romanow, 2002). There is still much more that needs to occur to create a balanced and holistic health system (Health Canada, 1998; Lalonde, 1974; Lemchuk-Favel, 1999b). The population health approach, used by the Public Health Agency of Canada and Health Canada, is based upon guiding principles and twelve determinants of health (Health Canada, 1998). The population health approach has been used as a lens for creating health and health care policy in Canada including for off-reserve Aboriginal people (Health Canada, 1998; Romanow, 2002). However, First Nations and Inuit Health branch has not fully embraced this approach (Kulig et al., 2007; Lemchuk-Favel, 1999b). As the population health approach has not been embraced by other policy makers and levels of government, there continues to be a divide between a holistic approach and a curative approach, which prevents a move toward the ideal system advocated by Aboriginal people (Lavoie, 2011).

The Assembly of First Nations (2005b), the Royal Commission on Aboriginal Peoples (1996a) report and Romanow (2002) report argue that First Nations jurisdiction over health through self-determination and self-governance can create a health care system that is ideal. The ideal First Nations health care system has many different and interconnected features that are readily available in mainstream health care systems, but integrates culture, language and traditional Aboriginal medicine (H. Peters & Self, 2005; Turton, 1997). The ideal health system would be a blend of the traditional First Nations health and healing practices available in communities and the western biomedical system providing scientific and pharmaceutical care in harmony. The ideal First Nations health care system must also balance jurisdictional issues, capacity development, creation of partnership arrangements, and introduce an integrated method of providing traditional healing (Lemchuk-Favel, 1999b). It is this ideal health care system that the four First Nations communities in this study are trying to achieve.

## 2.5 Organization and Delivery of Health Services for First Nations

Each province and territory administers health care differently based on the needs of its citizens, funding objectives, and available resources. The *Constitution Act* grants the federal government exclusive power over First Nations people and the reserves, but provincial and territorial governments have exclusive jurisdiction over health care for their residents with the exceptions of First Nations and Inuit, veterans, RCMP staff, Canadian Forces personnel, federal inmates, and some refugees (Savard, 2008). There is considerable confusion regarding whether Section 91 (24), which pertains to ‘Indians and lands reserved for Indians’ or Section 92, which pertains to provincial responsibility for establishing and delivering health services take precedence with regards to First Nations health care (Savard, 2008; Scott, 1993). Jurisdictional issues, therefore, can have a profound influence on all aspects of First Nations health care (Lemchuk-Favel, 1999b). Additionally, the federal government has two departments handling First Nations health and social services; Aboriginal Affairs and Northern Development Canada (formerly Indian and Northern Affairs Canada) and Health Canada’s First Nations and Inuit Health branch (FNIH) (Lavoie, 2011; Scott, 1993). Similarly, each province can have more than one ministry assigned to dealing with Aboriginal health and social services, which further complicates the jurisdictional issue of who, how

and what health care and social services are provided to First Nations people living on reserves (Savard, 2008; Scott, 1993).

Even with the endless jurisdictional issues that plague the organization and delivery of primary health care in First Nations communities, there are still many health issues that need to be researched and addressed in Aboriginal health (T. K. Young, 2003). Aboriginal people are facing a pandemic; the prevalence of diabetes for First Nations adults is three to five times the national average (Assembly of First Nations, 2007, 2009; Brede, 2008). Many First Nations diabetics are diagnosed younger, have more complications and need more medical care than non-Aboriginal diabetics (Brede, 2008; Ho, Harris, & Ford, 2006). Some of the key issues that have emerged with regards to receiving diabetes care for First Nations people on reserve are: access, lack of communication (government-to-government, between health professionals, and across systems), health human resources, funding, cultural appropriateness, integration of traditional healing and medicine and location of services (National Aboriginal Health Organization, 2004; Peiris, Brown, & Cass, 2008). Bent, Havelock, and Haworth-Brockman (2008) found additional barriers with regards to health care in general, that included transportation, language, age, lack of empowerment, education, abuse and discrimination. All of these issues can influence how often, where, and when First Nations people access health care. Therefore it is important to know the issues that may be perceived as barriers, the current research in the area, and solutions that have been used in First Nations communities.

First Nations people are not necessarily looking for more health care as provided through western medicine, but rather they wish to have improved health overall (Barker, 2009). Based on the social, environmental and cultural conditions that First Nations people face on reserves, First Nations people desire a health care system that acknowledges these conditions, yet embraces their culture, spirituality, and traditional ways of healing (Barker, 2009; De Pauw, Larocque, & Cooper, 2010). The organization and delivery of health care in First Nations communities must address conditions beyond the scope of traditional western medicine. Therefore the western medical establishment must embrace the knowledge that Aboriginal people and communities can provide including traditional medicine and healing (Brede, 2008; De Pauw et al., 2010; Kelm, 2004).

### **Location of Health Services**

The location of health services is an important factor in access, utilizing and managing chronic illness like diabetes. The further away a community is from a major urban centre, the less primary,

secondary and tertiary levels of health care are available (Fontaine, 2005; Minore, Boone, Katt, Kinch, & Birch, 2004; Tarlier, Browne, & Johnson, 2007). Physicians and nurses are the most common access points for remote and isolated First Nations communities (Hay, Varga-Toth, & Hines, 2006). “Generally speaking, the further away rural community is from an urban centre the fewer the options for health care services and the less specialized the service providers are” (Hay et al., 2006, p. 63).

For isolated First Nations communities, the nursing station is considered the primary health care facility, especially where there is no road access (Hay et al., 2006). The nurses, who are the primary health professionals, live in the community for a specified period of time or can be permanently stationed there (Hay et al., 2006). The other health professionals (doctors, specialists, dentists) are organized to enter the communities at specific times for a short timeframe, which is usually less than 5 days every month (Hay et al., 2006). Community Health Representatives (henceforth known as CHRs), home care staff, nurse practitioners, and other support workers provide much of the primary and secondary health care (Chenier, 2004; Hay et al., 2006).

There are many services not available in First Nations communities because of the location, lack of health human resources, and funding. Services like palliative care, major surgery, cancer care, major trauma, nutrition and addictions services may not be available, “not be culturally or linguistically appropriate, or only available sporadically through visiting specialist programs” (Hay et al., 2006, p. 25). The lack of availability in or near the First Nations communities forces community members to travel to receive the required services (Tarlier et al., 2007). The more isolated and remote the First Nations community is, the more likely they are to be impacted by high staff turnover, lack of resources, have a difficult time recruiting and retaining the appropriate staff, which affects the location of delivery of health care as it may require First Nations community members to leave the reserve to access primary health care (Tarlier et al., 2007).

### **Health Human Resources**

The lack of health human resources or having consistent staff can cause problems with access, quality and organization and delivery of care. Ho et al. (2006) found that if there was a high turnover of primary care staff, there is a direct effect on the availability of primary care. Therefore as First Nations communities take increasingly more control over their health care through the Health Transfer Policy, they must ensure that they adequately staff their health centre or nursing station (Ho



et al., 2006; Lavoie, 2005; Minore et al., 2004; Royal Commission on Aboriginal Peoples, 1996c). Minore et al. (2004) found that “sporadic and inconsistent care” created patient backlogs, longer wait times, and caused some patients to fall through the cracks.

One of the primary reasons that health care staff do not stay employed with the First Nation is salary (Hay et al., 2006; Lavoie, 2005; Royal Commission on Aboriginal Peoples, 1996c). Depending on the level of funding received through the Health Transfer agreement and other separate contribution agreements with FNIH, some First Nations health authorities do not have adequate resources to pay nurses a salary that would be equivalent to mainstream health care facilities (Allec, 2005; Gideon, Gray, Nicholas, & Ha, 2008; D. Smith et al., 2008). The lack of adequate funding also decreases the training and professional development opportunities that primary care staff be able to access (D. Smith et al., 2008). Staff turnover can decrease the quality of care received, the access to a primary care professional, and how care is delivered in First Nations communities (Lavoie, 2005; Minore et al., 2004).

Tarlier et al. (2007) found that the level of preparedness to practice in the complex environment of a remote or isolated First Nations community fostered social distancing in nurse-patient relationships and influenced the health of the patients. Therefore First Nations health authorities must ensure that there is mentoring and training made available to staff after they are hired (Jordan, Boston, MacNamara, & Kozolanka, 2000). Training and mentoring with regards to First Nations culture and worldview is especially important as there is an extreme shortage of qualified First Nations health care professionals (Health Canada, 2011b; Lavoie, 2011; Royal Commission on Aboriginal Peoples, 1996c).

McKee, Clarke, Kmetc, and Reading (2009) also heard diabetic patients suggest that healthcare providers connect with community members in a variety of settings to nurture a trusting relationship. First Nations communities have a significant number of social events that would allow health professionals, especially those that do not live in the community, to further understand their patients and their lifestyles (Mashford-Pringle et al., 2011). If health professionals attended some of the social and cultural events in First Nations communities, they could begin to have a better understanding of their patients’ lifestyles and the culture and language in the community (Bartlett, Iwersaki, Gottlieb, Hall, & Mannell, 2007; McKennitt, 2006). Attending such events will also

improve understanding of ‘Aboriginal English’ and create an open path of communication (A. Roy, 2001).

## **Communication**

Communication is an important variable to improving access, organization, and delivery of health care (Towle, Godolphin, & Alexander, 2006). The Royal Commission on Aboriginal Peoples (1996c) recommended that communication between various groups and people were necessary for improving health and health care for First Nations people. One recommendation in the Royal Commission on Aboriginal Peoples (1996c) report was that traditional healers and western medical professionals need to open a dialogue about how the two systems of healing can work together in a collaborative manner. The Blueprint on Aboriginal Health report also highlighted the need for communication between traditional healers and medical professionals in a manner that would assist with a seamless health care service to First Nations people (Minore et al., 2004; Walker et al., 2010). Open and effective communication between these two groups can provide First Nations patients with a wider array of health care options to improve their health.

It is also important for health professionals to speak with other health professionals to reduce contraindicated medications and laboratory requisitions, and to ensure that First Nations patients are receiving the best possible care, especially when the location of the care can be in a number of locations (Chandler, 2008; Lavoie, 2005). An interdisciplinary team of health professionals can develop a health plan for individuals, but this cannot be accomplished without open and effective communication amongst the health professionals (Postl & Moffatt, 1988). In the Expanding the CIRCLE study, health care professionals expressed their concern that different professionals did not communicate with each other and that the medical records of First Nations patients were not shared, which increased the cost of treatment, caused contraindicated medicines in some cases, and left the patient with a large amount of information to understand.

In addition to communication between health professionals, there is a need for health professionals to provide culturally and linguistically appropriate communications to their patients to improve outcomes, adherence to treatment and prescriptions, and reduce further complications (Cass, Lowell, Christie, & et al., 2002; McIvor et al., 2009). When health professionals speak with First Nations patients, there may be a barrier as they may not understand the language used by the health professional in explaining their condition, treatment, or follow up care (Cass et al., 2002). Jordan et

al. (2000) found that if treatment and knowledge were not provided within a cultural context, the patients would not be likely to follow the instructions they were provided. “As well, the Western medical approach to the treatment and management of diabetes does not typically meet the needs of Aboriginal people with diabetes because of cultural differences in worldviews on spirituality, traditional medicine, diet, lifestyle, and acceptance” (McKennitt, 2006, p. 31). Therefore, health professionals must understand the culture, language and worldview of the First Nations patients that are seen in their practice.

With the jurisdictional issues that First Nations health care is plagued with, it is important for the different levels of government to have open communication. The Royal Commission on Aboriginal Peoples (1996b) report recommended that consultations and collaborations be developed between the federal, provincial and Aboriginal leaders. Allec (2005) found that the different levels of government have begun to discuss the jurisdictional issues and how to reduce barriers and gaps in health care services. However, even with tripartite committees that communicate the needs of each level of government, there is still much communication that needs to occur (Lavoie, 2011; McIvor et al., 2009).

### **Self-management**

Minore et al. (2004) found that patients wished to build a relationship between themselves and their health care provider, but some health care providers do not have the resources or time to make personal connections. McKee et al. (2009) found that patients wished to have health care providers connect with the community outside of the health care setting so that a trusting relationship can be developed. Finally, the Royal Commission on Aboriginal Peoples (1996c) report recommended that health care providers look at their patient's lives beyond the issue that brought them for care in the first place.

### **Community Resources**

Linkages between health delivery and community resources are necessary for communities to continue to improve their health systems. Lavoie (2011) found that when communities had collaborations and partnerships with external stakeholders, the communities were more likely to have a variety of health programs and services that met some of the community's needs. The Royal Commission on Aboriginal Peoples (1996c) report recommended that all First Nations communities

seek to embrace the health care professionals in their community, encourage community members to become educated in the health sciences, and to connect with external stakeholders.

### **First Nations Health Care within the Canadian Health Care System**

The Canadian health care system began as a privately funded and delivered system until the beginning of universal hospital insurance in the late 1940s (Health Canada, 2011a). Over the next two decades, other national pieces of legislation also assisted in creating the universal health care system that is presently in place (i.e. *Medical Care Act*, HIDS, Federal-Provincial Fiscal Arrangements, Canada Health Transfer, etc.). The *Medical Care Act* (1966) introduced cost-sharing for medical services, but with increased expenditures and a decreasing budget, the federal government moved to block funding for all health and post-secondary education in 1977 (Health Canada, 2011a). The provision of universal health care directly affects First Nations people by removing financial barriers for all Canadians, including First Nations people, but also perpetuates some of the jurisdictional problems relating to eligibility to receive the so-called ‘non-insured health benefits’ (NIHB) (Borrows, 2010; Waldram et al., 2006).

With the introduction of the *Canada Health Act* in 1984, provinces and territories were provided with criteria and conditions that must be met to receive their cash contributions under the Canada Health Transfer (Bent et al., 2008; Chenier, 2004; Health Canada, 2011a). However there are some specific groups of Canadians that are considered to be federal health care clients; First Nations and Inuit, Canadian Forces personnel, veterans, Royal Canadian Mounted Police, federal prison inmates, and some refugee claimants (Chenier, 2004). “Whether or not the federal government conforms to the five principles of the [Canada Health Act] – public administration, comprehensiveness, universality, portability, and accessibility – in providing health services to federal clients, as is required of the provinces and territories, has never been fully examined” (Chenier, 2004, p. 15).

Each province and territory provides similar health care services (i.e. access to physicians, local specialists, and hospitals) and is required to provide these services to First Nations people as outlined in the *Canada Health Act* (Bent et al., 2008; Chenier, 2004; Health Canada, 2011a). As both the federal and provincial governments are responsible for providing health services to First Nations people, there is a possibility of integrating the two health care systems. However First Nations

people living on reserves are not generally considered users of the mainstream health care system because of the federal government's fiduciary and legal responsibilities to this unique population (Boyer, 2003; Lavoie et al., 2010). Therefore while First Nations people can access and use the mainstream health care system off the reserve, the services provided are not likely culturally sensitive and do not connect with traditional medicine (Lavoie et al., 2010).

## 2.6 A Brief History of Government-First Nations Relationships

Aboriginal people had legal, political, social, economic and health systems prior to contact that were based on interconnectedness and holism, while maintaining balance of the body, mind, and spirit of individuals, families, communities and societies (J. Miller, 1991; Perdue & Green, 2008; Waldram et al., 2006). Aboriginal people were willing to share the land and resources, and assist with hunting and the fur trade in return for metal utensils and firearms (J. Miller, 1991; Perdue & Green, 2008). The relationships formed with British and French settlers in Upper and Lower Canada were created under the premise of being allies and partners in peace (J. Miller, 1991). To maintain this beneficial relationship, the King of France gave many gifts annually to Aboriginal people (Allen, 1992; Frideres & Gadacz, 2001). The British wanted to maintain this relationship after defeating the French in the Seven Years War, and King George III issued the *Royal Proclamation of 1763* and recognized that Aboriginal people were distinct political entities who were sovereign (Allen, 1992; J. Miller, 1991). The Aboriginal-nation-state relationship continued with little tension until the end of the War of 1812 when the boundaries between Canada and the United States were clearly defined with no Indian Territory demarcated (Cornell, Curtis, & Jorgensen, 2004). The broken promise of an Indian territory contributed to the growing tension and distrust between Aboriginal people and the British (Cornell, 1988; Cornell et al., 2004; Perdue & Green, 2008).

After Confederation, the newly born Canadian state entered into treaties with First Nations as it expands northwestward. The so-called "numbered treaties" - from Treaty I (1871) to Treaty XI (1921) were created to acquire more land in exchange for money, gifts, and some government services (J. Miller, 1991). The four First Nations communities in this study are represented by Treaties 5, 6, and 7. In only one treaty, Treaty No. 6 signed with the Northern Alberta and Saskatchewan Crees in 1876, was health care mentioned. This is the Medicine Chest clause. The Medicine Chest clause stated that medical supplies and assistance would be found at the home of the

local Indian agent and be freely available to all members of the signatory First Nations communities (Borrows, 2010; Gibson, 2009; J. Miller, 1991; Waldram et al., 2006).

The fractured relationship between the British and Aboriginal people was further harmed as the *British North America Act* (BNA) of 1867 replicated the British and French political and legal systems in the new country of Canada with no Aboriginal input (Boldt & Long, 1984; Borrows, 2001; J. Miller, 1991). Yet these systems would affect a large part of Aboriginal people's lives (Gibson, 2009; J. Miller, 1991; D. Turner, 2006). The BNA gave the new Canadian government the responsibility for 'Indians' and all aspects of their lives like a parent/child relationship (Alfred, 2009; Gibson, 2009; J. Miller, 1991). The parental role of the federal government was viewed as the only solution to the 'Indian problem' as Aboriginal people were 'savages' and in need of support and civilization (J. Miller, 1991; Surtees, 1982). The BNA also gave the provincial governments control of health care with the exceptions of marine, military and 'Indians', thus creating a jurisdictional confusion about the care of First Nations people that has lasted to present day (Waldram et al., 2006).

Within a decade, the Canadian government enacted the *Indian Act* (1876), which created further limitations and restrictions upon First Nations people who were deemed eligible for registration. Status or registration, which was determined by the Department of Indian Affairs, determined every aspect of a First Nation person's life from identity, eligibility for services, residence, livelihood, land use to health care (Alfred, 2009; Boldt & Long, 1984; J. Miller, 1991; Weaver, 1981). This practice was borne from the assimilation policy of the government that believed that those First Nations people that looked more like the British settlers could blend into society and be a part of the economy. This was seen as the best possible solution for their health and well-being as entering Euro-Canadian society would be of great social and economic benefit (Alfred, 2009; B. G. Miller, 2006). The decisions that Indian agents made in the creation of band rolls has had impact to this day. It has caused tension to grow between First Nations people and the government, as traditional methods of community acceptance is not part of the current registration system nor do First Nations people determine who can register under the *Indian Act* (Alfred, 2009; Borrows, 1994, 2001).

The *Indian Act* created restrictions on mobility, use of traditional knowledge including traditional healing and medicine and band governance (Anderson et al., 2006; Barman, Hebert, & McCaskill, 1986; Gone, 2007). In addition to this shift in control, there was also an increase in western medicine and health care available to First Nations communities and people (Waldram et al., 2006).

The increasing use of western medicine further suppressed traditional and cultural healing practices (Anderson et al., 2006; Gone, 2007; Stewart, 2008). Some scholars (Alfred, 2009; Duran et al., 2008; Gone, 2007) argue that some cultural and healing practices continued in secret, but this further depressed the First Nations spirit and culture, which negatively affected mental and physical health (Gone, 2007).

First Nations health care was initially delivered informally by various outside agents such as the police, military, missionaries and Hudson Bay Company employees. A formal “Indian health service” was created within the Department of Indian Affairs in 1927. In 1945 it was transferred to the then newly formed Department of National Health and Welfare’s Medical Services Branch (Waldram et al., 2006; T. K. Young, 1984). After World War II there was an increase in the number of facilities on or close to reserves which increased the access to health services (Waldram et al., 2006; T. K. Young, 1984). First Nations health care policy in this era was created without First Nations consultation and by the 1940s it appeared that First Nations people had disappeared from the media, which further decreased the potential for input and debate (Alfred, 2009; Boldt & Long, 1984; Malloy, 2001, 2003; Waldram et al., 2006; Weaver, 1981).

Residential schools were opened in the 1880s and ran until 1996 (Stonechild, 2006). Generations of First Nations children were subjected to the rudimentary learning institutions where they experienced physical, sexual, emotional and verbal abuse (Aboriginal Healing Foundation, 2008; Stonechild, 2006). These schools were designed to eradicate First Nations languages and cultures by indoctrinating First Nations children in western worldview and teaching European languages (Battiste, 1986; Stonechild, 2006). Many First Nations parents and Elders recommended that Aboriginal children attend these schools to acquire a western education (Wotherspoon, 2004).

Like many Canadians, First Nations people and communities were intently watching the civil rights movement in the United States between the 1950s and 1960s (Cardinal, 1969). Small First Nations organizations were developing across Canada based on the American Indian Movement (AIM) organization and the National Congress of American Indians (NCAI) in the United States (Alfred, 2009; Cornell, 1988). While these organizations received little attention in the Canadian media, they were gaining support amongst Aboriginal people as they believed participation could save their cultures, languages, and improve their health and well-being (Alfred, 2009; Cardinal, 1969; Gibson, 2009).

The Alberta Indian Association was the precursor organization to the National Indian Brotherhood (which later became the Assembly of First Nations) and was led by First Nations people who wanted to see a change in the degree of control they had over all aspects of their lives (Alfred, 2009; Cardinal, 1969; Gibson, 2009; Weaver, 1981). First Nations people received the right to vote between 1960 and 1969, but the government still fully controlled all aspects of First Nations peoples' lives (Surtees, 1982; Weaver, 1981). Another civil right afforded to First Nations people in 1968 was the freedom to leave the reserve without the permission of the Indian agent (Surtees, 1982; Weaver, 1981). First Nations people were still doubtful of any government involvement and saw the new 'rights' as another ploy at assimilation, however, there were increased interactions between First Nations people and government officials (Alfred, 2009; Gibson, 2009). Civil rights allowed Aboriginal people to begin to voice their concerns (Boldt & Long, 1984; J. Miller, 1991).

The complex and tenuous relationship between First Nations and the federal government is still evolving. However, the socio-political history that Aboriginal people have faced has influenced current health and social issues (Hackett, 2005). First Nations health care and social services were becoming much more expensive as the Hawthorn Report (1967) was released. The report provided support for First Nations people to be treated as 'citizens plus' (Gibson, 2009; Weaver, 1981). The Hawthorn Report (1967) further explained that First Nations people were one of the founding groups of Canada. As such, they should be afforded a special place in Canadian history and in future policy and program developments (J. Miller, 1991; Posluns, 2007). If the Hawthorn Report had been brought forward earlier under a different government, it may have had a positive impact on First Nations – government relations, but this was not the case (Weaver, 1981). The Hawthorn Report was commissioned prior to the Trudeau government and the change in policy direction toward an 'equal and just' society (Weaver, 1981). This new policy direction relegated the Hawthorn Report to the periphery and the recommendations were not acted upon (Weaver, 1981).

Through all these assimilationist and oppressive policies, First Nations people have experienced trauma that is experienced by all family members and the community (Kirmayer, Simpson, & Cargo, 2003). The soul wound that is created by these negative policies runs across one generation, but is shared by subsequent generations as if the experience had happened to all (Duran, 2006). Stewart (2008) argued that healing from this history will take time and can occur through many different processes. It is important that First Nations individuals, families and communities work together in the healing process.



As the civil rights movement energized Aboriginal people to fight for their civil rights, they began to publicly advocate for their health and education needs based on the Hawthorn Report (Weaver, 1981). However the Canadian government was moving toward social justice and equality for all Canadians in 1969. The release of the *Statement of the Government of Canada on Indian Policy*, or the White Paper, was a major turning point in the relationship between Aboriginal people and the Canadian government (Alfred, 2009; Lavoie, 2011; Stonechild, 2006; Weaver, 1981). The intention of the White Paper was to eliminate special status for registered First Nations people and allow them to have the same rights and freedoms that all Canadians had (Weaver, 1981). Aboriginal people across Canada were offended with the intentions of the White Paper because it essentially meant that after more than 100 years since Canada was created, they would be ‘dismissed’ and assimilated with the signing of a document (Weaver, 1981). The White Paper is highly significant to First Nations health policy and health care as it forced the federal government to review the policies and legislation that pertained to Aboriginal people (Alfred, 2009; Olsen, 1994; Weaver, 1981).

## 2.7 Current Policies Affecting First Nations Health Care

“Looking back on their historic experience with the franchise, Indigenous people may be wary of the electoral option because it symbolizes their subordination to the state and their acceptance of a policy of assimilation” (Murphy, 2008, p. 211).

The complex patchwork of policies and legislation that affect every aspect of Aboriginal people’s lives has not allowed for their voices to be heard (Lavoie, 2005, 2011). Policy development requires policy actors, a window of opportunity and positive societal influence (Howlett, 1994). Much of the policy development that has occurred in Aboriginal health policy, has occurred as a result of necessity (i.e. no past development in the area like the Indian Health Policy), or changes in political power (i.e. *Self-Governance Act* of 1995). Until the 1960s, Aboriginal representatives were not invited to speak on the behalf of their people, nor were there viable advocacy organizations (Olsen, 1994; D. Smith, Varcoe, & Edwards, 2005; Weaver, 1981).

It is interesting to note that the two major federal First Nations health policies are documented within a few pages with a limited description, no clear policy instruments for implementation and a lack of evaluation. Both the *Indian Health Policy* and the *Health Transfer Policy* are comprised of three

pages that look similar to a letter of intent rather than a policy about a special segment of the Canadian population (Lavoie, O'Neil, & Reading, 2008). The lack of clear policy direction has slowed progress toward full implementation of these policies and has allowed senior bureaucrats a greater degree of latitude on how to implement and evaluate the policy's effectiveness (Lavoie, 2005; Lemchuk-Favel, 1999). It is likely that all First Nations policies within the policy patchwork should be reviewed to determine if there are any contradictions or overlap (Olsen, 1994; VandenBurg, 2009). Though the literature recommends a review of First Nations health and health care policies, there does not appear to be any academic articles that have accomplished this task.

The following policies, legislation and reports are important to the understanding of how self-determination and self-governance could influence First Nations health care.

### **The Indian Health Policy of 1974**

The *Policy of the Federal Government concerning Indian Health Services* (1974), which is considered the first Indian health policy, was released by the federal government and it proposed transferring responsibility for health to the provinces and territories (Health Canada & Saunders, 2006). This policy followed the concepts of the White Paper in that Aboriginal people should be treated like all Canadians (Health Canada & Saunders, 2006). The federal government argued that there was no treaty obligation to provide health care to First Nations and Inuit people (Health Canada, 2007b). However this policy was never truly implemented as there were many protests, but this left the federal government with the need to acknowledge what responsibility they did have in First Nations and Inuit health (Jacklin & Warry, 2004).

### **The Indian Health Policy of 1979**

In 1979, the Minister of the National Health and Welfare (now known as Health Canada) introduced the *Indian Health Policy* (Crombie, 1979), which reaffirmed the federal government's commitment to First Nations and Inuit health. The policy was comprised of three pillars that gradually became the mandate of the Medical Services Branch (renamed First Nations and Inuit Health Branch or FNIH in 2000) (Health Canada, 2007a; Lavoie, 2005). This policy was clearly moving in the direction that First Nations leaders had advocated for. The three pillars of the policy were: community involvement, community development, and intersectoral and intergovernmental collaboration in health care services. The relationship between First Nations and the federal

government was highlighted with this policy and acknowledged that improving health for First Nations and Inuit people was a goal for both parties (Lemchuk-Favel, 1999b). This policy provided First Nations people an opportunity to have input and a measure of control over their health care (Crombie, 1979; Gibson, 2009; Lavoie, 2005; Waldram et al., 2006). Over the next few years, the government held consultations with experts, academics and First Nations leaders to determine how to move the locus of control from government to First Nations as recommended in the *Indian Health Policy* and the Berger Report (Berger, 1980; Lavoie, 2005).

### **The Health Transfer Policy/Program of 1986**

After the 1982 Community Health Demonstration Program, which evaluated the process of future transfers to First Nations communities for health, the Health Transfer Policy was implemented in 1986 (Lavoie, 2005). The Health Transfer Policy provided First Nations communities the opportunity to create a health care plan that could be more responsive to the specific community's health needs and reaffirmed the federal government's commitment to First Nations health (Lavoie, 2005). Many First Nations communities began the process involved in signing a Health Transfer Agreement, but some were not able to complete the process for a variety of reasons (Lavoie, 2005). For those First Nations that did create a health care plan and signed an Agreement, they have seen changes in the health care provided by FNIH, the provincial health authorities and their First Nation government (Lavoie, 2005). Provincial initiatives for First Nations have assisted all First Nations communities, but particularly those communities that have entered into an agreement under the Health Transfer Policy (Lavoie et al., 2005).

The Agreements were intended to provide First Nations communities with the ability to adapt and adopt health policies and programs as needed by their communities. Lavoie (2005) found that this may not be the case in some First Nations communities as they appear to only hold administrative authority over their health care systems. This administrative control allows communities to develop a plan, budget and hire staff, but changes must be agreed to by FNIH (Jacklin & Warry, 2004; Lavoie, 2005). There is a limited amount of flexibility, and the funding does not assist with capacity building, which is needed by many First Nations communities (Lavoie et al., 2005). In addition, Lavoie, Forget, and O'Neil (2007) found there were inequities in the funding. Lavoie (2003) also argued that the inadequate funding causes First Nations health authorities and band councils to only serve the status community members as this is all the funding covers. However there can be non-

status community members and people from surrounding non-Aboriginal communities that wish to access the health care services at the First Nation health centre because the location is closer (Lavoie, 2005; Olsen, 1994). It must be noted that only existing health services and funding can be transferred (Olsen, 1994). Lavoie (2005) further argues that the transferred services do not see an increase in funding. Therefore it is imperative to create agreements and partnerships with provincial and municipal health organizations and governments to provide adequate health care services (Lavoie, 2005, 2011). When First Nations communities create or wish to amend their health plans, the proposed activities must be approved by FNIH staff; this can further reduce flexibility and create gaps in services available (Lavoie, 2005; Olsen, 1994).

By the late 1980s, there were a few First Nations communities which had successfully signed the tripartite agreement with FNIH to take responsibility for their own health services (Gibson, 2009; Lavoie, 2005). One of the biggest issues with the policy has been the inability to deal with the broader socio-economic factors that affect health (Jacklin & Warry, 2004). Another issue is the degree of knowledge of Aboriginal people that doctors and nurses working in the community have as this can affect communications and treatments (Postl & Moffatt, 1988).

Health Canada's Departmental Executive Committee (DEC) fully supported the Health Transfer Policy and viewed devolution of health resources and health care as the only solution to improving health in the mid-1990s (Health Canada, 1999). The Health Transfer Policy has been evaluated as a good start to a self-determining First Nations health care system. In an attempt to further improve First Nations health care and support the work of the Health Transfer Policy program, Health Canada, the province of British Columbia and First Nations leaders in British Columbia have entered into a tripartite agreement in 2010 that will allow a First Nations organization to assist First Nations communities across British Columbia in providing health care in the communities, while the province provides linkages and services where possible (Gideon, personal communication 2010).

### **The Royal Commission on Aboriginal People (1996)**

The Royal Commission on Aboriginal People (RCAP) was completed in 1996 after 5 years of consultation, policy reviews, and submissions from a variety of sources including Aboriginal people and organizations. Strictly speaking, it is not a policy document (such as a White Paper), but a fact finding mission upon which policies are supposed to be made. The final report had many recommendations with regards to health (Royal Commission on Aboriginal Peoples, 1996a). Some

of the recommendations focused on structural barriers to access and delivery of health services, communication, and health human resources (Royal Commission on Aboriginal Peoples, 1996a). Structural barriers such as funding, jurisdictional issues of who provides which services, and how different levels of government must communicate with each other for the well-being of Aboriginal people (Lemchuk-Favel, 1999b; Royal Commission on Aboriginal Peoples, 1996a).

The RCAP recommended that funding provided for primary health care services be reviewed. Additionally, the Royal Commission on Aboriginal Peoples (1996c) report recommended that the First Ministers and Ministers of Health meet with federal government officials and Aboriginal leaders to discuss how and by whom services are provided. Lavoie (2011) recently found that jurisdictional issues surrounding delivery of health services still exist across the country. There is considerable confusion regarding the responsibility of First Nations health care as the *Constitution* separates First Nations (federal responsibility) and health care (provincial responsibility), and the need for First Nations-controlled health care remains an elusive goal (Lavoie, 2011; Savard, 2008; Scott, 1993).

As with the fate of many royal commissions throughout modern Canadian history, implementation of recommendations often fails to measure up to the aspirations and expectations at their original creation.

## 2.8 Conclusion

The literature reviewed in this chapter outlines the importance of access to health care for First Nations people as well as the importance of self-determination and elimination of jurisdictional conflicts. The complexity of First Nations health care, specifically in the organization and delivery of the health care system, necessitated this study. Building upon this prior knowledge, the following chapters present my research project into the organization and delivery of health care in four First Nations communities in Canada, particularly the perceived level of self-determination in these First Nations health care systems.

There are concerns regarding status and identity, which can lead to some First Nations people not being able to access and afford health care. While this is not a focus of this study, these issues will be a future concern and will be minimally discussed in this dissertation.

The different definitions of self-determination may affect the perception of control as First Nations view self-determination through a different lens than the federal and provincial governments. The funding available for the federal government's self-determination is substantially less than that needed to organize and delivery health on reserves, and currently the federal government will only support self-administration, not true self-determination. My research seeks to determine if this is indeed the case and if there are other factors that may connect First Nations with the ability to gain true self-determination in health care. It is apparent through the literature review that there have been no studies that have looked at the perception of self-determination, although many scholars have address the need for self-determination in health care.

## Chapter 3 Methodology

### 3.1 Introduction

This chapter discusses the research approach for this dissertation including the theories used, the conceptual framework, and the research design. The research design is described in detail and includes research questions, critical lens criteria, data collection, how participants were recruited, and data analysis. Finally, this chapter will introduce the four First Nations communities of Blood Tribe, Lac La Ronge Indian Band, Garden Hill and Wasagamack First Nations.

This study was designed around an Indigenous conceptual framework (Medicine Wheel), but as the study progressed it became apparent that a western conceptual framework was also required. Culture, language and worldview are important to all aspects of First Nations life, and the health care system is no exception. To look at health care in First Nations communities, I used a Medicine Wheel conceptual framework (p. 54) which illustrates the interconnectedness between the socio-political history, the organization and delivery of health care, the perceived level of self-determination in each of the four First Nations communities and their health care system. The western conceptual framework uses the same variables, but shows linear connections between the variables. It was my intention to provide an Indigenous perspective, which Wilson (2008) believes requires an Indigenous framework and methodology. However there is a need to bridge the two worldviews, Aboriginal and western, so both conceptual frameworks assist with providing this bridge. This chapter provides a detailed reflection of the research methodology and sociological theories used for this dissertation.

### 3.2 Statement of the Problem

In my literature review I found a few studies focused on illnesses and specific policies (health transfer policy), and other studies that looked at self-determination and policy development, but there were none that incorporated all of these aspects. The literature highlighted that many First Nations people must leave their community to receive specialized care and that health care received outside of community can affect a person's health (i.e. longer recovery, inability to follow instructions, long waits to follow up on initial visits, and no social support from family) (Hay et al., 2006; Jacklin &

Warry, 2004; Minore et al., 2004; Tarlier et al., 2007). Thus it is important to determine what services are provided and how health care is organized in First Nations communities.

There was little literature that discussed the structures involved in on-reserve health care systems; the literature briefly describes the nursing stations (Minore et al., 2004) or provides outlines of what the First Nations communities provide in secondary and tertiary services when they have health transfer agreements (Jacklin & Warry, 2004; Lavoie et al., 2010), but the organization and delivery of primary health care on reserve is not reviewed. Lavoie (2005) acknowledges that communities which have signed health transfer agreements have limited control over primary care, but further discussion is not provided. Jacklin and Warry (2004) discuss the limited control that Wikwemikong First Nation has in primary health care, but the organization and delivery of the primary health care is not provided in detail. The organization and delivery of primary health care in First Nations communities can be as diverse as the communities and cultures, but there is a need to understand the different structures that exist to further study which are best practices or the elements that may work in other communities.

As discussed earlier, First Nations health care must be holistic, relevant, timely, locally governed and provided, as well as being culturally appropriate. First Nations peoples and communities argue that they never relinquished their inherent right to self-determination and that regaining self-determination is essential for improving the health and healing of their communities (Alfred, 2009; Borrows, 1994; Boyer, 2003). This study explores how self-determination is manifested in the organization and delivery of First Nations health care, focusing on diabetes care as an indicator of how health care is delivered, in four First Nations communities in Canada.

According to the First Nations Regional Health Survey (FNRHS) (2004), First Nations people living on reserve are four times more likely to have diabetes than other Canadians (prevalence of 19.7%), with one in 3 First Nations adults aged 50 to 59 years having a diagnosis of diabetes. With such a high prevalence of diabetes in First Nations communities, many First Nations people need to access diabetes care. Diabetes care is funded through specific contribution agreement funding from First Nations and Inuit Health (FNIH), Health Canada. The program requires fund recipients to provide preventative and promotional activities and treatment for diabetes. The activities provided are not dictated or prescriptive; thus allowing First Nations health authorities to manage and choose how the funding and programming looks for their community (Mashford-Pringle et al., 2011). This could be



considered a first step toward self-governance. Therefore looking at the organization and delivery of diabetes care can show how health care is provided in these four First Nations communities.

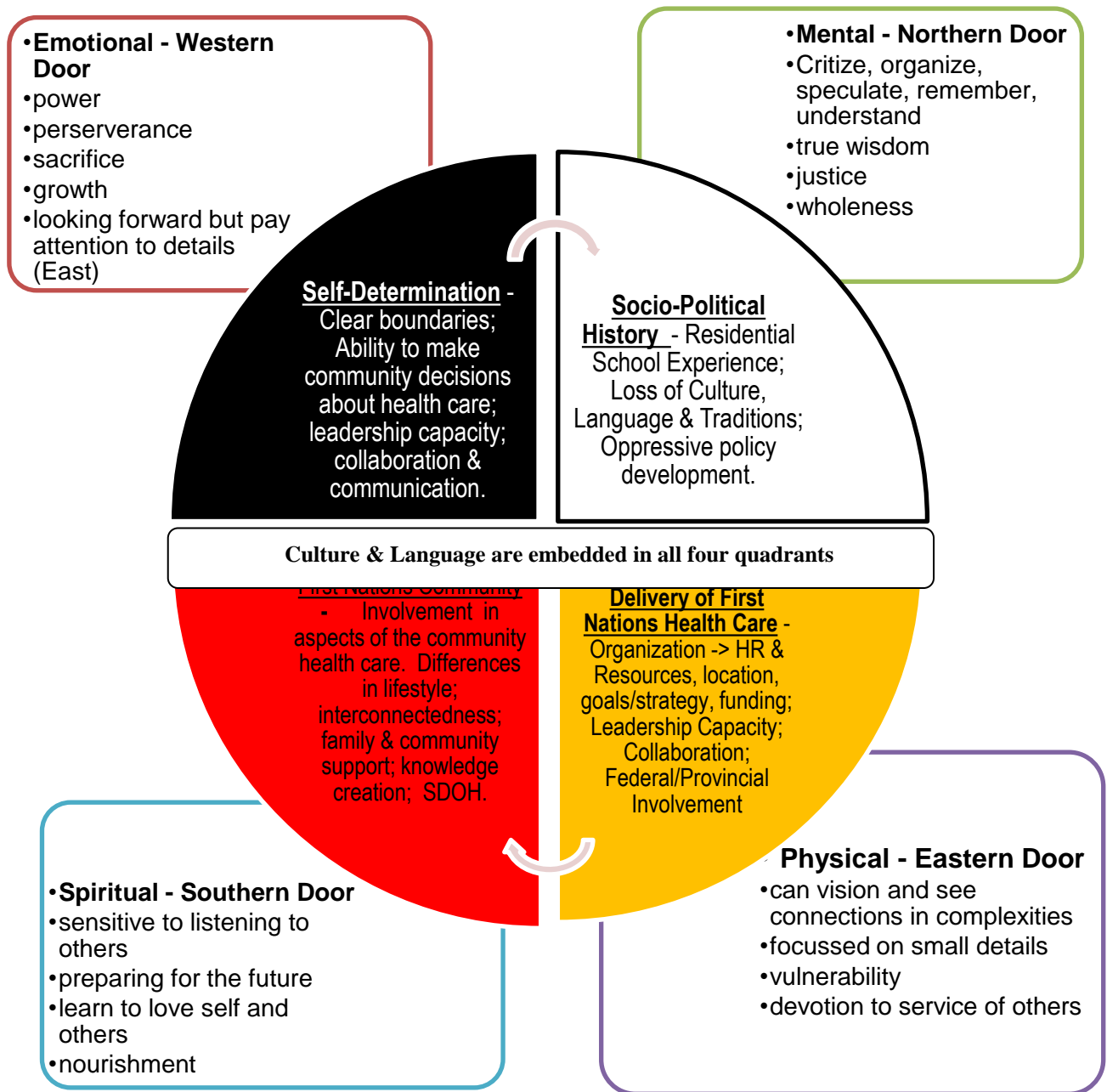
Many scholars (Lavoie et al., 2010; Minore et al., 2004; Tarlier et al., 2007; N. Turner, Gregory, Brooks, Failing, & Satterfield, 2008; Waldram et al., 2006) have examined aspects of how the socio-political history has affected health and health care for First Nations people and the degree of self-determination experienced in running it. Other scholars (Long & Dickason, 2011; B. G. Miller, 2006) have provided rich detail of the colonization and assimilation effects that have occurred from the point of contact to present day. However, there are relatively few studies that examine the effect of contact and colonization on the health care system provided to First Nations people and the degree of self-determination experienced in running it. Lavoie (2005) and Jacklin and Warry (2004) focus on the health transfer policy and agreements between the First Nations communities and FNIH with a brief discussion of how primary health care is organized and delivered in First Nations communities today. There is no discussion of when contact was made, the potential impacts that contact may have had on health care or self-determination, or how primary health care is affected by the contact or policies created by the federal government, who are responsible for First Nations health care. Therefore this study will examine when contact was established and the impacts of the socio-political history on the community's health care system and the levels of self-determination present.

### 3.3 Conceptual Framework

A conceptual framework provides the researcher with “a system of concepts, assumptions, expectations, beliefs, and theories that supports and informs” the research (Maxwell, 2005, p. 33). The conceptual framework can be either shown as a visual aid or may be a written passage that provides a method to look at the key variables, concepts and underlying theories (Maxwell, 2005; Verniest, 2006). Researchers use conceptual frameworks to provide readers of the material with ways of arranging the complex array of concepts, variables, theories, and beliefs. Components of the conceptual framework are developed by ‘borrowing’ key ideas from the literature, personal knowledge and the research (Maxwell, 2005). Personal knowledge is central to an Indigenous conceptual framework as the researcher’s beliefs about knowledge production and beliefs do have an impact on the research study, but there must also be unification of western and Indigenous methodologies (Kovach, 2009).

For this dissertation, there are two conceptual frameworks; the Medicine Wheel Framework and the Western paradigm framework. Both frameworks use the same variables, but from different worldviews and with different knowledge. Figure 1 (below) is a modified Medicine Wheel framework that builds upon the work of H. Graham and Leeseberg Stamler (2010) and Wilson (2008). "...putting ideas in a circle or wheel indicates that they are interrelated and each blends into the next. It also implies that the ideas flow from one to the next in a cyclical fashion," (Wilson, 2008, p. 70). In this way, all the parts (variables) are seen as interdependent and interconnected. Wilson (2008) further explains that paradigms and variables are value laden, which is clearly the case in the Medicine Wheel framework. There are many traditional teachings associated with the four aspects of the Medicine Wheel, which can be noted in each part of Figure 1. Tafoya (as cited in Wilson, 2008) argues that western paradigms look at "individual components rather than by looking at the total person and the complexity of the connections and relationships," (p. 56) which is why I argue that two conceptual frameworks are needed as this dissertation is attempting to bridge Indigenous ways of knowing with western knowledge systems. Marks, Cargo, and Daniel (2007) state "limited attention to understanding relations amongst domains and their sub-classifications in a comprehensive conceptual framework specified a priori can lead to an overlooking of existing or desirable indicators representing particularly key classes of influences on Indigenous health" (p. 95). Therefore using the two conceptual frameworks have assisted me with seeing the variables from different perspectives and ensuring that I looked at the relationships that variables have to each other.

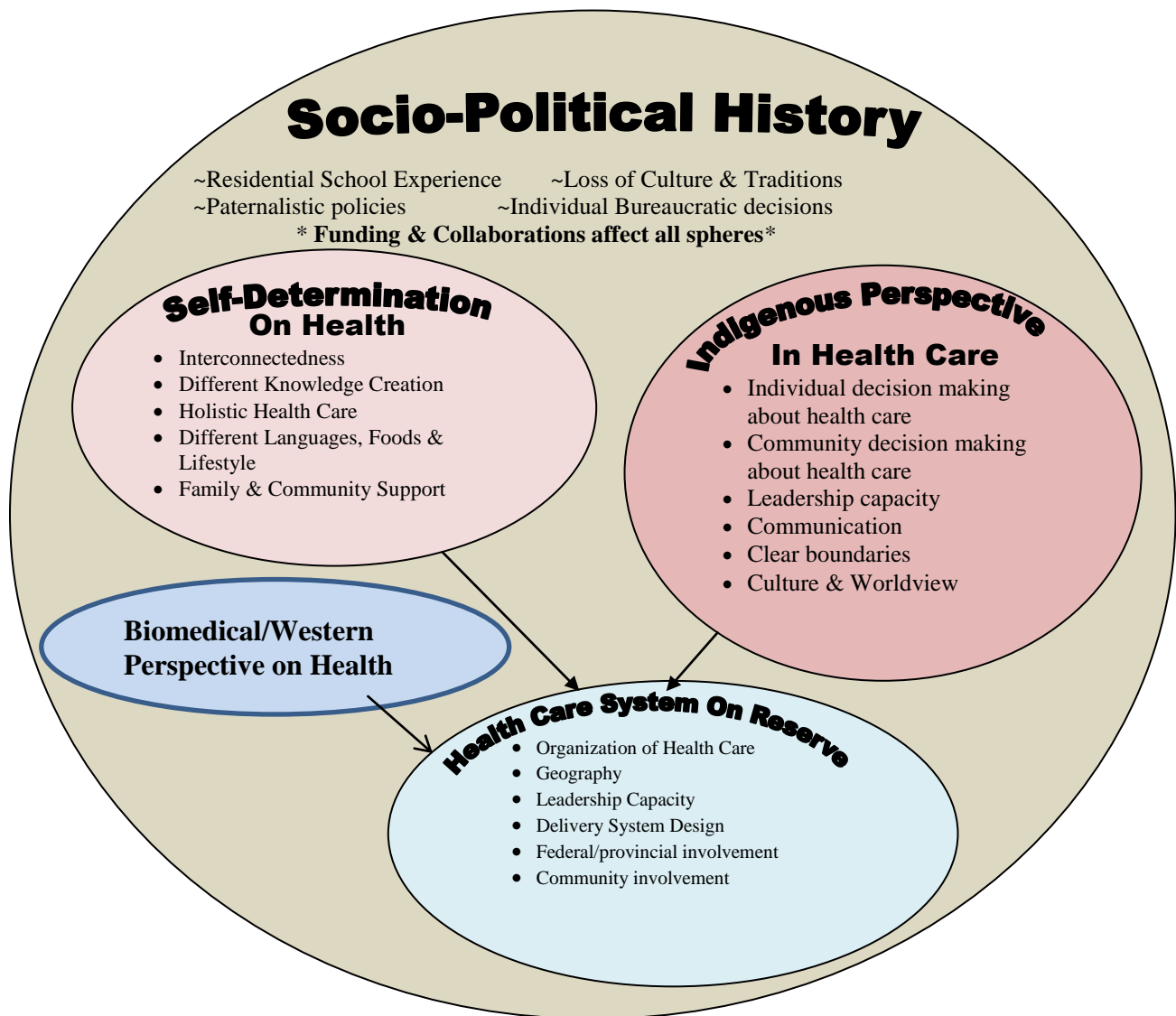
### **Figure 1 Medicine Wheel Conceptual Framework**



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The data collection, analysis and the writing of this dissertation have incorporated both conceptual frameworks and the traditional teachings associated with the Medicine Wheel framework. The same information is listed in both conceptual frameworks, but is circular in the Medicine Wheel framework and linear in the Western paradigm (Figure 2).

**Figure 2 Conceptual Framework Illustrating Western Paradigms**



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This conceptual framework highlights the importance of the socio-political history on all aspects of First Nations health care. In the criteria tables, funding and collaboration were not specifically in the socio-political history table, but as these two variables have considerable impact on all aspects of First Nations health care, they are represented in the overarching socio-political sphere. The Indigenous perspective has influence in how self-determination is developed and also has influence and impact on the mainstream health care system through culture, language and worldview. The health system has been separated as self-management and personal skills would occur within the

context of a First Nations perspective in First Nations communities, but the health system would be developed and designed based on mainstream bio-medical approach to health care. The health system could be perceived from a First Nations perspective which illuminates the ideal First Nations health care system or hybrid, or a mainstream biomedical perspective for future research initiatives.

These concepts and variables were important in the collection, coding and analysis of all data for this study. These conceptual frameworks closely resemble the thought processes that assisted in the analysis, findings, and discussion sections of this dissertation. Through an Indigenous worldview as shown in the Medicine Wheel conceptual framework, a holistic concept of health includes physical, spiritual, emotional and mental aspects for individuals, families and communities. Therefore the primary research question pertains to what influences the organization and delivery of health care in First Nations communities and discusses the perceived control of the system from three different perspectives (First Nations, provincial and federal governments).

### 3.4 Research Questions

I have decided to provide some key factors that connect self-determination to First Nations health care (Chapter 4), and then an analysis of the level of perceived self-determination (Chapter 5), and finally an analysis of the different typologies of First Nations health care (Chapter 6). As discussed at the beginning of this chapter, the literature examined showed a gap around the organization and delivery of health care in First Nations communities. Self-determination and the organization and delivery of health care to First Nations communities are vitally important to improving the overall health and well-being of First Nations communities. The primary intent of this study was to discover the organization and delivery of diabetes health care in four First Nations communities, the perceived level of self-determination in such a system from the three levels of government (federal, provincial and First Nations), and the connections of both aspects to socio-political history. In order to achieve this aim, the following objectives were also necessary:

1. To describe health care organization and delivery structures in the four First Nations communities, using diabetes as an example when appropriate;
2. To compare and contrast the perception of control that each level of government (federal, provincial and First Nations) and other First Nations community members has about health care in each of the four First Nations communities; and

3. To identify the different socio-political history of the four communities and how that might link self-determination to perceived levels of First Nations health care.

To further understand First Nations health care, these secondary questions will also be answered by my dissertation:

1. How do different First Nation communities arrange and negotiate their health system?
2. How much decision-making authority or self-determination do First Nations governments have over the health programs and services provided to their community?
3. What role does the degree of contact with western paradigms have on the perceptions of self-determination in health care?

This study will provide an initial understanding of the organization and delivery of primary health care in First Nations communities, and will illuminate the perceived level of self-determination and control that First Nations leadership, provincial and federal government bureaucrats believe exists in primary health care on reserves. It is anticipated that these findings will assist First Nations leaders and communities, and inform health and health care policy making for First Nations communities.

### 3.5 Research Design

First Nations health care is complex and there are many different variables that must be considered in the analysis and reporting of the findings. Wilson (2008) argues that any research of Indigenous issues should use an Indigenous methodology, and Smylie et al. (2003) and H. Graham and Leeseberg Stampler (2010) argue that qualitative methods allow the participants to provide knowledge as is done in an Indigenous setting. Using a multiple case study approach afforded me the opportunity to provide a snapshot of the organization and delivery of First Nations health care in the four First Nations communities as demonstrated in Chapter 6. Kovach (2009) states that Indigenous qualitative research is inclusive and “honours multiple truths” (p.27) and has a “strong narrative component as part of its method and presentation of [the] findings” (p. 35), which is seen in Chapter 5 about the perception of self-determination in health care. Additionally, qualitative research allows

for different views to be heard, which can be decolonizing and healing for Indigenous peoples (Kovach, 2009; L. T. Smith, 1999).

It is conceivable that a mixed methods approach would have further enriched the study by providing some statistical knowledge of specific funding, participation numbers in secondary and tertiary programs, and health care visits, but time and funding limitations prevented this work. A mixed methods approach could have been used for this study as it would have provided some statistical data on the number of primary health care visits to the community health clinic or nursing station. It may have also provided some statistical knowledge of length of visits, and the number of community members that have the educational background for the primary care positions. The statistics would have further assisted in developing the case studies, but it is not clear that they would have provided more context than the interviews alone did. Due to time and funding restraints, I decided that the qualitative case study approach would provide the most appropriate data to reflect each community's health care system and their self-determination of that system. The disadvantage to not including a questionnaire or collecting statistical data about the health care clinic has been limited to understanding of how community members use the clinic for their health care. This is beyond the scope of the current research question and should be further examined in future research.

With four unique First Nations communities participating in this study, I needed a method of reporting the complexities of their health care systems as well as doing some comparison between communities. Therefore I used a comparative case study approach. The study builds upon a previous qualitative study, Expanding the CIRCLE, where the primary research question was about the quality of care for diabetes patients in the four selected First Nations communities. The four communities have been treated as four unique cases within this study.

The current study was envisioned through my participation as the Senior Research Fellow on the Expanding the CIRCLE study. Therefore it is necessary to provide some background and previous work that initiated this study. The CIRCLE (Canadian First Nations Diabetes Management Evaluation) study was a three year national diabetes research study conducted by Dr. Stewart Harris at the University of Western Ontario in 2007-2009. The main purpose of the CIRCLE study was to develop a comprehensive understanding of the current clinical management of type 2 diabetes in First Nations communities in Canada. The study identified gaps and inconsistencies in diabetes care, and determined the best clinical strategies to achieve optimal health care delivery in 19 First Nations

communities across Canada. The CIRCLE study determined that the quality of diabetes care has influence on the patients' management of their diabetes. To further examine the quality of care provided to First Nations diabetes patients, the Expanding the CIRCLE study was established by co-investigators Dr. Stewart Harris at the University of Western Ontario and Dr. Onil Bhattacharya at St. Michael's Hospital.

In August 2010, I was recruited to the Expanding the CIRCLE: Capacity Enhancement for Aboriginal Health Leaders of the Future study funded by the Aboriginal Diabetes Initiative. The Expanding the CIRCLE study was intended to build capacity among Aboriginal students conducting health services research and knowledge translation specifically in diabetes care. I was hired in the second phase of the project to conduct community qualitative interviews and observations to look at the quality of diabetes care in the four selected First Nations communities; Blood Tribe, Lac La Ronge Indian Band, Garden Hill First Nation and Wasagamack First Nation. A rigorous selection and consent process was undertaken to determine the participation of both communities and individuals for the study, both of which are described below.

### 3.6 Selection of Study Sites

The Expanding the CIRCLE study used a matrix of relevant diabetes indicators to rank the 19 First Nation communities that participated in the original CIRCLE study funded by First Nations and Inuit Health, Health Canada. The research team used clinical indicators (i.e. number of diabetes visits, A1C, blood pressure, amputation rates, etc.) with the intent to choose two higher performing and two lower performing communities. However, an initial analysis revealed that there were no clear outliers and the research team selected 4 communities with some outstanding variation and that also represented different isolation levels. This selection process occurred before I began as the Senior Research Fellow. Semi-isolated communities are described as having road access and being located less than 90 kilometres to physician services with an available health centre in the community (Health Canada, 1999), whereas isolated communities are described as a geographic area that has scheduled flights, however it does not have year-round road access and flights may be delayed or cancelled by weather (Public Health Agency of Canada, 2009). In the end, two semi-isolated communities (Blood Tribe and Lac La Ronge Indian Band), and two isolated communities (Garden Hill and Wasagamack First Nations) were chosen and represent semi-isolated and isolated First



Nations in three provinces over three treaty areas (Treaties 5, 6, and 7) which allowed for comparison of different political contexts and administrative practices.

Full descriptions about the four First Nations communities will be provided later in this chapter. Wasagamack and Garden Hill First Nations in Manitoba are considered isolated communities, while Lac La Ronge Indian Band in Saskatchewan and Blood Tribe in Alberta are considered semi-isolated. In each case, I used data from twelve interviews conducted for the Expanding the CIRCLE study with the additional 11 interviews with government leaders from this study.

### 3.7 Data Collection

#### **Key informant interviews**

The Expanding the CIRCLE study interviews were conducted in person between August and September 2010 with funding through Health Canada's Aboriginal Diabetes Initiative. The Expanding the CIRCLE data were collected with the research team's equipment (i.e. audio recorder and computer with password protection). The audio recordings were downloaded frequently and backed up on USB memory sticks to ensure that data were not lost and could be transferred to a professional transcriptionist upon completion of the data collection. There were ten interviews conducted that followed the interview guides and one informal interview for follow up data (see Table 6). In the end, there were 12 interviews from the Expanding the CIRCLE study that were analyzed (see Table 5). I audio recorded and frequently backed up the audio files on a password protected USB memory stick that was stored in a locked cabinet. Upon completion of interviews, the audio recording was transcribed to a password protected computer and backed up on password protected USB memory stick and stored in a locked cabinet. At the end of the transcriptions, the audio recorder was cleared of any interviews. All interviews that were analyzed are listed in Table 6.

The additional 11 interviews with government leaders were conducted by telephone (see Appendix E – Research Tools: Interview Guides) and focused on issues found in the literature; funding, the organization of health care services, the decision-making structure, Aboriginal socio-political history, and the management of health human resources for First Nations communities in the three provinces, with specific mention of the four communities when possible. Criteria were developed through themes that emerged in the literature regarding the access, location, funding, human resources, partnerships, leadership and capacity building, culture, language, worldview, policy

development, self-determination, and impact of the socio-political history including residential schools and colonization. The questions were designed to elicit information regarding the organization and delivery of First Nations health care, management of this system, external and internal factors influencing the system, and the participants' perception of self-determination.

Questions pertaining to themes were grouped together with a short description that would provide participants with an understanding of what the group of questions would be asking about. The questions were discussed with my committee and the site coordinators for each community before they were added to the interview guide.

The qualitative interviews were conducted with consenting participants in each level of government. All key informants remain anonymous and the transcriptions were pass code protected. The key informants provided consent to the interview and to being tape recorded. All participants and communities had the opportunity to withdraw at any time. As a part of the data set, observational data were also coded and analyzed. As I conducted the interviews, I revealed my Aboriginality in the consent forms that were emailed to participants and read before the interview began. I did not ask participants to reveal their identity or culture, but most participants did reveal if they were of Aboriginal descent.

The research team for the Expanding the CIRCLE study had established site coordinators in each community during the CIRCLE study. These site coordinators were individuals who work or live in the selected communities, and they assisted by arranging the participant interviews for the Expanding the CIRCLE study in late August 2010. For the Expanding the CIRCLE study, the research team was interested in the perceived quality of care provided to community members with type 2 diabetes. To ascertain this, the site coordinators recruited patients, health professionals (doctors, nurses, Community Health Representatives, and Diabetes Educators), and band and health leadership participants. This provided a snapshot of different perspectives regarding the quality of care and concerns about the existing system.

For the Expanding the CIRCLE study, a total of 27 people were interviewed across the four First Nation communities (Table 5). Ashley LaPlante, the Junior Research Fellow, and I took turns taking notes during the interviews and audio taped the interviews in their entirety. After the interviews were completed, we walked throughout the communities and spoke to community members, observed the community and its assets, then returned to our lodgings to write up the notes and

memories. When speaking with community members, we learned about what occurred in daily life; activities, accessing food, primary care for diabetes, and about culture and traditions. All four communities were visited for two or three days in August and September 2010.

**Table 5 Number and Description of Expanding the CIRCLE Participants**

<b>Respondent Title</b>	<b>Number of Respondents</b>	<b>Qualifiers</b>
Patients	12	3 patients per community
CHRs	3	1 of 3 – Blood Tribe 1 of 6 - Lac La Ronge 1 of 2 - Garden Hill
Nurses	4	1 of 8 – Blood Tribe 1 of 5 – Lac La Ronge 1 of 4 – Garden Hill 1 of 2 - Wasagamack
Doctors	2	1 of 2 – Blood Tribe 1 of 2 – Garden Hill
Health Care Directors or Managers	3	1 of 1 – Garden Hill 1 of 1 – Wasagamack 1 of 1 – Lac La Ronge
Band Council Members with Health portfolio or Chief	3	1 of 2 – Wasagamack 1 of 2 – Garden Hill 1 of 2 – Lac La Ronge

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For this current study, I once again contacted the site coordinators to assist with seeking approval and support for this current research project, and to identify provincial or federal government participants that interacted with each community. It was determined that interviews needed to be conducted with the provincial government managers at their health ministries in each of the three provinces (Alberta, Saskatchewan and Manitoba), and with federal government managers at First Nations and Inuit Health, Health Canada in each of the regions (Alberta, Saskatchewan and Manitoba) as well as at least two participants at the national office in Ottawa, Ontario. During telephone discussions between May 10 and June 21, 2011, the site coordinators identified some potential government participants and provided verbal consent that their community would participate in this study. An initial contact with a former colleague at First Nations and Inuit Health, Health Canada began the dialogue for finding the federal government participants in early June 2011.

The potential participants identified by the site coordinators and the federal government contact were approached by telephone and email in early June 2011. Using a snowball sampling, as I completed interviews with participants, I asked if they knew of other potential participants and they provided further contacts. The province of Saskatchewan was approached through a number of contacts, and hesitantly agreed to participate near the end of August 2011.

I conducted telephone interviews with federal and provincial government bureaucrats (n=10) in the months of June and July 2011 (Table 6). These telephone interviews were audio recorded to later transcribe for the study. All participants for this study provided verbal consent following the description and discussion of the project, the expected benefits and harms related to participating, and the measures that would be taken to protect their privacy, confidentiality and anonymity. All participants from this study received the interview guide (Appendix E - Research Tools: Interview Guides) prior to their interviews. The interviews were conducted by telephone at a time that was mutually convenient, and followed an open-ended interview guide (Appendix E - Research Tools: Interview Guides). All interviews were audio-taped and ranged from 1 hour to 2 hours in length, with an average length of 55 minutes. All of the participants spoke English and did not require translation. Many of these participants (60% or 6 of 10 participants) were of Aboriginal descent. The majority of health care professionals (4 of 7 participants) and all of the Health Care Directors and band council members were of Aboriginal descent. In total, there were twenty-three interviews used as primary data for this dissertation.

**Table 6 Number and Description of Participants for Current Study**

Respondent Title	Respondent Numbers	Qualifiers
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Provincial government participants - with at least one participant from each province	<b>4</b>	1 of 5 – Alberta 1 of 2 – Saskatchewan 2 of 2 - Manitoba
Federal government participants - with at least one participant from each region and at least one from National office	<b>6</b>	2 of 4 - Alberta 1 of 2 – Saskatchewan 2 of 2 - Manitoba 2 of 50 - Headquarters
Doctors*	<b>2</b>	See Table 1
Nurses*	<b>4</b>	See Table 1
Band Council Members or Chief*	<b>3* + 1</b>	See Table 1
Health Care Directors or Managers*	<b>3</b>	See Table 1

**\*These participants were originally interviewed for the Expanding the CIRCLE study. One Chief conducted follow up interview after Ethics approval for the current study.**

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Two of the provincial participants asked about whether I would be interviewing the Regional Health Authority (RHA) staff because in Manitoba and Saskatchewan the funding and direct management for First Nations health and health care is provided through the RHA. As this study did not have ethics approval for contacting RHA participants, it was decided that future studies may wish to include participants from the local level. It must be noted that there was difficulty in obtaining participants from Saskatchewan Health or the province of Saskatchewan.

## **Document review**

In addition to the interview data, I also retrieved government documents pertaining to all four First Nations. Some of the documents were created by the federal government and were publicly available (i.e. treaties, *Self-Government Act*, *Indian Act*), while other documents were provided by government participants at the end of the interview. The websites for all four First Nations communities and their Facebook web pages were also reviewed. For two of the communities, Blood Tribe and Garden Hill, there were also YouTube videos about community life that were viewed.

Documents were included if these specifically pertained to Blood Tribe, Wasagamack, Garden Hill or Lac La Ronge. I did not locate any academic literature on any of these four communities, but there were a number of websites that were publically available, and are listed in the reference section. After reviewing the data on the websites, I determined if I already had the data through another source, and if it had not been collected elsewhere, I added it to the documents for review. I excluded documents that did not specifically reference one of the communities, or if there was more current information available especially when reviewing internet sources. If documents or websites

were created before 2005, they were excluded as newer information was readily available. However with the government documents, all were included if the content encompassed one or more of the communities.

### **Field observations**

In previous visits to the communities, I participated fully in daily community life and talked with community members, health care professionals and First Nations leaders. I compiled notes about the community in general and took an assortment of photographs and videos of community life. For the current study, the non-participant observational data obtained in the community visits in August and September 2010 were transcribed into Word documents that were added to the NVivo data set for coding and analysis. These written observations averaged 10 double spaced typewritten pages per community that discussed the community conditions and processes and reviews of documents related to the community included in the study. Pictures taken in each of the four communities were set aside for the findings and discussion chapters of this study. Archival research had been conducted during the Expanding the CIRCLE study and included both electronic (i.e. Internet-based) and hard-copy issues of newspapers in addition to minutes and reports of meetings, letters, and similar documents. These documents and notes from reviewing these documents were included for analysis.

## **3.2 Study Limitations**

This dissertation does not attempt to provide empirical evidence about the communities achieving self-determination in health care, but rather provides information about the complex connections between the socio-political history, health care, and the perceived level of self-determination in health care based on research and observations. One limitation of this qualitative research is researcher bias. As an Aboriginal person, I have a personal interest in learning more about First Nations health care and how the federal government works with First Nations communities to provide health care. Although, I have not resided on a reserve and have limited knowledge of First Nations governments, I think I can understand and relate to the issues from a personal perspective.

The study was also limited by the finite group of participants available. As stated in Chapter 2, First Nations health refers to those on reserves; First Nations and Inuit health is under the jurisdiction of

the federal government, whereas Aboriginal health is considered to apply to all Aboriginal people living off reserve, thereby falling under the jurisdiction of the provincial government. There are few provincial government managers who work in First Nations health, if any. Similarly, there are a small number of FNIH managers, nationally or regionally, that deal with the organization and/or delivery of health care or diabetes care. Additionally, most First Nations communities have one health director and one band council member with the health portfolio. Therefore the number of potential participants is finite, and there were some potential participants that did not wish to participate in the study. Due to the variability between communities, the results from only four communities cannot be generalized for all First Nations communities in Canada.

The study highlights the First Nations health care systems' organization and delivery structures in only four communities, and the possible issues that surround these distinct structures. However, the study could be replicated and broadened to be more representative of all First Nations in Canada. The multiple case study methodology and Medicine Wheel conceptual framework are unique to this study and my knowledge, but similar studies could build upon these structures.

While the multiple case study methodology has allowed this dissertation to understand First Nations health care organization and delivery and the influence of self-determination, it does not provide a broader awareness of other issues and does not allow for a causal relationship (Gerring, 2007). The case study methodology has provided insight into these four specific cases and how they compare to each other, but not how these four First Nations communities compare to other communities (Gerring, 2007).

### 3.3 Analysis Plan

The data collected from the qualitative interviews were transcribed verbatim and downloaded into NVIVO 9 software. The observational notes were also entered into NVIVO 9. Using this software, the interviews were coded and analyzed using thematic analysis related to the research objectives - Health Care System, Self-Determination, Socio-Political History, and First Nations Community. The criteria for these four themes (Table 7) were developed from the literature with broad categories being provided in the left column and more focused and narrow indicators in the right column. These criteria were used in the coding and analysis.

**Table 7 Criteria for Variables**

Self-Determination Criteria	Structured Criteria
Ability to make community decisions about health care	<ul style="list-style-type: none"> <li>• First Nations leadership (Band and/or health) can make decisions about policies, programs, services and staffing for community health care</li> <li>• First Nations community leadership holistically develops policies, programs and services with knowledge of the impact on the health of the community members</li> </ul>
Leadership capacity	<ul style="list-style-type: none"> <li>• The leadership is knowledgeable about health and health care with a vision of future directions to improve the health of the community.</li> </ul>
Funding	<ul style="list-style-type: none"> <li>• First Nations communities have or are advocating for funding to provide the necessary programs, services and health care in the community</li> <li>• Health transfer funding is provided for secondary and tertiary services like diabetes in the community</li> </ul>
Collaboration & Communication	<ul style="list-style-type: none"> <li>• First Nations leadership collaborates and/or partners with federal, provincial and/or local governments to improve the health and health care in community</li> <li>• Communications between health workers, community and band leaders are working well.</li> </ul>
Based on own norms, laws and cultures	<ul style="list-style-type: none"> <li>• First Nations have control of policies, programs and laws that incorporate their norms, laws and cultures.</li> </ul>
Clear boundaries	<ul style="list-style-type: none"> <li>• First Nations must establish clear boundaries around legal, political, policy, and health to have self-determination.</li> </ul>
Health Care System Criteria	Structured Criteria
Health System: Organization of Health Care	<ul style="list-style-type: none"> <li>• Overall organizational leadership in chronic illness care</li> <li>• Organizational goals for chronic care</li> <li>• Improvement strategy for chronic illness care</li> <li>• Incentives and regulations for chronic illness care</li> <li>• Senior leaders are involved.</li> </ul>
Delivery system design/re-orient health services & Leadership Capacity	<ul style="list-style-type: none"> <li>• Practise team functioning (meetings, roles, accountability defined)</li> <li>• Appointment system for scheduling and follow ups</li> <li>• Planned visits for diabetes</li> <li>• Continuity of care (coordination between primary care providers and specialists)</li> </ul>
Federal and Provincial Involvement	<ul style="list-style-type: none"> <li>• Evidence-based guidelines</li> <li>• Involvement of specialists in improving primary care</li> <li>• Provider education for diabetes</li> </ul>
Community	<ul style="list-style-type: none"> <li>• Linkages between the health delivery system (or provider practice) and community resources play important roles in the management of diabetes</li> </ul>
Build healthy public policy	<ul style="list-style-type: none"> <li>• Partnerships with community organizations</li> </ul>
Social and Political History of First Nations Criteria	Structure of Criteria
Residential school experience	<ul style="list-style-type: none"> <li>• The logistics (opened/closed, number of students, etc.) have direct impact on First Nations communities' health and well-being</li> <li>• Healing from residential schools can occur in a number of ways including reclamation of the school, revitalization of language</li> </ul>



	and/or culture, or self-medicating behaviours
Loss of culture or traditions due to Indian Act amendments	<ul style="list-style-type: none"> <li>• The <i>Indian Act</i> and amendments prohibited ceremonies, use of language in certain situations, forced relocation, created elected band councils, and prevented hunting and fishing other than on reserve lands or with permission of the Indian Agent</li> </ul>
Paternalistic policies	<ul style="list-style-type: none"> <li>• Government policies that prohibited voting, congregated in groups of 5 or more, the <i>Indian Act</i> and amendments, and the <i>Expropriation Act</i> have forced First Nations people to lose some culture, language, traditions and identity (eligibility criteria of band vs. Indian Affairs)</li> </ul>
Policy Development	<ul style="list-style-type: none"> <li>• First Nations people have not had input into policy or legislative actions of the federal or provincial governments between 1867 and the 1970s; (some authors argue this continues to present).</li> </ul>
<b>Aboriginal Worldview/First Nations Community Criteria</b>	<b>Structure of criteria</b>
Interconnectedness	<ul style="list-style-type: none"> <li>• Everything (animate or inanimate) are connected and rely on each</li> <li>• Physical, spiritual, emotional and mental aspects of life are connected and need to be balanced</li> </ul>
SDOH approach that encompasses more than primary health care- holistic	<ul style="list-style-type: none"> <li>• Wrap-around approach that embraces the need for physical, spiritual, emotional, and mental aspects of a person to be a part of health care</li> <li>• External factors beyond biomedicine need to be addressed, but are not necessarily a part of the health care system (i.e. housing, water, infrastructure)</li> </ul>
Knowledge is created differently based on worldview	<ul style="list-style-type: none"> <li>• Historic policies, culture, language and tradition are part of how knowledge is created</li> <li>• Language and culture comes from the land, and knowledge is created from these sources</li> </ul>
Differences in language, foods, and lifestyle	<ul style="list-style-type: none"> <li>• There are 60 First Nations languages in North America. Elders state that the language comes from the land</li> <li>• Based on the land base of a First Nations group, there was specific game, fish and agriculture eaten</li> <li>• Culture and language came from the traditional territories of First Nations communities and has been passed through generations by oral traditions</li> </ul>
First Nations culture, language and knowledge are a part of health	<ul style="list-style-type: none"> <li>• There are health professionals, resources, programs and services that are provided in Aboriginal languages and/or incorporate First Nations' concepts of health and well-being</li> <li>• Knowledge of traditional medicines and healing are considered or incorporated into health care</li> <li>• The culture of the community is reflected in the health care</li> </ul>
Family and community are important in health and healing.	<ul style="list-style-type: none"> <li>• Cultural teachings, passed through generations, highlight the importance of family and community for health and well-being</li> </ul>

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### 3.4 Ethical Considerations

The Expanding the CIRCLE study underwent ethics review and was granted approval on August 18, 2010 by the University of Western Ontario Research Ethics Board. The current study has utilized

observational data and 13 of 27 interview transcripts from the Expanding the CIRCLE study. Therefore the research protocol for this current study included the University of Western Ontario Ethics protocol and approval when it was submitted to the Human Subjects Ethics Review Committee of the University of Toronto in March 2011. Ethics approval was granted on April 21, 2011 by the University of Toronto Human Subjects Ethics Review Committee.

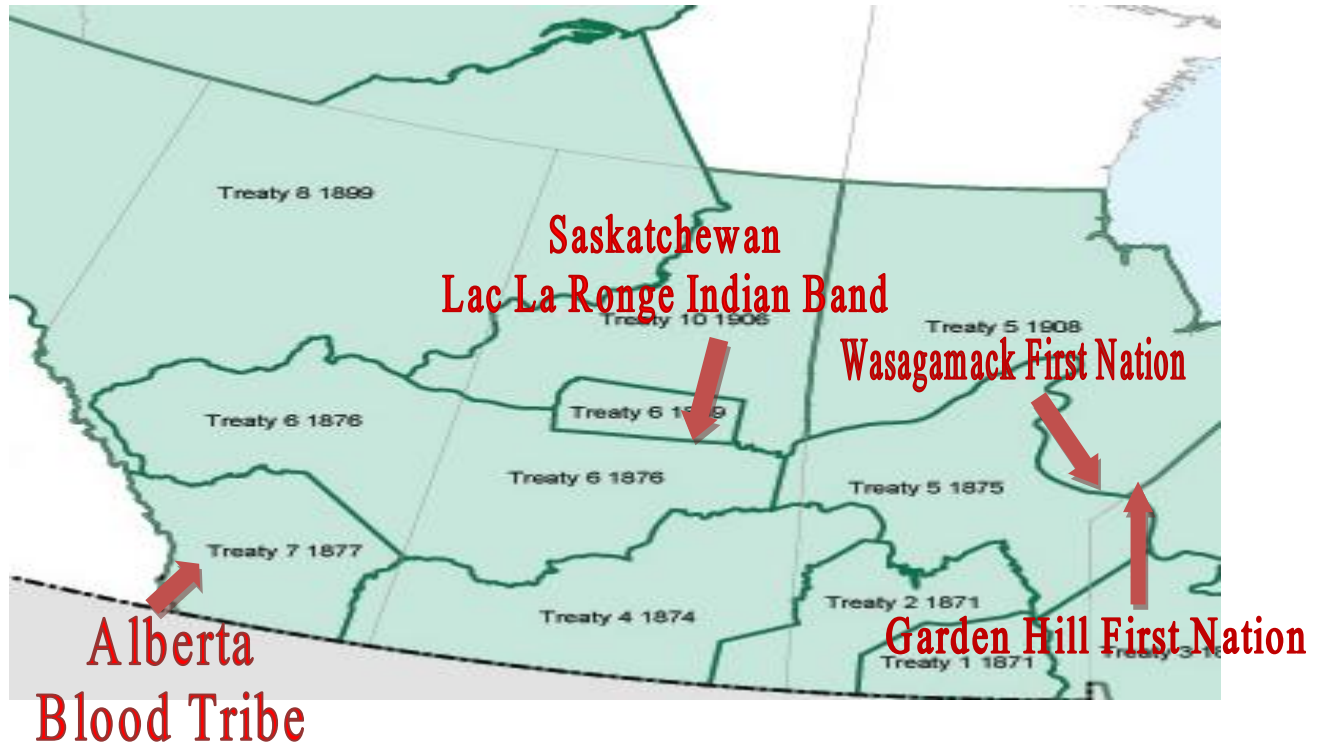
All participants were provided, via email, a copy of the participant information sheet (see Appendix C - Research Tools: Participant Information Sheet), a copy of the appropriate interview guide (Appendix E - Research Tools: Interview Guides), and a participant consent that was read to each participant prior to the start of the telephone interviews (see Appendix D: Verbal Consent). All participants were informed of how to withdraw, the risks associated with participation, and how to reach the University of Toronto Ethics Board and my supervisor.

### 3.5 Study Setting: Introduction to the First Nations Communities

The four First Nations communities studied come from three treaty areas (5, 6 and 7), and are located in three provinces (Alberta, Saskatchewan and Manitoba). Blood Tribe is located in southwest Alberta and Lac La Ronge Indian Band is located in the centre of Saskatchewan. Garden Hill and Wasagamack First Nations are located in northeast Manitoba. In the following pages, community profiles are provided to assist with understanding the findings and discussion. The community profiles were developed using the literature, observational data, and through document review.

Figure 3 shows the location of the four First Nations communities.

**Figure 3 Treaty Map of the Four First Nations Communities**



### **Blood Tribe, Alberta**

The Blood Tribe is a part of the Blackfoot Confederacy, which includes the Peigan, Siksika, South Peigan (Blackfeet) and Blood peoples in Alberta. The Blood Tribe or Kainai, are considered the oldest residents of the prairies with the largest reserve in Canada because of the land mass. South Grow Regional Initiative (2009) states that the Blood Tribe community is located 70 km from Lethbridge, 200 km from Calgary and 91 km to the Coutts/Sweetgrass border crossing with two major highways and two secondary highways running through the community. The community is considered semi-isolated. It has some economic development in the areas of agriculture, gemstone mining, house construction, oil and gas development, and small business and tourism (Blood Tribe, N.D.). However, there are no grocery stores in the Blood Tribe territory at the time of my visit.

The population was 10,062 in 2006 (South Grow Regional Initiative, 2009) and the population has increased by 8.3% between 2001 and 2006 (Statistics Canada, 2007a). However the Blood Tribe website estimates there are almost 12,000 people living on the reserve. According to Statistics

Canada (2007a), the average income of First Nations people in Alberta that are 15 years and older and working full-time is \$31,004 compared to \$ 43,003 for the general Alberta population. South Grow Regional Initiative (2009) stated that the average income is \$ 27,523 for Blood Tribe adults working full-time. There is significant gap in the average income of the Alberta population and the Blood Tribe average income, which may have an impact on their health and diabetes.

The Blood Tribe Department of Health (BTDH) was established in 1984 and signed their first health transfer agreement with FNIH in 1997. Based on my observations and through the interviews, I have created the organizational chart in

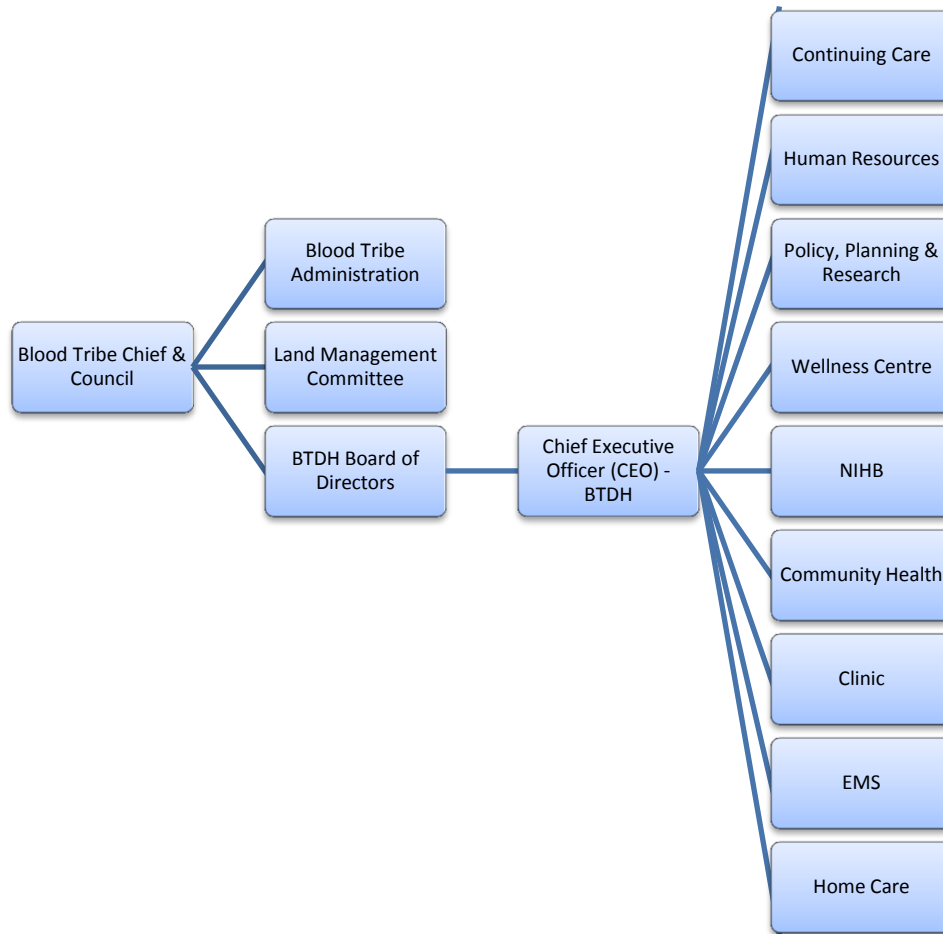
Figure 4 to illustrate the hierarchical structure of BTDH. This organizational chart was not obtained from the community and does not necessarily reflect the official organization of the BTDH.

Through the interviews and my visit to the community in August 2010, I observed that the Chief Executive Officer (CEO) for BTDH takes direction from the Board of Directors, the community and the Chief and band council.

The majority of staff at the health clinic were of Aboriginal descent and all of those interviewed for the Expanding the CIRCLE study and this study were from Blood Tribe. The health care and band

council staff interviewed had some post-secondary education, which was not the case for the patients interviewed.

**Figure 4 Blood Tribe Inferred Non-Official Department of Health Organizational Chart**



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### **Lac La Ronge Indian Band, Saskatchewan**

Lac La Ronge Indian Band, originally the James Roberts band, is a Woodland Cree community and a member of the Prince Albert Tribal Council. The Lac La Ronge Indian Band (LLRIB) is comprised of six reserves and 18 separate reserve lands; Grandmother's Bay, Hall Lake, La Ronge, Little Red River, Stanley Mission, and Sucker River (Lac La Ronge Indian Band, 2011). The first Chief, James Roberts, signed the Treaty 6 adhesion in 1889 (Lac La Ronge Indian Band, 2011). Treaty 6 contains the Medicine Chest clause that ensures that a medicine chest and medical care are available to First Nations peoples on reserve.

The reserve begins in the farmlands of central Saskatchewan and ends in the boreal forest in the east to the Churchill River in the north and west. The Lac La Ronge Indian Band is the largest in Saskatchewan and one of the ten largest in Canada (Lac La Ronge Indian Band, 2011). Lac La

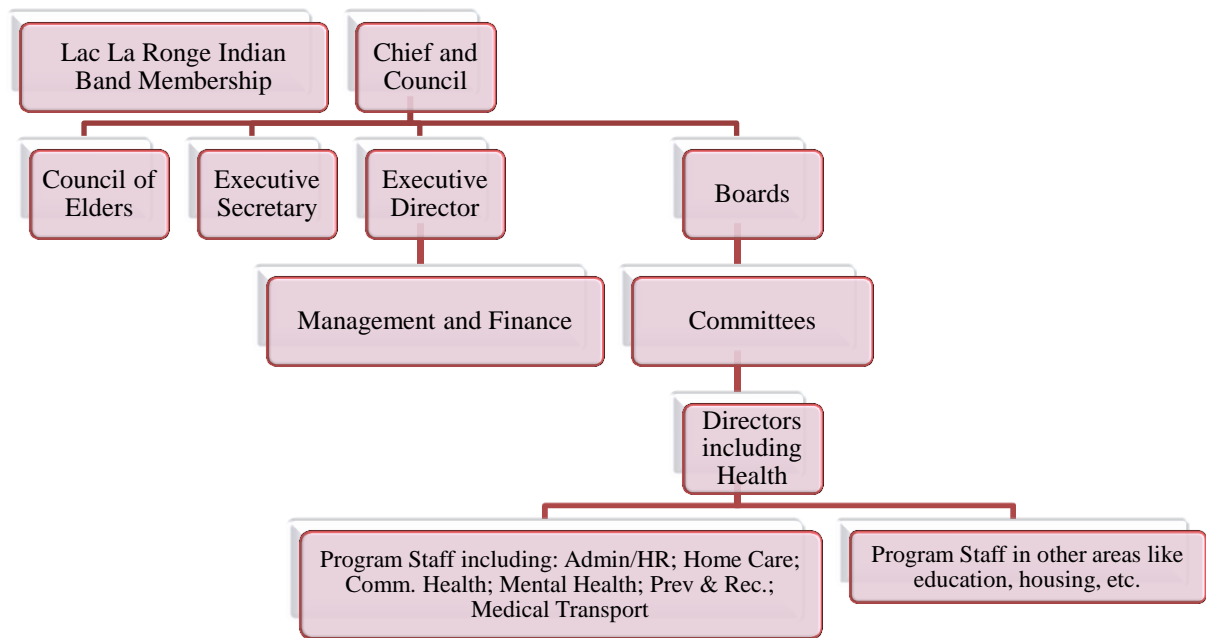
Ronge Indian Band is situated around the town of Lac La Ronge, a non-Aboriginal town. Kitsaki reserve is located beside the town of Lac la Ronge and appears to be the centre of the Lac La Ronge Indian Band. Kitsaki reserve is located approximately two and half hours north of Prince Albert and 5 hours from Saskatoon, with one provincial highway crossing through the community. However three of the outlying reserves do not have year round road access. There is a community owned grocery store in Kitsaki and small stores in the outlying communities.

The remote communities send their members to La Ronge for medical help, but Grandmother's Bay does have a nursing station (La Ronge participant). The Lac La Ronge Indian Band Health Services Department signed their first Health Transfer agreement in 1993. Lac La Ronge Indian Band is one of 3 First Nations to have a multi-community agreement. LLRIB Health Services Department has signed subsequent agreements to allow for health programs and services. In addition to their health transfer agreement with FNIH, LLRIB Health Services Department has been successfully running Nursing and Home Care, Home and Community Care, the Aboriginal Diabetes Initiative, and the Health Information System programs through contribution agreements with short-term funding provided by FNIH (La Ronge participant). Figure 5 shows the LLRIB organization specifically showing the Health Services Department based on speaking with Lac La Ronge participants.

The population was 9,247 in May 2011 increased from 5083 in 2001 (Lac La Ronge Indian Band, 2011). There has been a 17.5 percent increase in the population whereas there has been a -1.1% decrease in the general Saskatchewan population (Statistics Canada, 2007c). Language is important to Aboriginal culture as noted in Chapter 2. In Lac La Ronge Indian Band, 55.9% of the population speaks an Aboriginal language at home compared to 16.1% in Saskatchewan, and 72.4% of Lac La Ronge community members consider an Aboriginal language their mother tongue compared to 25.6% of the general Saskatchewan population (Statistics Canada, 2007c). The Lac La Ronge Indian Band Education Department has created a Woodland Cree curriculum and this is being incorporated into the band schools from kindergarten to grade 12 (Lac La Ronge Indian Band, 2011).

The staff at the Jeannie Bird Health Clinic was all of Aboriginal descent and the majority was from the community. The health care staff had varying levels of post-secondary education, which had caused an issue in continuity and availability of qualified health care staff.

**Figure 5 Lac La Ronge Inferred Non-Official Indian Band Health Services Organizational Chart**



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### **Wasagamack and Garden Hill First Nations, Manitoba**

Island Lake First Nation is comprised of Wasagamack, Garden Hill, St. Theresa Point, and Red Sucker Lake First Nations. These four communities were traditionally one large community that was separated by the government when residential schools were implemented, with families divided for attendance purposes (Garden Hill participant). These communities receive their health transfer agreement funding from FNIH as a collective through the Four Arrows Regional Health (henceforth known as FARHA).

The Island Lake First Nations have a shared airport in Garden Hill First Nation and access through a winter ice road, and thus are considered isolated. To reach Wasagamack First Nation in a non-emergency situation, a person would take a flight to Garden Hill and a water taxi, which is a small fishing boat, across the lake for about 50 minutes. There is an off-reserve island, Stevenson Island, where health care professionals and visitors can stay when visiting Garden Hill First Nation. There are water taxis that take people between the communities, Stevenson Island, and the off-reserve Northern store, which is also on a small island near Wasagamack. Other non-First Nations people



live on Stevenson Island for business purposes like the RCMP and local construction company employees. Wasagamack First Nation has a small nursing station and professionals' lodgings. Water aircraft can land by the nursing station, but it is prohibitively expensive to use on a regular basis. These two First Nations communities are approximately 610 km north of Winnipeg, and 284 km south east of Thompson, near the Ontario border (Wasagamack First Nation, 2011).

The population of Wasagamack First Nation was 1,160 in 2006 and increased by 3.6 % between 2001 and 2006 (Statistics Canada, 2007d). Aboriginal Affairs and Northern Development Canada states there are 1,881 people as of 2011 (Aboriginal Affairs and Northern Development Canada, 2010d). According to Statistics Canada (2007d), the average income of Wasagamack First Nations people that are 15 years and older and working full-time is \$23,106 compared to \$ 35,472 for the general Manitoba population. From the 2006 Census, over 93% of the community considers an Aboriginal language as their mother tongue and 87% speak the language at home (Statistics Canada, 2007d). There are a number of businesses in the community including McDougall's Pool Hall.

The 2011 population of Garden Hill is 4,243 according to Aboriginal Affairs and Northern Development Canada (2010b). The population has decreased by 6.1% between 2001 and 2006 (Statistics Canada, 2007b). According to Statistics Canada (2007b), the average income of Garden Hill First Nations people that are 15 years and older and working full-time is \$25,348 compared to \$35,472 for the general Manitoba population. There are a number of commercial and business services available in Garden Hill including some that are owned and operated by Garden Hill residents like Chicken Delight.

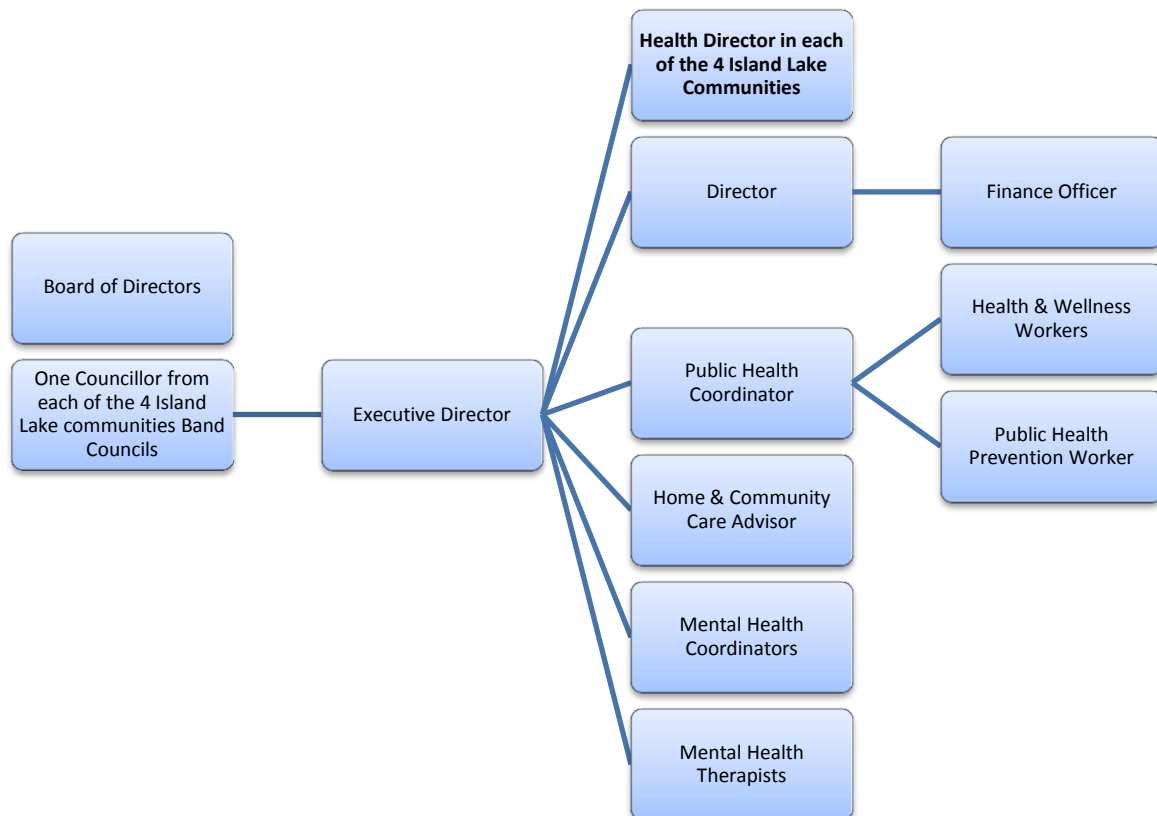
The four Island Lake First Nations signed the adhesion to Treaty 5 in 1909. The communities did not receive electricity until 1999. While there are unpaved roads throughout Wasagamack First Nation, there are no walking trails and it is difficult to walk on the roads after wet weather. The homes are spread out across the reserve and there are 20 km of internal roads on the reserve. It must be noted that the community has been in negotiations with the federal government to improve infrastructure as many of the homes in Wasagamack do not have running water or indoor sewage (Wasagamack First Nation, 2011).

**FARHA is run by a board of directors, which are comprised of representatives from each of the Island Lake First Nations. The Executive Director ensures that the funding is provided to each of the four First Nations with the staff at FARHA. Figure 6 below illustrates the**

**organizational structure of FARHA. The Health Director in Garden Hill First Nation, with direction and funding from FARHA, provides public health programs and services.**

Figure 7 and Figure 8 illustrates the organizational structure of health care services at Wasagamack First Nation and Garden Hill First Nation based on my observations and data.

**Figure 6 Four Arrows Inferred Non-Official Regional Health Authority Organizational Chart**

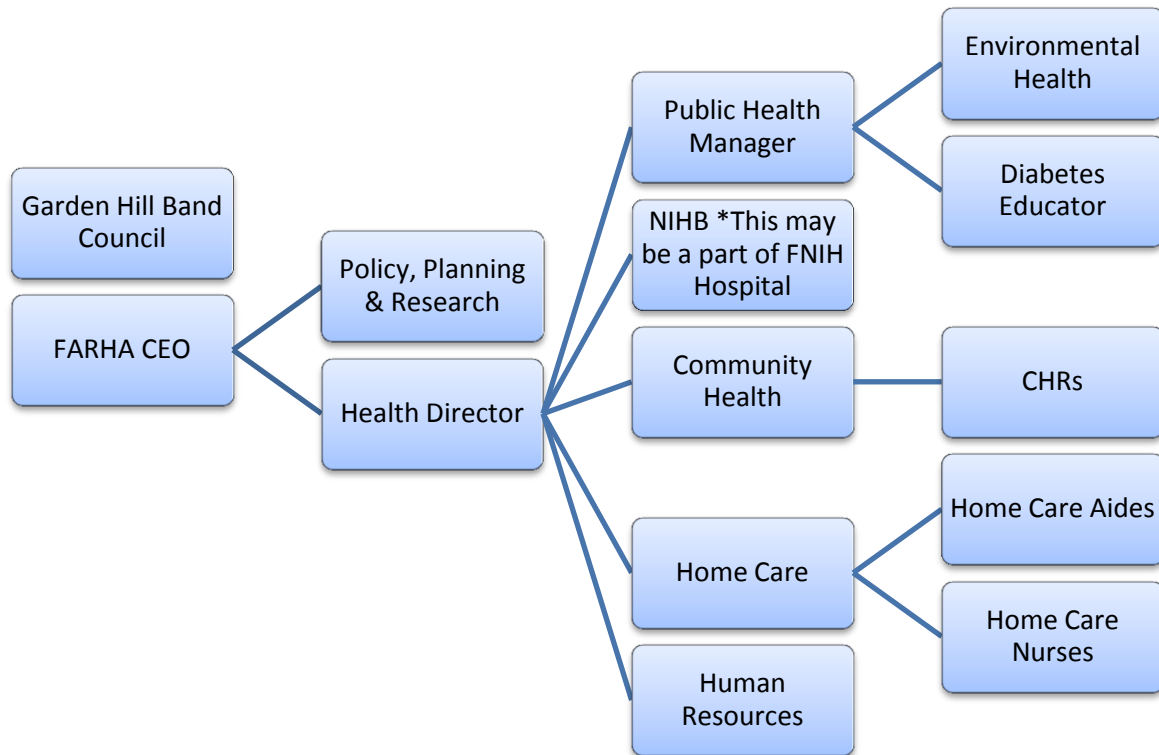


**Figure 7 Wasagamack Inferred Non-Official First Nations Health Services Organizational Chart**



Created by A. Mashford-Pringle (2012)

**Figure 8 Garden Hill Inferred Non-Official First Nations Health Organizational Chart**



Created by A. Mashford-Pringle (2012)

There was interaction between the Garden Hill Band Council and the FARHA CEO and Garden Hill Health Director, but the reporting structure was not clear from my observations. Any services not offered at the FNIH nursing station or through the FARHA services were available at the two hospitals in St. Theresa Point or Garden Hill, or in Winnipeg via flights from Garden Hill. Manitoba Health funds the renal hospital in Garden Hill First Nation. The hospital was located here because of the high incidence of diabetes and renal failure in the four communities.

### **Community comparisons**

Information about the four First Nations communities is listed in Table 8. Blood Tribe and Lac La Ronge Indian Band are semi-isolated and have larger populations than Garden Hill and Wasagamack First Nations, which are considered isolated and have smaller populations. Blood Tribe participants' state there is just over 10,000 people on the reserve. Lac La Ronge participants estimate there are 7,000 people on the six reserves, while Garden Hill participants estimate 3,600 people and

Wasagamack participants estimate 1,600. The population sizes reported in Table 8 are considerably different (Aboriginal Affairs and Northern Development Canada, 2010a, 2010b, 2010c, 2010d; Statistics Canada, 2007a, 2007b, 2007c, 2007d) and vary widely from the participants' estimates. The government statistics are based on census completion rates or Indian status registration, which can explain the variability, but estimates provided from the community participants may reflect band newsletters or their knowledge of their community. The population size determines funding and could be a contributing factor to the level and type of health care professionals available in the community.

The income levels vary among the four communities, which may be a result of the community members' ability to retain employment off the reserve in the semi-isolated communities. However in the isolated communities, participants stated that many community members lived on social assistance and other government subsidies.

All four communities have high unemployment rates with Wasagamack First Nation being the highest at 33.9 percent, and the most isolated of the four communities. Blood Tribe is located within an hour's drive of Lethbridge, thereby assisting community members with seeking employment off-reserve, which increases their income and decreases unemployment.

The education statistics provided on Statistics Canada's Community Profiles website do not reflect the population size previously stated in the table. In fact, for all four communities the declared numbers are substantially lower than the population size reported by census and INAC data.

However, the majority in all four communities had less than a high school diploma. As previously mentioned, Blood Tribe and Garden Hill have highly educated staff working in their health care services, which may not be accurately reflective of the communities as a whole.

**Table 8 Community Information for the Four First Nations Communities**

<b>Community Information</b>	<b>Blood Tribe, Band # 435</b>	<b>Lac La Ronge Indian Band, Band # 353</b>	<b>Garden Hill First Nation, Band # 297</b>	<b>Wasagamack First Nation, Band # 299</b>
Isolation Level	Semi-Isolated	Semi-Isolated	Isolated	Isolated
Clinic type	Health Clinic	Mainstream Walk-in Clinic/Nursing Stations in isolated	Nursing Station/Renal Hospital	Nursing Station

		communities		
Population - INAC - February 2012	11,469 less 3,384 off reserve	9,468 less 3,469 off reserve	4,266 less 596 off reserve	1,884 less 163 off reserve
Population - 2006 Census	4,195	5,075	1,900	1,160
Average income on reserve for those 15 years and older - INAC Community Profile Information	\$31,185	\$15,502	\$17,198	\$17,082
Unemployment rate	23.9%	28.5%	25.0%	33.9%
Education Level:				
No degree, certificate or diploma	1,460	2,260	925	535
High school diploma or equivalent	535	350	75	80
Trades or non-university certificate	690	380	110	75
University - less than a Bachelor's degree	105	95	15	10
University - Bachelor's degree or higher	135	70	10	15
Languages Spoken	Blackfoot and English	Cree and English	Oji-Cree and English	Oji-Cree and English
Treaty Status	Treaty 7 signed in 1877	Treaty 6 Adhesion signed in 1889	Treaty 5 Adhesion in 1909	Treaty 5 Adhesion in 1909
Tribal affiliation	Blood Tribe	PADC Management Company Ltd.	Island Lake Band	Island Lake Band
Total Federal Health Funds	\$ 11,053,276 - 2010/11 fiscal year	\$ 8,168,558 - 2008/09 fiscal year	\$4,085,329 - 2009/10 fiscal year	\$ 0.00 - 2009/10 fiscal year
Total Federal Funding	\$ 94,461,625 - 2010/2011 fiscal year	\$ 56,457,872 - 2008/09 fiscal year	\$31,625,465 - 2009/10 fiscal year	\$ 17,329,616 - 2009/10 fiscal year

Created by A. Mashford-Pringle from various government documents (2012)

Recently, the federal government mandated that all federal funding must be made publicly available. Aboriginal Affairs and Northern Development Canada (AANDC, which was formerly known as Indian and Northern Affairs Canada or INAC) had electronically published the audited statements for the four communities on their website. However the audited statements for all four communities are not for the same fiscal year and cannot be compared. Wasagamack First Nation's audited statement is notable as there is no funding allocated to health.

These brief community introductions provide some cursory information, but there are complex and fragmented issues surrounding all of the statistics provided that will not be discussed in this dissertation. However it is necessary to understand that the social determinants of health clearly need to be addressed in First Nations health care systems. As will be discussed in the following chapters, these four First Nations communities have attempted to provide a holistic approach to health care in varying degrees.

## Chapter 4

### Factors Influencing Self-Determination in First Nations Health Care

#### 4.1 Introduction

The socio-political history that First Nations peoples and communities have experienced, which was described in Chapter Two, has had an influence on First Nations health care systems. Residential schools, the *Indian Act* and policies, the relationship between First Nations and government, and education all have been factors in the development of the present organization and delivery of First Nations health care. In addition, the way that First Nations people view the world has factored into the way they view health care systems. In this chapter, these factors will be examined to show their connection to self-determination in First Nations health care.

#### 4.2 Socio-political history

The amount of time and the intensity of contact that First Nations communities have with the dominant society can have an influence on the organization, structure and health and governance systems (Boldt & Long, 1984). Blood Tribe has had high intensity contact over the past two hundred years, whereas Lac La Ronge, Garden Hill and Wasagamack have not experienced as long or intense contact as Blood Tribe. Lac La Ronge has experienced an increased intensity of contact with the dominant society only since 1947 when the highway was extended into Kitsaki reserve - the largest community of the six that comprise Lac La Ronge Indian Band. Garden Hill and Wasagamack First Nations experienced intense contact with the implementation of the residential schools and then limited contact until the late 1990s when electricity and regular flights were introduced. Blood Tribe and Lac La Ronge have health care systems that mirror or utilize the dominant society's health care system, which could be attributed to the length and intensity of contact with the dominant society.

The following sections will discuss how interactions with Euro-Canadians have affected the lives of First Nations people, and how these interactions have shaped the health care system that the four First Nations communities in the study have. Residential schools, loss of culture and language and assimilationist policies have affected each of these communities, but to differing degrees, which has differing effects on their health care systems and their ability to take control of the system. The ideal First Nations health care system discussed in Chapter 2 outlines a system that blends or combines traditional healing and medicines with the biomedical health care system to provide a holistic



approach to health and well-being. This ideal health care system would acknowledge many of the factors outlined in this chapter like the socio-political history, education issues and Aboriginal worldview, but would also maintain the biomedical health care services provided to all Canadians.

### **Residential school experience**

Red Crow College in Standoff, Alberta was originally St. Mary's Residential School, which opened in 1884 and closed in 1975. It has been transformed to provide the Blood Tribe with a post-secondary education facility on the reserve. Red Crow College became the first tribal college in Canada in 1995 and has assisted many Blood Tribe members in completing their high school and post-secondary education. Figure 9 below is a picture of Red Crow College as it now stands. Having a post-secondary institution on the reserve that is governed and guided by the Blood Tribe administration, has allowed for integration of culture, language and worldview into the curriculum. The number of Blood Tribe members with high school completion is still low, but is increasing, which leads to improvements in leadership, economic development and other areas that are considered among the social determinants of health. One participant stated that Blood Tribe members understand the need for education and are beginning to see an increase in the number of graduates. However low educational attainment can impair a person's ability to understand or relate to the knowledge given about their illness. Education of Blood Tribe members may increase the number of health professionals who wish to work in the community, and can improve the community members understanding of treatment instructions, as some Blood Tribe participants noted in their interviews. B. Roy, Fecteau, and First Nations on Quebec and Labrador Health and Social Services Commission (2005) found that First Nations people with higher levels of education were more likely to receive primary health care and attend diabetes programs.

**Figure 9 Red Crow College – Formerly St. Mary's Residential School**



Source: Harry Palmer© (2007). A Portrait of Canada; [www.aportraitofcanada.ca/?p=3702](http://www.aportraitofcanada.ca/?p=3702)

The communities that comprise the Lac La Ronge Indian Band first met the new settlers in the late 1840s when the Anglican mission was established. The Lake La Ronge Mission Indian Residential School was opened in 1914 and closed in 1947 when the Anglican mission moved to the community of Stanley Mission (Prince Albert Grand Council, 2008). Interest in the area was greatly increased with the addition of the dirt road from Prince Albert to Lac La Ronge in 1947 (Prince Albert Grand Council, 2008). One participant stated that contact with mainstream Canada did not truly begin until after the road was created, and while residential school affected the community, culture and language were maintained throughout the residential school era.

The four Island Lakes First Nations have experienced a history of assimilation and oppression. Hackett (2005) discussed that many of the northern Manitoba communities did not have much contact until the means of transportation were improved. The winter road that connects the Island Lake First Nations to Winnipeg was not completed until 1967 and there was limited airplane access until 1936 (Hackett, 2005). It is assumed that many children from the Island Lake First Nations went to Cross Lake Indian Residential School, which opened in 1915 and closed in 1942, but there is no evidence of which residential schools that the community children attended. The community of Island Lake First Nation was separated into four communities in 1969 according to community

participants. During my visit to the community, one community member related this story about the impact of residential schools and other policies on all four of the Island Lake communities:

“And residential school and where they kicked in the religion. And they teach you that your ways are wrong too. That’s one of the reasons why this uh, people and like from centuries and want them there now. They used to be one band so when the religion, religion came to our community uh, they split them. They destroyed the families. So, like for instance my grandfather and he died when he was over 80, they literally split families like uh, our religion is United Church and people in St. Theresa are mainly Roman Catholic right uh, whereas Wass [Wasagamack] and other communities is half and half and so, so is uh, you know, is uh Red Sucker, there mainly United. So, my grandfather is a United, and his brother is more Catholic. And then they split the family right in half so, it’s done in the families.

I: So, is there any talk about, because when they did that they also spilt you guys in, up, away from each other you’re not like near each other like you would have been?

Yeah, moved away, yeah, this uh, how our practices in traditional medicine were banished because uh, this white man came into our community and says this is the devil work, this is, devil worshipers that was uh, as they were practicing their religion because this is the way.”

This community member talked about how families were separated to attend the local residential schools and enter into the different religions, which created four distinct communities with different health systems. This history has affected traditional healing, medicines, and the development, organization and delivery of health care services in all four communities. D. Smith et al. (2005) state that little attention has been paid to the “implications of residential schools for health policies and programs,” (p. 41). Therefore understanding the impact and implications that residential schools have had on individuals, families and communities can be a factor in how First Nations health care systems are designed, organized and delivered today. One legacy of residential schools is colonization and indoctrination of the western worldview (including language, culture, religion, values and beliefs). Some of the community participants are more aware of the effects of residential school on their health care system. However when they communicate about the biomedical primary care, they acknowledge that to decolonize and heal from residential schools, there must be a blended

health care system that incorporates both traditional healing and medicines with the biomedical system.

### **Loss of culture and language**

One participant explained how reclaiming culture and language is needed:

“... we just have to keep moving forward, can’t let these things from the past hold us back. And that’s what I always hear through the young people um, they are always asking how come we don’t this, how come we can’t make um, and you know, I tell them “It’s up to you if you want to make it, nobody can tell you, you can’t.” And nobody can tell you that you’re not a First Nation because you are a First Nation wherever you go in this world, you will be always be a First Nation. See that’s one thing that irritates me the most is when they think about what happened at residential school and what’s happening today, I hope one day they will realize that by accepting themselves, they are accepting the culture. When I see some of them saying they are very religious and you know, they are very spiritual I understand that part but what I don’t understand is why they can’t accept themselves for who they are. So, that’s what irritates me, is when they try to be an apple you know, red on the outside and white on the inside. It’s just disappointing to see like people actually reject their own identity when they should be embracing it you know, I, I myself grew up in a religious family and I went to the Christian High School and I, I know what I am talking about you know? I don’t just say things because I heard expressions, you know?”

The majority of participants would like to see more incorporation of culture, language and worldview into the health care system. One mechanism to do this is to have self-determination in health care. Blood Tribe has not implemented traditional healing and medicines into the health centre, but rather have knowledge of some traditional healers who they ‘touch base’ with periodically. Lac La Ronge, Garden Hill and Wasagamack have limited influence on the incorporation of culture, language and worldview in their primary health care systems as they do not staff or manage the health facilities. However Lac La Ronge and Garden Hill use the health promotion and prevention programs and services to incorporate culture, language, and worldview.

The majority of Blood Tribe primary health care professionals are from the community, and if they are not familiar with Blood culture, language and traditions, they are mentored and provided cultural awareness training. The primary health care professionals are employed by FNIH in Garden Hill and Wasagamack and are fee-for-service staff in La Ronge, but many of the participants noted that there should be some cultural training provided to assist them with understanding the issues that community members face.

In all four communities, there are older people that speak only their communities' Aboriginal language. Some participants felt that this may be an issue when trying to translate information for these patients as some English words do not translate into Oji-Cree, Blackfoot or Cree. One community member told me that there was no word in Oji-Cree for 'banana'; the community identifies bananas as the 'yellow curved fruit'. The individual said that the doctor had recommended to eat a banana or orange as a sweet food, but the individual had trouble trying to explain in Oji-Cree what these were as there were no words for these or 'blood sugar'. Gregory and Hart (2009); Ho et al. (2008); Newbold (1998) found that providing health care instruction in a way that a patient understands can improve the uptake of self-management instructions. Therefore all four communities should be working toward improving the knowledge of the health care professionals and increasing the culture, language and worldview that is incorporated into the health care system. Self-determination could assist with this infusion.

### **Assimilationist policies**

Due to the Indian Residential schools experience, coupled with other negative policies, all four communities are dealing with the question of whether their culture and language need to be revitalized and what that means. Garden Hill participants suggested that the community experienced indoctrination for generations, which has left a deep divide among community members as to whether to attempt revitalization, but their Oji-Cree language survived. In Wassagamack and Lac La Ronge, cultural activities were practiced outside of the Indian agent's knowledge. However all of the four communities are now attempting to further revitalize traditional lifestyles including traditional healing and knowledge of traditional medicine.

Mental health is an issue in all four communities, which is the result of the historic trauma experienced by Aboriginal people. Some government participants acknowledged that the community members are still healing from residential schools and that the community as a whole needed to heal

from the effects of residential school. One Blood Tribe participant noted that a part of the healing was taking St. Mary Residential School and reclaiming it to provide the community with post-secondary education, which would help them today and in the future. However another Blood Tribe participant noted that there were a number of people who attended residential schools and now suffered depression and post-traumatic stress disorder (PTSD). These mental health illnesses often affect the person's ability to take care of their own illnesses such as diabetes. Mental health issues have been experienced in all four communities as a result of the assimilationist policies. Kirmayer et al. (2003) and Duran (2006) found that the paternalistic policies create mental health problems that affect the individual, family, and community, and continue to be a part of the First Nations memory which extends across generations. In the four communities, the interactions between First Nations and mainstream society have not been positive and particularly helpful. Moving forward, these communities will need to determine how and what their collective identity should be as it will have an impact on the health, structure and management of healthcare in their communities, the criteria used for self-determination, and the steps that the community must take to gain self-determination in health care.

The *Indian Act* and the amendments to the Act have prevented these four communities from practicing their traditions, cultures, languages or to develop businesses that involve agriculture or livestock (J. Miller, 1990). Blood Tribe and Lac La Ronge participants said that the communities were beginning to revitalize and reclaim their traditions, cultures and languages. However, the negative experiences with the residential schools have left Garden Hill and Wasagamack in 'limbo' as community members are unsure of how to reclaim and revitalize their cultures and traditions. The extent of the disconnect from their cultures, languages, and traditions has influenced the development of the health care system in each of the four communities; Blood Tribe and Lac La Ronge health care systems are more similar to the dominant society health care systems than those of Garden Hill and Wasagamack, which have retained more of their languages and healing practices. By distancing and isolating Aboriginal communities from mainstream Canada, there is also a disembodied view of how the assimilationist policies have affected First Nations communities. "Thus, there is a complex interplay between geographical context and the historical socio-economic and political contexts of Aboriginal people's health, and it has profoundly influenced the health and social status of Aboriginal Canadians" (Tarlier et al., 2007, p. 130). This also sets up doubts about how needs of western medicine should be incorporated in the health care system.

### 4.3 Education Issues

Formal education is important in the organization, delivery and administration of health care. Many scholars have found that the education of the health care professionals regarding culture, language and history may impact the relationship between professional and patient. For government bureaucrats, without education, they may not be able to create and implement responsive and culturally appropriate policies. The four First Nations communities in the study have experienced challenges in finding qualified candidates with cultural sensitivity for health care positions. Many participants highlighted these issues in the interviews.

#### **First Nations professionals**

Education is a huge barrier for all Aboriginal people, which is reflected in the low completion rate of high school education is among all four of the First Nations communities studied. There are some health professionals such as Community Health Representatives (CHRs) and home care aides that do not require accreditation or post-secondary degrees. These para-professional positions have a high turnover rate, but have a good relationship with community members. As a government participant confided:

“...on the whole, [they are] people with maybe grade 10 or grade 12 education. Some of them now have some diploma, but they’re primarily people who are well-grounded in the cultural and spiritual background of First Nations. Now that doesn’t mean they know all First Nations, but they’re a bit like helpers.”

Lavoie (2011) and Lemchuk-Favel (1999) argued that the salaries are low and stagnant, and the potential pool of candidates are often from the community who may not have had the resources (an available high school or alternative school) or money to complete their high school education, or beyond. Therefore in these four communities, the health directors’ have made compromises; having high paid and educated workers not from the community or lower educated, but eager to learn community members. Gregory and Hart (2009) argue that employing staff is a delicate balance in First Nations communities. Hiring less educated community members immediately reduces the workload on others. This issue should be further investigated to determine the effects of hiring community members of lower education on the overall structure of the First Nations' health care system and on the patient's self-care.

Blood Tribe has attempted to assist interested community members with an aptitude in the health sciences to obtain their degrees in nursing, nutrition and medicine. However, the number of community members that wish to obtain these credentials is small and would not even replace the existing staff, if they should leave. The mentoring of community members has been a priority for the Blood Tribe, but has not been as successful as the community would like (Blood Tribe participant).

One government participant said:

“...a lot of the human resources that communities could benefit from if they could really tap into their use and had some high quality education. They could be successful in improving their high school completion. If there was more grooming or support to, for different careers. Especially in bigger communities!”

There was limited research about the challenges of assisting para-professionals wishing to further their education. Assisting these First Nations people with moving away from the ‘margins’, through education and training is often seen as a decolonizing tool (Stephens et al., 2005; Stonechild, 2006).

It was interesting to find out that many of the Garden Hill health professionals had higher levels of education than was seen in other communities. Bobbish-Rondeau and et al. (1996), Lavoie (2005), and Jacklin and Warry (2004) found that some para-professionals did not have a high school diploma. However in Garden Hill First Nation Health Services, many of the staff have college and/or university education. This is supported by the Canadian Population Health Initiative (2002) study that First Nations communities must assist those people working in the health portfolio with attaining further education, which would lead to increased capacity. As Barker (2009) noted, health human resources must be trained, have professional association support, and have post-secondary education support, which was found among many of the community members working in health for Garden Hill.

### **Government bureaucrats’ cultural knowledge**

“I’m well aware of the residential schools program... and the people that are delivering this here are exceptional, but in terms of formal training, I would have to say not so much. There is an understanding, recognition of, that all of the history comes into play. So when I think about diabetes specifically, the impact of how life is changed makes a big difference. At this level, it makes a huge difference, with the



rate of diabetes among First Nations being three to five times higher.” (Government participant).

Some of the participants were concerned that the federal and provincial government bureaucrats were not knowledgeable in the area of Aboriginal socio-political history and its impact on current health status and health care for First Nations people. The Royal Commission on Aboriginal Peoples (1996a) report had recommended a course to educate government employees working with Aboriginal people and issues, but since the release of the report, there has been little done to ensure that government employees have the knowledge of Aboriginal people and their history (Hackett, 2005). Bobbish-Rondeau and et al. (1996), Towle et al. (2006) and Hunter, Logan, Goulet, and Barton (2006) found that people, health professionals and government bureaucrats, who worked with First Nations people, needed a basic understanding of the socio-political history that Aboriginal people have faced in order to provide assistance in a culturally appropriate and sensitive way. Hunter et al. (2006) further argued that an understanding of the culture could ensure that work, like policy development, would be more appropriate and sensitive if all stakeholders had the same base of knowledge about First Nations people. Many of the government participants stated that they had limited knowledge and would like to see more knowledge provided. However it must be noted that both the provincial and federal government participants for the study stated that there were many Aboriginal people working in Aboriginal health at the federal and provincial levels.

Training may also assist policy makers with seeing policy development in a more holistic manner. The social determinants of health and the population health approach to health look at a variety of factors that impact the health of individuals, families and communities. This is similar to the holistic manner in which Aboriginal people view health. The social determinants of health, like income and employment, can have a tremendous impact on when, how and why First Nations people access health care (Cass et al., 2002). Government bureaucrats can have significant impacts on the organization and delivery of First Nations health care, and ultimately on First Nations self-determination. Therefore government bureaucrats’ knowledge should be supplemented through training and education to meet the needs of First Nations health care and self-determination goals.

## 4.4 Aboriginal Worldview

The values, beliefs and traditions a person has about their world are the foundations for their worldview. In many Aboriginal communities, there are traditional teachings and knowledge, culture,

language and holism that also make up this worldview. The following sections show aspects of an Aboriginal worldview and how these aspects have influenced the health care system, and First Nations beliefs about self-determination and health care.

### **Interconnectedness**

Many scholars (Adelson, 2005; Duran, 2006; Kovach, 2009; Lane et al., 1984; Ten Fingers, 2005) have reported that First Nations cultures see all things (animate or inanimate) as connected and interdependent. There are many levels that these interconnections can be occurring as Ten Fingers (2005) has shown. Lane et al. (1984) have explained that the Medicine Wheel teachings that many First Nations people receive and believe in are focused on balancing the four aspects of life or self; physical, spiritual, emotional, and mental. Balancing all of these areas of a person's life is considered by many First Nations cultures as the 'good' path or 'balanced' way of life. Adelson (2005) found that Cree people tried to find and maintain balance in these four directions of self in order to achieve health and well-being.

The social determinants of health originally defined by the Lalonde Report in 1974 and revised by Health Canada in 1998, established key factors that seem to determine health status; for example education, environment, physical health, health services, and social support (Adelson, 2005; Allec, 2005; Health Canada, 1998). The socio-economic conditions of most First Nations people are vastly different those experienced by the mainstream population. Many First Nations communities have poor and substandard housing, lack of employment, poverty, substance abuse, domestic violence and child welfare concerns (Allec, 2005; Boyer, 2003; Brede, 2008; National Aboriginal Health Organization, 2004). Additionally, some First Nations communities do not have running water or have been on boil water advisories for many years (Brede, 2008; Stastna, 2011). This creates an imbalance in the Medicine Wheel and challenges health actions to go beyond individual care that revolve around an individual's symptoms to a more holistic approach that includes public health programs and services.

Providing culture and language training may assist policy makers with seeing policy development in a more holistic manner. Many participants voiced concerns about the housing, transportation, and social supports that all four communities were living with. Brede (2008) argued that communities need to ensure that all community members have access to health care, which would require the communities to assist their citizens with transportation to the local health care clinic. The Health

Council of Canada (2005) argued that including traditional healing and medicine may benefit First Nations people's health. Kelm (2004) found that traditional healing and medicine helped to bring First Nations to health and well-being. Therefore it is important to assist these four First Nations communities with incorporating traditional medicine and healing into their health care systems, which may assist with improving health and encouraging self-determination of the health care system. Blood Tribe, Lac La Ronge and Wasagamack have incorporated some aspects of culture, language, and worldview into their secondary and tertiary services, but in Garden Hill, the community is still determining whether returning to traditional ways is their community's direction.

Balance in systems and institutions must also be achieved according to the Medicine Wheel teachings. Blood Tribe has established a well-organized health care clinic. Lac La Ronge has established a partnership for primary health care and provides public health programs and services on reserve. While Wasagamack and Garden have relied heavily on the FNIH nursing station to provide primary health care, both communities provide differing levels of health promotion and illness prevention programs and services. However, as some participants noted, traditional medicines and healing have not been incorporated into the health care systems. Two participants did state that the majority of health care professionals in the Blood Tribe health care clinic were Aboriginal and many were from the community. In the other three communities, there have been some responses of including traditional medicines and/or healing.

In all of the communities, there are community members that still hunt, fish or gather traditional agriculture. Some of the traditional foods for Lac La Ronge, Wasagamack and Garden Hill have been "...lean meat, like moose meat and beaver and whatever, and ducks. Soups and stuff like that, and they are perfectly healthy, and the elders never...started eating all the pork and bacon and stuff like that" (Lac La Ronge participant). Many of the elders and seniors have passed on the knowledge of traditional foods to younger generations, but there is still a need for a program that would have children and youth "communicate with the elders, like making home visits and teaching them and helping them out with whatever they need and at the same time learning to speak in Cree, talking about the diabetes and things like that..." (Lac La Ronge participant), which will assist with keeping the worldview, culture and language strong in the four communities. One community participant explained the reason for including culture and worldview into diabetes care:

“...we really need to start looking at is sort of how do you cook traditional foods not in 5 pounds of lard and then take your bread and dip it into the lard after you’ve done frying all of your meat you know, that there’s better healthier ways to do it, that kind of stuff. So that to me is the biggest area that we’re lacking and people don’t have, you know, people will exercise and do all the stuff they have to do because they know walking and that kind of stuff is healthy stuff but then they will go home and they will eat a bucket of KFC, it just, they don’t understand why they are not losing weight. I think we really have to look towards healthy living, a whole healthy living arm within the department that works on promoting people to live not the way the non-aboriginal community lives but the way we live in our community. So, that we are trying to change the way that we do things in our way. Rather than you know, in my mind the non-aboriginal way. We do things differently than other people do and we need to do it our way but the healthy way. Because in the old days they didn’t fry their stuff, they prepared it over a fire or whatever, or they froze it and they dried it and they eat it dry and you know, they didn’t put a pound of lard in their dried meat which they do nowadays.”

Similarly, some community members told me that health professionals do not understand why they still make traditional foods with lard instead of healthier alternatives. One community member said that many of the homes in Wasagamack and Garden Hill do not have a stove with an oven, so they rely on frying bannock, fish and other game instead of baking, which would be a healthier option.

As many participants noted, there are a number of factors beyond health care that affect the health of First Nations people. Housing was noted as a major concern in all four communities. Adelson (2005) and the Royal Commission on Aboriginal Peoples (1996c) report state that all of the social determinants of health must be considered by health care professionals and that the health care system must holistically address these barriers to improve the health of First Nations people. Therefore it is important for health care professionals, government stakeholders, and First Nations community leadership to work in collaboration to improve the living conditions found in First Nations communities.

Access to market foods is also a concern shared in the four communities. Lac La Ronge owns and operates its own grocery store, which allows for greater input of foods that the community wants or

needs, because it is still expensive to import foods for the community. The expense of importing market foods is exacerbated in Garden Hill and Wasagamack as these two communities are fly-in for much of the year, adding the cost of transport to the cost of food. With a limited selection of foods, community members often choose inexpensive and filling options that may not be healthy. Bobbish-Rondeau and et al. (1996) similarly found that remote First Nations communities consumed less healthy foods because of the expense and lack of knowledge about how to cook or use traditional foods.

Lac La Ronge participants noted that some traditional foods, which had been made for generations in a healthy way, are also being 'westernized' by the use of market additives. The lack of traditional game and fish in Wasagamack and Garden Hill has forced the communities to be more dependent on market foods. Gone (2007) argued that the loss of traditional foods was another form of colonization. Therefore First Nations leaders should advocate for restocking of game and fish in their waters and lands to provide the communities with a way to take back control of one aspect of their lives.

### **Individual, family and community support**

One impact of residential schools was the loss of intergenerational teachings and learning about traditions within families. This history has impacted traditional healing, medicines, and the development, organization and delivery of health care services in all four communities. D. Smith et al. (2005) state that little attention has been paid to the “implications of residential schools for health policies and programs” (p. 41). Therefore understanding the impact that residential schools have had on individuals, families and communities can be a factor in how First Nations health care systems are designed. Residential schools forced western institutions and knowledge into the lives of Aboriginal children, who then internalized this knowledge and are now asked to develop, organize and delivery health care services in First Nations communities. In the four First Nations studied, it is apparent that the length of contact and the indoctrination of western knowledge have influenced the design and delivery of health care in their communities. Of the four First Nations communities, Blood Tribe has had the longest contact with Euro-Canadians, thus more time and interaction to learn the Euro-Canadian values, beliefs, and worldview and incorporate into their own worldview. However, the other three communities have had less contact with Euro-Canadian society with the exception of residential schools and the impositions of the local Indian agent. As such these three communities

have retained more of their cultures, languages, and worldview than Blood Tribe, which may have had an impact on the development, design and delivery of the health care system.

All participants from the communities and the government participants of Aboriginal descent argued that family and community support was important for health care systems. There was no literature found that supported this view. However, Duran et al. (2008), Lane et al. (1984) and Kelm (2004) state that family and community support have been a traditional way to deal with adversity. Diabetes and other long-term health conditions may require support from family and the community to assist the patient with managing their illness. Blood Tribe and Garden Hill participants said that the communities have clearly tried to assist individuals diagnosed with diabetes and other chronic conditions by improving the facilities in the community. Lac La Ronge and Blood Tribe have both built and independently fund long-term care and Elder residences, with no government assistance, as these are one method of supporting individuals and families in their communities. Participants from both communities expressed that these facilities are expensive to operate and are in jeopardy of continuing these services without assistance from the provincial government. Some participants, government and community, stated that jurisdictional issues may prevent a formal funding agreement from being obtained, which would force the community to either relinquish this self-determining aspect of health care, or send their seniors to provincial facilities that are outside of the community. The community participants noted that the communities are very supportive of these facilities, but the cost could prevent them from providing these much needed supports.

## 4.5 Holistic Approach to Health Care

“Culture is a dynamic lived process that is inclusive of beliefs, practices, and values. Culture, however, is more than beliefs, practices and values that can be reduced to a list of personal characteristics. Culture is not homogenous or static and is not a single variable. Rather, culture comprises multiple variables and affects all aspects of experience; it is inseparable from historical, economic, political, gender, religious, psychological, and biological conditions,” (Kleinman and Benson, 2006 as cited in Gregory & Hart, 2009, p. 20).

Health care must take culture and spirituality into consideration (Gregory & Hart, 2009). Therefore a brief understanding of Aboriginal culture and spiritual beliefs is necessary to understand how health care may be perceived by different groups, especially First Nations communities. Turton (1997) argues that Aboriginal people have a health culture that is unique and emerges from their worldview. First Nations Healing (2010) put forward the ideal First Nations health care system that incorporated First Nations culture, spirituality, traditional healing and medicines. Many of the community participants agreed that incorporating traditional healing, medicines and spirituality would definitely improve the health care system. A few First Nations participants went further to state that any First Nations health care system not only required First Nations communities to be in control of the system, but they must also be holistic and look beyond just the immediate symptoms of individuals and families.

Although Garden Hill residents are divided about whether to revitalize culture and traditions, the community has developed ways to incorporate traditional healing, medicines, and teachings about health into the public health services provided by paraprofessionals through the health transfer agreement. Some of the government participants believed that Garden Hill had partnered with some non-government organizations, like the University of Manitoba, which had provided the band leadership with the opportunities to have more control over the programs and services provided and how to incorporate traditional healing and medicines as well as traditional knowledge and teachings into the programs. The self-determination provided to Garden Hill band council and health leadership appears to have assisted the community's well-being and reconnection to their culture and language. However the incorporation of these traditional healing practices is not as integrated in the other three communities. In fact, Blood Tribe participants were uncertain if there were any traditional healers in the community as many community members left the community for these services. Lac La Ronge participants have access to traditional healers and medicines, but these valuable assets have not been integrated into the health care system and have had limited integration in the secondary and tertiary health services provided by the community.

The social determinants of health discussed in Chapter 2 do influence First Nations people's lives. Blood Tribe participants explained that there is a housing shortage and that there are not enough places for people to get groceries or exercise on the reserve. In fact, many Blood Tribe citizens are forced to find transportation off the reserve to grocery stores, exercise facilities, and employment. These determinants of health can affect other determinants of health in a negative cycle. Therefore

addressing the social determinants of health in a holistic manner within the community can assist with addressing diabetes and health care by providing First Nations people with adequate resources to deal with their health condition. One government participant stated that "...the big issues like water, housing, food supply" are challenges that community members should not have in addition to their diabetes.

All four communities have housing issues. There is currently a waiting list in each community for new homes as there is not enough funding to provide enough homes for all the families that need or want them. Some homes are overcrowded with "two or three generations of the family trying to live in a two bedroom house" (Blood Tribe participant). This overcrowding affects diet, mental health, hygiene, and the expenses to "try to feed everyone, especially the ones that normally move on out to their own families" (Blood Tribe participant). Blood Tribe, Lac La Ronge and Garden Hill are trying to build more homes, but the population is growing quickly. One First Nations participant noted:

"...many crowded situations here and um, it really affects the diets of the adults and the children because they have really no choice if they want to be cooking something really healthy then they have to cook it for everybody in the household which is, which gets expensive. And so some people in the household are not, in a lot of the crowded situations some people are not contributing to the household income. So again, the single mothers are paying for their adult children and their own children and sometimes their grandchildren. So, they are trying to stretch their welfare dollar or they're stretch a low income dollar further and further and they can't do it."

Healing, culture and returning to a 'good path' are important to some of the community members and participants in this study. The challenge that these four First Nations communities face is one of determining the balance between culture, language, and worldview and that of the mainstream world. Many of the participants noted that culture, language and worldview may be impeding the full development of a "good health care system that respects us and gives us what we need to become healthy again". One participant noted that traditional healing and medicines were available in the communities, but incorporating traditional medicine had not been a priority for the four communities. Similarly, all of the health leadership and band councils acknowledged the need to incorporate traditional healing and medicines into the existing health care system. However there is a lack of time, resources, and knowledgeable people available to provide such services. Some of the



participants suggested that it is time to discuss how to combine the western bio-medical approach with the traditional approach in order to move forward.

Traditional medicine and healing can be very useful for patients and health professionals alike. Traditional healers and Elders can provide advice to patients about reducing their negative health behaviours, which builds upon what the health care professionals are espousing to the patients as well. Many of the government participants believed that the communities would determine how to incorporate traditional healing and medicine into their health care systems, whereas most of the community participants stated that time, funding and a lack of awareness of how or when to incorporate traditional healing and medicines had slowed their inclination to incorporate these services into their health care systems. Jacklin and Warry (2004) discuss that FNIH is unwilling to take responsibility for malpractice liabilities associated with incorporating traditional medicine services into the existing First Nations health care systems. Therefore if these four communities wish to include traditional healing and medicines in their health care systems, they would be forced to fund malpractice insurance, which would be costly.

Lavoie et al. (2010) argued that the federal government provides health care policy for First Nations communities and it does not necessarily reflect First Nations cultures, but Alcantara and Whitfield (2010) found First Nations communities that incorporated culture, language and traditions as well as the western political and policy paradigms were more successful in attaining self-determination and self-governance. It is apparent that Garden Hill, Wasagamack and Lac La Ronge have incorporated their culture and languages into their policy development, but this is at a local level and is not reflected in the provincial or federal level policies or political systems. Some government and community participants felt that Blood Tribe had not incorporated their culture, language and traditions into the political system or policy development, which has led to external non-First Nations government partners perceiving the community as being successful in their self-determination and governance of health care.

Blood Tribe, Lac La Ronge and Garden Hill are considered successful in creating a First Nations health system by government bureaucrats. However Blood Tribe Department of Health mirrors the western health system and has not incorporated Aboriginal knowledge, traditions, medicines or healing practices, which is important to moving toward the ideal First Nations health care system. By mirroring the existing western health care system, Blood Tribe can leverage more support from

provincial and federal bureaucrats because the system looks similar to what they are familiar with. Whereas Lac La Ronge uses the mainstream health care system, and Garden Hill has non-Aboriginal health care professionals, but both of these communities have incorporated culture, language and worldview into their secondary and tertiary services funded through the health transfer agreement. In the Royal Commission on Aboriginal Peoples (1996c) report, it was stated that to decolonize in health and improve the health of First Nations people, there needs to be good communication with all parties understanding the system and issues. Blood Tribe has done just that by replicating the western system in the Blood Tribe community, while the other three communities have developed communications with the governments, these communities have attempted to find additional methods to create a holistic health care system similar to the ideal First Nations health care system described in Chapter 2.

Self-determination in health care is the ultimate goal of First Nations communities. The federal government currently provides funding, human resources, and assists First Nations communities to develop partnerships or collaborations with their respective provincial government. However the current health care system in each of the four First Nations communities is designed or at least reflects what the federal government perceives to be an adequate system, but there are many aspects of the ideal First Nations health care system missing. Cornell et al. (2004) showed in **Error! Reference source not found.** (Chapter 2) that self-administration does not allow First Nations communities to design their health care system to include culture, language, traditional healing and medicines, or spirituality into the existing health care system. Therefore it is necessary for First Nations communities to have more control of the health care system to allow them to continue to move toward the ideal First Nations health care system, which would be holistic – including public health prevention and promotion as well as biomedical care – and interdisciplinary. Each of the four communities has achieved differing levels of the ideal First Nations health care model, but only Garden Hill and Lac La Ronge appear to be continuing to move toward this ideal. It appears that Blood Tribe and Wasagamack are not working toward the ideal First Nations health care model at this time, but there is the potential for both communities to continue on this journey if they gain more self-determination over their health care systems.

## 4.6 Conclusion

Rae (2009) argues that past research has found colonialism is the root cause of poor health, thus revitalization with a “genuine, effective and legitimate self-government in the interests of the people” is necessary (p. 5). The impacts that assimilation policies, like residential schools, have had on these four communities is not immediately apparent. However all four of these communities have incorporated these important issues into their worldview, which has influenced their decisions about designing and using their health care systems.

The participants from the four communities illustrate the need for this information not to be forgotten and that these factors will influence how the communities move forward with attaining self-determination in their health care systems. This chapter provided an Indigenous perspective of external factors that have influenced the health care system and self-determination of that system. It is clear that self-determination of health care is important as the socio-political history continues to create barriers and disrupt the four communities with revitalizing and reclaiming their traditional healing, medicines and holistic approach to health and well-being.

The four First Nations communities have struggled to meet the criteria set forth by the federal government (in the Handbook on Health Transfer, 2004) in terms of receiving greater flexibility in their health transfer agreements. However, each of these four communities is also trying to work toward the ideal First Nations health care system, which would ultimately lead the community to self-determination in health care. The criteria listed in Table 7 **Error! Reference source not found.** (Chapter 3) for self-determination is reflective of the western paradigms for self-determination. First Nations people perceive self-determination in manner consistent with how the federal government perceives self-governance; decision making ability, clear and established boundaries of responsibility, ability to make laws with strong and knowledgeable leadership, who can collaborate with other levels of government and obtain adequate funding for the health care system. With greater degrees of self-determination, these four First Nations communities can determine how, where and when to blend traditional healing, medicines, and knowledge into the existing biomedical model of health care. However with full self-determination, these communities could move toward a holistic approach to health care, which would look at more than just the physical aspect of an individual and include spiritual, emotional and mental aspects of an individual, their family and the community at large. The perception of self-determination in health care for these four communities

is important and could assist the communities with healing from the socio-political history that they have already endured.

## Chapter 5 Different Perceptions of Self-Determination

### 5.1 Introduction

Self-determination in any aspect of a person's life can influence the other areas in their life; for example control over employment can change what a person can purchase, such as healthy foods. Having the ability to determine where, when, how and who will provide health care is a right that most Canadians have. However for most First Nations people, they do not have the ability to make decisions about their health care as choice is often limited.

Despite the many limitations of the health transfer policy and Health Canada's lack of commitment to support true self-determination in health (Jacklin & Warry, 2004), all four of the First Nations communities in this study have made strides in gaining greater control over their health services. Self-determination in health is evident in all the communities as they have chosen strategies to help them to achieve their goals to improve primary care and specialized services. Each of the communities is aware of their progress and continues to work with their provincial and federal government counterparts to increase awareness and understanding of their abilities leading to self-determination.

This chapter will illustrate the perceived level of self-determination the communities have from the federal, provincial, First Nation, and health professional perspectives. The interviews with different types of participants clearly highlight the different perceptions about the level of self-determination that each of the four communities has over their health care system.

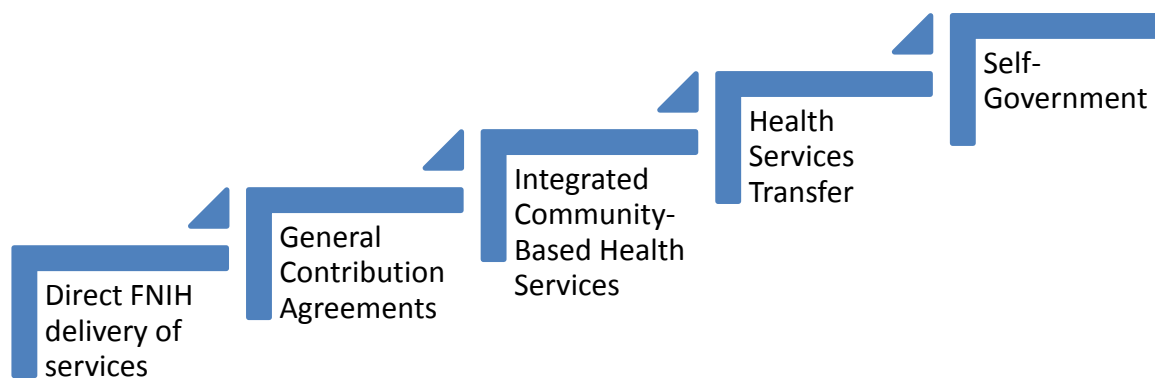
### 5.2 Federal Government Officials

Through policies such as the Health Transfer Policy, Self-Government Policy, and the Indian Health Policy, federal government staff become familiarized with the government's definition of self-determination and self-government as part of their role. Self-determination is not clearly defined, as discussed in Chapter Two, but the federal government does define self-government in a manner similar to how First Nations scholars and organizations define self-determination, which is the ability to make decision that are culturally and community relevant. The federal government:

“... is committed to working out government-to-government relationships at an agreed-upon pace acceptable to First Nations. These government-to-government relationships will be consistent with the treaties, the recognition of the inherent right of self-government, Aboriginal title, and Aboriginal and treaty rights under section 35 of the Constitution Act, 1982. Furthermore, in the international context, Canada supports the recognition of a right to self-determination for indigenous peoples which respect the political, constitutional, and territorial integrity of democratic states” (as quoted in A. Roy, 2001, p. 84).

In the Health Transfer Policy Handbook (2004), the level of control that a community has, is dependent on community ‘interest’ and based on their eligibility, interests, needs and capacity. In Figure 14 below is an adaptation of what the handbook outlines stages that First Nations people must work through to obtain what First Nations define as self-determination and the federal government defines as self-government.

**Figure 10 Health Canada's Mechanisms for Delivery of Health Services in First Nations and Inuit Communities**



\*Adapted from Health Canada (2004). Health Transfer Agreement Handbook 1, p.1.

As previously stated, the federal government indicates that they provide self-determination through the Health Transfer Agreements. However communities must meet criteria leading toward self-government. Although self-government is shown as the final option for First Nations communities, it

is clearly stated that communities wishing to enter into self-government agreements, must approach Indian and Northern Affairs Canada (now AANDC) with Health Canada assisting in the negotiations (Health Canada, 2004a). However if First Nations communities do wish to negotiate self-governance agreements, the agreements will be for all infrastructure and institutions, not just health. Many of the federal government participants believe their role is to assist First Nations communities with increasing their leadership capacity. “[T]he more capacity they have, the more independence or the more flexibility that they can have around things” (government participant). Another federal government participant spoke about the role of bureaucrats working with First Nations; “so my primary objective is to facilitate health outcomes by increasing the capacity of community level to self-determine.” FNIH staff assist First Nations communities with moving toward health transfer and increased flexibility available under such an agreement according to some federal government participants.

Although one government participant noted that there were “levels of agreements, based on leadership capacity and ability”, with region-wide planning and delivery, leadership and capacity building may not be as important in future agreements. However, in “[e]ach community, the leadership can determine the direction and we don’t want or have any control over that” (government participant). This statement clearly is not pursued by all federal government bureaucrats as some of the federal government participants who work with First Nations communities state that there is established criteria that FNIH bureaucrats must apply to determine a community’s flexibility and control over their health system. Lavoie (2011) stated that the goals of individual funded programs do not necessarily align with community needs, but may assist with showing the community’s capacity. One federal government participant stated that there are no published criteria for the communities, but that the relationship between the FNIH bureaucrat and the community as well as their previous experience with contribution agreement programs and services is considered when determining the level of flexibility assigned to a community.

Many of the federal government participants noted that the leadership capacity of First Nations communities, like Lac La Ronge, has an impact on their relationships. The federal government has provided training and attempts to empower band councils to be involved and have ‘big picture thinking’. This helps to build capacity and improves communication between the federal government bureaucrats and the band council about health care. Some of the federal government participants noted that the training provided by the government does assist them with capacity

development, but staff in management positions may not always remain in their position. Therefore it is necessary to provide leadership and capacity training repeatedly. The Health Council of Canada (2005) found that Aboriginal people must be a part of the health care reform, and that training may assist First Nations people to be full partners in health care including taking on more leadership capacity.

Some federal government participants believe First Nations communities are moving toward more flexibility. Most of the federal government participants provided their interpretation of the guidelines to self-determination for First Nations communities to obtain control of their health care. As was discussed earlier in this section, the definition of self-government is similar to the First Nations definition of self-determination. When the federal government participants spoke about self-determination, it was clear that the definition that they understood was to have the ability to make individual choice about when and where to access health care. Some participants spoke about communities having control over the administration of the funding, planning the programs and services, but all participants noted that First Nations communities, regardless of the flexibility they are afforded, must adhere to the guidelines for accountability that Health Canada have written in the handbooks for health transfer (Health Canada, 2004a, 2004b). Lavoie (2011) found that First Nations communities do have some flexibility within their health transfer agreements, but that the government bureaucrats who oversee the agreement make the judgment of how much control there is in a First Nation community. Therefore different First Nations communities will have different levels of flexibility under the same programs or transfer agreements, which Malloy (2001, 2003) found in many federally funded programs and services.

In Alberta, one federal government participant said “well, from the outside looking in, it seems that they [Blood Tribe] have complete control over their health care. And they have been quite proactive about defining what it is that they want and need for their community.” The federal government participants spoke highly of the work and leadership capacity in Blood Tribe, which those participants argue allows Blood Tribe to have more control. One participant further explained that Blood Tribe has “a fair bit of *administrative* control”, which Lavoie (2011) and R. Smith and Lavoie (2008) argue does not allow First Nations communities to do more than oversee paperwork and flow money without being able to make decisions based on community need. All of the federal government participants believed that the Blood Tribe Department of Health has strong financial and administrative management and can make changes and adjustments with minimal input from FNIH.



The federal government participants view their role as providing communities, including Blood Tribe with the tools to become self-determining and that they are to assist with capacity development amongst the leadership (both band and health specific). However based on the Blood Tribe participants' responses, there is a difference of opinion about the level of control the Blood Tribe has in managing the community health care (see later section in this chapter).

Lac La Ronge is unique in Canada with six communities in one health transfer agreement because all of the communities share one chief. There are only three such agreements across Canada. The federal government participants perceived that Lac La Ronge was receiving some flexibility in their health transfer agreement as they have shown leadership capacity. "I think they [Lac La Ronge] have a lot of control and so they work within the context of this regional plan because we [federal, provincial and First Nations governments] have all agreed that it has value for everybody" was how one federal government participant explained the level of control. Health Canada (2004a) has outlined the criteria for First Nations communities that chose the health transfer approach; this criteria includes having a mandate through a band council resolution, evidence of successfully administering programs and strong leadership capacity with community involvement. According to the federal government participants, Lac La Ronge has met some of the criteria for increased flexibility. The Assembly of First Nations (2005a) and Loppie and Wien (2009) argued that if the health leadership was capable of managing the health care system, then with communication and mentorship, the band leadership would quickly be able to assist the health leadership with self-determination in health care. J. Graham and Bruhn (2009) found that strong leadership in First Nations health services can improve self-determination in health, which will assist the community in improving health status and accessing culturally appropriate health care.

Wasagamack and Garden Hill are funded through a health transfer agreement signed by Four Arrows Regional Health Authority (FARHA). FARHA was created to unite Island Lake First Nations communities' health care as the communities are related by geography and ancestry. Many of the federal government participants acknowledged that smaller First Nations communities must build their leadership and ensure that they have the appropriate level of capacity to receive flexible health transfer and contribution agreements. Some federal government participants noted that 'flexibility' with the health transfer agreement occurs when a community has strong and consistent leadership at the band and health services levels, has shown that they can effectively manage contribution agreements, and involved the community in many aspects of program delivery. One participant

noted that “Wasagamack is still growing and developing”, which the Wasagamack participants agreed was beginning to happen.

Two federal government participants believed that the leadership in Garden Hill has already learned how to negotiate new partnerships and relationships in a way that will benefit the community’s health, and as such the community is moving toward greater flexibility and control of their health care system. During the discussion about control in Garden Hill, one federal government participant said that the control the community was attaining would only cover the programs and services funded under the health transfer agreement until the community and the province negotiated a tripartite agreement that devolved control of primary health care to one or both of these governments. “They have a health transfer agreement, but FNIH still provides the primary health care services because they are remote.” One federal government participant said “I think we are moving toward FNIH transferring nursing stations to the province and the province to the First Nations. But that will be over time.” The perception is that while control may not be held by the community, it will be in the future. The idea of a tripartite agreement or partnership between the three levels of governments was discussed in the Royal Commission on Aboriginal Peoples (1996c) report and expanded in the Romanow (2002) report.

The federal government participants suggested that the criteria for moving toward self-determination are available in the Handbook for Health Transfer (Health Canada, 2004a), but some of the participants noted that individual bureaucrats can interpret the criteria based on their knowledge and experience with the First Nation community. One of the key criteria that all of the federal government participants felt that First Nations should have for increased flexibility and self-determination was strong leadership capacity. The federal government participants did not outline the exact criteria for strong leadership capacity, but rather detailed that this was a requirement for them to allow more flexibility. First Nations participants understood the need for strong leadership, but were not aware of what was exactly required by the federal government.

Some of the federal government participants also noted that while training is often provided to assist band councils, para-professionals and others working with First Nations communities. These participants stated that the training often had to be repeated because of high turnover of community, government, and health care staff. With the criteria being less than transparent and continual changes in staff at both the government and community levels can further restrict First Nations

communities on their path to self-determination in health care and incorporation of the ideal First Nations health care system. Most of the participants had expressed concern in the lack of knowledge of First Nations people that government and health care professionals had, which they felt may detract from First Nations moving toward self-determination in health care.

Most federal government participants perceived that all four communities had some control of their health care systems generally, but knew that leadership capacity, communication, and collaboration with provincial and federal governments would increase the community's ability to control their health care system. Most federal government participants perceive strong leadership capacity, both at the band and health levels, as the key to increased flexibility that leads to self-determination. The federal government has worked with First Nations and the province of British Columbia to create a tripartite agreement that allows First Nations a high level of self-determination in health care, which some federal government participants believed would occur in other provinces in the future. Health Canada (2008) has begun negotiations with First Nations and provincial governments across Canada to develop a health care system that meets the needs of First Nations communities and allows First Nations people to have greater control of the system. However at the time of this study, these negotiations had not begun and it is unclear how or when changes to First Nations health care systems may occur.

### 5.3 Provincial Government Officials

Alberta, Saskatchewan and Manitoba have large Aboriginal populations and there are several treaties signed in each province. As discussed in Chapter Two, under the *Canada Health Act* and the *British North America Act*, the provincial governments are responsible for providing and administering health care to all citizens, with some notable exceptions including First Nations people living on reserves. As one provincial government participant explained “we are really aware of their treaty rights and don’t want to do anything to jeopardize them”. D. Smith et al. (2005) found that provincial governments acknowledge the needs of First Nations people living on reserve, but are hesitant to ‘jump in’ without consulting the federal and First Nations governments because of the jurisdictional issues. Therefore, the provincial government perceptions of self-determination in First Nations health care differ from their federal government counterparts.

In the province of Alberta, the provincial government participants believe that Blood Tribe “have complete control over their health care”, but that not knowing what is available and transportation to get to necessary health services are barriers to having ‘true self-determination’ over their health care. The Alberta government participants were more concerned with individual self-determination in health care than the collective First Nations community self-determination over the health care system. The provincial government participants stated that the Blood Tribe has a lot of control in their health system and were definitely working on full self-determination. In addition to providing health care to the community, some provincial government participants stated that Blood Tribe has collaborated with surrounding health organizations to provide some services on the reserve for non-Aboriginal people on a fee-for-service basis.

Alberta Health Services is the operational arm of the health ministry, which works closely with Blood Tribe and other First Nations communities in Alberta. However one participant noted “there is no policy, but I would say that what we do is only come on to First Nations if we’re invited”. One participant noted that Treaty Six affects a large number of Alberta First Nations, and the provincial government is hesitant about assisting First Nations because they do not want to damage any treaty obligations. Therefore the provincial bureaucrats will not ‘jump in’ to assist Blood Tribe unless invited or specifically asked as they do not want to deny the treaty rights that are afforded to Blood Tribe. This creates multiple jurisdictional partnerships that have different policies about health care services. Lavoie (2011) found that this patchwork of policies is confusing for First Nations and may impede access to health care services, and may further put strains on the relationships between First Nations and the federal or provincial governments. Therefore jurisdictional issues about policies and funding for First Nations health care may influence the level of self-determination that a community like Blood Tribe believes they have. However, the participants agreed that Blood Tribe has developed a strong relationship with the provincial government and is a ‘gold standard’ in health care delivery with “a lot of community control”.

In Saskatchewan, the provincial participant refrained from commenting on the level of control in Lac La Ronge. However the participant did state that Lac La Ronge had access to a good health care system, which they could influence through partnerships and networking. The provincial government participant believed that Lac La Ronge had many challenges because of its size and geographic diversity, but “they are very much involved in a number of different initiatives” that may assist them in gaining leadership capacity for future self-determination in health care.

In Manitoba, the provincial participants were interested in working more collaboratively with First Nations communities, but the local health care system was designed and delivered by the regional health authority with little input from the provincial government. In this way, regional health authorities have substantial influence with regards to the organization and delivery of health care for ‘mainstream’ Manitobans. One government participant noted “I think in some ways FNIH has kept them back. They have separated them from the RHAs [regional health authorities] and the RHAs have services that can be helpful and assist them with having some self-determination in health care.” As Lavoie (2005, 2011) has asserted, First Nations communities are often caught in jurisdictional dilemmas unaware that there are ways to gain control over their health care system. Garden Hill and Wasagamack may be able to have more control in their health care systems if they were partnered with the regional health authority, which would ultimately link them to the provincial government.

The province of Manitoba has been working with First Nations communities and the federal government for many years as a tripartite agreement was created in 1964 to establish Manitoba’s jurisdiction to provide health care in four northern First Nations communities. While Garden Hill and Wasagamack are not among the four communities, it is clear that the provincial government is willing to partner with First Nations and the federal government to provide health care services. One participant spoke about how the nursing stations established from the 1964 agreement could assist Garden Hill and Wasagamack with having more control of the health care system because this example shows the province can work with the First Nations communities to design a system that fits the needs of the community including the culture, language and history. One Manitoba government participant noted that the provincial government is aware of First Nations issues, including health. The Minister has indicated that collaboration must occur as well as increased knowledge and understanding of First Nations socio-political history will assist provincial government bureaucrats to work with First Nations communities according to one provincial government participant. Allec (2005) outlined possible methods to adapt primary health care for First Nations needs in Manitoba, and the province’s willingness to work toward these new approaches to First Nations health care. However there will need to be negotiations between the three levels of government to reach an agreement that allows Garden Hill, Wasagamack and other First Nations communities in Manitoba to take more control of their health care systems.

One government participant noted that Wasagamack First Nation was still developing its leadership capacity, but that FNIH and Manitoba Health wished for them to take over their health care system. “They have to acknowledge health. Health cannot be taking a back seat all the time. Recognizing the social disparities and the economic situation helps, but the rates for diabetes are climbing” according to one participant. While R. Smith and Lavoie (2008) argue that communities must have leadership capacity, which Wasagamack may be lacking, D. Smith et al. (2008) agree that Wasagamack must place health first and work toward building the necessary requirements to take control of their health care system.

In contrast to the perceptions about Wasagamack, the provincial government participants stated that Garden Hill does have some control and are working toward increasing the level of self-determination in health care. Garden Hill participants want to take more control, but participants believe that Garden Hill only has a limited amount of control. One provincial government participant noted that Garden Hill had found alternative ways to have increased self-determination in health care by partnering and working with external stakeholders to improve diabetes care and working toward improved healthy living strategies. This is similar to Cornthassel (2008) argument that those alternative solutions may assist First Nations communities with gaining self-determination in areas of interest, like health.

Some of the provincial government participants indicated that individual self-determination in health is more important than assisting communities with self-determination in health. In Alberta and Manitoba, there is a clear sign that the provincial governments wish to work with First Nations communities to incorporate traditional healing and medicines, culture, language and worldview into the health care system. Additionally, the government participants from these two provinces indicated that their respective Minister of Health was interested in improving Aboriginal health by working with First Nations communities. This willingness to work with individual First Nations communities may lead to increased self-determination in health, and why some First Nations communities appear to have more self-determination in health than others according to the government participants.

All of the provincial participants seemed to be more interested in individual self-determination rather than collective or community self-determination in health care on reserves. Some of the provincial participants noted that access to health care was the key to individual self-determination in health

and that community self-determination was a matter to be discussed between the federal government and First Nations communities. Thus the provincial participants stated that their mandate and goal was to assist First Nations communities, when called upon, with ensuring that individual First Nations people have access to the health care system provided by the province in order to improve the health of First Nations people. However First Nations participants argued that the provincial health care systems did not necessarily provide culturally and linguistically appropriate health care and that access to the provincial health care system would not be the only factor to improving the health of First Nations individuals. In fact, some of the First Nations participants argued that to improve First Nations health (individual or community) required blended health care system, like the ideal First Nations health care system, in which culture, language, traditional healing and medicine were seen as necessary components to improving the health of First Nations people.

## 5.4 First Nations Leaders

Self-determination has been a goal that First Nations leaders, both in First Nation government and health care, would like to see all First Nations communities attain. Their perceptions of the current situation regarding the level of self-determination are clearly different than those expressed by the federal and provincial government participants. These First Nations participants clearly indicate their perception of self-determination in health care and how they will be aware when they reach it. Some of the First Nations participants acknowledged some of the aspects outlined for the ideal First Nations health care system that was discussed in Chapter 2.

The organization and delivery of health care in Blood Tribe mirrors the provincial health care system, with fee-for-service physicians, health clinic located in the centre of the community, and access to a variety of health professionals and does not have traditional healing or medicines incorporated. Blood Tribe has had stable long-term leaders at the band and health department. These leaders established partnerships with external stakeholders and government representatives as the Royal Commission on Aboriginal Peoples (1996b) report recommended. However, some community participants were concerned about the integration and connection of the leadership to traditional knowledge, healing and worldview, which they believed were necessary for authentic First Nations leaders wishing to move toward full self-determination in health care. National Aboriginal Health Organization (2004) and Bluesky (2003) argue that once a First Nations

community has self-determination, culture, language and worldview can be reclaimed and incorporated into all aspects of community life. The ideal First Nations health care system indicates that there would be an integration or combination of biomedical and traditional health systems (First Nations Healing, 2010). Therefore Blood Tribe is in the position of continuing their journey to self-determination in health care. From my observations and the interviews with Blood Tribe participants, many acknowledged that while there is a health transfer agreement, there is difficulty in making changes to health programs and services without agreement of FNIH.

The Blood Tribe participants believe that their health care system has provided them with some level of self-determination, but their perception regarding the level of self-determination over health care is far less than both the federal and provincial government officials. The federal government participants believe that the Blood Tribe has developed sufficient leadership capacity and has almost complete control over their health care system. The provincial government participants believe that Blood Tribe is almost fully self-determining in their health care system. The difference in perceptions of the level of control must be a factor in the organization and delivery of health care for the Blood Tribe because when an organization feels that they must follow guidelines and objectives, they believe they have less ability to provide their own input. However if Blood Tribe participants believed that they had full control of the health care system, they would see the funding guidelines, objectives and goals as areas that they might strive for as opposed to those that they are mandated to achieve and forced to work within. This concept is in agreement with M. Atleo (2008), who found that “[o]nce a part of the process, First Nations can negotiate change in its underlying assumptions and strategic direction. Participation permits First Nations to negotiate change in actions that do not reflect First Nations values,” (p. 45).

Lac La Ronge participants felt that the community had some degree of self-determination in their health care, but Health Canada and FNIH have the ultimate control and could change the direction of health care when they feel because there is a need for transparency and accountability attached to the funding provided for the health transfer agreement. This perceived control by Health Canada has led Lac La Ronge to communicate often and in detail with Health Canada, but the mandates of the specific agreements prevent the community from making the changes that address the community’s needs. As one Lac La Ronge participant stated, “if you make a drastic change in the [health] plan, well...” the consequences can be severe. The Lac La Ronge participants firmly believed that the Health Director could make small or subtle changes to the health plan, but major change could not



occur without extensive consultation. One community participant noted that the five-year health transfer agreement allows the community to have full control over the money that goes directly to the Lac La Ronge Health Services for the management and board to approve of the work plan.

However,

“...that approval is a recommendation to the chief in council and then it goes to chief in council for final approval. ... It’s chief in council that is difficult to change because there is certain mandate under Health Canada for each of your contribution agreements on what you can and cannot do with funding. ... Yeah, so your flexibility, you have to have prewritten your proposals in advance um, even your community health plan which is 5 years, you write it for 5 years projecting, if you make a drastic change in that plan well... They come after you so it’s not really easy to change so you really have to have your whole planning process very well laid out.” (Community participant)

In Lac La Ronge, the band participant perceived the community to have some self-determination while the health leadership participant perceived the community to have little. This variation may be a result of the difficulty to get approval from the band council and Health Canada. Regardless of the slight variation in responses, the Lac La Ronge participants agree that the community must work with the provincial health care system to provide health care to their community because they do not have the human resources to provide such care on the reserve. D. Smith et al. (2008) found that taking control of the health care system requires First Nations communities to build management capacity in order to provide adequate health care.

For both Garden Hill and Wasagamack participants, they perceived that both communities had no control over the community’s health care, but the health participant in Garden Hill felt they had a small amount of control in health care. In both communities, health care is arranged and provided by FNIH employed health care professionals, which some participants believed helped the communities with building leadership capacity and community development as they were not focused on recruiting and staffing health care professionals. Wasagamack participants acknowledged that they did not have control of health care and that they need to build their leadership capacity before attempting to increase their control, or self-determination, in health care. Garden Hill participants believe the community and leadership are ready to take more control of the health care system.

Lac La Ronge and Garden Hill have established strong and capable leadership in the band and health department. Lac La Ronge needs to further develop relationships with provincial and federal government representatives and Garden Hill must develop relationships with government representatives independently of FARHA in order to further increase the leadership capacity of the community. Olsen (1994) argues that both government and First Nations leaders must be flexible and adaptable. Based on some of the participants' responses, both Lac La Ronge and Garden Hill are forging these relationships with the two levels of government and continuing to increase the capacity of the leaders in their communities. Therefore after trusting relationships are built, the two communities may continue to work towards self-determination in health care. However Wasagamack needs to work on increasing leadership capacity before developing relationships with provincial and federal government bureaucrats and striving for self-determination in health care.

All of the communities should be concerned with their leaders leaving or not being re-elected as the communities require a continuity of leadership to continue to move toward self-determination in health care. Through lived experience, the current health directors and band councils have found ways to connect with government bureaucrats and their agendas, which Brant-Castellano (1980) believed would assist First Nations in their quest for self-determination in health care. Therefore building community capacity in health and leadership should be priorities in all four communities as they will need educated, knowledgeable, and culturally connected community members that can assist the communities with asserting their right and ability to be self-determining in health care as J. Graham and Bruhn (2009) found.

The perception of control in health care for community participants was low, whereas government participants believed that there was more control in three of the communities than the communities themselves perceived. The semi-isolated communities (Blood Tribe and Lac La Ronge) perceive they have some control, whereas the government participants believed that Blood Tribe had full control and Lac La Ronge almost had full control. Garden Hill and Wasagamack believed they had little or no control, but government participants felt that Garden Hill had moderate amounts of control in health care and were certainly moving toward self-determination in health care. These differences in perception point to a need to understand the nature of self-determination from all perspectives before developing strategies to help this happen.

## 5.5 Health Care Professionals

During the Expanding the CIRCLE study, health care professionals were interviewed about the health care system. These participants were not asked specific questions about self-determination, but their responses to questions about the health care system provide some insight into their perceptions of the community's control of the health care system.

Blood Tribe health care participants were all of Aboriginal descent and most are from Blood Tribe. The participants believed the community has struggled with what self-determination is and how to achieve self-determination when the definition was unclear. However, these participants felt that the community had achieved some control in the health care system as they had a health care clinic with Aboriginal staff and were able to provide many services to the community based on their funding and partnerships. Blood Tribe is unique in the literature as there are no other First Nations communities that have a full complement of Aboriginal health care professionals, and no other community has been able to access their own members as health care professionals.

The Blood Tribe participants were interested in discussing the lack of communication between the health care team, the health and band leadership, the provincial and federal governments. One participant noted that there were many instances where the health or band leadership had meetings with the provincial or federal government but did not relay this information back to the health care professionals, which impeded the health care professionals' ability to obtain community feedback about potential changes or needs. The participant felt that if the communication was lacking between these key players, then it would be difficult to gain full control of the health care system because directives, objectives, and needs could not be discussed and planned for. The Royal Commission on Aboriginal Peoples (1996b) report recommended that clear communications strategies be developed at all levels of government and that intergovernmental communications needed to be provided to all people involved, which should include the health care professionals. Blood Tribe may have an issue with communication, but there is consensus from the participants that there is some self-determination in their health care system.

The Lac La Ronge health care participants worked for the 'mainstream' medical clinic and health clinic in the town of Lac La Ronge. One of the participants was of Aboriginal descent, but not from the community or surrounding traditional territory. These health care participants perceived the level of self-determination to be low, but noted that the community had a lot of administrative control over

the health care system; the health director could utilize the medical clinic to fulfill health care requirements associated with the health transfer agreement. One participant discussed how the community “ha[d] not really pushed for control... they seem comfortable this way.” The health care participants are not community members or government bureaucrats and may see the current health care arrangement as comfortable, familiar and organized to benefit Lac La Ronge community members.

In Garden Hill, one participant was of Aboriginal descent and the other two were non-Aboriginal people. The Aboriginal participant believed that Garden Hill had found innovative ways to meet the needs of the community by obtaining partnerships with external organizations, so this participant stated that while Garden Hill may not have self-determination, the community had adapted and found alternative methods to gain a level of self-determination over health – not health care. The non-Aboriginal participants felt the community had some control over the health care system and were well-positioned to take more control in the future if they continued to work with Health Canada and the federal government. Jacklin and Warry (2004) found that at a local level, government bureaucrats were unable to assist First Nations communities with non-traditional health care approaches which could lead to increased levels of self-determination, similar to the situation discussed by the health care participants in Garden Hill.

Finally in Wasagamack, there was one non-Aboriginal health care participant who discussed the community’s inexperience as the key factor as to why they had no control in their current health care system. The participant stated very frankly that the community had many other health and social issues that had preoccupied the band and health leadership’s time and resources, thus the community had not developed the appropriate level of leadership capacity needed to take control of the health care system in Wasagamack. However, the participant noted that FARHA should work with the Chief to develop the leadership capacity and assist the community with achieving some level of self-determination in the health care system. The Assembly of First Nations (2005b) argued that for small communities, it would be advantageous for tribal health authorities or larger Aboriginal organizations to mentor or assist with the leadership development and capacity building.

The health care participants in the four communities perceive the level of control similar to the band and health leadership, which is not similar to the federal and provincial government participants’

perceptions. It is interesting to note that the Aboriginal health care participants acknowledged the need for more self-determination, whereas the non-Aboriginal participants noted only the issues.

## 5.6 Discussion

The perception of control or self-determination varies depending on the level of government (federal, provincial, or First Nations) and the interactions the participant has had with First Nations health care systems. In Table 10 below, the perceived level of self-determination in First Nations health care is shown.

**Table 9 Perceived Level of Self-Determination in Health Care by Government Levels**

Participant/Community	Blood Tribe	Lac La Ronge	Garden Hill	Wasagamack
<b>Federal Government</b>	High	Medium	Medium	None
<b>Provincial Government</b>	High	N/A	Medium	None
<b>First Nation Government</b>	Medium	Low	None	None
<b>Health Leadership</b>	Medium	Low	Low	None
<b>Health Care Professionals</b>	Low	Low	None	None

Created by A. Mashford-Pringle (2012)

The perceptions about the level of self-determination in Blood Tribe and Wasagamack are somewhat consistent; there is a perception that Wasagamack has no control and that Blood Tribe has some control. In the other two communities, Garden Hill and Lac La Ronge, the results are not as clear. Band and Health leadership in Garden Hill and Lac La Ronge perceive control to be low, but the government participants perceive the two communities to have some self-determination in health care. These differences in perception illustrate different definitions of control. Governments perceive self-determination to mean control of administrative processes, within strict parameters

dictated by federal or provincial governments. Additionally, the provincial government saw self-determination from an individual perspective not a collective, but wanted to assist First Nations communities with gaining more self-determination in health from a provincial perspective. Community and health care professional perceive self-determination to mean control over the allocation of resources, uses of traditional medicines and working toward the ideal First Nations health care system that was outlined in Chapter 2. There is clearly a difference in level of perceived control that community members see versus that of their government counterparts, which can lead to the amount of support and flexibility the communities receive with funding, human resources, and leadership capacity development. Even the criteria for strong or effective leadership capacity are not created by First Nations communities, but rather by federal and provincial bureaucrats. Therefore communication and mutually created criteria may assist First Nations communities with increasing their perception of self-determination as was stated by the Royal Commission on Aboriginal Peoples (1996c) report and Lemchuk-Favel (1999).

Warry (1998) discussed the need for communities to achieve self-determination in health care to achieve a health care system that was culturally appropriate and community sensitive. However if the different levels of government do not perceive the same level of self-determination, it may be difficult to attain the requirements needed to increase their flexibility, which in turn will increase their level of self-determination. The definition of self-determination is only one issue, but there is also an issue about the guidelines and criteria for achieving increased flexibility that leads toward self-determination. The guidelines and criteria are created by non-First Nations people and those who may not be familiar with the realities faced in First Nations communities or the socio-political history that First Nations people and communities have faced. Therefore arguments can be made for either a western biomedical system only or a blended system, like the ideal First Nations health care system.

The ideal First Nations health care system provides a holistic framework where primary health care is complemented by public health programs and services including those for chronic diseases, mental health and prevention and promotion programs and is staffed by an interdisciplinary team of health professionals that can be accessed by community members as needed. The blended or ideal health care system would also allow First Nations communities to infuse culture, language, and traditional healing and medicines into primary care and primary health care. Chandler and Lalonde (1998) found cultural continuity reduced the rate of suicide in some First Nations communities, thus it can

be extrapolated that the ideal First Nations health care system would also provide positive and protective factors in primary health care as First Nations communities would be looking at the holistic health of individuals and families, not just the absence of disease. In the ideal First Nations health care system, First Nations communities would have more than just administrative control although they would still have to work with the funding government's guidelines and criteria for the funding. Self-determination in the ideal First Nations health care system should be defined as having full control over the health care system to ensure that a holistic and interconnected health care system integrates traditional healing and medicine with biomedical primary care (First Nations Healing, 2010; Loppie & Wien, 2009; Royal Commission on Aboriginal Peoples, 1996c).

Blood Tribe participants believe they have some control over the health system in the community and where they can access services, whereas the provincial and federal participants felt that Blood Tribe had a lot of the control over the health system in the community. This difference in perspective has influenced the organization and delivery of care. The perceived level of control, or self-determination, varies depending on the vantage point of the participant and the knowledge of Aboriginal socio-political history. Participants that were of Aboriginal descent perceived low levels of self-determination, but also noted that the communities addressed this by 'being creative' and finding external partners that could assist them with meeting the health care needs of the community.

Lavoie (2011) found that First Nations communities do have some flexibility within their health transfer agreements, but that the government bureaucrats who oversee the agreement make the judgment of how much control a community may have. Therefore the perception of the level of self-determination provided by the federal and provincial government participants is important to the eventual ability of these four communities in obtaining increased self-determination for their health care systems. As Malloy (2001) argued, government bureaucrats can assess Aboriginal communities based on their individual perceptions and implement policies based on their individual interpretations, which could also impede these four communities from obtaining more control in their health care systems if the bureaucrats do not perceive the community as being capable of handling increased control in the health care system. For example, Wasagamack participants acknowledged the need to increase their leadership capacity, which Lavoie et al. (2005) and the Royal Commission on Aboriginal Peoples (1996c) report argues is required for a First Nations community to have any measure of self-determination. The government participants were aware of the limited control that Wasagamack First Nation had over the health care system, but most believed that it would take the

community time to develop leadership capacity that would be able to effectively operate health services in the community. Both federal and provincial government participants suggested that capacity building of para-professionals and cultural and history awareness training for government bureaucrats may assist Wasagamack First Nation in taking more control over their health care sooner. Training and education about the socio-political history and culture for government bureaucrats and para-professionals would assist with moving toward the ideal First Nations health care system as everyone would have similar knowledge and understanding of the needs of First Nations health, history, and culture.

Lavoie (2011) argued that leadership capacity within the band council and the health services was necessary for a First Nation community to take control of their health care. These differing perspectives of what is required to obtain greater control of the health care system are precisely the issue that First Nations communities face; without direct indicators, many First Nations communities continue to languish waiting for the federal government bureaucrats to determine if the community is sufficiently ready to take increasing control of the health care system. In the ideal First Nations health care system, there would be agreement between federal, provincial and First Nations leaders about what the indicators of readiness for self-determination are; these indicators should not be determined by the federal government alone. The Royal Commission on Aboriginal Peoples (1996c) report and Romanow (2002) recommend that open and transparent criteria assist all parties in a collaboration, and as such, there is a need for clear and open communications for the development of such indicators and criteria.

J. Graham and Bruhn (2009) found that strong leadership in First Nations health services can improve self-determination in health, which will assist the community in improving health status and accessing culturally appropriate health care. All four of the communities are aware that they need strong leadership, but it is difficult to determine how to 'create' a strong leader who is knowledgeable about First Nations, their culture, language and worldview, but is also knowledgeable about government practices and how to manage large complex systems, like health care. Participants spoke about training and education for all levels of government to introduce them to concepts of Aboriginal history, culture and language, which may assist in developing stronger and clearer communications between First Nations leaders and government bureaucrats which may lead to increased self-determination as 'everyone would be speaking from the same page'.



The provincial and federal government participants felt that Garden Hill and Lac La Ronge had some control and were displaying indicators that the community was ready for more control of the health care system. However many of these participants noted that clear roles and responsibilities and increased funding would assist the community to increase their level of self-determination in health care. Vanden Berg (2009) stated that First Nations communities need clear boundaries, roles and responsibilities to assist with increasing their self-determination. At the present time, the boundaries, roles and responsibilities are defined and regulated by the federal government through FNIH and AANDC bureaucrats. First Nations participants believed that the boundaries and responsibilities should be created in partnership or through consultation instead of being imposed upon their communities. Participants from Garden Hill and Lac La Ronge understand that the band and health leadership roles and responsibilities need to include engaging the community, which happens in both communities, but more so in Garden Hill.

The process of devolving health care actively engages First Nations communities and the provinces, which can lead federal, provincial and First Nations governments to find innovative ways to provide self-determination in health care (Rae, 2009). In the province of Manitoba, there seems to be some discussion about devolving health care, which should increase communication and assist with increasing self-determination in health care. However, if First Nations communities are forced to take control of devolved programs or services, like health care, when the program's structure, reporting requirements and partnerships are already established, this produces self-administration, not self-determination (Rae, 2009). It is important for all First Nations communities to attain true self-determination, not self-administration as was discussed in Chapter Two. However, if First Nations communities do not want to negotiate devolution on the federal government terms to possibly increase their level of self-determination in health, the federal government may have a 'take it or leave it' attitude (Rae, 2009), which can lead to less self-determination if the health care system is simply devolved to First Nations communities or provincial governments. It is apparent that in Manitoba, Garden Hill and Wasagamack must voice their concerns and communicate their specific needs in order to reduce the potential for a negative impact of the possible devolution of health care to the province.

## 5.7 Conclusions

All four communities have started their journey toward self-determination in their health care systems. The path that each community chooses is different and marked by different partnerships, collaborations, funding, communication, incorporation of culture, language and worldview, and proximity to non-Aboriginal towns and cities. Blood Tribe is seen by government participants as having self-determination, whereas Lac La Ronge has some control and working toward increasing this control. Garden Hill has more control than Wasagamack, but government participants felt that Garden Hill was just beginning to take control, whereas Lac La Ronge was well on the way to increasing the amount of control the community had in health care. The perception of control is different when speaking with community participants as Blood Tribe, Lac La Ronge and Garden Hill felt they had some control, but not as much as government participants believed the communities had. Therefore the definition used for self-determination by federal, provincial and First Nations governments must be unified and agreed to by all three governments. S. Atleo and Assembly of First Nations (2011) argue that self-determination must allow First Nations communities to organize and deliver primary health care that is culturally appropriate and integrated with the biomedical health care provided in every province. It is important to clearly define self-determination and the criteria that First Nations communities are required to attain in order to receive self-determination. Regardless of the criteria, First Nations communities will never have full self-determination as the funding will always come with requirements and external goals from the federal or provincial government.

There are number of key factors that assist First Nations communities to strive for self-determination; leadership capacity, funding, collaboration, incorporation of culture, language and norms, clear roles and responsibilities, and good communication. Leadership capacity, funding, collaboration and clear roles and responsibilities have been determined by federal government bureaucrats with little input by First Nations people. According to the First Nations Healing (2010), Royal Commission on Aboriginal Peoples (1996c) report, and S. Atleo and Assembly of First Nations (2011) argue that incorporation of culture, language and norms as well as collaboration and good communication are essential to the ideal First Nations health care system, which First Nations communities appear to be striving toward. Blood Tribe appears to be closest to attaining self-determination in health care, but traditional healing and medicines and culture may not be incorporated into the health care system. Wasagamack would then appear to be farthest from

attaining self-determination in health care as they are building leadership capacity, lack adequate funding, do not have established collaborations with provincial and federal government representatives, or clear boundaries. Lac La Ronge has many of the key factors, but does not have collaboration or clear boundaries with the province, which has prevented the community from attaining self-determination in health care. Garden Hill has many of the key factors, but has found alternative methods to provide some measure of self-determination in their health care by partnering with external stakeholders and finding alternate sources of funding to provide what the community requires in terms of their health.

The perception of self-determination was different depending on the participant's exposure and knowledge of the First Nations community in question. However, many of the federal government participants were interested in collective community self-determination with some vague criteria developed within the Handbooks for Health Transfer (Health Canada, 2004a, 2004b), that provided individual bureaucrats with ample interpretation leeway. The federal government participants perceived that all four of the communities were moving toward self-determination and that their assistance to meet the 'established' criteria outlined in the Handbooks for Health Transfer was quite different than the perceptions that provincial and First Nations participants stated. It is apparent that the criteria used by federal government participants and other federal bureaucrats can and does have tremendous impact on First Nations and their path to self-determination in health care (Malloy, 2003). There is an urgent need for First Nations leaders to consult with the federal government to create transparent criteria that has specific goals and deliverables in order to continue the path toward self-determination in health care.

The participants from the First Nations communities all stated their community had low or no self-determination in health care. This perception could be reflective of the unspoken desire to create the ideal First Nations health care system, which incorporates traditional healing and medicines with the biomedical health care system that all Canadians are entitled to and enjoy. This is important because if First Nations communities are striving for the ideal First Nations health care system, or a blended system, then their perception of how close the community is to having an ideal system would influence their perception of the level of self-determination currently experienced. Therefore many factors are influencing the perception of self-determination regardless of where a person is situated. The perception of self-determination in First Nations health care is influenced by employment (government bureaucrat versus First Nations leadership and community membership), knowledge of

the socio-political history (advanced knowledge of assimilation policies and programs versus limited understanding and awareness of the traumatic past), criteria about the health care system (biomedical health care versus the ideal First Nations health care system), and the experience of the health care system (patient and community member experience of the existing system versus an ‘outsider’ perspective with knowledge of only a biomedical health care system). Therefore, the level of self-determination in each of the four First Nations communities appears to be at different levels depending on the participants’ vantage point. All four communities give the impression that they are moving toward the ideal First Nations health care system, which would lead them to full self-determination of that system. However, the existing funding methods and ‘guardianship’ by the federal government has diminished the community’s ability to attain full self-determination in health because of the accountability requirements associated with the funding arrangements. This will be further discussed in Chapter 7.

## Chapter 6 First Nations Health Care Typologies

### 6.1 Introduction

This chapter will look at the different patterns of First Nations health care systems in the four First Nations communities. The literature on First Nations health care systems is meager and does not provide many examples of how health care is organized and delivered in First Nations communities. Health Canada (2004) does provide one ‘gold standard’ example of Eskasoni First Nation in Nova Scotia, and there are some other First Nations highlighted in dissertations and thesis (Jacklin, 2007; Maar, 2005). However unlike the provincial health care systems, there is relatively little discussed about the organization and delivery of health care in First Nations communities. Some scholars (Cornell, 1988; Lavoie, 2011; Wilson, 2008) believe that it is important to understand and record the typologies of First Nations health care so policy development and community planning can benefit from examples and practices associated with other First Nations communities. With Health Canada moving toward devolution through tripartite agreements between the provinces and First Nations leaders, knowledge of the existing typologies can provide examples and insights into better practices in community (personal communication with Valerie Gideon, September 2009).

There are four distinguishing features that define the health care delivery system: geographical location, the health transfer agreements, federal-provincial involvement, leadership capacity and engagement, community participation, and the overall organizational design. These will be discussed in detail in this chapter.

### 6.2 Geographical Location

The four communities are located in three different provinces under three different treaties with a variety of access to ‘mainstream’ communities. For Blood Tribe and Lac La Ronge communities, being semi-isolated allows community members access to a larger array of health care options compared to Wasagamack and Garden Hill. The location of these communities can impede the development of an adequate health care system; human and material resources may be limited because of the remoteness of the community.

“Residents of remote communities are further removed (in both time and distance) from the level of definitive treatment that is available in larger population centre, and thus lack the safety net implied by proximity to secondary- and tertiary-level health services. These patients are also more likely to be affected by health-care delivery issues such as high staff turnover, lack of supports and resources within the community, and difficulty recruiting and retaining highly qualified personnel (Fontaine, 2005; Minore et al, 2005)” (Tarlier et al., 2007, p. 128).

The physical location of the health care clinic or nursing station in the four communities is not necessarily easily accessible by all community members because there is no public transportation to assist community members with attending doctor’s visits. While the health care facilities are centrally located for the four communities, some community members may have long distances to travel to arrive at the facility. The location of the health care facility can constrain some community members from accessing primary care (Bobbish-Rondeau & et al., 1996). Ho et al. (2006) argues that transportation can disrupt the ability of community members to get health care, and to follow up on self-care plans. Wasagamack, Garden Hill and Blood Tribe all have health care facilities located on the reserve, whereas Lac La Ronge utilizes the medical clinic in the town of Lac La Ronge, which is a few kilometers off reserve. This requires all of Lac La Ronge community members to travel to seek primary health care services. The health directors in each of the communities have worked diligently with home care and the full time nurses to ensure that community members living in the outlying communities have access to some primary health care. Lavoie and Williams (2009) stated that secondary and tertiary care can help to prevent hospitalization, but will not eliminate it.

Hay et al. (2006) found that the physical location of primary health care must be within the community; otherwise First Nations people do not access the health care until much later in their illness. The size of the four communities can hinder people from accessing the health facilities. However for Blood Tribe community members, there are mainstream health care facilities in Lethbridge, Cardston, and Fort MacCleod. Lac La Ronge community members can take a two hour drive to access Prince Albert’s medical facilities, but Garden Hill and Wasagamack are limited to the primary care facilities found in the four Island Lake communities.

Although the health care facilities in each of the four communities are centrally located, some community members need to seek transportation to get health care services because the communities are spread out over vast tracks of land. The closer services are located to the community, the more likely that First Nations people will access them (Minore et al., 2004), and transportation to these services is also an issue (Hackett, 2005; Pohar & Johnson, 2007). Hay et al. (2006) found that the further away from an urban centre that a First Nations community was located the fewer options and services might be available. Blood Tribe Health Clinic has primary health care, dentistry, optometry, pharmacy and other services available on a daily basis. This is significant as not all First Nations communities, even those located close to urban areas, have such services (Hay et al., 2006). Garden Hill, Wasagamack, and to some extent Lac La Ronge community members, are limited to the services in their communities as there are few alternatives.

In all four communities, participants said that community members were required to leave the reserve to access specialists and specialized services like dialysis or ophthalmologists. However, in the province of Alberta, there is a specialized diabetes mobile unit that enters all First Nations communities to improve diagnosis, follow up and treatment for First Nations people. The SLICK program was funded by Health Canada and works closely with Alberta Health. The program is described by one government participant as "...go[ing] out to do one of the local First Nations and the dietician, the physician and the nurse actually do assessments in the community." This service helps to alleviate diabetes diagnosis wait times and can assist community members to enter appropriate programs sooner.

Access to a pharmacy may be overlooked by health care professionals not familiar with what is available in First Nations communities (Minore et al., 2004). While Blood Tribe and Lac La Ronge have access to a pharmacy and many specialists within a short drive from the community, Wasagamack and Garden Hill struggle with filling prescriptions and getting patients out of the community for specialists' appointments. H. Peters and Self (2005) found that health care professionals need a liaison person in hospitals and other mainstream health care facilities to advise health care professionals of resources that are available to First Nations patients. Similarly, Minore et al. (2004) found communication between First Nations health care facilities and outside care facilities can further derail a person's recovery or self-care.

Figure 9 provides an aerial shot of the Blood Tribe facility and the access to the centre from the reserve road. This facility provides the health care services for the community. The health care facilities for Lac La Ronge are shown in Figure 10, but they also have a public health facility – Jeannie Bird Health Clinic – which is located on reserve. Figure 11 illustrates the FNIH nursing station compound located in Wasagamack, and Figure 12 shows the Garden Hill Regional Renal Hospital. It is necessary to see the variation in the physical facilities as some are more approachable than others. For example, when I was in Garden Hill, FNIH was building a new nurses' residence, which made accessing the facility more difficult than normal. In Wasagamack, the FNIH nursing station is located at the far end of the reserve, whereas in Lac La Ronge and Blood Tribe, both facilities are newer with easy access for all communities' members that have access to vehicles.

**Figure 11 Picture of Blood Tribe Health Centre**



Taken by A. Mashford-Pringle (2010).©



**Figure 12 Picture of Lac La Ronge Medical Clinic**



Taken by A. Mashford-Pringle (2010)©

**Figure 13 Picture of Wasagamack Nursing Station Compound**



Taken by A. Mashford-Pringle (2010)©

**Figure 14 Garden Hill Regional Renal Hospital picture**



Taken by A. Mashford-Pringle (2010)©

The remoteness of a First Nation community can affect recruiting and retaining health human resources, especially primary health care providers. The remoteness of the community limits the number of health professionals willing to visit or live in the community (Peiris et al., 2008).

Wasagamack First Nation is very isolated in that there are no direct flights and the winter road is only available for a few weeks each year, whereas Garden Hill has direct flights to the community, and Blood Tribe and Lac La Ronge are on major highways with flights close to their locations. Hay et al. (2006) found that physicians and nurses were the most common health care professionals in rural and remote First Nations communities, and the further away from an urban centre, the less specialized the service providers are. Participants in each of the four communities discussed the difficulty of recruiting health care professionals that were willing and available to work in their community. The difficulty increased for Wasagamack and Garden Hill, but even in Blood Tribe and Lac La Ronge, which are close to large urban centres, the participants discussed the difficulty in filling positions like dietitians and nurses. Lavoie (2011) found that many remote First Nations communities were more likely to rely on FNIH health care professionals than less remote communities.

While salary has been the biggest issue for recruitment of many First Nations health human resources (Minore et al., 2004), Blood Tribe participants have stated that they are operating the health clinic on a fee-for service plan, which is the same as the mainstream system. Wasagamack and Garden Hill health care professionals are employed by FNIH, with some nurses being employed by the band. In Lac La Ronge, primary health care professionals are part of the mainstream provincial health system, but there are other health professionals (nurses, dietitians, dental assistants) that are employed by the band. Blood Tribe and Lac La Ronge participants noted that there has been difficulty in staffing positions because of salary and the remoteness of their communities. If these two communities have difficulty recruiting and retaining employees, then it is highly probable that Garden Hill and Wasagamack have even more difficulty in staffing as the communities are more isolated.

As the mainstream health care system changes, so too must the First Nations health care systems. One change was in hospital discharge as patients are being released earlier from hospitals to be at home to heal instead of staying in a hospital for long periods of time. To adequately provide care for these patients in First Nations communities, another stream of funding beyond the Health Transfer agreement was established. The intention of providing First Nations communities with these funds is

“to develop their own sort of plan starting with home care” (government participant). The Home Care funding provides funding to communities to provide home care, but not long-term home or acute care (government participant). Kulig et al. (2007) noted that separate contribution agreements can be yearly or for multi-year funding, but that these programs are highly prescribed with specific objectives. Therefore the communities must administer the program or service as directed by FNIH, which may not allow for culture or language to be considered. This model removes a degree of self-determination and does not help with the progression toward self-governance.

### 6.3 Health Transfer Agreement

Maar (2004) argues that the creation of the Health Transfer Policy may be considered the beginning of “serious negotiations concerning the transfer of Aboriginal control over health care to the local level” (p. 56). One goal of the Health Transfer Policy was to provide First Nations communities with support to build capacity to provide community-based and culturally appropriate health programs within federal government guidelines. Health Canada provides communities with handbooks, forms and websites to assist First Nations communities with moving toward signing a health transfer agreement. There are some mandatory programs and services that must be provided (shown in Table 9) with the funding provided under the Health Transfer agreement. While First Nations communities are required to provide these programs and services, which have a long list of objectives and goals, their community members also provide input about the health care needs of the community. The health care needs identified by the community may not align with these mandatory programs and services and then the funding gets used creatively to meet the health needs of the community.

**Table 10 Health Transfer Policy Mandatory Programs and Services**

<b><u>Mandatory Programs &amp; Services</u></b>
Communicable Disease Control including Immunization
Environmental/Occupational Health and Safety
Treatment Services
Environmental Health Services
Medical Officer of Health Services
Professional Nursing Supervision

Created by A. Mashford-Pringle (2012) from Health Canada documents

All four of the communities are health transfer communities with a defined health plan and have established the health management structure designed by Health Canada in the Health Transfer Policy Handbook (2004). Lavoie and Williams (2009) and Jacklin and Warry (2004) have found that once a community signs their health transfer agreement, the funding is fixed which can cause challenges for competitive salaries, infrastructure, and to meet the emerging needs of the community. As some participants stated, the communities cannot provide competitive salaries and they are having increasing difficulty recruiting and retaining qualified and trained staff. However some of the government participants stated that the greater the leadership capacities in the community, the more flexibility communities have in using the funds, which should help the community with meeting their needs. To alleviate the financial stress, Blood Tribe, Lac La Ronge and Garden Hill have found other sources of funding for specific programs, which allows them to increase their staffing complement and improve some services. However, like Lavoie and Williams (2009) note, Blood Tribe and Lac La Ronge receive funding for health programs like Aboriginal Diabetes Initiative that have specific goals and objectives and these do not necessarily align with the community's needs. Funding will continue to be an issue for all of the communities as their population is growing and the needs are changing.

Many participants highlighted the need for better funding to further improve the health care system, which is similar to Lavoie's (2005; 2011) findings. The patchwork of funding for the health transfer

agreement and then separate funding agreements for all other programs and services limits the amount of interdisciplinary work that can occur as silos are created through the funding. Programs like home care and diabetes care are separate contribution agreements and not connected to the health transfer agreement (government participant). Therefore Blood Tribe must adhere to program guidelines and objectives that are not necessarily complementary and there is much more administrative work (reporting, finances, and oversight) that needs to occur with these multiple contribution agreements. This administrative burden can limit the time and resources allocated to all health issues or creating an interdisciplinary team of health professionals. For example, Blood Tribe management must spend time with overseeing the management of the individual programs and services with limited resources and escalating demands of the programs.

The funding for both Wasagamack and Garden Hill flows through a health transfer agreement that is signed by FARHA. The health transfer agreement funding is intended to provide secondary and tertiary services according to Health Canada (2005). Lavoie (2011) found that the majority of the health professionals working in these services are employed by the First Nation, which is the case in Wasagamack and Garden Hill. However the amount of funding is less than needed in the four Island Lake First Nations, which has been found by many studies (Berger, 1980; Jacklin & Warry, 2004; Kulig et al., 2007; Lavoie, 2005; Royal Commission on Aboriginal Peoples, 1996a). Therefore FARHA with assistance from the four Island Lake communities must apply for separate and specific contribution agreement funding from FNIH like the Aboriginal Diabetes Initiative. The funding provided to FARHA, provides Garden Hill and Wasagamack with limited control as approval must be granted by FNIH for changes to programs, services or allocation of funds. Quinonez and Lavoie (2009) found that seeking approval limits flexibility and undermines self-determination, which was noted by some participants in this study.

The Health Directors advocated for more funding and partnerships, but will need support from health care professionals, band council, and the provincial and federal governments to assist in developing more relationships and increasing the funding that will improve the current health care system. Lavoie (2005) found that the funding provided under the health transfer agreements was insufficient and did not increase even when the population sizes increased. Romanow (2002) agreed that First Nations communities needed assistance in developing partnerships to improve health and health care. Therefore the health directors must continue to move toward this goal so that they can assist their communities. However, Garden Hill clearly has moved beyond this and has begun to see

improvements in the community, whereas Blood Tribe and Lac La Ronge are still determining which partnerships are beneficial. Wasagamack has relied heavily on FARHA to lead them to the appropriate partnerships and will need to work on this area of their health care system.

Lac La Ronge Health Services are funded through a health transfer agreement that covers six communities. Some of the participants noted that this agreement is unique in the province of Saskatchewan as the agreement and funding are intended to cover more than one community. The communities are not located close to each other, and this strains the funding provided. Therefore to ensure that the communities receive primary, secondary and tertiary health care, Lac La Ronge Health Services has received funding for programs like the Aboriginal Diabetes Initiative. Lavoie et al. (2005) found that transfer and contribution agreements have been funded by “a mix of historical and per capita based funding” (p.24) that creates funding inequities and revisions to this system are needed in order for First Nations communities to continue to provide needed programs and services that are adequately funded. Lavoie and Williams (2009) argues that funding has increasingly become the biggest challenge faced by First Nations communities around provision of health services. Jacklin and Warry (2004) state that communities like Lac La Ronge, apply for these programs and services to increase capacity and to assist with community needs. However, the community is continuing to grow and there are new emerging issues, like elder care, that are challenging the funding provided. Lac La Ronge Health Services will need to look at their partners and collaborators for further assistance in the coming years in order to maintain the health services provided. Lavoie et al. (2005) and Health Canada (2005) argued that partnerships and collaborations are essential for First Nations communities to provide adequate health care that meets the needs of the community.

R. Smith and Lavoie (2008) found that FNIH identifies as a primary funder with extensive knowledge and capacity to provide primary health care in First Nations communities. R. Smith and Lavoie (2008) also found that while First Nations communities wish to take control of their health care, they may lack the capacity and experience to locate and hire health professionals. Therefore, all four communities need to continue to build the leadership capacity and develop relationships with external stakeholders to assist with their vision of self-determined health care. Many of the community participants agreed that the four communities needed to have more flexibility with their health transfer agreement funding, which allow them to design a health care system that was

culturally appropriate and community-centred. This is similar to what the Assembly of First Nations (2005b) stated in their report for the Blueprint on Aboriginal Health in which they stated

“[a]s a cornerstone of a primary health care model, a flexible funding arrangement, leveraging all existing community health programs (CHP), would ensure the success of this Strategy. Distinct community approaches would be tied together by a standard of care defined in terms of population health/health determinants (including housing, social, education and environment). It is expected that most communities would choose to blend Traditional and Western approaches,” (p. 10).

## 6.4 Federal-Provincial Involvement

The Romanow (2002) report stressed the need for multi-jurisdictional partnerships to assist First Nations communities with the challenges of health care. It is evident that Romanow (2002) intended to emphasize the need for community partnerships, but also that there is a need for provincial and federal governments become partners with First Nations for the future of health care. Maar (2005) argued that First Nations communities “have entered into agreements with governmental sectors to transfer the design, development, and delivery of many aspects of health programs to the local level” (p. 92). However these agreements do not necessarily provide First Nations communities with self-determination of their total health care or even aspects of this system. Therefore it is necessary to look at the involvement of the federal and provincial governments with regards to First Nations health care in their respective provinces/regions.

Brede (2008) argues that transferring full control of health care is not a simple or quick fix, and that collaboration is necessary to move toward a functioning and sustainable health system. Most of the participants noted that Blood Tribe, Lac La Ronge and Garden Hill had established partnerships and collaborations with a number of external stakeholders like regional health organizations, the provincial and the federal governments, and businesses. The Royal Commission on Aboriginal Peoples (1996c) report recommended that First Nations organizations establish a relationship with governments to ensure that an indigenous voice was found in policy development and to ensure that health care is holistic and culturally appropriate.

Garden Hill has established some fruitful partnerships with researchers at the University of Manitoba. In these partnerships, Garden Hill has gained valuable evidence of their needs, activities, and future directions, which they have used to seek out more partnerships to address the needs found in the research. Lac La Ronge has many partnerships with businesses to assist with economic development, which their leadership sees as an alternate path to improving health care in the community. While Blood Tribe has many good partnerships, they have become somewhat self-reliant and use the partnership when required for change. Wasagamack has relied on FARHA and will need to further develop partnerships to help with improving their health care system.

The federal government participants clearly stated that the federal government is open to having discussions with provincial governments and the Assembly of First Nations to improve the health care provided to and in First Nations communities. While the Assembly of First Nations acts as an advocacy group, the organization cannot speak to specific issues in specific communities. Therefore it is necessary for communication to extend beyond the Assembly of First Nations and incorporate provincial/territorial organizations, and individual First Nations communities. Some of the community leader participants stated that they rarely had the opportunity to speak with federal government senior management, both in the region and the national headquarters, to discuss and perhaps resolve issues in health care.

There have been meetings between the federal and provincial government senior management and the Assembly of First Nations according to some of the participants. However even with these meetings, there continues to be jurisdictional issues, "...especially when money is a factor" according to one government participant. These jurisdictional issues make it difficult to move forward in any specific program or service without consent of all jurisdictional partners. All of the participants noted that further communication and relationship building must occur to reduce or eliminate the jurisdictional barriers that have created issues in First Nations health care. Lavoie (2011) also says that jurisdictional issues in health can hamper First Nations communities in creating a partnership with the federal government as provinces have authority over health.

All four communities have limited direct contact with the federal government as the community participants noted. Some of the federal government participants spoke about only getting involved with communities after they receive funding for a specific issue, and even then the contact is limited to ensuring the guidelines of the program will be met. Maar (2005) found that federal government



involvement was limited, but this did not stop communities from finding ways to improve their health care system.

Health care is the jurisdiction of the provincial governments as per the *British North America Act*, while First Nations are under federal government jurisdiction. This is evident in the participants' responses to the level and type of involvement that the three provincial governments have in First Nations health care. These participants acknowledged the treaties and other legal responsibilities of the federal government and expressed that their provincial Minister of Health had interest in First Nations health, but would remain 'removed' until asked by First Nations, or directed by the federal government. This is contrary to the Romanow (2002) report that highlights the need for all three levels of government (federal, provincial and First Nations) to work collaboratively to address the health care needs by reducing the jurisdictional barriers.

In Alberta, there has been a partnership created between the federal, provincial and First Nations governments to implement more diabetes care. The SLICK van is a mobile diagnostic unit that travels between all First Nations communities in Alberta to provide initial diagnosis of diabetes and some follow up for already diagnosed diabetes patients. This partnership has led to other discussions between the three levels of government about the needs of First Nations communities in Alberta. One participant stated that while the operational arm of the Alberta Ministry of Health was willing to assist First Nations communities, the Minister was very aware of Treaty Six and the implications that the treaty carries (the Medicine Chest clause). However there are ongoing meetings and discussions to improve the level and access to health care for First Nations people in Alberta.

The Director of Aboriginal Services at Alberta Health Services is a Blood Tribe member and has many years' experience working in Aboriginal health. This experience in Aboriginal health has provided the Director with insights into the socio-political history of Aboriginal people and the effects it has had on the health of First Nations people in Alberta. Therefore the Director's previous experience and knowledge of First Nations people and their health was perceived by Blood Tribe participants as positive and helpful in improving the health of First Nations people. While I did not speak with the Director directly, the staff in the Aboriginal Services unit were pleased with the policy direction that the Director and Alberta Health Services are taking. The Director has had discussions with First Nations leaders and FNIH staff and management. These discussions were intended to improve the health and care available to First Nations people in Alberta. Some

government participants believe that the discussions show clear leadership and understanding of the health care situation that First Nations communities face, including Blood Tribe. One government participant stated that having a senior provincial manager who was willing to work with both First Nations and FNIH would provide a clear message that all levels of government are concerned with the health of First Nations people.

The province of Saskatchewan has had limited interaction with First Nations communities except on specific issues and with limited funding according to the provincial participant. However in Manitoba, there has been strong involvement of the Ministry of Health with First Nations communities especially after the 1964 treaty which had the province ‘take over’ responsibility for nursing stations in four specific First Nations communities. One provincial participant said that the change to having responsibility for these nursing stations has led the Manitoba Ministry of Health to believe that they are an important component of First Nations health care. Additionally, there have been tripartite negotiations similar to those conducted in British Columbia in 2009 which will eventually have the province and First Nations governments work collaboratively to provide health care in the province without the federal government. Brede (2008) argues that transferring full control of health care is not a simple or quick fix, and that collaboration is necessary to move toward a functioning and sustainable health system.

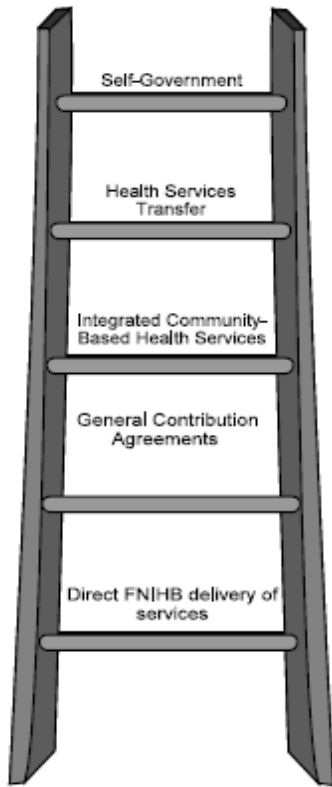
## 6.5 Leadership Capacity and Engagement

Leadership capacity in First Nations communities occurs at two levels – the band and the health authority. At present, band leadership for these four communities is through an election process similar to mainstream political processes instead of the traditional system of choosing a leader. Similarly, the health director or head of the health services is usually hired from among the community members. Therefore the level of education, experience and knowledge for providing leadership is limited and takes time to acquire. Capacity building requires strategic training and education opportunities that will benefit not only the individual in a leadership position, but will also assist the community with developing capacity and leadership abilities to work toward self-determination in health care. The communities must work with their paraprofessionals and leaders to gain direct practical experience in combination with a high level of education required for their professional development and leadership roles. It is also necessary to value traditional cultural knowledge that can be provided by the community and elders. Incorporating both cultural

knowledge and western education will assist First Nations leaders (health and band) to more effectively take control of their health care systems and work collaboratively with provincial and federal government bureaucrats because they will have bicultural knowledge of leadership. R. Smith and Lavoie (2008), D. Smith et al. (2005) and the Royal Commission on Aboriginal Peoples (1996b) report all argued that First Nations communities and organizations needed to create partnerships and collaborations in order to meet the growing needs of their community. These studies also noted that there must be strong leadership with the capacity to develop and maintain these relationships in a ‘good way’ that would benefit the community.

The criteria for ‘good’ leadership capacity has been established using western paradigms and does not necessarily reflect an Indigenous perspective regarding what is required to have leadership capacity. For First Nations communities to take control or have self-determination of their health care system, they must demonstrate that they have all the criteria outlined in the *Transfer of Health Programs to First Nations and Inuit Communities, Handbook 1 An Introduction to Three Approaches*. Health Canada (2004a) states “First Nations and Inuit communities interested in having more control of their health services can decide among three different approaches based on their eligibility, interests, needs and capacity” (p.1). These approaches include the Health Services Transfer, Integrated Community-Based Health Services, and self-government, but First Nations communities must demonstrate that their ability to be able to enter into one of these approaches, which comes from a ladder approach shown in Figure 15. These criteria continue the paternalistic policy of granting control to First Nations communities.

**Figure 15 Mechanisms for Delivery of Health Services in First Nations and Inuit Communities According to Health Canada**



(Health Canada, 2004a, p. 1)

All of the participants highlighted the tremendous capacity of the Blood Tribe leadership, both band and the health department, and how they have reached out to various stakeholders to ensure that the needs and concerns of the Blood Tribe were communicated and their needs were met. In Lac La Ronge and Garden Hill, there have also been long serving band and health leaders, but in Wasagamack, there has been a turnover of leadership at both the band and health authority. Most of the participants stated that strong and knowledgeable leadership was needed in each level of government (First Nations, provincial and federal) to improve health and health care. One government participant said "...the more capacity they have, the more independence or the more flexibility that they [First Nations] can have around things." This statement shows the federal government's perspective.

Blood Tribe and Lac La Ronge have shown and are acknowledged as having strong leadership capacity, yet FNIH has not transferred full authority. The Health Transfer Policy Handbook (Health Canada, 2004a) states that once a community has achieved strong leadership and the 'maximum allowable' flexibility, the next step for the community is to negotiate for self-governance. However

the document further stipulates that the First Nations community would be negotiating for full self-governance over all aspects of community life, which contradicts the *Indian Health Policy* of 1979, which clearly states that more control should be afforded to First Nations communities as they become ready. First Nations communities with strong leadership in health, may not be ready to take control of all programs and services (social, housing, etc.), which means that they cannot continue to build capacity as they cannot take over control in one area at a time. Cairns (2005) argued that First Nations communities should have the ability to take some measure of control in various aspects of their daily lives. Therefore it would be advantageous to allow First Nations to take responsibility and accountability of the health care system and provide adequate funding for the community to do just that.

Some participants stated that Garden Hill's Health Director and band council have developed a strong leadership capacity. Many of the participants believed that Garden Hill leaders have learned how to negotiate new partnerships and relationships in a way that will benefit the community's health. One participant stated "they have really good communication and know what they need." However another participant stated "some of it is external [control of health care], unfortunately. Like access to care is the biggest hold up, I believe." Minore et al. (2004) also found that strong leadership can help to develop a holistic health care system. Lavoie and Williams (2009) argued that First Nations health leadership that can communicate the community's needs and issues to policy makers and funders will assist the community with moving toward a self-determining health care system.

There are a number of Garden Hill First Nation Health Services staff who have completed college or university education. The band leadership and health leadership work with these employees and community members to ensure that programs and services for the community are culturally sensitive and will assist the community with improving their health. I spoke to a number of community members and staff who stated that the community wanted to build the leadership to become self-determining. By mentoring community youth to aspire to post-secondary education, the community is working on developing leadership and capacity for self-determination. Maar (2004) found that a formal approach to community capacity building is needed for paraprofessionals and those people in positions that work with the health system.

Blood Tribe, Lac La Ronge and Garden Hill have strong and effective leadership at both the band council and health leadership levels according to many participants. However, if any individuals in the leadership positions left or were not re-elected, the capacity, knowledge and experience may not continue which affects the control the community has in health care. Some participants spoke about recent elections and changes in leadership and the potential that these changes may have on continuing to move toward self-determination in health care. There was a concern that new leaders would require time to learn their position and build their experience before being able to tackle the issue of self-determination. This finding is similar to Lavoie (2011) finding that leadership capacity must be consistent and have longevity in order to move toward flexibility and control in the health care system.

## 6.6 Community Participation

Participants in all four communities observed that their communities want to be more engaged and have input into the health care system. However, there are some opportunities for community members to be engaged or provide feedback to the health care leadership in three of the four communities; Blood Tribe participants readily acknowledged that feedback and engagement was not sufficiently done. Garden Hill and Lac La Ronge participants state that there are formal and informal methods used to garner feedback and community meetings to provide the health care leadership with feedback on the existing programs, services and health care. Wasagamack participants acknowledged that town hall meetings provide the health care leadership with feedback about issues in the community and the television and radio stations also allow the health leadership to discuss the system with the community. The *Indian Health Policy* stated that community members needed to be engaged in the health care system. Similarly, Raphael et al. (2008) found that community engagement can improve the health of Canadians by understanding the social determinants of health that are currently affecting them, which can make the health care system more responsive to their needs.

Garden Hill, Lac La Ronge and Wasagamack regularly engage community members in discussions and informal feedback sessions to determine the current and pressing needs of their communities. In that way, front line workers become aware of the issues and they can provide information back to the health director about community concerns. Some participants in these two of these three

communities also noted that the health care professionals attempt to engage and interact with community members outside of the health care system. One participant in Garden Hill stated that the health care professionals and paraprofessionals not only live in or near the community; they could be seen at community events and engaging community members about a variety of issues outside of the hospital setting. Browne (2000) argued that health professionals engaging First Nations people outside of the health care setting can build trust and improve the health care system and the health of the people. R. Smith and Lavoie (2008) also found that community involvement can improve the knowledge of the health care professionals about their clients, which in turn improves the health care provided.

Some participants stated that many health care professionals do not have the time, or do not care what occurs in community. Consequently, these health care professionals do not find ways to incorporate traditional knowledge, medicines or healing into their own practice. All of the health care professionals in Blood Tribe and many in Garden Hill are of Aboriginal descent. In Garden Hill, some participants believed that the community was very involved in health and the health care because the health care team interacted with the community. In the other communities, there was less interaction and community members felt less motivation to provide their input and become involved in the health care system.

Community involvement could assist the First Nations communities with providing input and feedback as well as ensuring that community health needs were addressed. However community involvement is a two-way street and health care professionals must also want to become involved in the community according to the respondents.

## 6.7 Overall Organization of Health Care

As with all aspects of life, there is constant change, which First Nations communities have continued to adapt to. Health care is no exception, and some of these First Nations communities have developed a creative way to approach service development by testing different community-based and culturally appropriate solutions to local health priorities. In all four communities, the local health authority or department has designed and implemented health promotion and illness prevention programs by blending mainstream and First Nations concepts of community health. Garden Hill

found innovative ways to do just that by creating partnerships with university researchers and various government programs to provide healthy lifestyle options like a fitness clinic. Blood Tribe has partnered with regional health authorities and the province to provide additional diabetes diagnosis and testing. Lac La Ronge has developed a close relationship with the mainstream medical clinic to provide nutrition education. Wasagamack has developed health programs that are delivered in Cree. Maar (2004) had similar findings in Wikwemikong First Nation, where the community had found creative ways to provide mental health services to the community to reduce family violence.

The organization and structure of health care in each of the four communities is unique. Blood Tribe has developed a fully staffed health facility with the majority of the health care team, including the doctors, being Aboriginal and almost all from their own community. The Blood Tribe is a large First Nation community, but there are only 2 physicians (one is part-time), who are on the provincial fee-for-service payment system. There were no studies found where a First Nations community had a full complement of Aboriginal health care professionals. Therefore this unique situation in Blood Tribe needs to be examined further to determine the effects of having community members as health care professionals and how it impacts the health of the community. The health clinic located in Standoff provides health care, dental services, a pharmacy, optometrist services, and NIHB access. These services are co-located with the health promotion and illness prevention programs. Community members have only one location to attend these services, but through a separate contribution agreement, Blood Tribe also offers home care, which can assist community members with the day-to-day management of their health needs. The Royal Commission on Aboriginal Peoples (1996c) report and the First Nations Health Managers (2009) recommend that all First Nations communities attempt to establish this structure for their health care system.

Lac La Ronge is located around the non-Aboriginal town of La Ronge and because of the close proximity; Lac La Ronge's Kitsaki reserve utilizes the mainstream medical walk-in clinic and health centre. National Aboriginal Health Organization (2004) argued that First Nations health care has to have acceptable wait times and be culturally appropriate. Some of the participants felt that existing arrangements for Kitsaki reserve were acceptable, even if the health care was not necessarily culturally adapted, but some participants were concerned about the outlying communities that had nursing stations with a rotation of physicians who were in the community only for a few days every two weeks. As some participants noted, community members from the outlying areas must travel into Lac La Ronge to receive some health care. E. Peters (2002) argued that transportation may



prevent First Nations people from accessing health care at earlier stages of their illnesses, which Lavoie and Forget (2008) argued would increase the hospitalization rates and the expenses of health because more health care resources would be required to correct the illness than if it was treated earlier. Therefore it is important to ensure that the health care that outlying community members receive is adequate in their community, or that the cost of transportation is not prohibitive to seeking care before a crisis begins.

Similar to Lac La Ronge's outlying communities, Garden Hill and Wasagamack did not have full-time on-site physicians, but rather doctors and specialists who flew into the communities at regular intervals. Oster, Virani, Strong, Shade, and Toth (2009) found that diabetes patients with limited access to health care had poorer health outcomes. Therefore these communities must work toward improving their primary health care. However primary health is not funded by the federal government through the health transfer program or the provincial government, who sees First Nations health care as a federal matter.

Garden Hill and Wasagamack are remote northern Manitoba reserves, which take an hour's flight to access. Garden Hill First Nation does not employ the health professionals that work in the hospital, which means that they do not have the responsibility for recruiting and retaining health professionals for the community. Hay et al. (2006) found that the further away from an urban centre that a First Nations community was located the fewer options and services that might be available. The renal hospital in Garden Hill has a number of FNIH employed nurses that are available on 24/7 basis. There is a doctor available 3 to 4 days a week, and specialists visit the community frequently. Though this means Garden Hill has a finite set of health professionals that provide service in the community. Some specialists will visit the community, but many community members must leave the community to see an ophthalmologist. There is access to other specialists like endocrinologists, renal specialists, and foot care. Lavoie (2011) found that many remote First Nations communities were more likely to rely on FNIH health care professionals than less remote communities, which is true of Garden Hill. All of the doctors, including specialists, are funded by FNIH or Manitoba Health, and are brought to the community based on FNIH policies and the direction of the nurse-in-charge.

The location of Wasagamack First Nation is difficult to get to as there are no direct flights to the community. As the health care professionals are employed by FNIH, Wasagamack has limited control or input over the people hired to work in the nursing station.

“A nursing station is understood to be a field unit located in an isolated community where there is not road access to other health care facilities. They house field unit staff of two or more community health nurses or nurse practitioners and other support and primary health care staff organized to carry out primary health care services including urgent care, short-term in-patient care and public/community health” (Hay et al., 2006, p. 20).

With the physician only coming to the community for one day a week, the most severe cases are seen first. Tarlier et al. (2007) found that because of limited availability, many First Nations people are forced to travel to receive health care, and the more remote the community is, the more likely they are to have to travel outside of community for care. As policy, Health Canada (2005) stated that First Nations people living in remote areas have limited health care services and will likely need to travel to access care. Therefore, Wasagamack is not unique in the organization and delivery of health care, but through the health transfer agreement that Four Arrows Regional Health Authority has with Health Canada, it is possible to budget for health professionals that reside in the community. Minore et al. (2004) found that without a trusting relationship, First Nations patients in northern Ontario often waited until later in their illness, which could increase complications, especially for diabetes patients. Therefore the FNIH employed staff should be required to learn about Aboriginal people and the community that they will be stationed in, which would assist them with building relationships with the community. The remoteness of the community limits the number of health professionals willing to visit or live in the community (Peiris et al., 2008). Lavoie (2011) found that many remote First Nations communities were more likely to rely on FNIH health care professionals than less remote communities. Therefore, Wasagamack First Nation is similar to other remote First Nations communities in terms of what primary health care services they have and can access.

The Royal Commission on Aboriginal Peoples (1996c) report recommended that First Nations health organizations communicate and work with traditional healers and medicine peoples, but some participants noted that there were no connections with traditional healers or medicine people in all four communities. Some Blood Tribe and Wasagamack participants stated that there was just ‘no

time' or resources to establish these relationships. Lac La Ronge had some informal connections to traditional healers, but Garden Hill has begun to involve traditional healers and medicines wherever and whenever possible. Staffing and the funding provided through the Health Transfer agreement are not sufficient to allow the current staff to research, develop and maintain relationships with traditional healers, which Lavoie and Williams (2009) argue is a concern for First Nations health care.

As the mainstream health care system changes, so too must the First Nations health care systems. Patients are being released earlier from hospitals to be at home to heal instead of staying in a hospital for long periods of time. To adequately provide care for these patients in First Nations communities, another stream of funding beyond the Health Transfer agreement was established by FNIH. The intention of providing First Nations communities with these funds is "to develop their own sort of plan starting with home care" (government participant). The Home Care funding provides funding to communities to provide home care, but not long-term home or acute care (government participant). Blood Tribe, Garden Hill and Lac La Ronge have established their Home Care Teams, and review the funding and workload frequently to ensure that they can maintain the workload and see the community members that require home care services. Kulig et al. (2007) noted that separate contribution agreements can be yearly or for multi-year funding, but that these programs are highly prescribed with specific objectives. Therefore the communities must administer the program or service as directed by FNIH, which may not allow for culture or language to be considered. This model removes a degree of self-determination and does not help with the progression toward self-governance.

Some participants and community members spoke about the lack of culture and traditional healing. Some community members felt that FNIH employed health professionals should be required to learn more about Aboriginal people and their community specifically. Postl and Moffatt (1988) found that health care professionals must understand the socio-economic conditions of the community that they work in and H. Peters and Self (2005) found that non-Aboriginal health care professionals were more likely to blame the individuals instead of being knowledgeable about the social conditions that the patients faced. Therefore, it would be beneficial, as H. Peters and Self (2005) stated, for FNIH health professionals to understand cultures and the history before entering the community. Additionally, FNIH health professionals should be encouraged to connect with traditional healers in

the community to provide a holistic approach to health care as was recommended in the Royal Commission on Aboriginal Peoples (1996c) report.

## 6.8 Conclusions

The four communities are isolated or semi-isolated, which is one factor that shapes the health care system that can be provided in the community. Health human resources are an issue for the communities as they have had difficulty with finding and retaining staff. The human resources that are available in the communities are taxed and there is not enough time or resources to create mentorship or recruit more staff (Lac La Ronge participant).

Many participants highlighted the need for better funding to further improve the health care system, which is similar to Lavoie's (2005; 2011) findings. The patchwork of funding for the health transfer agreement and then separate funding agreements for all other programs and services limits the amount of interdisciplinary work that can occur as silos are created through the funding. Programs like home care and diabetes care are separate contribution agreements and not connected to the health transfer agreement (government participant). Therefore the communities must adhere to program guidelines and objectives that are not necessarily complimentary with additional administrative work (reporting, finances, and oversight) that needs to occur with these multiple contribution agreements.

In 2005, as the Assembly of First Nations prepared to meet with the First Ministers about the Blueprint on Aboriginal Health, they stated the following:

“It is highly desirable and efficient that First Nations Health Authorities have the flexibility – including within their funding agreements – to service the local catchment population, regardless of status, membership and residency (on/away from reserve). It would help provincial jurisdictions to provide quality service to its residents in surrounding areas. This would also be aligned with the *Corbiere* decision. First Nations would set priorities and make decisions with respect to the level of service and facility required at the community, tribal, Treaty and regional levels, based on the need of the serviced population and unique/defined standards

of care. This level of service should not be artificially prescribed based on an antiquated typology that is not periodically reviewed (e.g. Type 1-4 communities set according to number of kilometers from physician services). Instead a primary health care model which supports a lifelong continuum from prenatal to palliative care and adopts a holistic, multidisciplinary approach, would structure health services/facility planning, financing and policy development” (Assembly of First Nations, 2005b, pp. 4-5).

This statement by the Assembly of First Nations is in keeping with the discussion in this chapter and foreshadows the perceived level of self-determination in health care that will be discussed in Chapter 7.

The communities have established methods to provide health care, but the health promotion and illness prevention programs and services provided are regulated by the funding agreements. While there is some control of what programs and services are offered in the community, the amount of self-determination over the health care is limited to the relationship between the federal government bureaucrats and the community. Some communities have better relationships with the federal and/or provincial government bureaucrats; Blood Tribe and Garden Hill appear to have good working relationships with both federal and provincial governments. However the three provincial governments are very aware of the legal responsibilities of the federal government to First Nations people and hesitate to create dynamic relationships and partnerships.

Excluding Wasagamack, the communities have developed strong band and health leadership capacity, which continues to grow. However to improve the leadership capacity in all four communities, training, education and experience is required in order to increase the level of self-determination the communities have over their health care system. All of the communities intend to increase capacity of their staff and leaders, and to engage their community members to become involved in the health care system.

All four communities have uniquely organized their health care systems. Often scholars and government reports (Lavoie, 2011; Lemchuk-Favel, 1999b; Minore et al., 2004; Romanow, 2002; Royal Commission on Aboriginal Peoples, 1996c) have recommended that First Nations communities have their primary health care located on the reserve and be provided by health care professionals that are knowledgeable and respectful of Aboriginal history, culture, language and

worldview. Through my observation, I noticed that Blood Tribe and Garden Hill have accomplished this through communication, training, education, and strong leadership capacity. Lac La Ronge utilizes the mainstream medical and health clinics that are staffed by non-Aboriginal health care professionals, but the para-professionals that work in all six of the Lac La Ronge communities are of Aboriginal descent with the majority from these respective communities. The primary health care professionals are not necessarily of Aboriginal descent, nor do they necessarily have knowledge and awareness of Aboriginal history, culture, and language, but it is balanced by the paraprofessionals who do have Aboriginal knowledge and awareness. The participants acknowledged that Wasagamack is growing and building leadership capacity at this time, so their health care system is reflective of this stage in their development; FNIH provides the nursing station and staff for their primary health care needs with little input or direction from the community.

Although Wasagamack and Garden Hill have the same structure for primary health care (FNIH employed health care professionals), Garden Hill appears to have more influence over the organization and delivery of health care. In Lac La Ronge, the communities are working cohesively to determine how to provide primary health care, but have established comprehensive secondary and tertiary programs and services. Blood Tribe has developed a complete health care system, but the lack of funding has diminished the ability of the health care professionals' ability to provide adequate and culturally appropriate care. Romanow (2002) asserted "action must be taken to create new models to coordinate and deliver health services... and give Aboriginal people a direct voice in how health care services are designed and delivered" (p. 212). The four First Nations communities in this study are clearly attempting to have influence and control of their health care system, but have had obstacles (like human resources, funding, and collaboration) that hamper their continued attempts at obtaining self-determination in their health care systems.

All four communities are funded by FNIH's Health Transfer Program, with some notable differences. Blood Tribe is funded for their large population size, but they do not have any outlying communities to provide services for, although the size of the reserve is quite large and some community members are not near the health care facility. In Lac La Ronge, there are six communities funded under the health transfer agreement with the outlying five communities being remote. FNIH provides primary health care at nursing stations in these five communities, but Lac La Ronge is funded to provide secondary and tertiary care, which is difficult because of the location of the communities. Garden Hill and Wasagamack are members of FARHA, which flows funding to

the communities to provide secondary and tertiary services, but similar to the outlying communities in Lac La Ronge, finding qualified professionals is difficult and expensive. With growing populations in all four communities, the 'no escalation' clause in the health transfer agreements has forced the communities to find partnerships and other funding to support their communities health care needs. In addition to the Health Transfer Program funding, all four communities have successfully applied for other funding like the Aboriginal Diabetes Initiative, which assist the communities with meeting specific needs.

## Chapter 7

### Discussion and Recommendations

#### 7.1 Introduction

The four health care typologies are unique for each community and have been designed based on the community's immediate geography, leadership capacity, and government involvement. These typologies may be representative of many First Nations communities in Canada. Further study is required regarding the organization and delivery of health care in First Nations communities to illustrate the many different existing structures and the requirements that are needed to create the ideal First Nations health care system including self-determination and a reflection of the community's needs. Three of the four communities studied here have found innovative methods to address the community's health needs. Their health systems go beyond the western bio-medical methods of addressing health; which treats disease rather than remedying the root causes of the health concern through a holistic approach encompassing the social determinants of health. First Nations Healing (2010) outlined the ideal First Nations health care system, which blended bio-medicine, traditional healing and medicine, as well as a holistic approach to health using an interdisciplinary team. Incorporating broader factors that affect health and may assist with improving the health of Canadians and First Nations people would also assist with creating a health care system that could more closely meet the needs of First Nations communities.

The perceived level of self-determination of each of the four First Nations communities can be linked to the worldview, knowledge and awareness of First Nations people and their history. In addition the perceptions of self-determination differ according to the key informant's role, the extent of their knowledge of First Nations people, and the policies that they manage. The key informants responded based on their worldview, knowledge of First Nations people and their history, and their role in First Nations health care. From a federal government perspective, participants were aware of the Health Transfer Policy and appeared to have intimate knowledge of the requirements that lead First Nations communities to have the maximum flexibility allowable under federal government rules, which is not self-determination but rather self-administration, and had varying degrees of knowledge about First Nations people. The provincial government participants were also aware of the federal government policies, but appeared to be more aware of the treaties and First Nations history and how this affects their interactions (or not) with First Nations communities. First Nations



participants highlighted the need to work beyond the current system to meet community needs in health care. The First Nations health care professionals stated a ‘hopelessness’ that the system was not adequate and they were unsure how to address community needs and decolonize the system. Therefore much work needs to be done to address the differing perceptions and growing concerns of all those involved in First Nations health care.

## 7.2 How First Nations are Achieving Self-Determination in Health Care

This study illustrated some key factors that are important to First Nations health and health care; communication, adequate funding, the ability to fully utilize partnerships, and the perception of control. As of this time, the definition of self-determination is not consistent. However First Nations communities are required to follow the established criteria set forth by FNIH rather than having input into these criteria. The criteria do not reflect Aboriginal worldview and traditional knowledge, which hinders the communities’ ability to truly achieve self-determination as they may not be working toward achieving the same result as FNIH. Health Canada (1999), First Nations Healing (2010), and the Royal Commission on Aboriginal Peoples (1996a) report found these factors to be important for a responsive health care system. However these are only some of the factors that are important to self-determination in health care.

The data produced for this dissertation illustrated that Garden Hill First Nation has discovered better practices to assist the community on the road to self-determination in health similar to Eskasoni First Nation (Health Canada, 1999). By partnering with external partners like the University of Manitoba, Garden Hill has developed a holistic approach to improving health that allows them to have more self-determination over their health care system. In addition, the staff of Garden Hill’s Health Department were highly educated and understood the need to deal with all of the social determinants of health, which may have assisted them in creating these partnerships, building leadership capacity, and dealing with the community’s health needs.

Blood Tribe has more perceived control over their health care system, but participants see areas for improvement like communication and incorporating traditional healing and medicines into the system. Lemchuk-Favel (1999) found that communities have administrative control with varying

levels of control and input into community needs as FNIH has final approval of all health plans and changes. The perception of control by government participants may be a result of their knowledge of the mainstream health care system and the similarities with that of the Blood Tribe health care system. Many of the Blood Tribe participants acknowledged the need to incorporate traditional medicines and healing into their health system, but lacked the resources (human and financial) to do so, which has led them to be similar to the mainstream health care system in organization and delivery. Blood Tribe was fortunate to have many of their community members with health professional accreditation (doctor, nurses, and diabetes educator) compared to the other communities, but this has not translated into having a holistic approach that incorporates traditional medicine or healing.

To take more control, Lac La Ronge Indian Band has developed business relationships and partnerships with external health care organizations to improve the access and variety of services, but some community participants felt that there were still many service improvements that would assist all six of their communities. Lac La Ronge has some aspects of their traditional medicines and healing incorporated into the public health system, but as the community utilizes the mainstream health care clinic, there is limited ability to have self-determination in the health care system. Many of the community participants would like to have more primary health care services provided on reserve, but it is not financially feasible within the Health Transfer agreement. Lac La Ronge has developed strong leadership capacity and good external partners, but as the health care system was not delivered by the community, there was limited self-determination in the health care system.

Wasagamack participants were aware that the community needed to increase leadership capacity in order to assist them with moving toward self-determination in health. Wasagamack received their health care from FNIH employed staff, but the community did provide public health programs and services like Garden Hill. Although Wasagamack has not developed the partnerships that Garden Hill has, they did incorporate traditional healing and medicines into their programs and services. All of the participants acknowledged that Wasagamack was growing and that there is a lot of development that needed to occur before the community would have any measure of self-determination in the health care system. For Wasagamack, unlike the other three communities, all of the participants, regardless of where they were employed, agreed that the community had no self-determination in their health care system.

In the Health Transfer handbook (Health Canada, 2004a), First Nations communities are to create communication strategies that encourage community input, involve the band council, and create partnerships with provincial and regional health authorities to provide a health care system that is holistic. These factors are necessary to receive administrative flexibility that leads to self-determination according to Health Canada's idea of self-government in the health care system. Based on the interview results, Garden Hill and Blood Tribe have developed strong communication strategies with community members, but the participants stated that Garden Hill have achieved a high level of communication amongst community members, between band and health leadership, and with government bureaucrats. Whereas Blood Tribe had a high level of communication between health professionals and government bureaucrats, participants noted that more needed to be done to improve the communications between band and health professionals and with community members. However with limited dialogue about what the communications strategies and other criteria for administrative self-determination in health care, First Nations communities may not be willing or able to achieve these milestones as they may be in opposition to community needs.

Romanow (2002) and the Royal Commission on Aboriginal Peoples (1996c) report stressed the need for strong empowering partnerships. Romanow (2002) argued that Aboriginal health partnerships would assist First Nations communities with enhancing their current health care system by leveraging partner resources and assistance. Garden Hill has exceeded what Romanow recommended by interconnecting partnerships to create synergies that recognize and embrace holistic health. By engaging external partners, Garden Hill not only has a higher level of self-determination over the health care provided to and for the community, but also strives toward the ideal First Nations health care system through these partnerships. Blood Tribe and Lac La Ronge have partnerships as well, but the partnerships have not moved these communities toward the ideal First Nations health care system in the same manner as Garden Hill. Wasagamack has not developed these partnerships yet and they are needed for the community to move toward self-determination in their health care system.

In fact, using the Medicine Wheel framework illustrated in Chapter 3 (p. 55), Aboriginal worldview, knowledge and teachings are blended with the biomedical model of health care. Aboriginal worldview holds interconnectedness and holism in high esteem, while layering teachings about balance of the four aspects of being. To create the ideal First Nations health care system, First Nations communities must be able to incorporate the teachings, knowledge, worldview, and

medicines into the biomedical health care system. The organization and delivery of health care, community involvement, socio-political history and self-determination must be balanced, but as in traditional teachings, each of these components share, synergize and learn from each other in many different ways. For example, organization and delivery can provide the resources for First Nations communities to increase their capacity and experience in self-determination, which may lead to increased self-determination. To maintain balance in this framework, the community needs to discuss and incorporate the socio-political history into the health care system, which will then influence the organization and delivery of the system itself. Thus change in any one part of the Medicine Wheel quadrants must be met with similar changes in the other quadrants in order to maintain balance, which will likely improve self-determination as well as working toward the ideal First Nations health care system.

Lavoie (2011) found that the organization and delivery of First Nations health care has been influenced by biomedicine, but First Nations Healing (2010) argues that the health care system does not need to be either biomedical or traditional, but rather an integration of both. I found that the socio-political history (length of contact, residential schools, the location of the community, the impact of paternalistic policies, etc.) have had differing impacts on each of the four communities in the study. Further research could examine how the socio-political history is reflected in the organization and delivery of First Nations health care. For example, Blood Tribe and Lac La Ronge have health care systems that rely heavily on biomedicine, whereas Garden Hill and Wasagamack, to a certain extent, incorporate traditional medicines, healing and knowledge. Through the analysis of my interviews, it seems that Garden Hill is uniquely positioned with their health system reflecting their Indigeneity and biomedical knowledge; Garden Hill has ensured that all aspects of the system are holistic, transparent, respectful, community-driven and empowering. All four of the communities still need to improve their health care systems and build community capacity in order to continue to move toward self-determination in health care.

As was stated in the Royal Commission on Aboriginal Peoples (1996c) report and in the Romanow (2002) report, there is a need for transparent and open communications between the three levels of government as has been recently witnessed in the transfer of health care services in British Columbia. These four communities will be required to work with provincial and federal government leadership in order to make systemic changes that will assist all First Nations communities with attaining self-determination in health care, or other social services. Federal rules have not identified

a more gradual transition to self-governance, perhaps by enabling communities to take control of health care first, so communities have to meet all criteria for full control of all government functions. Some First Nations communities may not be at a stage of readiness to take full self-governance control, thereby stopping these communities from trying to achieve self-determination in one or more health and social services as their community requires. For example, Garden Hill is capable and prepared to take on more control of their health promotion and illness prevention and may also be able to take on more control of the regional renal hospital, but the current situation does not allow them to have more independence. Therefore further discussions and negotiations are essential to their ‘fight’ for self-determination in health care. Wasagamack is not in a position to take on more control and requires mentorship, education and training to prepare the community for the responsibilities associated with self-determination. However it can be argued that all of these communities had self-determination and self-governance, albeit more than a century ago, in health and health care. As these communities mature and change, true self-determination in health care could be granted to the communities, but there is still resistance by the federal government.

### 7.3 Importance of Self-Determination in First Nations Health Care

“If Health Transfer truly represents a movement toward self-government, funding would need to increase in relation to community-identified needs and the demonstrated ability to delivery effective health services” (Jacklin & Warry, 2004, p. 229).

All four of the communities have been working toward attaining greater flexibility in their health care systems, which will lead to increased self-determination according to Health Canada (2004a). This is based on the criteria established by Health Canada with limited input from First Nations leaders. However, the current Health Transfer Policy is vague and can be interpreted by federal government bureaucrats in variety of ways (Malloy, 2001). According to Jacklin and Warry (2004), it is necessary for the federal government to establish concrete indicators and stages that will provide First Nations communities with the requirements for achieving self-determination in health care. In this study, many participants stated that it was important to work collaboratively to determine indicators and stages rather than have the federal government with complete control. However as the community participants stated, the federal government must be cognizant of the socio-political

history of First Nations people and how their worldview differs in order to attempt to create such policies and directives. “The removal of the First Nations’ ability to negotiate these agreements and the explicit omission in the new policy of any recognition that agreements might serve as a tool to work toward self-determination have created a process that is now disempowering communities” (Jacklin & Warry, 2004, p. 230). Therefore any future policies for First Nations health care must include First Nations input and perspectives in order for self-determination to move beyond discussion to reality.

Policy development and implementation is influenced by the knowledge that the policy actors have about the subject (Malloy, 2001). In order to truly understand the impact of socio-political history in First Nations communities, it is extremely important that all those involved be educated about the effects that socio-political history has had on First Nations communities, and specifically the communities that the actor will be working with. This knowledge assists government bureaucrats, as well as community leaders, with a clearer understanding of how the community has come to this juncture in their organization and delivery of health care, as well as the perceived level of self-determination.

The assimilative and oppressive policies that have been implemented in First Nations communities have had differing impacts as was shown in Chapter 5. The intensity and duration of contact appears to have had influence on the organization and delivery of health care, and on the perceived level of self-determination that First Nations communities believe they have in this system. The Royal Commission on Aboriginal Peoples (1996b) recommended that one avenue to assist First Nations communities with healing was to provide more control to First Nations leaders over their community’s needs. Blood Tribe has a high level of perceived control according to the government informants, but to truly move to a healing perspective, which may improve the health of community members, the community must have a much greater degree of control. If Blood Tribe were provided with true self-determination as defined by Indigenous scholars, then they may be able to heal the intergenerational trauma that has stemmed from the oppressive policies. They may also be able to revitalize the culture and language, achieve more of the ideal First Nations health care system, thus leading to increased leadership and community capacity, and improving collaboration and communication. This ‘spiral’ would continue to move the community toward healing, cultural revitalization, and an increased level of self-determination in health. The spiral could ultimately lead

to further self-determination in other aspects of community life, which would lead to further healing from the socio-political history.

At present, First Nations communities administer health transfer agreements that provide them with administrative control and flexibility as leadership capacity, experience and collaboration increase. However, Jacklin and Warry (2004) argue that the health transfer policy is not intended to assist First Nations communities with moving toward self-determination rather the policy only provides what is stated in the *Indian Act* as the federal government's fiduciary responsibilities. Similar to Jacklin and Warry (2004) findings, Blood Tribe, Lac La Ronge and Garden Hill have shown they are capable and wish to participate in policy formation, but the federal government has restricted these communities to simply be recipients of the health transfer agreement. Ladner argues that "self-determination as it is operationalized by governments (creating structures of government, mechanisms of accountability and jurisdictions) can both enable and disable communities" (p.91). Further, Mercredi and Turpel (1993) state that self-government is necessary for poor and powerless communities as it will help to heal the community, and create capacity (institutional and human) that will assist with individual and community healing and improve health status. Blood Tribe, Garden Hill and Lac La Ronge leaders have continued to attain the requirements that will afford them more flexibility within their health transfer agreements, but will need to work with their communities to determine if they are ready to negotiate self-government agreements, which give them more autonomy in their health care systems.

In the Royal Commission on Aboriginal Peoples (1996b) report, there was a strategy suggested for systemic change to assist First Nations with moving toward having more control over their lives. The strategy consisted of four components:

- “ 1. The reorganization of health and social service delivery through a system of healing centres and lodges under Aboriginal control;
- 2. an Aboriginal human resources development strategy;
- 3. adaptation of mainstream services, training and professional systems to affirm the participation of Aboriginal people as individual and collectives in Canadian life and to collaborate with Aboriginal institutions; and

4. initiation of an Aboriginal infrastructure program to address the most pressing problems related to clean water, safe waste management and adequate housing” (p. 231).

It is clear from the Royal Commission on Aboriginal Peoples (1996b) report that the federal government has moved toward system change, but Jacklin and Warry (2004) argue that the “Health Transfer Policy appears to be nothing more than a superficial bureaucratic solution to the very real and deeply rooted sociocultural problems facing First Nations in Canada” (p. 231). Although self-determination in health care would provide First Nations communities with the ability to incorporate traditional medicines, culture and language, and work on improving the social determinants of health, this has not been the approach that the Health Transfer policy or the federal government has taken. It will take systemic change to improve the health and health care that First Nations communities, including those in this study, face. Self-determination in First Nations health care can provide cultural continuity, which Chandler and Lalonde (1998) state is a protective factor in First Nations health. Therefore moving toward the ideal First Nations health care system, which would include the incorporation of traditional knowledge, medicines and healing (cultural continuity), and building upon the partnerships that will assist with an interdisciplinary team of health care professionals, is not only beneficial to the communities, but necessary to improve their holistic health and well-being. When the health care system is controlled by First Nations communities, they can ensure the extent to which they move toward the ideal First Nations health care system; each community can incorporate traditional knowledge, healing and medicines as well as other aspects of culture, language and worldview. The current health care systems do not function in this manner and can be the reason that First Nations people and communities perceive they have no self-determination for their health or health care. From my analysis, it is important for First Nations communities to perceive that they have input into their health care system. Garden Hill and Lac La Ronge have found alternative methods to have some measure of control in the health system by partnering with non-government organizations to provide prevention and education programs and services.

Using my data, Blood Tribe, Garden Hill and Lac La Ronge have knowledge of their community’s health needs. However without the control to fully implement changes, they must continuously return to FNIH for approval on any change, which does not assist the communities with achieving higher levels of self-determination. If the communities had true self-determination, they would be



able to apply the findings of Chandler and Lalonde (1998) and Cornell et al. (2004) by revitalizing and incorporating Aboriginal worldview, traditional medicines and healing into their health care system. Thus increasing capacity, having the ability to define what self-determination is, and the steps toward both self-determination and self-governance, which would assist with healing and improving the health of the community. In order to achieve this change, First Nations leaders and scholars must take a prominent role in defining self-determination and the criteria that First Nations communities need to take to achieve it.

## 7.4 Recommendations

Communication between the First Nations communities and governments was important according to all of the participants. Internal communications between the health director and band council must be strong and clear in order to assist with moving toward self-determination. All participants acknowledged that First Nations communities moved closer to self-determination in health care if they had strong and open leaders who could communicate and work with government bureaucrats. It is recommended that communications strategies that build upon the characteristics outlined by Health Canada's Health Transfer handbook (2004) be further developed in all four communities. Additionally, it is important that FNIH and Health Canada become partners with First Nations communities to provide criteria for a successful communications strategy so that all communities understand what is necessary to move them toward greater degrees of self-determination.

The study was limited to three provinces because of time and funding, but there would be benefit in conducting this study in other provinces to determine if provincial governments are working collaboratively with First Nations communities and the federal government to assist First Nations communities with achieving self-determination in their health care. In addition to the research conducted here, it would be recommended to include the regional health authority or public health unit in the area that the First Nation is located. These additional participants can provide depth to the local context and possible insight into how First Nations can continue to work toward self-determination and the ideal First Nations health care system simultaneously. Understanding how provincial governments are working with First Nations communities may assist the communities with increasing their flexibility within their health transfer agreements. This will ultimately lead to more self-determination and possibly self-governance.

In British Columbia, the First Nations have recently signed a tripartite agreement with FNIH and the province to have health care provided by the provincial health care system with First Nations being equal partners in the development and implementation of health care for First Nations people. By comparing this new arrangement with the existing arrangements in the other provinces, it may reflect how self-determination influences the health care and self-reported health status of First Nations people. It is recommended that a larger research study that includes First Nations communities in many provinces and the newly created First Nations Health Authority in British Columbia be conducted.

Blood Tribe's health care professionals are mostly of Aboriginal descent. Conducting a study to determine if having Aboriginal health care professionals assists with improving self-reported health status, could have policy and education implications for First Nations, federal and provincial governments. Many participants in this study felt that the health care professionals (especially non-Aboriginal staff) were not aware of or considered the socio-political history or social and cultural conditions of the communities when they were building professional-patient relationships. Having a clear understanding of the socio-political history can assist health care professionals collaborating with provincial, federal or other health professionals to provide programs and primary care to First Nations people. Therefore if the health care professionals were of Aboriginal descent and had knowledge of Aboriginal history and current social conditions, it should improve the health care professional-patient relationship and this should have influence on improving the self-reported health status of First Nations people.

Finally, I would recommend providing training to all bureaucrats (provincial, federal and First Nations) in one province and using another province as a control group to determine if there is a change in policy development, communications, assistance towards self-determination in health care, and partnership between the levels of government. Many participants felt that the bureaucrats did not understand or acknowledge the history when developing or implementing policy, so with training, this may not be the case. By using another province as a control group, it can be determined if providing education and training regarding Aboriginal history and social conditions has any effect on the above indicators. This may lead to policy change that will assist First Nations communities with gaining more self-determination and lead to self-governance in health.

## 7.5 Conclusion

In this dissertation, I have investigated the perceived level of self-determination in First Nations health care based on participants from each of the three levels of government (federal, provincial and First Nations). I have identified four First Nations health care typologies through the study, which are in varying stages of attaining a blended or ideal First Nations health care system. Self-determination is the ability to make decisions that are culturally, linguistically and spiritually specific to an individual, family and community. Through the study, the four First Nations communities have developed their health care system based on their socio-political history. All four of the communities appear to be interested in continuing to work toward the ideal First Nations health care system that is a blend of biomedical and traditional medicines with a holistic, wrap-around approach to improving the health and well-being of their community members. However the variations in socio-political history that each community has faced has influenced the community's perceived level of self-determination in their health care system.

This study illustrated some key factors that are important to First Nations health and health care, such as communication, adequate funding, the ability to fully utilize partnerships, and the perception of control. The socio-political history that First Nations communities have endured is an additional factor that must be considered as these communities work toward self-determination in their health care as not everyone working in First Nations health has the same baseline of knowledge of the history. As First Nations communities across Canada move toward a higher degree of self-determination in health care, it will be necessary for all government bureaucrats, First Nations leaders, and health care professionals to have a similar understanding of the socio-political history of First Nations.

The perceived level of self-determination is subject to the power and control that the federal government currently has over First Nations communities. Federal government participants perceive a higher level of self-determination for those with administrative flexibility within the health transfer agreements. However First Nations communities perceive a lower level of self-determination because they have little control over the planning and provisions of health care in three of the four communities (Blood Tribe is the exception). The federal government defines flexibility, leadership capacity and the level of funding for public health programs and services. The control that the federal government has can be seen as similar to a parent/child relationship, in which the First

Nations communities are ‘growing up’ and with maturity wish to take further control from the parent. This imbalanced relationship is replicated in the primary care provided to First Nations communities, with little input or acknowledgement of traditional healing and medicines that may complement the biomedical care provided. Without control of the primary care system, First Nations people and communities continue to be in the subservient position and cannot adequately change the health care system.

“This historical analysis makes it clear that First Nations are left with no constitutional, judicial, or legislative mechanisms, domestic or internationally, through which they might gain leverage with federal officials to improve their health status. With all these other options eliminated, it is therefore not surprising that many First Nations have opted to participate in the transfer initiative, as a pragmatic policy choice of last resort” (Health Canada & Saunders, 2006, p. 34).

Through the analysis of the data, it seems that Garden Hill is uniquely positioned with their health system reflecting their Indigeneity and biomedical knowledge; Garden Hill has ensured that all aspects of the system are holistic, transparent, respectful, community-driven and empowering. All four of the communities still need to improve their health care systems and build community capacity in order to continue to move toward self-determination in health care. At this time, FNIH and Health Canada determine when a First Nations community has developed adequate leadership capacity and if they are able to manage their health system. This control by the federal government limits First Nations communities in having self-determination as they have not had input into the criteria for self-determination. However all of the four communities are moving along the continuum of a blended system that will combine the biomedical and traditional medicine models of health in a holistic manner.

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## Appendices

## Appendix A – University of Toronto Ethics Approval



UNIVERSITY OF  
**TORONTO**

OFFICE OF THE VICE PRESIDENT, RESEARCH

PROTOCOL REFERENCE # 26278

April 21, 2011

Dr. Kue Young  
Dalla Lana School of Public Health  
155 College Street  
Health Science Building, 6th floor  
Toronto, ON M5T 3M7

Ms. Angela Mashford-Pringle  
Dalla Lana School of Public Health  
155 College Street  
Health Science Building, 6th floor  
Toronto, ON M5T 3M7

Dear Dr. Young and Ms. Mashford-Pringle:

Re: Your research protocol entitled, "Diabetes care and Self-Determination in Four First Nations Communities in Canada"

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**ETHICS APPROVAL**

Original Approval Date: April 21, 2011

Expiry Date: April 20, 2012

Continuing Review Level: 1

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We are writing to advise you that the Health Sciences Research Ethics Board has granted approval to the above-named research study under the REB's delegated review process. Your study has been approved for a period of **one year** and ongoing projects must be renewed prior to the expiry date.

All your most recently submitted documents have been approved for use in this study.

**Any changes to the approved protocol or consent materials must be reviewed and approved through the amendment process prior to its implementation. Any adverse or unanticipated events should be reported to the Office of Research Ethics as soon as possible.**

**Please ensure that you submit an Annual Renewal Form or a Study Completion Report 15 to 30 days prior to the expiry date of your study. Note that annual renewals for studies cannot be accepted more than 30 days prior to the date of expiry, as per federal and international policies.**

If your research has funding attached, please contact the relevant Research Funding Officer in Research Services to ensure that your funds are released.

Best wishes for the successful completion of your project.

Yours sincerely,

Daniel Gyewu  
Research Ethics Board Manager- Health Sciences

**OFFICE OF RESEARCH ETHICS**

McMurrich Building, 12 Queen's Park Crescent West, 2nd. Floor, Toronto, ON M5S 1S8 Canada

Tel: +1 416 946-3273 • Fax: +1 416 946-5763 • [ethics.review@utoronto.ca](mailto:ethics.review@utoronto.ca) • <http://www.research.utoronto.ca/for-researchers-administrators/ethics/>

## Appendix B – University of Western Ontario Ethics Approval for Expanding the CIRCLE Study





## Office of Research Ethics

The University of Western Ontario  
 Room 4180 Support Services Building, London, ON, Canada N6A 5C1  
 Telephone: (519) 661-3036 Fax: (519) 850-2466 Email: [ethics@uwo.ca](mailto:ethics@uwo.ca)  
 Website: [www.uwo.ca/research/ethics](http://www.uwo.ca/research/ethics)

### Use of Human Subjects - Ethics Approval Notice

**Principal Investigator:** Dr. S.B. Harris

**Review Number:** 17245E

**Review Date:** July 07, 2010

**Review Level:** Expedited

**Approved Local # of Participants:** 16

**Protocol Title:** Expanding the CIRCLE: phase II capacity enhancement for aboriginal health leaders of the future

**Department and Institution:** Family Medicine, University of Western Ontario

**Sponsor:** HEALTH CANADA - HQ1100033 (9000148)

**Ethics Approval Date:** August 18, 2010

**Expiry Date:** February 28, 2011

**Documents Reviewed and Approved:** UWO Protocol, Verbal Consent Script, Confidentiality Agreement.

#### Documents Received for Information:

This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/ICH Good Clinical Practice Practices: Consolidated Guidelines; and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced study on the approval date noted above. The membership of this REB also complies with the membership requirements for REB's as defined in Division 5 of the Food and Drug Regulations.

The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the UWO Updated Approval Request Form.

During the course of the research, no deviations from, or changes to, the protocol or consent form may be initiated without prior written approval from the HSREB except when necessary to eliminate immediate hazards to the subject or when the change(s) involve only logistical or administrative aspects of the study (e.g. change of monitor, telephone number). Expedited review of minor change(s) in ongoing studies will be considered. Subjects must receive a copy of the signed information/consent documentation.

Investigators must promptly also report to the HSREB:

- a) changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
- b) all adverse and unexpected experiences or events that are both serious and unexpected;
- c) new information that may adversely affect the safety of the subjects or the conduct of the study.

If these changes/adverse events require a change to the information/consent documentation, and/or recruitment advertisement, the newly revised information/consent documentation, and/or advertisement, must be submitted to this office for approval.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

Chair of HSREB: Dr. Joseph Gilbert  
 FDA Ref. #: IRB 00000940

Ethics Officer to Contact for Further Information			
<input type="checkbox"/> Janice Sutherland ( <a href="mailto:jsutherl@uwo.ca">jsutherl@uwo.ca</a> )	<input type="checkbox"/> Elizabeth Wambolt ( <a href="mailto:ewambolt@uwo.ca">ewambolt@uwo.ca</a> )	<input checked="" type="checkbox"/> Grace Kelly ( <a href="mailto:grace.kelly@uwo.ca">grace.kelly@uwo.ca</a> )	<input type="checkbox"/> Denise Grafton ( <a href="mailto:dgrafton@uwo.ca">dgrafton@uwo.ca</a> )

*This is an official document. Please retain the original in your files.*

cc: ORE File

## Appendix C – Research Tools: Information Sheets



## **Information Sheet for First Nations Band Councils and Health Directors**

### **Diabetes Care and Self-Determination in Four First Nations Communities in Canada**

My name is Angela Mashford-Pringle. I am an urban Aboriginal PhD candidate at the University of Toronto's Dalla Lana School of Public Health. I am an Algonquin from Timiskaming First Nation in Quebec. My interest in First Nations health and health care came from my previous work with Health Canada and the Public Health Agency of Canada and research I did with the Expanding the CIRCLE Study, which was an Aboriginal Diabetes Initiative study about the quality of care.

In August 2010, I was the Senior Research Fellow in the Expanding the CIRCLE Study, which was looking at the quality of diabetes care. This is a new research project and separate from the Expanding the CIRCLE Study. I am now interested in finding out more about how self-determination and governance influences diabetes care for First Nations communities. I am currently involved in a research study that will examine the relationship between the level of self-determination and the organization and delivery of healthcare, specifically diabetes care, in four First Nations communities in Canada. The study is performed as a partial fulfillment of the requirements for my PhD degree in Health & Behaviour Science at the Dalla Lana School of Public Health, University of Toronto under the supervision of Dr. Kue Young.

Your participation in this study will provide useful information on this topic. I am interested in speaking to First Nations Health Directors, Band Council members (specifically those with the health portfolio), senior First Nations and Inuit Health branch (Health Canada) managers in Ottawa, Manitoba/Saskatchewan, and Alberta, and senior managers with the Ministry of Health in Alberta, Manitoba and Saskatchewan. I will be speaking with the Site Coordinators from the Expanding the CIRCLE Study in the four First Nations communities to help me to reconnect with participants like you. If you are over 18 years of age, have at least 1 year of experience with diabetes care and working with First Nations people and communities and you are willing to participate in the study, I want to talk with you. You will be asked to take part in a telephone interview that should take about 1 hour to complete. You will be asked questions about topics that will help to highlight how diabetes

care is developed, organized and delivered in First Nations communities and the level of self-determination you believe that your community has over healthcare. This research can assist your community with understanding how self-determination influences the delivery of diabetes care and health care in your community. Your Band Council will be provided opportunities for input throughout the process and will have a chance to comment on my final report for your community, which can be used to assist with changes to the diabetes care provided.

Participation in this study is strictly voluntary. You may withdraw from the study at any time until the analysis starts. Participation will be confidential and will be used for research purposes only. If you provide consent, I will record the interview under a code name that will be transcribed verbatim by the researcher only. You will be asked for consent for any quotes that may be used in my dissertation and all quotes will only be attributed to “Key Informant: Government or Leadership”. As far as I know, there are no foreseeable risks to you if you participate.

Miigwetch/thank you for your time and assistance.

Angela Mashford-Pringle

Phone (905) 855-5131

Email: [angela.mashford.pringle@utoronto.ca](mailto:angela.mashford.pringle@utoronto.ca)



## **Information Sheet for Government Participants**

Diabetes Care and Self-Determination in Four First Nations Communities in Canada

**My name is Angela Mashford-Pringle. I am an Aboriginal PhD candidate at the University of Toronto's Dalla Lana School of Public Health. My interest in First Nations health and health care came from my previous work with Health Canada and the Public Health Agency of Canada and research I did with the Expanding the CIRCLE Study, which was an Aboriginal Diabetes Initiative study about the quality of care.**

I am interested in finding out more about how self-determination and governance influence diabetes care for First Nations communities. I am currently involved in a research study that will examine the relationship between the level of self-determination and the organization and delivery of healthcare, specifically diabetes care, in four First Nations communities in Canada. The study is performed as a partial fulfillment of the requirements for my PhD degree in Health & Behaviour Science at the Dalla Lana School of Public Health, University of Toronto under the supervision of Dr. Kue Young.

Your participation in this study will provide useful information on this topic. I am interested in speaking to First Nations Health Directors, Band Council members (specifically those with the health portfolio), senior First Nations and Inuit Health branch (Health Canada) managers in Ottawa, Manitoba/Saskatchewan, and Alberta, and senior managers with the Ministry of Health in Alberta, Manitoba and Saskatchewan. I will be speaking with Site Coordinators in four First Nations communities to help me in finding participants like you. If you are over 18 years of age, have at least 1 year of experience with diabetes care and working with First Nations people and communities and are willing to participate in this study, I would like to talk with you. You will be asked to take part in a telephone interview that should take about 1 hour to complete. You will be asked questions about topics that will help to highlight how diabetes care is developed, organized and delivered in First Nations communities and what level of self-determination you think First Nations communities have in the area of healthcare. **This research is important for First Nations communities to further understand how self-determination influences diabetes care and health care. The**

**participating First Nations communities will have input into the final reports and my dissertation, which will benefit them in making changes to the diabetes and health care provided in their communities.**

Participation in this study is strictly voluntary. You may withdraw from the study at any time until the analysis starts. Participation will be confidential and will be used for research purposes only. If you provide consent, I will record the interview under a code name that will be transcribed verbatim by the researcher only. You will be asked for consent for any quotes that may be used in my dissertation and all quotes will only be attributed to “Key Informant: Government or Leadership”. As far as I know, there are no foreseeable risks to you.

**If you have any complaints or concerns about how you have been treated as a research participant, please contact Rachel Zand, Director, Office of Research Ethics at [Rachel.zand@utoronto.ca](mailto:Rachel.zand@utoronto.ca) or by phone (416) 946-3389.**

Thank you/Miigwetch for your time and assistance.

Angela Mashford-Pringle

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## Appendix D: Informed Consent

### VERBAL CONSENT SCRIPT [For Government Participants]

#### TITLE OF RESEARCH:

Diabetes care and Self-Determination in Four First Nations Communities in Canada

Greetings, my name is Angela Mashford-Pringle, and I am conducting interviews for my doctoral dissertation study at the University of Toronto. I am an urban Algonquin woman and hope to look at how diabetes care is organized and delivered in (First Nations community name) to further understand how self-determination might influence the healthcare structures.

#### PURPOSE OF STUDY:

I am asking that you take part in a short interview to help me better understand the relationships, funding, human resources and other issues surrounding diabetes care and health care in First Nations communities in Canada. I will give the results back to the First Nations communities. There are no known risks to you if you choose to participate in my study and you will not be paid for participating. If you choose to participate, I will be recording the interview so that I can transcribe the audio recording for coding and analysis.

I will be interviewing First Nations community leadership members, provincial and federal government staff working First Nations healthcare and diabetes care. Each interview will take about 45 minutes to 1 hour of your time. The interviews will be held to get your views on diabetes care in First Nations communities and how care is delivered and organized.

Your participation is voluntary. You can decline to participate, and you can stop your participation at any time **until I start the analysis, if you wish to do so, without any negative consequences. If you choose to participate, I would like to record the interview (with your permission) so I can have a more accurate record of what you say.**

**You will be given a special code name and your actual name will not be recorded or published. All of the papers pertaining to the study will be kept in a locked file cabinet, and all electronic**

**data will be stored in secured computer files on a USB device that is password protected and only I will have access to the records. At no point will individuals be identified in any way.**

Do you have any questions?

If you have any questions or concerns about the research, please feel free to contact:

- (1) Principal Investigator: Angela Mashford-Pringle, PhD Candidate, Dalla Lana School of Public Health, University of Toronto at [angela.mashford.pringle@utoronto.ca](mailto:angela.mashford.pringle@utoronto.ca) or by phone at (905) 855-5131
- (2) Faculty Supervisor: Dr. Kue Young, Professor, Dalla Lana School of Public Health, University of Toronto at [kue.young@utoronto.ca](mailto:kue.young@utoronto.ca) or by phone at (416) 978-6459

**If you have any complaints or concerns about how you have been treated as a research participant, please contact Rachel Zand, Director, Office of Research Ethics at [Rachel.zand@utoronto.ca](mailto:Rachel.zand@utoronto.ca) or by phone (416) 946-3389.**



## Appendix E – Research Tools: Interview Guides

### **Interview Guide: First Nations Health Directors and Band Council Members.**

After verbal consent that describes the study and their participation, the questions would be:

#### **General Information:**

- 1) Can you begin by describing your role in First Nations healthcare?
- 2) What relationship do you have with First Nations communities and their healthcare system?
- 3) What is your relationship with (name of First Nations community)?

#### **Funding:**

- 4) Can you tell me how your First Nations healthcare is funded?
- 5) Does your community have a Health Transfer Agreement?
- 6) Who receives the funding from the Health Transfer Agreement? Is it the Band Council or First Nations Health Authority?
- 7) Please tell me about the pros and cons of this funding arrangement.

#### **Partnerships & Government-to-Government Relationships**

*There are three levels of government that can affect healthcare in your community; federal, provincial and local as well as band governance. I want to learn more about these relationships and how you experience them.*

- 8) What is your relationship with the provincial ministry of health?

Probes: What kind of partnership or collaboration is there between (name of local First Nation community health authority) and the Ministry of Health for the province of (name of specific province)?

- What could improve this relationship? What does work well? What doesn't work well?

- What is your First Nations Health Department/Authority doing to work with the province?

- 9) What is your First Nations Health Department/Authority doing to work with FNIH and Health Canada?

Probes: What works well? What doesn't work well? What could improve this relationship?

- 10) What is your First Nations Health Department/Authority relationship with your local Public Health department?

Probes: What services does the local Public Health department provide to you? (if anything)

- What works well? What doesn't work well? What could improve the relationship?

#### **Health Human Resources:**

*Human resources in health make a big difference on healthcare is delivered in a community. I'd like to know more about how you experience these resources from the different levels of government.*

- 11) What human health resources does your health department/authority receive from the province (name of province)? What kind? How often?
- 12) Does your health department/authority receive any health human resources from FNIH?

Probes: Which FNHIH healthcare professionals come to your community? How often?

13) What health human resources does your health department/authority receive from local public health?

Probes: What kind of professionals? How often?

14) What health human resources does your health department/authority fund?

15) Can you provide an overview of what diabetic services are offered in your community?

Probes: Who provides those services?

- There are a number of diabetic specialists like endocrinologists, renal specialists, ophthalmologists, which of these people come to your community?

- How often? Who pays for these specialists to come?

### **Aboriginal Worldview**

16) What resources (human and/or paper) does the First Nations health department/authority provide in Aboriginal languages?

Probes: What difference does it make in your community to have resources in Aboriginal languages?

17) In what other ways does your health department/authority support Aboriginal culture in healthcare?

### **Self-Determination**

18) Who makes decisions about healthcare programs and services in your community?

19) What makes it easier or more difficult to make changes in healthcare for your community?

20) Is there anything else you wish to tell me about?

### **Interview Guide for Federal or Provincial Government staff:**

After verbal consent that describes the study and their participation, the questions would be:

#### **General Information:**

- 1) Can you begin by describing your role in First Nations healthcare?
- 2) What relationship do you have with First Nations communities and their healthcare system?
- 3) What is your relationship with (name of First Nations community)?

#### **Funding:**

- 4) What role does your organization play in funding First Nations healthcare?  
Probes: Please tell me about the pros and cons of this funding arrangement.  
Are there any other ways in which your organization assists First Nations with their healthcare?

#### **Partnerships & Government-to-Government Relationships**

*There are three levels of government that can affect healthcare in First Nations communities; federal, provincial and First Nations governance. I want to know more about the relationships between different levels of governments and the First Nations Communities you work with.*

- 5) What is the nature of the collaboration or partnership between (name of First Nations community) and your organization?
- 6) What is the nature of the partnerships your organization has with other levels of government (local, provincial or federal)?
- 7) In working with (name of First Nations community) what is working well, and what doesn't work well? What could be done to improve this relationship?
- 8) What is your organization (provincial/federal government) doing to work with First Nations communities towards meeting their healthcare needs?

Probes: What is working well? What doesn't work well? What could be done to improve this relationship?

- 9) What is your organization (provincial/federal government) doing to work with local public health authorities to assist First Nations communities with their healthcare?

Probes: What is working well? What doesn't work well? What can be done to improve or create this relationship?

#### **Health Human Resources:**

*Human resources in healthcare can make a big difference to how healthcare is delivered in a community. I'd like to know more about how your organization contributes to these resources.*

- 10) What human health resources does your organization provide to (name of First Nations community)?
- 11) How often do the healthcare professionals that your organization provides go to (name of First Nations community)?
- 12) What are the pros and cons of providing these human resources to (name of First Nations community)?
- 13) What could improve the health human resources in First Nations communities?

## **Socio-political history**

*There are number of issues that First Nations people have faced over the past two hundred years including residential schools, child welfare and adoption, forced relocation and a lack of access to healthcare. I'd like to know more about your organization's awareness and consideration for these issues.*

- 14) In your organization, have there been any discussions or knowledge exchange about residential schools or child welfare, forced relocation or lack of access to healthcare?
- 15) How is your organization taking these issues into consideration when they are working with First Nations communities?

- What influence do these issues have on your organization's policies?

- What influence do these issues have any influence on your organization's funding?

- What influence do these issues have any influence on your organization's interactions with First Nations communities?

## **Aboriginal Worldview**

*Aboriginal worldview is the way in which First Nations people view the world around them as they use culture, language, values and beliefs to guide their interactions.*

- 16) What resources (human and/or paper) does your organization provide in Aboriginal languages?

Probes: What are the barriers you face in providing these resources in Aboriginal languages?

What difference would having these resources in Aboriginal languages mean to First Nations communities?

- 17) What are other ways that your organization supports Aboriginal culture in healthcare?

Probe: Can you provide some examples?

## **Self-Determination**

- 18) What kind of control does (name of First Nations community) have over their healthcare?
- 19) What is your organization's policy on (name of First Nations community) taking more administrative control? Why? What are the issues you face in providing more control?
- 20) What does your organization do to support First Nations governments in taking control of their healthcare?
- 21) Is there anything else you would like to tell me about?