

TOWARDS HEALTHIER ABORIGINAL HEALTH POLICIES? NAVIGATING THE
LABYRINTH FOR ANSWERS

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Abstract

The purpose of this dissertation is to discuss and evaluate processes and institutional structures that influence relationships between Aboriginal communities and government in the development, implementation, and evaluation of health policy. It explores the changing nature of Aboriginal health policy and politics in Canada and examines the shift to self-determination that has transpired in Canada's Aboriginal health policies focusing on their application to Aboriginal peoples. This dissertation examines two Aboriginal health policies in Canada: the federal health transfer policy and Ontario's Aboriginal Healing and Wellness Strategy. Both policies are intended to improve health at the community level by supporting the development of community-based and culturally appropriate health programs. Thus, using community-based research methods, this dissertation maps some of the key political stakeholders in Aboriginal health policy, from local level community members and health representatives to peak provincial and federal Aboriginal organizations, to the offices of ministers in Canadian parliament. I reflect upon the processes and institutional structures that shape relationships between the Aboriginal community-controlled health sector and government.

I examine several First Nations communities in northern Ontario involving both federal and provincially supported initiatives to illustrate the strengths, weaknesses and paradoxes that surface from the implementation of locally controlled health programs. I contrast these efforts with a second First Nations community in Manitoba that operates solely under the federal health transfer policy. I juxtapose these two communities to assess whether additional layers of community-controlled initiatives make tangible differences to community wellness; particularly for Aboriginal peoples living off reserve. This dissertation is being written under the theoretical assumption that governance and community wellness are intrinsically linked. Arguably, there is a definitive correlation between self-determination and community well-being; self-determination may be a determining factor in improving conditions for Aboriginal peoples and understanding resiliency.

This dissertation is about a long lasting colonial legacy of social inequalities in Aboriginal health but also about the incredible successes in Aboriginal health. It is also about the many challenges of Aboriginal representation and self-determination in the context of contemporary Canadian society.

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Table of Contents

Chapter 1: The Health Policy Puzzle...1

Chapter 2: Aboriginal-Government Relations in Canada: A Review of the Literature...30

Chapter 3: Methods and Aboriginal Protocols: Research with Aboriginal Communities...80

Chapter 4: Towards Healthier Aboriginal Health Policies? An Overview of Aboriginal Health Policies in Canada...120

Chapter 5: The Practice and Politics of Community-Controlled Health Care...160

Chapter 6: Aboriginal Health Policies and Government Structures and Practices...200

Chapter 7: Piecing the Puzzle Together: Government, Self-Determination and Reconciliation...247

Works Cited...266

List of Appendices...279

Appendix A: Letter of Information for Aboriginal and non-Aboriginal Health Staff & Service Providers...280

Appendix B: Letter of Information for Government Officials...286

Appendix C: Letter of Information for Aboriginal Organizations...290

Appendix D: Focus Group Participant Information for Community Members...295

Appendix E: Focus Group Script...300

Appendix F: Recruitment Poster for Community Members...302

Appendix G: Recruitment Poster for Health Service Providers...303

Appendix H: Script for Oral Consent...304

Appendix I: Research Agreement...306

List of Tables and Figures

Tables:

Table 1 - Interviews and Focus Groups...**112-113**

Table 2 - Timeline of Policy and Economic Trends in Canada...**124-125**

Table 3 - The Continuum of Transfer...**145**

Table 4 - Overview of health programs and services provided by federal and provincial jurisdictions to First Nations people in Manitoba...**220**

Figures:

Figure 1 - Map of seven First Nations on Manitoulin Island...**100**

Figure 2 - Diagram of health care partnerships and service provision model on Manitoulin Island...**103**

Figure 3 - Diagram of choices in community services under the health transfer policy...**142**

Figure 4 - Diagram of Joint Management Committee Structure...**153**

Figure 5 - Developmental phases of the Aboriginal Healing and Wellness Strategy...**154**

Figure 6 - Diagram of current First Nation health delivery in Manitoba...**221**

Abbreviations

| | |
|--------|--|
| AANDC | Aboriginal Affairs and Northern Development |
| AFN | Assembly of First Nations |
| AMC | Assembly of Manitoba Chiefs |
| AHAC | Aboriginal Health Access Centre |
| AHWS | Aboriginal Healing and Wellness Strategy |
| CBPR | Community-Based Research |
| FNIHB | First Nations and Inuit Health Branch |
| HTP | Health Transfer Policy |
| INAC | Indian and Northern Affairs Canada |
| MAARC | Manitoulin Anishinaabek Research Review Committee |
| MHS | Mnaamodzawin Health Services Inc. |
| MSB | Medical Services Branch, Health and Welfare Canada |
| NIHB | Non-insured Health Benefits |
| NNADAP | National Native Alcohol and Drug Abuse Program |
| OCAP | Ownership, Control, Access, Possession |
| PTO | Political/tribal Organization |
| RCAP | Royal Commission on Aboriginal Peoples |
| TCPS | Tri-Council Policy Statement |
| TTR | Tootinaowaziibeeng Treaty Reserve |
| UOI | Union of Ontario Indians (Anishnabek Nation) |

Chapter 1

The Health Policy Puzzle

The ultimate failure to include Indians raises the basic question of how the demands of the Indians at the consultation meetings were perceived by the policy-makers inside government. It also requires us to understand how 'the Indian problem' was defined by the policy-makers and the public, for defining the problem that a policy is to solve is the first and the most crucial step in policy-making.

- S.M Weaver, Making Canadian Indian Policy

Introduction

The so-called Indian problem in Canada has been one of those political footballs that has been tossed about in Canadian politics since the time of Confederation and before (Dyck cited in Hedican 2008, 109). Edward Hedican writes, "It is an issue that appears to defy a rational, problem-solving approach, since there are so many different perspectives that have to be taken into account: historical, political, administrative, and cultural. It is a multifaceted situation that cuts to the heart of Canadian identity – how we see ourselves in a multicultural sociopolitical setting and how this view is played out in actual policies and administrative programs" (2008, 109).

It has become clear to Canadians that the Aboriginal population is in a disadvantaged position; as a result, the non-Aboriginal government has wavered from one policy direction to another: protectionism, assimilation, termination (Ponting and Gibbons 1980). For example, the state's assault on Aboriginal lands, language, culture, and social structures was highly disempowering (Ponting 1997, 117). In confiscating Aboriginal peoples traditional land base, the colonial state struck at the very core of Aboriginal existence. Historically, for an Aboriginal person, one's identity and understanding of

one's place in the cosmos were intimately tied to her/his relations to the land and the spirits which inhabit it. In 1887, John A. MacDonald asserted that "the great aim of our civilization has been to do away with the tribal system and assimilate the Indian people in all respects with the inhabitants of the Dominion as speedily as they are fit for change" (Cairns 2000, 17). Similarly, the government's assimilation policies, particularly the residential school system, also scarred and distorted Aboriginal peoples' identities. To Aboriginal peoples, the residential school phenomenon was a primordial event – an occurrence of such fundamental importance as to indelibly stamp its imprint on the unfolding of the people's history (Ponting 1997, 120). As stated in the Report of the Royal Commission on Aboriginal Peoples (RCAP):

Successive governments have tried – sometimes intentionally, sometimes in ignorance – to absorb Aboriginal peoples in Canadian society, thus eliminating them as distinct peoples. Policies pursued over the decades have undermined – almost erased – Aboriginal culture and identities (1997).

Thus, Aboriginal efforts to control and influence their own representation are attempts not only to counter misrepresentation that would otherwise prevail but also to counter the non-Aboriginal cultural bombardment they personally experience (Cairns 2000, 44). There has been so much inconsistency from one historical period to the next, from one government administration to another, that it has been near impossible to define the parameters of the problem with the result that Aboriginal policy making in Canada has been conflicting, confusing and unpredictable (Hedican 2008).

The Socio-Political Context

Contextual issues are often envisioned as those immediate circumstances surrounding a situation or event. Context can also be interpreted as those elements necessary and appropriate for creating an interwoven structure. For the purpose of this dissertation, I adopt the second meaning. In doing so, I argue that the contextual issues and perspectives discussed in Chapter Two of this dissertation are integral to the analysis and to revealing the importance of the case studies in the last three chapters of the dissertation. Aboriginal-Canadian relations can and should be understood as a unique set of historically constituted relations unparalleled in Canadian society and its history. In order to understand and interpret those relations at a given point in time, it is important to understand “where people are coming from”. Given the complexity of the issues and the ongoing tensions in Aboriginal-Canadian relations, particularly tensions surrounding health, it is important to understand the epistemological assumptions which ground the differing Aboriginal and non-Aboriginal visions of Aboriginal-Canadian relations. Implicit in both visions are different conceptual frameworks or logics flowing from different cultural assumptions based on different philosophies and values. A major assumption in this dissertation is that epistemology plays a direct role in policy-making when the partners in dialogue are from two distinct cultures; in effect, partnership comes to involve an expression of cross - cultural dialogue.

A second major assumption concerns the history and the nature of the Aboriginal-Canadian “partnership”. Beginning in the 1990s and under enormous pressure from a

revitalized Aboriginal leadership, the Canadian government has seen fit to recognize and enter into dialogue with Aboriginal peoples. Relations of oppression and domination are parts of the legacy of colonialism in Canada and form a background for these dialogues. The continued distrust of the Canadian State by Aboriginal peoples renders difficult current attempts at dialogue. Thus, the first part of this thesis is also intended to inform the overall discussion by making explicit the issues and tensions when these two worlds converge at the policy table when discussing self-determination, self-government and health.

The problem of language is one reason often cited in the literature for the lack of dialogue or failed dialogue in terms of policy-making with respect to Aboriginal-Canadian relations. Lack of linguistic precision can have the effect to disguise views and the paradigms operating underneath; accordingly, the meanings attached to key terms remain vague (RCAP 1996). Common examples include the terms “self-government”, “self-determination” and “sovereignty”. In other cases, the same words continue to be used but their meanings have changed overtime (RCAP 1996). The problem of language has deeper roots. Douglas West points out:

when Native peoples set out to describe their terms of reference for any number of political, social and economic actions and enterprises, they do so usually in English, the language of the dominant society, and according to the logic of the English-dominated social sciences. This alone may explain the inability of successive attempts by non-Native Canadian academics to define self-determination and self-government for Native peoples. It is simply not ours to define. Our definitions and actions come under the rubric of what George Grant once called “English-speaking justice.” In submitting land claims, in defining the territorial and institutional boundaries of self-government, Native peoples are most often

dependent on Euro-Canadian jurisprudence and its accoutrements for “justification.” (1995, 280).

According to West, this linguistic situation can create an epistemological dependency and reinforce hegemonic relations through discourse. It also serves to exclude Aboriginal epistemology which is central to understanding Aboriginal worldviews.

In Chapter Two, I explore both Aboriginal and non-Aboriginal visions of Aboriginal-Canadian relations through the lens of self-determination and self-government variously defined by Aboriginal and non-Aboriginal authors. An examination of these visions by means of including Aboriginal epistemology helps uncover not only a unique understanding of key concepts rarely addressed by non-Aboriginal analysts of Aboriginal-Canadian relations, it also provides a basis for understanding from Aboriginal perspectives why negotiations fail before they even reach the table (RCAP 1996). In dealing with Aboriginal worldviews and perspectives, it is important to employ “epistemic humility” and methodological caution. As a result, this dissertation employs numerous direct quotes from Aboriginal and non-Aboriginal stakeholders on the assumption that what is said, how what is said and who is doing the speaking are just as important to comprehension and to avoiding misinterpretation and appropriation.

Research Question(s): Piecing the Puzzle Together

I do not claim any originality in the idea that Aboriginal health is analogous to a puzzle. However, at this juncture of the thesis, there is no more appropriate metaphor to demonstrate the complexities of Aboriginal health policy. Like piecing together a puzzle, there are certain pieces bearing markers that facilitate the process such as the corners and

the edges. The most appropriate parallel for these guides when putting together the Aboriginal health policy puzzle are

1. the history of Aboriginal health policy and politics
2. the actors involved in Aboriginal health policy
3. the interplay between community-controlled health care and government
4. the ways in which health policies are translated into community programs.

Once there is a basic understanding of these structures, there is a better sense of how the processes of Aboriginal health policy work. However, similar to putting together a puzzle, after the border is complete, pieces begin to look the same and it is difficult to differentiate one from the other. Although understanding the four pillars stated above will lead to an overview of Aboriginal health policy, there are so many intricacies from one community to the next, it is difficult to understand how they fit together. Thus, the underlying research questions guiding this study ask:

1. What is community control and what are the politics of Aboriginal community representation?
2. Were Aboriginal communities empowered or disempowered when they adopted bureaucratic models and collaborative rather than adversarial approaches to government?
3. How and to what extent do models of Aboriginal self-determination influence the formulation of Aboriginal health policy?
4. What forms do shared power between Aboriginal peoples and governments take in terms of rebalancing Canadian-Aboriginal relations?

The purpose of this thesis is to examine the different visions and to understand the puzzle through a clear articulation of some key issues and debates surrounding Aboriginal-Canadian relations. I seek to uncover those processes and positions which facilitate decolonization and move us collectively toward relationships which are more equal and just. The picture that comes into focus when the pieces of this puzzle are put together is really an unclear understanding of a highly complicated system. My hope is that this thesis will lead the reader to an appreciation of the community-government relationships that shape Aboriginal health policy and politics.

Throughout this dissertation, I encourage the reader to pay particular attention to Canada's colonial legacy and the unfortunate ways that researchers have collected and disseminated their data. The phrase "nothing about us without us" captures the need for Aboriginal-controlled methodology and ethics. Differences between western and Indigenous worldviews continue to create barriers to meaningful collaboration as does the widespread view that western views of knowledge are superior to other knowledge systems. My hope is that this thesis can be used as a tool and a way to evaluate past research practices and to serve as a path for future relationships between Aboriginal communities and government.

It is also written with the recognition that this is one researcher's understanding of a complex puzzle. Due to the diversity of Aboriginal communities and the unique set of circumstances that each community encounters, there is no single model of community-government relationships that can be devised to accommodate every community and the

health professionals within them. I hope that Aboriginal communities and organizations can be empowered by research that provides them with insights into the economic and political relationships and processes that hinder them.

Community-Based, Participatory Research as an Alternative Paradigm in Political Science

It is essential to understand the hold that the discipline of Political Science has through its endorsement of “scientific” research to determine legitimate “findings”. This theoretical approach and accompanying research tools have the potential to privilege a certain epistemology. These structural barriers prevent the production of information by political scientists that has much relevance for use in the daily lives of Indigenous peoples and their communities. The scientific objectivity at the heart of the dominant epistemology and its implications for research have often objectified Indigenous peoples without taking into account their own epistemologies and knowledge. Assuming that Indigenous peoples think and reason like the dominant paradigm can be wrong headed, leading to a complete misunderstanding of Indigenous peoples. For this reason, researchers have sought out other approaches to learning about Indigenous thinking and to listening to their articulation of challenges that they face. (Ketchum, 2009).

Community-based Participatory Research, or CBPR, is one approach that is increasingly recognized as an important approach to conducting research *with* rather than *on* communities. As described in Chapter three, CBPR builds capacity at the same time that it studies locally relevant issues and concerns in collaboration with the community. CBPR is a process that equitably involves all partners in the research process and

recognizes the unique strengths that each brings (Jackson 2003). This approach begins with a research topic of importance to the community as well as the given scholar with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities. What sets CBPR apart from more traditional research paradigms, is its commitment to community action as part of the research process. CBPR projects also have the potential to provide data for policy submissions that put pressure on policy-makers and government. This project is one example of how health researchers in the academy can fit into health policy networks and processes.

The purpose of my research is to bring communities together in discussions about their visions of the future. What do they see as self-determination? Self-government? What would a healthy community look like? Through the use of CBPR, I examine ways in which a community's vision of health and governance can be reconciled (or not) with current Canadian and provincial governments' policy processes. The honouring of local knowledge, and in this case, Aboriginal epistemology and experience, involve entering into a process of learning from knowledges which at times stand directly in opposition to Western epistemology, worldviews and ways of coming to truth. When we enter the research process from the stance of a learner and actively engage in that learning process, the potential to avoid misunderstanding and misinterpretation based on ethnocentric assumptions is increased.

The Argument

One way that Aboriginal peoples have attempted to control and influence their own representation comes in the area of health. Across Canada, Aboriginal peoples consistently suffer from poorer health than their non-Aboriginal counterparts (Royal Commission on Aboriginal Peoples 1996). The gap in health status between Aboriginal and non-Aboriginal populations is an enduring legacy of colonization and encroachment of industrial forces on traditional lifestyles, sustained by the continuing political, social and economic marginalization of Aboriginal peoples. The diseases of westernization such as diabetes, obesity and heart disease, and health conditions related to the consequences of colonization – particularly family violence, addictions and trauma related to accidents and violence -- emerged as important community health and mental health concerns (Maar 2004). Given these broad determinants of Aboriginal health, reforming the healthcare system is only one avenue to Aboriginal health improvement, but it remains an important one.

Over the past forty years, it has become apparent that increasing the access to mainstream Canadian primary health care services without addressing the broader social determinants of health will not have a significant impact on improving the health conditions of Aboriginal peoples. Kue Young points out that “while the Canadian model of health care delivery to communities is more comprehensive than those of the advanced economies of other circumpolar countries, there are other aspects of primary health care, namely, community participation, self-reliance, and self-determination that have not

received much attention until recently” (2003, 420). The varying impacts of cultural relevance, community control and self-determination on the effectiveness of primary health care did not receive much attention until the late 1980s when the broader socio-political aspects of Aboriginal self-determination and self-government surfaced to the Canadian public consciousness (Maar 2004, 55).

In light of this background, my argument comes in three parts. First, effective health care arrangements for Aboriginal peoples must be built around these peoples having full access to their own self determination and to autonomy in deciding upon forms of self government. This thesis is about the move towards more Aboriginal self-determination when it comes to the formulation and implementation of health policy for Indigenous peoples. The concept of Aboriginal self-determination in Canada has serious implications in the field of health (Ponting 1986), most obviously at the level of community-based health care services. It is also related to the terms of improving the responsiveness of provincial and territorial health care systems and at the federal policy level (Peters 1999). The degree with which programs respect self-determination as opposed to top-down approaches dictates how likely those programs will be a success. With more self-determination, Aboriginal nations and communities could end up with very different institutional arrangements for the provision of health services and better health outcomes. Self-determination is also the foundation for social development and is expected to contribute to the healing process currently underway in many Aboriginal communities.

The relationship between self-determination and health is largely ignored in the literature, even though it is clear that there is a primary relationship between the two. Ladner argues that “while community wellness and healing are intricately tied to contemporary demands for self-government, there is very little written that addresses the relationship between self-determination and unhealthy communities. Even less attention is given to developing any measurable indicators of such a relationship” (2009, 88). Arguably, understanding better the relationship between governance and community wellness will allow for a more comprehensive understanding of factors for enhancing wellness and a more adequate response for how the pursuit of wellness might be developed and delivered (Ladner 2009).

For the purposes of this thesis, self-determination is defined as “involving the creation, maintenance and control of services in response to needs the community has identified” (Seidle 2007, 172). I argue that self-determination is a necessary condition for the improvement of Aboriginal peoples’ health and should be a fundamental condition for any policy aimed at mending Aboriginal quality of life (Salée, Newhouse and Lévesque 2006, 18). Aboriginal communities have argued that the process of self-determination needs to be initiated by the community and not imposed upon the community, as it has been over the past many hundreds of years. A project consistent with self-determination will be one where the community will be involved with the decision-making, planning, implementation and evaluation of that project; the aim is for total community control. A greater awareness of the social and political issues influencing the health status of

Aboriginal people is necessary to provide sensitive, culturally appropriate health care services.

The second part of my argument buttresses the first. I demonstrate the importance of self-determination and self-government through case studies of two government programs, the Health Transfer Policy of the Federal government and the Aboriginal Healing and Wellness Strategy of the Government of Ontario introduced in 1994. The federal policy moves very little in the direction of self-determination in comparison to that of the Ontario one. And this difference appears to have significant consequences for health and wellness in Aboriginal communities.

The federal government responded to the pressures of Aboriginal groups for self-determination with the release of the Indian Health Policy in 1979. However, the document failed to propose a mechanism to realize its goals of community development and intersectoral collaboration in Aboriginal health care. A further attempt, the Health Transfer Policy was announced in 1989. It was touted as an answer to 20 years of consultation and discussion between Aboriginal Peoples and government on the best way to deal with the inequalities existing between Aboriginal Peoples and non-Aboriginal Canadians (Lavoie 2004). The overall goal of the health transfer policy was to provide a framework for achieving self-determination in health by Canada's Aboriginal people. Health transfer provides opportunities to Aboriginal bands and communities to engage in local administrative control over aspects of health care (Gregory et al 1992). Health transfer is also intended to improve health at the community level by supporting the

development of community-based and culturally appropriate health programs, while maintaining federal guidelines on mandatory programs for areas such as communicable disease, environmental health, registration of health professionals and emergency response planning. Undoubtedly, the health transfer policy does provide greater community involvement in health care. However, as Marion Maar argues, “Aboriginal groups have time and again asserted that they seek control over, not involvement in health care” (2004, 55).

In 1994, Ontario took a ground-breaking and distinct approach to the governance and provision of health care services for Aboriginal people. The Ontario approach has the potential to serve as a model for other provinces and territories across Canada. Ontario began to restructure the province’s approach to Aboriginal health care services by adopting an Aboriginal health policy after extensive community consultation. This process involved the largest, single consultation of Aboriginal people ever undertaken in Ontario. During the consultation, the views of over 6,000 people representing 250 communities were heard. In 1994, the Aboriginal Healing and Wellness Strategy (AHWS) was implemented based on this policy and a provincial Aboriginal family violence prevention strategy. The intersectoral governance of AHWS represented a unique consensus partnership model (the Joint Management Committee) for decision-making between the Aboriginal community and government, involving eight Aboriginal provincial territorial organizations; independent First Nations coordinated through the Chiefs of Ontario, and eleven provincial ministries.

The AHWS represents all Aboriginal people, including non-status Indians, Inuit and Métis. It funds and supports the development of community-based health and mental health care services designed to improve Aboriginal health status and reduce family violence in Aboriginal communities within an Aboriginal model of care. AHWS programs emphasize community-driven, culturally-appropriate services; accessibility to primary care and a continuum of services; accessibility to primary care; and general improvements to access to western and traditional Aboriginal medicines (Minore and Katt 2007). As a result, Ontario has made great strides in sharing control over health services with Aboriginal stakeholder organizations and it has become a leader in this aspect.

Unfortunately, as of April 1st, 2011, the Joint Management committee has been dismantled due to administrative problems and internal conflicts between Aboriginal organizations. Similarly, the Aboriginal Health Access Centres, which consist of ten primary health care service organizations across the province, will have direct funding and accountability relationships with the Ministry of Health and Long-Term Care. Thus, AHAC funding administered under AHWS will now be directly administered by the Ministry of Health and Long Term Care.

However, upon closer examination, Aboriginal health policy in Ontario and in Canada more generally remains largely patchwork - and jurisdictional issues have increased rather than declined (Lavoie 2011). Lavoie suggests that a national umbrella Aboriginal health policy may be necessary to address significant gaps in service and jurisdictional ambiguities that directly impact the health of Aboriginal peoples.

The third part of my argument relates to leadership. In addition to self-determination and government programming that respects self-determination, I find that thoughtful and collaborative leadership in given communities ensures that self-determination and culturally sensitive programs can fully realize their potential. It is important to point out that health care is a space for the meeting of communities and the development of multiple discourses about the meaning of health for both government actors and community members, administrators and health care providers. Little attention has been paid to the conditions that facilitate effective collective work of organizations that come together with different and often competing interests. This coming together becomes inherently complex in terms of Aboriginal health, mainly because of historic inequalities - a recurring theme in the experience of both poor health and differential access to health care and also in the ways in which Aboriginal peoples have blurred the boundaries between the public and private spheres of health.

This dissertation contrasts the community-based Aboriginal approaches to health care issues with the highly bureaucratized nature of the Canadian government's approach. For Aboriginal peoples living in Canada, however, even their own experiences with health care policies are placed into wider community-oriented advocacy and activism. This dissertation illustrates how the health care needs of Aboriginal communities can become lost in government bureaucracy. This potential of loss poses some challenging questions of what will become of these grass-roots initiatives as the government further

distances themselves from Aboriginal health care. Will health care then become more pertinent and personalized as it falls back to control by community interests?

It is at this point that the role of Aboriginal leadership, i.e. Chief and Council and their relationship to their communities and with government becomes crucial. These leaders have a deeply conflictive role to play in their communities in that they straddle the boundaries of collective Aboriginal needs on the one hand and their relationship with government authorities and interests on the other as they sit on cross-jurisdictional coordination forums and other government committees. This dissertation reveals and sheds some light on the limitations on community-government health processes and the ways in which various subjective meanings are extracted from these processes. The present day cases discussed in Ontario and Manitoba illustrate some of the bigger uncertainties around Aboriginal health care. The information that I gathered provides insight into how health policies work in local communities and how the relationship between federal and provincial levels of government and Aboriginal communities continues to remain constrained by colonial thinking. Although this argument is not original in and of itself, the testimony that I have interpreted and the discourse analysis that I have employed provide a different and unique lens for exposing the strengths and weaknesses of the policies; I believe this insight could not have been ascertained through traditional political science approaches.

Studying Canadian Aboriginal Health Policy: Case Studies

In this thesis, I examine the changing nature of Aboriginal health policy and politics in Canada. It examines the shift to self-determination that has transpired in Canada's Aboriginal health policies focusing on their application to Aboriginal peoples. Policies and programs differ in their details from province to province and between territories. The fundamental values, however, are basically the same, as are many of the challenges and outcomes. This thesis maps some of the key political stakeholders in Aboriginal health policy, from local level community members and health representatives to peak provincial and federal Aboriginal organizations, to the offices of ministers in Canadian parliament. I reflect upon the processes and institutional structures that shape relationships between the Aboriginal community-controlled health sector and government. It is about a long lasting colonial legacy of social inequalities in Aboriginal health but also about the incredible successes in Aboriginal health. It is also about the many challenges of Aboriginal representation and self-determination in the context of contemporary Canadian society.

I consider the developments at the federal level by examining the health transfer policy, because federal programs set the stage for what has transpired at the provincial level. However, provincial and territorial governments provide the majority of services to Aboriginal peoples; consequently, changes in provincial/territorial practices are of great importance. The lack of cross-government collaboration and the failure to integrate

federal and provincial health policies are contributing factors to the vulnerability of Aboriginal peoples across Canada.

Thus, I examine several First Nations communities in northern Ontario involving both federal and provincially supported initiatives to illustrate the strengths, weaknesses and paradoxes that surface from the implementation of locally controlled health programs. It is in these communities that I am able to learn about and assess the Ontario policy. I contrast these efforts with a second First Nations community in Manitoba that operates solely under the federal health transfer policy. I juxtapose these two communities to assess whether additional layers of community-controlled initiatives make tangible differences to community wellness; particularly for Aboriginal peoples living off reserve. I write under the theoretical assumption that governance and community wellness are intrinsically linked. Based on my research, I suggest that there is a definitive correlation between self-determination and community well-being; self-determination may be a determining factor in improving conditions for Aboriginal peoples and understanding resiliency (Ladner 2009, 93).

This thesis occurs amid a number of broad and deeply rooted trends that have strongly influenced the extent to which the government has become interested in Aboriginal peoples' participation in health care. Due to extraordinary efforts by Aboriginal leaders and communities, Aboriginal issues are now commonly acknowledged within the political and legal arena in Canada. At the same time, and perhaps as a result of this greater visibility, Aboriginal health statistics have become an incessant source of

shame for the Canadian government. In 2004, the United Nations Human Rights Commission determined that Canada's number eight ranking on the development scale would drop to forty-eight if all Canadians assumed the health conditions of Aboriginal people registered under the Indian Act (United Nations Commission on Human Rights 2004). The ill health of this population raises questions about the nature of Aboriginal health policy and policy making in Canada (Warry 2004). The Canadian government has been compelled to respond with policies that are more supportive of Aboriginal peoples' control over their healthcare.

A second impetus for research on Aboriginal health policy and politics comes from a number of international conferences on Indigenous health including the *Fifth Gathering of Healing Our Spirit Worldwide* in Edmonton, Alberta in 2006. This gathering was a major international conference that was organized to provide guidance and direction for Indigenous peoples in developing models of healing, self-determination and wholeness. It brought together government officials, community-based organizations, non-government organizations, including Canadian-Aboriginal organizations, academics and a multitude of other organizations, departments and stakeholders involved in the development of Indigenous health policy. A common theme that emerged from this conference was the need to research the ways in which institutions function internally and in relation to other institutions and the multifaceted political, economic and social systems to which they belong. One of the key note speakers stressed the need to more fully comprehend how Aboriginal health policies are attained and how they are

developed, implemented and evaluated. The processes and networks that implement health policy also perpetuate the very inequalities in health that they claim to address.

It is therefore essential to examine empirically Aboriginal health policy and programs taking into consideration the political economy of health, or the broader structural inequalities which perpetuate poor health. One can then appreciate the interconnectedness of policy content, process and context. Similarly, more credence needs to be given to the impact of colonial structures and power relations that contribute to the health, social and economic inequalities in Canadian society.

A third reason for pursuing this research is my work experience as a policy analyst and researcher for both a National Aboriginal Organization and a government department in the area of Aboriginal health. These experiences provided me with an opportunity not only to learn how government policies are formed, but also to witness how networks and processes involved in the generation of health policy targeted to Aboriginal peoples in a country such as Canada are played out in offices, boardrooms and informal social gatherings. As a researcher, I have been able to observe more closely how policies at the government level reverberate at the community level into actual programs and services.

Finally, this thesis was written while a compelling new relationship has been underway in British Columbia. Beginning in 2005, significant steps have been taken toward improving relationships and consultation between First Nations in British Columbia and the provincial and federal governments. Miranda Kelly points out that “in March of 2005, a Leadership Accord was signed between the First Nations Summit,

Union of BC Indian Chiefs, and BC Assembly of First Nations to formalize a cooperative working relationship between the parties to represent First Nations of BC (2011, 7). Executives of the parties formed the First Nations Leadership Council (FNLC). In November of the same year, the FNLC signed the *Transformative Change Accord* (TCA) with the province of British Columbia and the Government of Canada. This agreement marked the beginning of the transformative collaborative and coordinated cross-jurisdictional partnership with the intent to make First Nations “full partners in the success and opportunity of the province (Kelly 2011, 7). On October 13th, 2011, a tripartite health agreement was signed by Health Canada's Leona Agulikkaq, British Columbia's health minister Mike de Jong, and representatives of the First Nations Health Council and First Nations Health Society.

Although the process is still a work in progress, this development of a new First Nations health governance system in British Columbia provides an exciting opportunity for change in the way that Aboriginal health policy is designed and implemented. As Kelly points out, “The ‘New Relationship’ in BC could launch a new era of First Nations health policy - an era when policy is not made *for* First Nations, but *by* First Nations” (2011, 10).

Despite the highly positive developments taking place in British Columbia, and as I show in Northern Ontario (Manitoulin Island), the federal government decided in early April of 2011 to close down the National Aboriginal Health Organization (NAHO). NAHO had played a highly important role in advancing research on Aboriginal health,

collecting and analyzing data, and leading community initiatives, such as programs to help people quit smoking, prevent suicide and avoid teen pregnancy. It had produced 12 issues of the *Journal of Aboriginal Health*, one of the best collections of Aboriginal health research in the world. In my interview with the Chief Executive Officer of NAHO in the summer of 2011, the CEO boasted about the various initiatives taking place within the organization that were having a positive impact on Aboriginal and non-Aboriginal Canadians:

We're in the knowledge translation business. We have three centres; we have one for First Nations, Inuit and Métis. I think one of the things that's exciting about NAHO is our social media work that we're doing now. And the website is turning out to be a really exciting part of NAHO. Last year we had 4.5 million hits on our website. We have had close to a quarter million downloads or requests for hard copies of our journal and other research initiatives that we're doing...the research that we're doing in our organization not only helps communities but also helps non-Aboriginal Canadians understand the impacts of colonization and historical trauma [NAHO CEO].

The government of Canada has also recently overseen 100% health funding cuts to the Aboriginal Healing Foundation (AHF), the Native Women's Association of Canada (NWAC), the Métis National Council (MNC) and the Congress of Aboriginal Peoples (CAP). Even more recently, the Assembly of First Nations (AFN) was forced to lay off staff after Health Canada reduced its funding by 40 per cent, making it the most recent Aboriginal organization to feel the impact of budget cuts at the federal agency. The AFN has stated that "the cuts will result in staff layoffs and would impact its supportive and facilitative role in informing the development of health policies and programs for First Nations." In the wake of crises such as Attawapiskat First Nation in Northern Ontario in

the Winter of 2011-2012 one would expect the government to ramp up its contributions to Aboriginal communities to avoid such embarrassments; however the opposite appears to be true. While the British Columbia example and my findings in Manitoulin Island suggest a possible new era of Aboriginal health policy development in Canada, these recent setbacks suggest that when it comes to the inclusion of Aboriginal peoples as equal partners, there is still a long way to go.

My research demonstrates that federal, provincial and territorial policies regarding Aboriginal health have been contradictory and inconsistent by focusing specifically on the implementation and evaluation of the federal Health Transfer Policy and Ontario's Aboriginal Healing and Wellness Strategy. The goals and objectives of these policies are intended to enhance Aboriginal self-determination in health care by providing Aboriginal control over the design, delivery, and administration of health services (Lavoie 2008). Although these policies are premised on community-government collaboration and have been marketed as mechanisms for healing and self-determination, their formation is still fundamentally rooted in and informed by Canada's colonial history with all of its attendant institutions, structures and practices. To support this, in my interviews with those at the community level, the majority of respondents felt that current government policy reduced the scope of self-determination while in my interviews on the government side many respondents felt that current policy was neutral, responsible and was shifting power back toward Aboriginal people. Structurally, these types of relationships within government are not unique. In the era of New Public Management,

these types of relationships occur in various sectors of government without any connection to colonialism. What sets the plight of Aboriginal peoples apart from other sectors of government is the promises that were made to them prior to colonization. The expectation of those that I interviewed on the Aboriginal side stated that they simply want the government to honour their commitments.

The creation of Aboriginal-Canadian relationships depends on dialogue not a monologue. As this thesis demonstrates, however, this dialogue often fails:

When efforts are made to find mutually agreeable strategies or solutions, the process is more akin to anti-dialogue than dialogue. The outcome does not usually produce what the people thought they had expressed as wants or needs. This outcome affirms that the process did not result in the creation or recreation of knowledge which characterizes dialogue or reciprocal interaction between two or more parties committed to finding mutually satisfactory answers. Consultations between Indigenous leaders and government officials and Indigenous officials and community people often fail to satisfy the purpose of the quest (Mussell 1993, 118).

Similarly, a study was conducted by a multidisciplinary team from the University of Northern British Columbia, the University of Manitoba, Simon Fraser University in British Columbia and the Assembly of Manitoba Chiefs indicating that a Health Canada program aimed at transferring control of health care into First Nations hands is yielding success. However, co-author Josée Lavoie concludes “Our results question the overall efficiency of the health care system which spans federal and provincial jurisdiction, as long as policy decisions may continue to be made by one party while ignoring the impact of the other” (2009, 249). Thus, it is the nature of what comprises constructive dialogue that I address in chapter 7 of this thesis.

From my point of view, the post-colonial challenge as represented by the Aboriginal perspective of collaborative dialogue contains two fundamental prerequisites necessary for constructive dialogue: the ability of Canadian governments and institutions to share power and their openness to accepting and respecting Aboriginal worldviews. These perspectives provide insight into why dialogue in the context of negotiating Aboriginal concerns often results in two monologues that fails to hear “the other”. Thus, a core theme of this dissertation is respecting Aboriginal difference and sharing power in designed and related programming. In this regard, there needs to be a framework to improve Aboriginal health status through providing equitable access to health care, culturally appropriate services, and support for Aboriginal-designed and delivered programs.

From a political perspective, at least two important changes have occurred in the landscape of Aboriginal health in the last forty years. The first change is the establishment of the community-controlled health sector in 1979. This change is discussed at length in chapter 3. The second major change occurred in the late 1990s with the development of formal partnerships and other participatory approaches for the community-controlled sector to work collaboratively with government stakeholders. The small amount of literature in this second phase is due in part to the fact that developments in the 1990s are seen as less politically exciting and less revolutionary than activism that took place in the 1960s and 1970s. Some of the Aboriginal elders with whom I have spoken as part of this research who were at the forefront of the health movement in the 1960s have a sense of

hostility towards the younger generation who they believe have sold themselves out to government and to mainstream society. A tension exists between adversarial responses that took place in the 1960s and 1970s with the more current forms of community advocacy, that of negotiation and partnership with government which has not been studied in any amount of detail. Little is said about the political relationships between the Aboriginal community-controlled health sector and local, provincial and national levels of government.

Organization of the Thesis

I develop my argument in this dissertation in the following steps. Chapter 2 introduces the key concepts of self determination and self-government and reviews the history of their debate and formulation in the academic and public literatures. This review of the key concepts for this thesis provides the background thinking for the definition of self-determination that I have provided in this chapter, when I introduced my argument. Chapter 3 focuses on the methods that I used to collect and disseminate my data. I highlight the importance of community-based, participatory research and outline the steps that I undertook over a two year period with the intent of providing a qualitative model that future researchers can use as a means to engage with problems of health care systems. Chapter 4 describes the history of Aboriginal community-controlled health initiatives, namely, the federal health transfer policy and Ontario's Aboriginal Healing and Wellness Strategy with the goal of providing a background that will be instrumental in fully understanding the analysis in the remaining chapters. This chapter also considers

some existing gaps and challenges in Aboriginal public health which are likely to continue despite the transfer of control over some aspects of these problems. Once I determine a general platform of policies which currently shape community-controlled health initiatives, chapters 5, 6 and 7 take up the challenge of critically analyzing how government-community partnerships around these policies impede or advance the success of such initiatives, especially in the context of Aboriginal self-determination.

A Note on Terminology

I acknowledge that it is misleading to describe Aboriginal peoples as a single collective group since the term “Aboriginal” covers three categories (Indian, Métis and Inuit) and the term “Indian” itself is a legal fiction, behind which there are numerous Aboriginal nations with their own histories and separate community identities – Cree, Dakota, Dene, Ojibwa, Sioux, and so on – and belong to fifty-three nations speaking dozens of distinct dialects that fall into eleven language groups (McGillivray et al. 1999, xiii). For the purpose of this thesis, the term Aboriginal, meaning literally ‘from the beginning’, denotes:

- those of First Nations descent, including the Inuit of northern Canada, registered or ‘status’ Indians, most of whom are also ‘Treaty’;
- non-registered Indians descended from those not registered in the early days of the Indian Act or deregistered under a variety of provisions in the Indian Act (out-marriage for women, military service for men, voluntary enfranchisement);

- and Métis, descendants of Canadians and Indian partners, who constitute one or more distinct cultures. Métis also refers to those of other Euro-Aboriginal descent.

‘Indian’ as used in this thesis refers to registered Indians under federal aegis.

Chapter 2

Aboriginal-Government Relations in Canada: A Review of the Literature

Indigenous peoples, as a specific form of exercising their right to self-determination, have the right to autonomy or self-government in matters relating to their internal and local affairs, including culture, religion, education, information, media, health, housing, employment, social welfare, economic activities, land and resource management, environment and entry by non-members, as well as ways and means for financing these autonomous functions. Article 31: Draft UN Declaration on the Rights of Indigenous Peoples.

The purpose of chapter two is to review the literature and develop viable concepts of self-determination and self-governance that apply to contemporary health issues in Aboriginal communities across Canada. Furthermore, the goal of this chapter is to demonstrate how the concept of self-determination has evolved over the years. From the literature, two important themes have surfaced in relation to the development of Aboriginal self-determination in Canada. The first theme suggests that the progression of the development of Aboriginal self-determination as a local concern has moved in a direction that places the issue largely with different levels of government. The second theme that emerges is that there is a continuous desire by Aboriginal people to develop institutions and processes of government that reflect Indigenous philosophies and ideals. In reviewing the literature, however, I argue that a serious gap exists; there has been limited systematic assessment and acknowledgment of these ideals in defining self-determination. This absence has serious implications in the field of Aboriginal health policy because the notion of self-determination prior to colonization has no resemblance with current government priorities and practices. This problem raises the question as to whether livelihood is improving for Aboriginal people. In the last forty years, there has

been a shift in the development of policies that focus on self-determination. The question that remains is whether this increased effort from government constitutes a platform for Aboriginal communities to enhance community wellness, or has this shift merely promoted a paradigm paralysis by repackaging colonial policies and practices.

A substantial body of literature has been produced about Aboriginal self-determination and self-government in Canada during the past four decades. This canon of literature includes academic scholarship by Aboriginal and non-Aboriginal writers, policy and position papers established by various bodies commissioned by the federal government and proposals and responses from Aboriginal political associations. This large literature provides a tremendous cross-reference analysis of some of the more compelling and prominent ideas about self-government during this period. It is beyond the scope of this chapter to provide a comprehensive review of the research literature, because such a review could occupy several volumes. Rather, in this chapter I provide a broad overview of the types of studies that have been completed in the past couple of decades. My own definition provided in Chapter One grows out of this overview.

Moving beyond a traditional literature review, this chapter explores at a theoretical level the evolution in understandings of self-determination and of self-government held by Aboriginal peoples, various scholars, both Aboriginal and non-Aboriginal, and policy makers. My goal is to demonstrate at a critical level the evolution of the meaning of these terms up to the period when the respective federal and provincial policies were introduced. This chapter provides the reader with an understanding of the policy context

that shapes the lives of Aboriginal communities and of the challenges and dilemmas of co-existence grounded in a respect for Aboriginal difference. Chapter two demonstrates how the concepts of self-determination and self-government have shifted over time. Initially these concepts were in the hands of Aboriginal peoples and are now being discussed and defined by scholars and government. Chapter two also illustrates the systematic withdrawal of power that once laid with communities. It is only through community-based, participatory research that power can be re-balanced and voice can be given back to Aboriginal communities and to the individuals within these communities.

The voices of Aboriginal peoples are now absent from the self-determination and self-government discourse. There is a lack of consistent and systematic examination of what Aboriginal ideas of political thought are. The method that I have chosen in Chapter three brings these ideas, philosophies and values to the forefront; unlike scholars that examine these issues at a broader community-state level, this research explores the tensions, challenges and successes within communities themselves. Incongruencies between community visions and government visions are a far too simplistic analysis. In order to truly understand these concepts, one needs to begin by listening to the voices of Aboriginal people which can be accomplished well through community-based participatory research.

The Hawthorn Report

Prior to engaging in a discussion of the origins of self-government, it is necessary to briefly examine the history of events leading up to the 1970s when the development of

self-government first began to take root. Prior to 1960, Aboriginal peoples were invisible to Canadian politicians and the concept of Aboriginal self-government was non-existent. With respect to Aboriginal policy, two major reviews were undertaken over the course of the decade in the 1960s with the intent that social policy should change. The first review was the establishment of the Hawthorn Commission. The subsequent Hawthorn Report exposed the appalling conditions of Aboriginal peoples and introduced the idea of “citizens plus”, a concept that reinforces the commonality of all Canadian citizens, while recognizing the difference of Aboriginal peoples. John Richards describes the report as breaking conventional wisdom by insisting on the diversity among Aboriginal peoples in Canada and on the survival into an indefinite future of Indian reserves. Richards points out that the report stressed the importance of better education. He writes, “Hawthorn acknowledged that better education would encourage many Indians to choose to live off-reserve, but forced assimilation was not the goal. If Indians wanted their cultural identity to survive, it would. The choice was up to the Indian” (2006, 12).

Although the Hawthorn Report strongly supported giving the maximum decision-making power to Aboriginal communities, the small size of the large majority of these communities and their limited resources precluded acting on this optimistic assessment. David Newhouse, a Native Studies professor at Trent University and a Haudenosaunee scholar has noted that “The Hawthorn Committee was struck simply to assuage the public’s concern regarding the plight of the country’s Native population. Despite the seemingly progressive measure taken in striking the commission, official attitudes of the

period appear at best indifferent toward Indian peoples and their situation” (2001, 8). In the end, the report was ignored by the Federal government, which instead opted for the publication of a White Paper in 1969 with proposed solutions to the Indian problem.

The 1969 White Paper

The White Paper of 1969 was presented to Parliament by Jean Chrétien, who was at the time Minister of Indian Affairs and Northern Development in Pierre Trudeau’s first government (Richards 2006, 12). This was the department’s second major review carried out over the course of the decade. The White Paper of 1969 ignored the policy recommendations of the Hawthorn Report and presented another thinly disguised form of the assimilationist goal based on a candid rejection of any special Aboriginal rights (Richards 2006, 13). The White Paper called for the abolition of the Indian Act and the phasing out of reserves in favour of complete assimilation of Aboriginal Peoples into Canadian society. The Paper also argued the “treaties” were anachronisms and should be dissolved, thus attacking one of the most fundamental dimensions of First Nations – State relations inscribed in the Royal Proclamation of 1763. According to the White Paper, the problem with past Aboriginal policy was its attempt to accommodate traditional ways. These ways no longer fit with a modern, democratic society based upon individual political and civil rights.

As such, the publication of the White Paper catalysed a country-wide political movement challenging the its basic premises. The Aboriginal community argued that they had rights originating from the treaties in addition to having rights as Canadians. It was at

this time that the National Indian Brotherhood (now the Assembly of First Nations [AFN]) emerged as a strong national political voice and released a position paper entitled *Indian Control of Indian Education*. In addition, the First Nations in Alberta published a “Red Paper” critiquing the basic premises of the White Paper, that was largely adopted by aboriginal peoples across Canada. The need for resistance strengthened Aboriginal organizations working at the provincial level and led to the argument that Aboriginal people could govern certain aspects of their lives that the current government services were unable to deliver (Abele et al. 1999, 260). It is evident that the direction that Aboriginal organizations were taking in the early 1970s was a leading toward self-government.

Lashing Back: Grassroots Activism towards Self-determination

By the 1970s, a series of published criticisms generated by leaders such as Harold Cardinal and Howard Adams in books that presented the history of Aboriginal and European relations from the Aboriginal perspective, also engendered activism on many fronts. Aboriginal intellectual writings focusing on history can be said to begin around 1969 with the major political mobilization surrounding the White Paper and the publication of Harold Cardinal’s scornful response to it, titled “The Unjust Society” noted above. Intended for a wide audience, Cardinal’s work garnered considerable attention and helped to facilitate the process of educating mainstream non-Aboriginal Canadians about the inequalities of the past. Framing his argument around Trudeau’s objective of building a just society, Cardinal analyzed aspects of Canadian history that he considered central to

the unjust society that Aboriginal peoples had experienced. He focuses on the residential school system, the process of assimilation, bureaucratic red tape, and government incompetence (Cardinal 1969, 1-2). Cardinal is vehemently critical of the White Paper and argues that:

The MacDonald-Chretien white paper, which proposes to determine the future of all Canadian Indians, one vital element is missing. The role of the Indian has been totally overlooked. In sections where nominal obeisance is made to the Indian, he is allotted the role of the puppet that does only what is wanted of him, never what he wants. The attitude of the federal government screams at the Indian, "Yours is not to reason why but to do as I bid." (Cardinal 1969, 140).

Similarly, First Nations writer Howard Adams' "Prison of Grass" is also critical of Canadian society and the federal government. Adams devotes the majority of his book to highlighting many of the same issues Cardinal had raised five years before, especially, the history of land seizure, the social problems created by colonization, and Aboriginal peoples exclusion from Canadian society (1975, 67-8). Adams reminds us that "For the Indians, reserve life meant the end of basic freedoms such as speech, assembly, franchise, and civil rights. They were not even allowed to leave their reserve without written permission from the government agent, who could grant or deny a pass on the basis of personal whim" (1975, 69). Adams explains the many phases and layers of oppression but describes the suffering by Aboriginal peoples as victims of colonialism. Adams describes specifically the colonizing process as it directly affected and altered traditional Aboriginal societies located within Canadian borders.

In short, the release of the White Paper triggered the rise of national and provincial/territorial Aboriginal organizations as advocates in the arena of high politics.

The high politics of debates concerning Aboriginal rights and land were paralleled by a growing policy preoccupation with the poverty of Aboriginal peoples. Aboriginal writers of this period confronted a changed political environment in which the same colonial practices still prevailed.

The Trudeau era also saw ground-breaking developments in dealing with the problem of land and Aboriginal title. Abele and her associates have noted that “the modern era of treaty-making begins in 1973, when the Supreme Court of Canada ruled in the Calder decision that Aboriginal land rights and title continued to exist in Canada” (1999, 264). In the Calder decision, six of the seven Supreme Court justices determined that Aboriginal rights that were not exclusively outlined in the Royal Proclamation of 1763 but were in fact pre-existing the Declaration, Hence, what came to be termed aboriginal rights were inherent principles of possessing land that could only be extinguished through agreements between First Nations communities and the Crown..

Former Grand Chief of the Assembly of First Nations Ovide Mercredi and First Nations Judge Mary Ellen Turpel presented a comprehensive analysis of this point in their book “In the Rapids: Navigating the Future of First Nations” where they argued that the Royal Proclamation of 1763 did not create Aboriginal rights, rather it recognized them as pre-existing. Mercredi and Turpel maintained that:

Our peoples were placed on this land by the Creator, with a responsibility to care for and live in harmony with all her Creation. By living this way, we cared for Earth, for our brothers and sisters in the animal world and for each other. Fulfilling these responsibilities meant we governed ourselves, and lived a certain way. This is the source of what we call our inherent right of self-government (1993, 31).

First Nations scholar John Borrows has more recently argued that the Royal Proclamation is part of a treaty between First Nations and the Crown which stands as a positive guarantee of First Nations self-government (Borrows 1997, 155). Borrows argues that Aboriginal rights survived to form and sustain the foundations of the First Nations/Crown relationship and to inform Canada's subsequent treaty-making history (1997, 156). These sentiments are consistent with many treaty Nations during the first period in the evolution of self-government.

Thus, the Calder decision of 1973 was ground breaking because the court recognized Aboriginal "nations" as being self-governing. The decision epitomizes the turning point in Canadian/First Nations relations and the pursuit for self-governance. Michael Asch has argued that the Calder decision forced the government to reverse its policy that in 1969 was assimilationist and failed to recognize Aboriginal rights as existing (Ash 1997).

Re-balancing of Power: Government and Academia's New Stake in Self-Determination

In the early 1980s, the federal government was beginning to take it upon itself in deciding what might be entailed in providing First Nations authority consistent with the idea of self-government. Newhouse points out that "Academics were for the first time becoming seriously interested in the exigencies of self-government, further distancing the community-based organizations from the debate" (2001, 15). Aboriginal scholars and writers were also re-examining the idea of self-government being defined as an inherent

right. Newhouse continues to argue that “This resulted in many of these writers for the first time clearly equating self-government with self-determination and Native independence within the confines of Canada” (2001, 16). “Pathways to Self-Determination: Canadian Indians and the Canadian State” by Long, Little Bear and Boldt was the first academic work dealing exclusively with self-government. Much of the literature by various First Nations writers in this book explored the complexities of self-government while laying the foundation for what these writers saw as theoretical incongruities between how the federal government was beginning to approach the questions concerned with Aboriginal self-government and how First Nations approached the issue. The writers in this volume recognized the importance of community-based participation and the necessity for an informed Aboriginal citizenry.

First Nations scholar Oren Lyons discusses the philosophical basis of Aboriginal self-government and notes:

The primary law of Indian government is spiritual law. Spirituality is the highest form of politics, and our spirituality is directly involved in government. As chiefs we are told that our first and most important duty is to see that the spiritual ceremonies are carried out. Without the ceremonies, one does not have a basis on which to conduct government for the welfare of the people (1984, 5).

Lyons further argues that the current system of government is detrimental to First Nations people and suggests “A society in which decisions are made with reference to four-year election terms will encounter many problems” (1984, 7). For Lyons, the natural law prevails regardless of what any international tribunal may decide. Thus when a government develops laws to rule the people, it must frame those laws in accordance with

the natural law, otherwise the laws will fail (1984, 12). Similarly, Marie Marule's discussion of the Aboriginal philosophy is also enlightening and conveys important messages that parallel those of Lyons. She writes, "We still have a chance to shape our institutions so they will conform to our traditional philosophies and ideologies and to adapt these to contemporary times so they will be useful as they were previously to our community" (1984, 44). Marule proposes a model of government available to Aboriginal peoples that places the locus of authority in the smallest political unit, family clan groups and band communities. What is most interesting about the arguments proposed by Lyons and Marule, is a constant desire to develop structures and processes of government that are based on Aboriginal thought and that reflect Aboriginal ideas.

A further theme that emerges in this discussion of self-government, is that Aboriginal writers at this time saw their communities not as bands on reserves, but as nations. Tom Porter has argued for example that:

Traditional Indian government is foolproof because it is based on integrity, justice and real democracy. We are talking about the nationhood that God gave us, nothing else, because we are the Indigenous natural people. We in the East, the Iroquois, are having nothing to do with Canada's Constitution or the American Constitution, because the Creator gave us our own Constitution over one thousand years ago. When Indian leaders seek Indian government, they take the guidance of the Creator (1984, 21).

Similarly, Del Riley has noted "We are nations within Canada, and have not given up our sovereignty. We have shared with Canada and have given all we can give. In order to meet our objectives, Canadians must now share with us" (1984, 163). Rudolph Rysler further analyzes the relationship between selected Indigenous nations in various parts of

the world to the governments of the countries in which they are found. Ryser concludes that “nowhere does a model of relations exist between Indigenous populations and nation-states that is acceptable to Indigenous peoples” (1984, 27). There are, however, hundreds of examples of nation-state and Indigenous-nation relations where the dominant political and economic interests used deception in ways aimed at the elimination of Indigenous nations. For Ryser, there are Indigenous populations that carry out governmental activities as separate and distinct peoples, but too many feel they must ask the nation-state to give them the power to govern themselves (1985, 35). Thus, according to Ryser, it is up to the people to take the initiative to assert their nationhood to the rest of the world; it cannot survive by asking someone else to allow it to exist. For many Aboriginal scholars in the 1980s, important questions were raised for the first time relating to self-government; the idea of self-government in Canada was becoming viewed more and more as a legitimate pursuit.

Non-Aboriginal writers were also attempting to define self-government and to understand the issues of Indigenous peoples with respect to self-government. There was a wide variety of views as to what Aboriginal self-government meant, ranging from “nationhood” to local school boards. Diverse and conceivably conflicting views were evident amongst various scholars. Noel Lyon’s work entitled “Aboriginal Self-government: Rights of Citizenship and Access to Governmental Services” was a useful starting point for examining these questions. Lyon provides a controversial analysis of the citizenship rights of Aboriginal peoples, and what rights and government services

Aboriginal peoples would gain, or relinquish, with the establishment of self-government.

Lyon defines self-government as “an attempt to shift the real power of decision and the administration of public services to native communities” (1984, 2). He proposes a series of concise propositions about Aboriginal self-government. Some of these included the right to determine who is a member of the community; the idea that no single model of Aboriginal government is possible, given the great variety in culture, size, location and other circumstances among Aboriginal communities; the right of Aboriginal peoples as Canadians to essential public services; and that governments, especially Ottawa, will have to restrain the impulse to control everything of importance (Lyon 1984, 67-8). Lyon is clear in his belief that Aboriginal governments will be shaped by the distinct cultural values and traditions of Aboriginal peoples and will do for them what provincial and municipal governments do for other Canadians. Cultural diversity combined with the sharp differences between all Aboriginal cultures and the majority culture in Canada means that the model of self-government that Lyon proposes is fairly comprehensive, capable of responding to each particular community and to the basic needs of its members. It is up to each community to determine for itself the form of government, the process for establishing it and the priorities and levels of service in basic matters like health, housing, education, social services and economic opportunity (Lyon 1984, 5).

Similarly, Rick Ponting addresses the question: What effect will Aboriginal self-government have on the attainment of Aboriginal aspirations, especially at the level of local communities? Opponents of constitutional entrenchment of self-government fear

that benefits of self-government might not be experienced by all members of the community. However, Ponting argues that the full benefits of self-government cannot be matched by mere administrative and programmatic factors. He addresses these concerns and uses as a vehicle the concept of community social vitality. Ponting adopts this concept from Matthew's work on the resettlement of outport communities in Newfoundland. Ponting notes "There, Matthews demonstrated that the lack of economic viability of a community need not necessarily entail that community's demise as a sociologically viable collectivity" (1986, 359). Matthews work further demonstrated that a threshold level of social vitality may be a prerequisite for, or a cause of, both political efficacy and economic vitality. Ponting concludes that:

There are sound sociological and social psychological reasons to expect that even for those Indian self-governments that are only mildly successful the net sociological impact of Aboriginal self-government on individuals will be profoundly positive – that their communities will experience fundamental gains in social vitality that will be reflected in positive changes in the lives of individuals (1986, 362).

One of the main thrusts of Aboriginal aspirations is the desire for greater self-determination and social justice. Ponting notes "The discussion of the reclamation of lost leadership potential suggests that Indian self-government will undoubtedly give Indians greater control over their own destiny" (1986, 366). The second point was identified by Ponting as economic development. He argues that, "Many aspects of this discussion of community social vitality have touched indirectly on this – for instance, the breaking of the welfare dependency syndrome; the greater validity of policies based on legitimated and localized decision-making procedures; the attenuation of alienation and the increased

sense of individual and collective pride; the forging of a role for the private sector; and the reclamation of temporarily unavailable leadership potential” (1986, 366). Ponting maintains that all of these factors provide grounds for hope for the success of economic development.

The final factor Ponting addresses is the retention of Aboriginal culture. Ponting points to the revitalization of the schools and the resurgence of cultural pride and the flow of symbolic expression in government ceremonies. In the end, Ponting suggests that although some failures are inevitable, Aboriginal self-government is quite feasible sociologically (1986, 366-367).

David Hawkes and Evelyn Peters also provide an overview of self-government, touching on a variety of important issues. In contrast to the work of Lyon and Ponting, Hawkes and Peters examine the practical problems associated with self-government agreements. Two main themes emerged in their work: obtaining adequate funding, and ensuring adequate processes and structures for implementation. Hawkes and his associate defined self government as “the fusion of the will of the people to be self-governing, and having the financial resources to meet that goal” (1986, 7). Hawkes and Peters found that when self-government legislation associated with the James Bay and Northern Quebec agreement came into effect in 1975, Canada’s first modern Aboriginal land claim settlement, neither the federal or provincial governments, nor the Aboriginal peoples were aware of the actual costs involved (1986, 7). The authors have noted that “Although the James Bay Cree have not found the scope of their jurisdiction to be a problem, their

experience demonstrates the limitations of non-justiciable funding arrangements” (1986, 8). The James Bay Cree also found that implementation was hindered by a lack of coordination among federal government departments, as well as within them. Hawkes and his associate continue to point out that “each department or branch struggled independently to meet the terms of the agreement, but each lacked the appropriate authority or expertise” (1986, 8). Thus, while Lyon argues that Aboriginal peoples’ right to self-determination is an inherent right and includes the right to define membership in Aboriginal communities, Hawkes and Peters take a much more cautious approach concentrating on the problems of making self-government legislation a reality after agreements had been signed.

Political Scientist Roger Gibbins discusses a set of issues surrounding the implementation of Aboriginal government and brings the discussion one step further than the one presented by Hawkes and Peters. Gibbins argues that recognition of the principle of self-government does not mean that Aboriginal government is feasible or even desirable. Instead, implementation confronts some major problems of institutional design. Gibbins focuses specifically on citizenship and on political and intergovernmental problems associated with self-government. These problems are related to conditions which Gibbins argues should be imposed on the constitutional entrenchment of Aboriginal government and which would significantly narrow the scope of that government.

The first problem Gibbins addresses is citizenship with regards to taxation. While Aboriginal peoples would likely argue for a tax exempt status based on their surrender of Aboriginal title and paying taxes to their own government, this would gather large dissent from many Canadians. He addresses the potential backlash from non-Aboriginal Canadians and notes:

There are potential political problems with the Canadian public's reaction to a "free-rider" status. This reaction is troublesome in that it could undermine political support for fiscal transfers from the governments of Canada to Indian communities. Second, Canadian governments will insist on the power to tax non-Aboriginal residents of Indian communities and are very unlikely to tolerate Indian communities serving as Canadian tax havens that shelter individual and cooperate entities from federal and provincial taxation (1986, 370).

The broader concern for Gibbins is that continued dependency of Aboriginal governance on fiscal transfers from the larger Canadian community gives federal and provincial governments the power to force Aboriginal compliance with conventional taxation (1986, 370).

Gibbins further argues that the localized structure of self-government is not feasible and would have to be more reflective of Canada's federal system of government. Gibbins suggests for example that "Integration will require a 'senior' Indian government that will be able both to bargain with other governments and to enforce intergovernmental agreements within its own constituent communities" (1986, 373). Given that self-governments would be forced to work hand in hand with the Canadian federal state, Gibbins concludes that a structure similar to that of the Canadian and provincial

governments would ease the transition of implementing institutions within Aboriginal communities.

The third and final argument raised by Gibbins involves problems associated with protecting individual and collective rights. Gibbins maintains that the Charter of Rights and Freedoms is most vulnerable in a small, homogeneous community. Because of the close bonds shared by members of the community, Gibbins fears that scenarios will play out whereby the good of the community is put before the right of the individual. Gibbins' concern is that "Within such communities, individual rights and freedoms may come under intensified pressure from the majority community. Moreover, the small size of Aboriginal communities coupled with extensive kinship ties may prevent any effective separation of powers and may encourage nepotism and corruption" (1986, 375).

While Gibbins offers a carefully reasoned critique that is particularly applicable to forms of self-government based on Aboriginal sovereignty, Gibbins' emphasis on the protection of individual rights offered to Aboriginal peoples and others by the Charter of Rights and Freedoms is problematic. First Nations lawyer Roberta Jamieson in a strongly worded critique has noted that "such protections are weakened by the ability of any province to exempt itself from certain provisions of the Charter, and that Canadian governments do not have a 'shining record' of having protected Indians' individual rights in the past" (1988, 131). Jamieson also addresses Gibbins' concern about how Aboriginal governments could be accommodated in the web of intergovernmental relations. She points to the great creativity and multiple special provisions that Canadians have

demonstrated or devised in the past in making special arrangements among governments (1986, 132). She observes, for example, that “Quebec collects its own income tax and manages Canada Pension Plan funds but British Columbia does not. Constitutional provisions on French exist for New Brunswick, but not Alberta. You have overlapping or shared jurisdictions. The constitution even guarantees flexibility to the provinces on the form their governments may take” (1988, 135).

In short, while the concerns raised by Hawkes, Peters and Gibbins are not totally unfounded, and although Aboriginal self-governments face numerous challenges, self government can also be expected to bring multiple benefits to the grassroots Aboriginal population in terms of numerous aspects of community social vitality as demonstrated by Lyon, Ponting, Jamieson and other First Nations scholars.

Thus, what one sees from the literature in the 1980s is that Aboriginal participation and control over the issue of self-government was quickly diminishing while the idea of self-government would now lie with the federal government as demonstrated by many non-Aboriginal scholars. It is somewhat ironic that non-Aboriginal academics during this period were becoming gravely engrossed in the debate. As a result, this involvement further detached community-based organizations from the negotiation table despite the attempts made by Aboriginal scholars and writers to continue the battle.

Partnership and Joint Governance: A Multilevel Reality

By the 1990s, it was clear that academics and grassroots Aboriginal leaders were rejecting the Canadian government’s concept of self-government and in return were

determined on having this right recognized as an inherent right rather than a delegated right. First Nations scholar Gary Potts notes:

Not only was the push for self-government being established on the basis that it was an inherent right, treaties were now being promoted as containing provisions that recognize the right to self-government...on a nation-to-nation basis that First Nations are sovereign nations under their laws (1992, 35-6).

Newhouse points out that “Whether or not the First Nations were sceptical of government motivations or just intent on formalizing the concept of self-government for future negotiations, there was no reduction in the amount of work or number of reports being produced” (2001, 24).

One of the most notable reports Newhouse is referring to is the Royal Commission on Aboriginal Peoples (RCAP). In the wake of the Oka Crisis and the failure of the Meech Lake Accord, the federal government of Brian Mulroney appointed RCAP in August of 1991. The Commission finished and published its final report in December, 1996. The RCAP report covers every aspect of Canada-Aboriginal relations in a sustained and remarkably integrated analysis, including a detailed synopsis on Aboriginal self-government. Implementation of the report has been uneven and opinions amongst scholars about the report’s approach vary; these approaches will be discussed below.

Unlike the grassroots vision of self-government which sees each separate nation as capable of negotiating its own self-government provisions within Canada, RCAP suggests that only once the reconstitution of up to 80 Aboriginal nations takes place and their formal recognition as nations occurs can they exercise their right to self-government and sphere of jurisdiction implicit in section 35 of the Constitution Act of 1982 (Ladner

2000, 85-6). First Nations scholar Kiera Ladner is critical of RCAP's approach and argues that RCAP's vision of Aboriginal governance is one of negotiated inferiority (2001, 241). Ladner points to several of RCAP's major shortcomings. For example, she notes that "RCAP places limitations upon the right of self-government. Such limitations include the continued application of the Canadian Charter of Rights and Freedoms and a test of 'good governance'; meaning that any government must have the three basic attributes: legitimacy, power and resources" (2001, 245). Many Aboriginal peoples would argue that the provisions of the Charter represent a continuation of the colonial legacy and the forced imposition of western Eurocentric values and traditions on Aboriginal communities.

A second and related problem that Ladner refers to is the recommendation by RCAP of a third chamber of parliament, an Aboriginal Parliament, which would be similar to the Canadian Senate and which would act in an advisory capacity on matters of Aboriginal concern (Ladner 2001, 247). Again, it appears that much of the RCAP vision is inconsistent with the vision of governance to which many Aboriginal peoples aspire.

Finally, Ladner disagrees with the manner in which RCAP has framed the entire question of Aboriginal nationhood and its position on reconstituting nations. Ladner points out that "RCAP's position is that nationhood is intrinsically linked to size as a measure of capacity, or to the existence of economies or units of scale; that is, to political entities large enough to both warrant and exercise of good governance" (2001, 249). Ladner is quick to argue that the majority of students of nations and nationalism do not

cite size as a component of their conceptualizations or definitions. Ernest Renan has also argued that “a nation is a soul, a spiritual principle. Only two things constitute this soul, this spiritual principle. One is the past, the other is the present” (1994, 17). Daiva Stasiulus and Nira Yuval-Davis further add to this debate by suggesting that there must be a common destiny within this political project (1995, 19).

In the end, Ladner argues that RCAP does not adhere to Aboriginal aspirations and assumes that Aboriginal peoples are not true nations but bodies of people that can be re-organized as Aboriginal nations that exercise the delegated powers and responsibilities of inferior governments, regardless of what treaties say (Ladner 2001, 260-1). Though RCAP spends much time developing models and explaining why self-governance is necessary for developing capacity and meeting community needs and aspirations, it never fully explains the relationship between governance and community well-being or how increased self-determination impacts communities in crisis. It is simply assumed and affirmed but never measured and no indicators for measurement are advanced (Ladner 2009).

Similarly, Patricia Monture-Angus argues that “even a Royal Commission is a construct of colonial power...to be true to First Nations processes would require an opportunity for communities (as communities) to come to a consensus on what the solutions are” (1999, 12). In her view, less emphasis should have been placed by the Commissioners on what the Canadian government would accept. This concern severely limited the opportunities and vision of the Commission at the same time as it created a

pressure toward status quo solutions and processes (Monture-Angus 1999, 12). Monture-Angus contends that the notion of self-government is too narrow because it is imagined within colonial meanings—only allowing a limited form of self-management over Aboriginal poverty, misery, and oppression. She advocates for the articulation and development of Aboriginal self-determination and sovereignty—defined and informed by Aboriginal peoples according to their values, experiences, and histories.

Similarly, McDonald and Depew have also added that the national model as promoted by RCAP is a dangerously naïve strategy (1999, 357). Political Scientist Alan Cairns is less concerned than Ladner, Monture-Angus and McDonald and Depew, although he points out that RCAP's undertaking of finding a place for Aboriginal nations in the constitutional order to exercise self-rule overlooked the connectedness of the system (Cairns 2000, 158). For Cairns, the grassroots reality of the RCAP report portrays massive interdependence, which for Aboriginal nations means massive and unavoidable dependence. He continues to argue that, "The Commission's large constitutional nation-to-nation vision clashes with its separate analyses elsewhere of the realities of interdependence in numerous concrete policy areas at the local level. The Report's macro-and-micro-perspectives appear to be driven by different logics that do not meet" (2000, 159). However, it must be noted that Cairns passionately supports the idea of Aboriginal people as "Citizens Plus", the need for a strong common citizenship as well as the survival of a distinct modernizing Aboriginality in self-governing communities.

The Inherent Right to Self-Government

In 1995, an inherent rights policy was developed by the federal government subsequent to a comprehensive consultation process with both Aboriginal representatives and provincial and territorial governments. The objective of the Policy was to ensure that Aboriginal people have greater control over their lives, and at the same time recognises that the most just and practical mechanism for achieving this is through negotiated settlements (Indian and Northern Affairs Canada *Federal Policy Guide: Aboriginal Self-Government*, 1995). As such, the Canadian Government agreed to constitutionally protect particular aspects of self-government agreements as treaty rights under section 35 of the *Constitution Act, 1982*. The implementation of the inherent right was intended to create First Nations governments that operate outside the *Indian Act*. Governments, First Nations and observers all agree that the regime established by the *Indian Act* is a badly outdated formula which rests on colonial assumptions about the First Nations-Crown relationship (Dacks 2004, 672).

While all sides condemn the *Indian Act*, it has not proven possible to repeal it, for lack of agreement on what would replace it. Moreover, there is a difference of opinion among scholars and the Aboriginal leadership concerning explicit constitutional entrenchment of the inherent right to self-government. As noted above, the Royal Commission on Aboriginal Peoples accepted that this right is recognized in the Constitution. However the Assembly of First Nations prefers to have the right to self-government stated directly so that there can be no doubt by governments whether the

right exists (Assembly of First Nations, Discussion Paper on Governance 2001, 16). Also, the federal government has pursued a very active policy of devolving to First Nations the design and delivery of programs that it formerly administered (Abele, Graham and Maslove 1999, 282-283). However, these powers are exercised under the *Indian Act*, which decrees that the Minister of Indian and Northern Affairs (INAC) can veto decisions of band councils, alter their form, suspend their operations or terminate them (Dacks 2004, 672). Brizinski argues that Canada's recognition of the inherent right to self-government is little more than a policy on rights rather than a legal definition of those rights which is essentially the negotiating position of Canada. It sets out what Canada is willing to negotiate in a self-government package and that there is no room for sovereignty. Accordingly, the policy suggests that Aboriginal jurisdiction must be harmonized with existing municipal, provincial and federal jurisdictions (Brizinski quoted in Newhouse 2001, 30). Other academics during this time have argued that self-government should be a national priority and it should be practised through the constitutional process when it becomes available and also within the constitutional framework (see for example Hylton 1999; Morse 1999; Slattery 1992). Brown and Kary have also noted that "there is potential for adaptation in the federal system to meet the requirements of Aboriginal government as well as the ways in which Aboriginal political culture and institutions can help to redefine the meaning of Canadian Federalism" (1996. 120).

In summary, the 1990s was a period of negotiations and reports. Academic writings during this time further advanced the need to define self-government. Scholars began to examine what self-government was and how the Canadian government could more effectively integrate this principle into its political and legal agenda. Also evident in the literature at this time was that the government began to emphasize that self-government was an inherent right. Again missing from this discourse were the grassroots and political voices that were prominent three decades ago in the construction of the self-government ideal.

Current Debates on Aboriginal Self-Government: Where do we go from here?

In the 1990s, First Nations wanted self-government outside the *Indian Act* on the basis of the inherent right. The contemporary role of legal scholarship is fleshing out Aboriginal rights, in searching for and finding constitutional space for the future exercise of a third order of Aboriginal government. Important questions and objections continue to arise, however, concerning the implications and the feasibility of such systems of governance.

In his book “First Nations? Second Thoughts”, political scientist Tom Flanagan has generated strong reactions from those interested in political and legal decisions on Aboriginal rights. In the opening of the book, Flanagan describes the existence of what he calls an “Aboriginal orthodoxy . . . widely shared among Aboriginal leaders, government officials and academic experts” regarding the basic assumptions of Canadian Aboriginal policy. Flanagan sees this orthodoxy as a tight, interlocking series of mutually supporting

propositions (Flanagan 2001, 4). If this orthodoxy is pursued, Flanagan warns that “Canada will be redefined as a multinational state embracing an archipelago of Aboriginal nations that own a third of Canada's land mass, are immune from federal and provincial taxation, and are supported by transfer payments from citizens who do pay taxes” (2004, 5). Flanagan’s book challenges this framework as unworkable and ultimately destructive towards Aboriginal people. Flanagan continues to argue that we lack systematic evidence about what works and does not work in the area of band government. He poses the following questions:

Why do some communities seem well administered, entrepreneurial, and fiscally responsible, while others seem prone to patronage, factional in-fighting and chronic overspending? Is it just a question of local leadership? Do cultural differences among First Nations also make a difference? Are some organizational structures more effective than others? (2001, 51).

Flanagan is also concerned that with the onset of self-government; on each reserve, he suggests, the Aboriginal elite will do well for itself by managing the cash flow of government programs and enterprises, but most people will remain mired in poverty and misery (Flanagan 2001, 55). In the end, Flanagan’s solution is that of assimilation. He notes:

In order to become self-supporting and get beyond the social pathologies that are ruining their communities, Aboriginal people need to acquire the skills and attitudes that bring success in a liberal society, political democracy, and market economy. Call it assimilation, call it integration, call it adaptation, call it whatever you want: it has to happen (2001, 47).

Flanagan’s book appears to be a contemporary version of the 1969 White Paper. For Flanagan, “self-government increases the incidence and severity of communities in crisis

by causing further marginalization, reducing the leadership and governing capacity and exacerbating poverty of Aboriginal peoples” (Ladner 2009, 92). I would suggest that “First Nations: Second Thoughts” argues for a post-imperial Canada and is insensitive to the need for some positive policy response to Aboriginal difference. Similarly, Cairns (2000) and Widdowson and Howard (2008) have also argued that self-government will negatively affect and result in situations of communities in crisis.

In his article “Implementing First Nations Self-Government in Yukon: Lessons for Canada”, Gurston Dacks takes a less controversial approach than Flanagan and raises important questions of how First Nations should divide energy and resources between pursuing inherence and strengthening the capacity of their existing institutions. Dacks argues that the Yukon experience diminishes the promise of powerful and meaningfully self-determining governance that First Nations see in the principle of inherence. He points out that Aboriginal peoples confront profoundly difficult questions as they contemplate the future directions that the pursuit of self-government should take (Dacks 2004, 674). For Dacks, the question of staffing First Nations governments raises a critical factor limiting their ability to broaden their jurisdiction. This factor is human capacity. According to Dacks, “First Nations no longer merely deliver a limited array of programs. Their responsibilities have grown and they want to assume additional areas of jurisdiction. Moreover, they want to redesign the programs that they formerly delivered, but that were defined by Indian and Northern Affairs” (2004, 678). These changes represent more self-determination; however, they also require staff with the expertise and

skills needed to allow them to succeed. Dacks continues to argue that “the skills required are technical, ranging from financial management to geology and social work...chiefs and councils need new skills to enable them to work with other governments on the basis of equality rather than the *Indian Act*” (2004, 678).

Dacks also argues that the small number of Yukon First Nations people and their relatively low level of educational attainment also places limits on the availability of individuals with expertise necessary to fill the administrative needs that the arrival of self-government has created (Dacks 2004, 678). Adding to the problem is the pattern of First Nations governments hiring and training First Nations staff only to find that a number of them leave to take up positions with the Government of Yukon, the federal government or private-sector employees. These positions tend not only to be better paid, but also to be unencumbered with the frequent drawbacks of employment with First Nations which include short-term contracts, other sources of employment insecurity, and the stresses of trying to meet high expectations with limited resources.

Dacks further argues that “to the extent that it is relevant in their situations, First Nations need to negotiate power-sharing and other-co-operative relations with other First Nations, public governments and private sector agencies that may enable them to capture the efficiencies that new public management concepts promise” (2004, 691). This process will take a long time to accomplish and to delay it in favour of emphasizing inheritance will affirm and honour the fundamental self-definitions of First Nations and serve as an empowering experience for them (Dacks 2004, 691). However, the Yukon case illustrates

a delay in developing the institutional strength needed to address the pressing economic and social challenges facing First Nations people today. Dacks concludes by noting “the Yukon experience with implementing self-government presents even more starkly the difficult choice that First Nations already face between inherence and institution-building, and between birthright and pragmatism” (2004, 291).

In short, the views of Flanagan and Dacks are important efforts in creating substantial debate around the current situation of Aboriginal peoples in Canada and do in fact point out some of the contemporary implications of self-governing processes, including the feasibility of such systems of governance. However, these scholars must not simply treat Aboriginal people as a subject. Their works must include Aboriginal people as participants and leaders.

Other scholars who examine Aboriginal self-government agreements in Canada are critical of such agreements examining their colonial underpinnings but provide a cautiously optimistic tale of the potential empowerment of Aboriginal peoples to gain more control of their communal lives outside of government confines. According to Taiaiake Alfred, most of Aboriginal peoples’ energy thus far has been focused on escaping state control and on securing legal and political recognition for Indigenous governing authorities. He asks, “What will an Indigenous government be like after self-government is achieved?” The hope is that Indigenous governance structures will reflect Indigenous cultural values, but the fear is that they will instead model current colonial structures by incorporating European concepts of sovereignty and power (2001, 5). Alfred continues to

argue that “in most cases, these agreements create new bureaucracies and put in place new levels and forms of government based on the colonial model, or new capitalist relationships with non-Indigenous business partners. These new arrangements benefit a few people, mainly elected officials, entrepreneurs, lawyers, consultants, and, to a much lesser extent, the people who staff the various structures” (2005, 30). For Alfred, large-scale statist solutions like self-government and land claims are irrelevant to the root problem.

In her book, *Navigating Neoliberalism: Self-Determination and the Mikisew Cree First Nation*, Gabrielle Slowey analyzes political and economic decisions facing the Mikisew Cree First Nation (MCFN) around Fort Chipewyan, Alberta in the context of global neo-liberalism. Slowey bases her study on experiences gained during a summer work term at Fort Chipewyan in 1997, and on her subsequent policy analysis and follow-up visits. Slowey’s argument suggests that neoliberal globalization may have positive consequences for some First Nations communities because the government is largely taken out of the equation. It is through the minimization of government, Slowey argues that First Nations communities can foster greater prosperity through participation in the market and thus further their movement towards self-determination. While Slowey’s research provides provocative arguments and interesting information (particularly on MCFN governance), Clinton Westman criticizes her data as thin:

although Slowey draws on her field time to offer insights about the MCFN community, there is no discussion of ethnographic methods, reflexive considerations of the researcher’s role, or research ethics. Rarely are MCFN

members quoted at length, although interviews appear to have been central to Slowey's methodology. Indeed, much of her data comes from anonymous interviews with representatives of government or industry (2011, 172).

Furthermore, it is not clear whether Slowey believes that neoliberal globalization will have negative or positive outcomes for communities. Thus, she sidesteps questions of First Nations' agency and of the possibility of other advocacy solutions.

Daniel Salée and Carol Lévesque (2010) argue that a new type of advocacy is emerging for Aboriginal communities, one that is not reliant on the state. Aboriginal peoples have the ability to positively impact their communities by reversing colonial domination toward the "re-appropriation and control of key instruments of collective empowerment" (2010, 102). Their argument pertains specifically to Cree communities that have taken over control and management of forest resources. Thus, the authors suggest that the Cree have largely succeeded in reversing the colonial domination to which Aboriginal peoples have been submitted. The authors claim that their research "offers a defence for an analytical stance that appreciates First Nations' political and policy choices from the perspectives of what they actually mean for the communities involved rather than from the point of view of normative and theoretical absolutes" (2010, 99). Although these are interesting examples of a growing advocacy, Salée and Lévesque caution that not all communities have the same sort of natural resources available to them and thus makes this type of advocacy a limited one. In the end, Daniel Salée and Carol Lévesque suggest that self-determination is not a concept that is agreeable to all communities. They write:

Ours is a plea to appreciate First Nations' political and policy choices from the perspective of what they actually mean for the communities involved. The content of recognition and self-determination will vary according to time, place and actors. Where nothing short of full self-determination will do for some, a more moderate, conciliatory, "work-within-existing-institutions" approach might be sufficient for others. In the end, the priorities of the communities concerned, the way they understand and envision their future and development has to be respected and should be the main focus (2010, 126).

Using the concepts of dysfunction theodicy and social suffering, Stephanie Irlbacher-Fox examines three case studies involving negotiations between Canada and the Dehcho, the Délînê, and the Inuvialuit and Gwich'in First Nations in the Northwest Territories. Dysfunction theodicy is described as Canada's Aboriginal policy that positions Indigenous people as the cause of their problems and the state as the source of redemption. Social suffering is an analytical category used to examine the consequences of institutional oppression, injustice, and inequality. Dahshaa is a Gwich'in word and refers to the process of finding rotted, dried spruce wood. Irlbacher-Fox argues that this form of wood is a precious good, integral to the final stages of tanning moosehide. It requires an expert to be able to locate dahshaa, which is similar to tanning in that it requires a training process, learning not only the skills but also the underlying values of being a tanner. Irlbacher-Fox draws on tanning as a Dene framework that can be used for interpreting self-government negotiations between parties with different worldviews (2010, 44). She writes, "Similar to the way that impatient neglect of specific steps required in the tanning of moosehide can reduce the effectiveness of the overall tanning process, decontextualized policy approaches to negotiations can undo much effort at relationship repair both before and after the event" (2010, 151). The author draws insights

into how moosehide tanning helped provide a window into what self-government could be psychologically, spiritually, and culturally (2010, 172). Irlbacher-Fox argues that they do not want to be “Aboriginals,” defined and controlled by the Canadian government. Ultimately, her analysis of the power relationships within these negotiations shows how the state attempts to use coercion to get the Dehcho to agree to Canada's predetermined outcomes. Irlbacher-Fox's ten years of ethnographic accounts can also be read as a manual for how to carry out respectful and appropriate research with Indigenous peoples.

Thus, from the literature over the past four decades, several gaps can be identified. The first is that for the most part, the voices of grassroots Aboriginal peoples are now absent from the self-government discourse. A second gap suggests that there is a lack of consistent and systematic examination of what Indigenous ideas of political thought are. Finally, the majority of academics continue to focus on the philosophical possibilities of self-government, rather than developing more practical models and strategies for its implementation. Academics pay little attention to what is occurring at the negotiation table. Through the use of community-based, participatory research and using health as an area of study, my research engages in discussions of community visions of the future at the local level.

Paradigm Shift or Paradigm Paralysis?

While it is difficult to dispute the fact that much has changed on the surface of Aboriginal-state relations, whether such change represents genuine progress is an issue that continues to be intensely debated. When discussing the same set of developments and

policies in Aboriginal-state relations over the last four decades, some scholars see a paradigm shift (Russell 1996; Abele and Prince 2002). These scholars suggest that from the now infamous 1969 White Paper on Indian Policy that sought to abolish Indian status and make Aboriginal peoples “full citizens of the communities in which they live” to the negotiation of treaties and self-government agreements in British Columbia, Yukon and elsewhere, the shift in discourse and policy is indeed remarkable. Other scholars see a paradigm paralysis and emphasize the extent to which the federal Aboriginal “policy paradigm” has remained stagnant (Alfred 1999; Ladner and Orsini 2003).

Political scientists Kiera Ladner and Michael Orsini employ a neo-institutionalist concept of path dependency and argue that Canada’s Aboriginal policies are deeply set in a long-standing colonial paradigm. This stagnation so thoroughly pervades the whole bureaucratic and political mindset that it has become virtually impossible to bring about any real modification of the unequal dynamics of power relations between Aboriginal people and non-Aboriginal Canadians. A kind of bureaucratic and political inertia is at play, casting Aboriginal people as inferior, subaltern beings. As a consequence, the establishment of a truly egalitarian relationship between them and the Canadian state and such that any possibility of renewing Aboriginal governance is blocked (Ladner and Orsini 2004, 2005). Such an explanation steers us on a different and, in many ways, more promising path to understanding why things hardly ever change for Aboriginal people. Alfred (1999), and Turner (2004) take a similar position and argue that recent policy changes are more adequately depicted as a “readjustment” of the various mechanisms

deployed by the state to maintain a hegemonic position to constrain Aboriginal self-determination within the boundaries of existing constitutional norms established by the dominant society.

Following Michael Murphy, it would be fair to say that the current changes in Aboriginal policy are at least partly the result of conflicting visions in which the standard of “change” is measured. If one starts from the standpoint of past policies which have included the Indian Act, residential schools and other assimilation projects, it is clear that things have changed. However, if one measures the standards of critical postcolonial theories and Aboriginal self-determination claims, the picture is obviously much less clear. These disagreements over the nature of current dynamics are also a sign of a broader problem in the academic literature on the relationship between Aboriginal peoples and the state. Murphy argues that this debate continues to be clouded by the wide gap that exists between the theory and practice of Aboriginal self-determination. He points out that there are many excellent discussions of Aboriginal rights and self-determination from the perspective of normative and legal theory (see Borrows 1997; Tully 2000; Kymlicka 2001). However, there are far too few examples in the literature that link normative questions with detailed case studies (Murphy 2003, 8). For Murphy, analysis needs to be “supplemented by research into the actors, institutions and policy developments that are closer to the level of implementation and the day-to-day functioning of the relationships between Aboriginal peoples and the state” (2005, 8). Similarly, Kiera Ladner argues that there has been little written on the nuts and bolts of

implementation. She writes, “Instead, a growing body of literature had developed in law and politics that engages theoretical debates pertaining to matters of constitutionality (jurisprudence and legal, historical and political justification) and scope” (2009, 92). Similarly, Frances Abele and Michael Prince argue that perspectives on the relationship between Aboriginal peoples and the state put much emphasis on the “high politics” of constitutional recognition, rights interpretation and treaty negotiations, perhaps to the detriment of empirical analysis of dynamics “on the ground”.

Aboriginal Self-Determination and Health: Understanding the Impact of Self-Determination on Community Wellness

Where current policies allow, most First Nations and Inuit communities have some form of self-determination with respect to health where services are delivered by organizations controlled by Aboriginal people (this will be discussed in more detail in chapter 4). Policies have emerged validating “by Indigenous for Indigenous” health services and public funding has been allocated specifically to support these organizations. These policies have become understood as an endorsement of Indigenous self-determination.

Ever since contact with the Europeans, Aboriginal communities and nations have sought to retain and regain control over areas of their life. As previously argued in this chapter, for the past forty years, Aboriginal communities have advocated taking over control of government services offered in their community (Belanger and Newhouse 2008). Self-determination is to be used to replace earlier policies of assimilation, by

promoting Aboriginal participation in policy development and in service delivery (Belanger and Newhouse 2008).

Self-determination in health matters can mean Aboriginal communities finding a way to have a voice in provincial and territorial political and health care systems. Thus, in the health field, the implementation of self-government has implications for the administration of services and the general well-being of Aboriginal peoples and ultimately, for the renegotiation of the political space Aboriginal peoples occupy within their political landscape (Belanger 2008). Acknowledging this goal requires securing increased control over local services and implementing mechanisms to ensure that Aboriginal peoples have a voice within their respective governments (Lavoie et al. 2008).

Even though there is some apprehension surrounding the idea of providing what can be seen as preferential support for services on the basis of ethnicity, and shifting levels of political commitment, Canada continues to defend its support of “by Indigenous for Indigenous” controlled services as the preferred mechanism for alleviating inequalities experienced by Aboriginal people. The need to promote Aboriginal participation in policy and program design, as well as service delivery, is constantly emphasized. Self-determination can lead to choice and flexibility in Aboriginal organizations pursuing local priorities. Contracting has emerged as the main implementation mechanism for these forms of self-determination. Within the Canadian context, the government’s accountability framework is insistent on well defined contractual agreements, with standardized performance indicators that can be aggregated regionally and nationally to

ensure appropriate performance monitoring (Health Canada 2004). Securing additional funding for Aboriginal health from Parliament is more readily achieved by identifying nationally-defined health gains that elicit sympathy (the elimination of Diabetes, for example) than by suggesting additional funding to be used by Aboriginal communities as they see fit. Flexibility in contractual arrangements appears to go against the prevailing ideals of accountability in public administration and public perception of appropriate interventions. It is here that an apparent contradiction with self government occurs. As a result, the area over which choices may be implemented, and the right of the state to rule on the appropriateness of certain choices, remain matters of debates. Such debates mean that self-government remains an area with blurred and re-defined boundaries that builds on conceptual paradoxes rather than clear objectives (Lavoie 2005).

Health has never received the kind of attention from scholars, particularly those in political science and public policy, that other aspects of self-determination have generated. Because the urgent need to improve the economic situation of Aboriginal peoples logically underlies all other questions, scholars have given these debates the most attention. It would seem that improvements in health, through changes to the health care system, are not likely to be as dramatic in the absence of more basic changes in the socio-economic position of Aboriginal peoples (Waldram, Herring and Young 2006). What I argue, however is that some of the changes related to health policy definition and delivery are just as important as the longer standing ones related to economic development and constitutional arrangements. It is important to examine the historical relationship between

governance and community wellness in order to understand its contemporary manifestation. Keira Ladner writes, “Doing so provides a foundation for understanding both this relationship and the continued existence of communities in crisis, for it allows us to see how the destruction of Indigenous systems of governance continues to impact the health of communities and a community’s ability to cope with crisis” (2009, 88).

Indigenous conceptions of governance differ strongly from the political tradition which emerged in Europe, including the British parliamentary system of government dominant in Canada (Ladner 2006). European systems of government were designed by and designed to maintain the privilege and power of those ‘superior beings’ who claimed dominion over the earth and the right to rule other humans anywhere in the world. They are systems of hierarchy, power and authority. By contrast, Ladner points out that:

Within the parameters of Indigenous thought, governance is “the way in which a people lives best together” or the way a people have structured their society in relationship to the natural world. In other words, it is an expression of how they see themselves fitting in that world as part of the circle of life, not as superior beings who claim dominion over other species of humans (2003, 125).

For example, the Blackfoot Confederacy created a complex web of clan, society and bundle structures (spiritual beings) of governance at the sub-national, national and confederal levels. Each of these operated within its set area of responsibilities or jurisdictions and in a manner defined and confined by their own constitutional order (Ladner 2006, 3). In the meantime, the Plains Cree had a more individualistic system of government made up of a council of family representatives with societies and institutions having a more limited role than the Blackfoot political system (Ladner 2006). These are

just examples of two Indigenous groups in Canada. What they illustrate is that prior to colonization, Indigenous systems of governance had the capacity, tools and authority to deal with particular situations of crisis within their communities. Ladner argues “institutions were responsible and accountable, and operated in accordance with consensual governance as it was operationalized and institutionalized in each nation’s political system” (2009, 89).

Indigenous governance was traditionally viewed in terms of creating peace and living the best way possible. Taiaiake Alfred argues that Indigenous nations were made up of strong families that supported each other by intense extended affiliations and the supportive networks of clans. He writes,

Our people put a priority on knowledge and Indigenous intelligence; they were always thinking and constantly assessing the possibilities of growth and adaptation to new realities. They possessed spiritual power and were guided in the conduct of their lives by their Indigenous customs and religious beliefs. They were unified in their communities and in their actions...Reciprocity and mutual obligation were the foundations of human interactions and of relationships with other elements of creation. This created the kind of solidarity that allowed them to withstand the challenges of survival in harsh physical environments and against evil forces – that allowed them to survive intact as people and as nations (2005, 84).

Even with the chaos, crisis and community breakdown that resulted from colonization, many Indigenous systems of governance were able to provide for the survival of nations by minimizing crisis and providing leadership and guidance. The fact that self-determination was a factor in community wellness and communities in crisis historically can be seen in the negotiations of both Treaty Six and Treaty Seven. Both the Cree and

the Blackfoot leadership agreed to sign the treaties in so far as the Crown would help them in keeping whiskey traders out. The relationship between the Blackfoot and the American traders was viewed as having a negative impact on the nation and the source of much of their health crisis at the time. Being rid of this destructive relationship was seen as a way of facilitating the reestablishment of good governance and healthy communities (Ladner 2009). Following the establishment of reserves which fractured Aboriginal identities on both a personal and collective level, traditional systems of governance continued to have some success in their efforts to help communities cope. For example, both the Blood nation and the Blackfoot confederacy defended their cultural and spiritual autonomy from the Canadian government's efforts to shut down the Sundance (Ladner 2006). Similarly, many communities achieved great economic success in the early reserve years, largely due to the development of a highly competitive agricultural industry on reserves throughout Canada.

Despite the early success in facilitating the adaptation and in guiding communities through the crises of life under a colonial regime in the nineteenth century, Aboriginal peoples were phased out of Canada's growing resource economy and the Canadian government developed an agenda of political and cultural genocide (Ladner 2009). The government gave its support to the growing settler populations arising from immigration, a policy that had grave consequences for aboriginal peoples who were "in the way of progress" .. Ladner writes, "however one chooses to look at, or candy coat this practice of

regime replacement, the fact remains that the Canadian government chose to impose their own system of governance over both Indigenous nations and their lands” (2009, 90).

Regime replacement did not provide for better government or governments that were more capable of dealing with unhealthy communities; rather Indigenous populations were forced to accept the reserve system, the loss of their land, the loss of their sovereignty, the the elimination of historic economies. They were placed in residential schools while suffering from mass unemployment, the demise of their culture, and the destruction of their communities by means of violence, alcoholism and starvation (Ladner 2009). Regime replacement was intended to provide for easier government control and administration for the federal government by depriving the traditional tribal leaders of their position and by imposing an elective system of government as it saw fit. The elected Band Council were regarded as the means to destroy the last vestige of the old tribal system, what the first Indian Act termed as the “life chiefs”, and thus the traditional political systems of First Nations peoples to select their leaders (Tobias, 1976). Ladner writes,

band councils were not provided with the tools, jurisdictions and structures of accountability that are typically associated with government. Such that band councils have no decision-making ability that is not subject to the authority of the federal government, no inherent or constitutionally defined jurisdictions or responsibilities and no ability to generate revenue or to create the financial capacity to operate as a government aside from government transfers and income from band owned businesses.

Thus, ultimately, the federal government through its Department of Aboriginal Affairs and Northern Development still has the authority through various means to override all by-laws.

Currently, the band council system functions within the confines of designated jurisdictions which provide a façade of government, that is, governments which have the ability to address the problems, needs and aspirations of communities (Ladner 2009). In reality, this is just a false impression on behalf of the government as band councils continue to function within the same system that defined and confined them in the past. While band councils have the ability to operate schools and other services within the community, they simply do not have the capacity to act and respond to community needs. Band councils become accountable and financially dependent on the federal government (Ladner 2009, 91). What this situation means is that in terms of ensuring healthy communities, band councils are simply unable to respond to community needs and thus cannot assure that resources and programs are provided to respond to community needs. Thus, even when a band council attempts to forge ahead, facilitating healing and well-being within the community, more often than not, the council lacks the resources or the ability to govern. However, this situation changes when a band government overcomes its legitimacy crisis and leadership discrepancy and increases its capacity to govern (Ladner 2009).

Limitations of the current literature on self-determination

As Keira Ladner points out in her article entitled “Understanding the Impact of Self-Determination on Communities in Crisis”, much of the literature including the works of Henderson (1994, 1996, 2000, 2006 and 2007), Ladner (2001, 2003a, 2003b, 2003c and 2009), Borrows (1994, 1997 and 2002), Barsh and Henderson (1996), Little Bear, Boldt, and Long (1984), Brock (2004) and White (2002) does not directly address the impact of self-determination on community wellness. These works on Indigenous governance and self-determination have largely focused on treaty federalism, Aboriginal tenure and dialogical governance and do not discuss in any measurable way the impact of increased self-determination will have on healthier communities. There are only a few scholars within Political Science who have more substantively made the connection between self-determination and community wellness. For example, Mercredi and Turpel framed self-government as a requirement for poor and powerless communities who lack responsible government and who are unable to govern within and to respond to the needs of their communities. For these authors, self-government will serve to heal communities in crisis and will create capacity for communities to manage internal disputes and address broader issues of individual and community wellness.

Similarly, the Harvard Project on American Indian Economic Development finds that there is a positive relationship between good governance and community well-being and more importantly finds that nation building is a requisite for successful economic development. The Harvard Project illustrates that communities who face situations of

crisis can be transformed through increased self-determination thus effectively demonstrating the power of self-determination and the importance of this relationship. Similarly, several policy institutes such as the Institute for the Research on Public Policy (IRPP), and the Canadian Policy Research Networks (CPRN) are engaging in important projects that examine the correlation between community wellness and its relationship to governance. In a paper from the CPRN, Frances Abele provides a rich synthesis of the diversity of Aboriginal peoples in Canada and the challenges facing them. She notes both those challenges which also confront non-Aboriginal Canadians and those that affect most particularly the futures of Aboriginal peoples (CPRN 2004, iii). Abele argues that policy innovation in the form of changes to the Indian Act system of government is necessary if community health is to change for the better. In the meantime, in a paper for the IRPP, Papillion examines the influence that the James Bay Northern Quebec Agreement and the ensuing self-government agreements have had on the quality of life among the Cree and Inuit. Papillion finds that while there has been some measurable positive impact, results have been mixed.

What is most interesting about these two articles is that while Abele explains why changes to the Indian Act are necessary if real change is to occur at the community level, Papillion is quick to remind us that increasing self-determination by changing the political system will not occur unless other changes in terms of human and fiscal capacity are not properly dealt with. However, both of these authors point out that there are institutional realities that work against self-determination and the ability of communities to enhance

their resiliency and more effectively deal with the health of their communities. Ladner writes,

even if a leader or group of leaders were to engage within the band council system who simply unilaterally exercised increased powers of self-determination (creating responsible and accountable governments), their capacity to govern with a long-term vision and/or engage and sustain long-term commitments (community development) is completely diminished by the two-year election cycle mandated by the Indian Act (2009, 96).

While changes to the electoral system in Manitoba are currently being proposed, these changes still leave the Indian Act system of government virtually unchanged (Ladner 2009).

In the meantime, there exists a growing body of literature outside the confines of the governance literature which offers further insight into the relationship between self-determination and community wellness. This literature suggests that there is increasing recognition that control is an important determinant of health independent of poverty, physical environment and other social determinants of health outcomes (O'Neil et al. 1999). The widely referenced Whitehall studies (see for example Marmot et al. 1978; Marmot 2002) have provided important evidence to suggest that individuals who feel that they have a higher level of control over the conditions of their work life have better health regardless of income levels. In Canada, Chandler and Lalonde have produced an important and provocative study showing that lower suicide rates are found in First Nations People in British Columbia who exhibit higher levels of cultural continuity, which is defined as a higher level of sustained control over the cultural and political processes in the community (Chandler and Lalonde 1998, 200). More recently, Chandler,

Lalonde, Sokol and Hallet have also identified knowledge of language as well as “band level measures of community control over the delivery of health, education, child protection and policing services, and the achievement of a degree of self-governance” as protective factors in suicide variability, and thus community well-being and resiliency (2007, 392). Examining the literature as a whole, it becomes clear that there is a relationship between self-determination and community well-being and that self-determination may in fact be a determining factor in the health of a community. While Indian act governments are described as lacking legitimacy, many leaders within their communities have demonstrated that some resemblance of responsible and accountable government can be attained without getting rid of the Indian Act. They do so by emphasizing self-determination, taking control of the machinery of government within the community and thus emphasizing community priorities, needs and aspirations (Ladner 2009). It is not necessarily about programs and policies but about leadership with vision and the capacity to make important change that reflect the health of the community and promote resiliency. What such visions entail are highly contested within the literature. For example, Ladner argues in *Burnt Church*, New Brunswick that several women within the community challenged the state of crisis that had ensued. As a result, community members joined together as a community in search of the means for economic well-being, and began to talk about and rebuild their rights as a nation (2009, 94). This example of political mobilization illustrates that increased self-determination can positively affect the health of the community. Additionally, this example shows how leadership

operationalizes responsible government. Thus, the importance of my research lies in its ability to bridge the literatures of health studies and political science. As noted above, governance and self-determination with regards to health are covered independently by these two disciplines. In contrast, my research examines the interdependence between the two. In the end, the literature supports the notion that self-determination is related in important ways to the health of Aboriginal communities. However, there is little research that factors governance and leadership into this equation.

In the second part of this dissertation, I focus on health policy processes which led to the creation of the Health Transfer Policy and the Aboriginal Healing and Wellness Strategy. An analysis of the development, implementation and evaluation of these health policy processes provides insights into the power dynamics which facilitate partnership and dialogue. Acceptance of Aboriginal difference and shared power are articulated as two key dynamics. I used a case study approach for this research because this approach can provide “a richness and depth to the description and analysis of micro events and larger social structures that constitute social life” (Orum et al 1991, 5). The purpose of a case study includes the analysis of the relation among parts of a phenomenon and of its significance for future events. Such a look to the future is particularly relevant for my research. In the next chapter, we move one step closer to examining these issues in practice.

An examination of the research approach, research context, and research methodology in Chapter three acts a bridge between the theoretical content of Chapter

two and the chapters to follow which address the case studies. The dilemmas articulated previously render research itself problematic; the question becomes how to do research in “an unjust world” and in this instance, when research involves Aboriginal people? Framed in this way, the issue becomes less abstract. This question sets me on a search for an approach to research which connects to the alternative theoretical framework discussed in Chapter two, which overcomes colonial practices and ethnocentric bias in Western research.

Chapter 3

Methods and Aboriginal Protocols: Research With Aboriginal Communities

Research is probably one of the dirtiest words in the Indigenous world's vocabulary.

- Linda Tuhiwai Smith, Decolonizing Methodologies

“At least you’re not an Anthropologist. And don’t expect to work in Aboriginal communities, researchers are not welcome in communities.” These were some of the words of advice that I received from colleagues before embarking on my fieldwork. Thus, the purpose of chapter three is to continue the discussion around Canada’s colonial legacy, with particular attention on the methods that researchers have used to collect and disseminate data. The value of community-based, participatory health research approaches is reiterated throughout this chapter as are the concepts of ownership, control, access and possession. I outline the steps that I undertook over a two year period with the intent of providing a qualitative model that future researchers can use as a launch pad to engage with problems of health care systems.

Aboriginal research designs include a collection of Aboriginal theoretical frameworks, methods and approaches that guide the research process (Porsanger 2004). Thus, the process of employing Aboriginal research designs involves ensuring that the research process is performed in ways that are considered ethical, respectful, applicable, sympathetic, authentic, beneficial and relevant to the experiences of Aboriginal peoples (Porsanger 2004). Kovach argues that all research methodologies contain within them a particular epistemology and that an Aboriginal research design is differentiated by being based around an Aboriginal epistemology or worldview (2004, 55). Aboriginal research

designs commonly focus on social justice, community engagement and action to improve the health and well-being of Aboriginal communities and peoples. The inclusion of a decolonization praxis component within Aboriginal research designs is congruent with the value of giving back to the community.

In tracing the development and uses of community-based, participatory research with Aboriginal peoples, Jackson demonstrated a strong interest in Aboriginal defined and Aboriginal-controlled research approaches. Such approaches emerged with the politicization of Aboriginal organizations (Jackson 2003). Politicization in this context means that research projects take account of issues pertinent to communities in order to foster community development. Thus, community-controlled studies on land use, environmental assessment, and health and social needs were early subjects of such research approaches. Jackson underscores the methodological achievements of these studies for dealing with the technical nature of problems and solutions “through a participatory, investigative process”, employing sophisticated quantitative as well as qualitative methods (2003, 53). Regarding the conduct of research, control over all aspects of the production of knowledge by communities as co-researchers is recognized as essential to cultural survival (Hoare et al 1993, 45-46). The involvement of Aboriginal people as co-researchers is intended to strengthen a community's capacity to do research and develop solutions which advance self-determination. Marlene Brant Castellano and Jeff Reading write:

Writing policy that applies to First Nations, Inuit and Métis peoples in Canada has become more interactive as communities and their representative organizations

press for practical recognition of an Aboriginal right of self-determination. When the policy in development is aimed at supporting “respect for human dignity” as it is in the case of ethics of research involving humans, the necessity of engaging the affected population becomes central to the undertaking (2010, 1).

Linda Smith’s book *Decolonizing Methodologies* sets the scene for an extensive critique of Western paradigms of research and knowledge from the position of an Indigenous and colonized Maori woman. Differences between western and Indigenous worldviews continues to create barriers to meaningful collaboration as does the widespread view that western knowledge systems are superior to other knowledge systems. The recognition that Indigenous peoples have their own understandings, practices and management goals has important implications. Thus, Smith’s book challenges traditional Western ways of knowing and researching and calls for the decolonization of methodologies and for a new agenda of Indigenous research. According to Smith, “decolonization” is concerned with having “a more critical understanding of the underlying assumptions, motivations and values that inform research practices” (2006, 1).

Historically, research within Aboriginal communities in Canada has been problematic in that it has focused on top down, outside in approaches. There has been an assumption of open access to research where Aboriginal people bear the risks, but not the benefits. Ultimately, research is done on the relatively powerless by the relatively powerful. Research – qualitative and quantitative – is used to justify the disempowerment of Aboriginal and other marginalized groups. Dislike of researchers and discomfort with research is not unique to Canada. Indigenous people in Australia, New Zealand and the

United States express similar concerns. Thus, when Linda Tuhiwai Smith's book was published, it began to alter the way that we do research.

We are justly called to task, as researchers, for our responsibilities in scientific colonialism. Researchers are viewed with feelings of distrust by Aboriginal people because of our historic roles in acts of measuring, quantifying, and rendering pathological societies and cultures (Smith 2006). Aboriginal social and kinship structures, language, ritual, music, art, economy, trade, migration patterns, diet, traditional medicines and healing practices were documented in the archives of benevolent researchers. Humanitarian societies, missionaries, colonial administrators and government officials used this regulated knowledge of Indigenous people in order to better control them (Smith 2006).

In the past several decades in Canada, researchers have engaged in a reflexive critique of our relationships to the people we study. In their study on Aboriginal research ethics, Marian Maar and her associates have noted that:

There was a clear and immediate consensus that Aboriginal research ethics and protection of Aboriginal knowledge must be addressed before research can begin, because past research often exploited Aboriginal communities and failed to acknowledge Aboriginal perspectives and values. Such research was often an extension of colonial practices. Outside experts with little or no understanding of Aboriginal people and communities were commonly in control of all aspects of research projects. Without emphasis on a two-way knowledge exchange between communities and researchers, research rarely had a positive impact on Aboriginal health (Maar et al. 2010, 9).

As a result, we have progressively changed our research methodologies in an effort to restore past practices and endeavor to empower rather than disempower the communities

with which we work. Despite these changes, the legacy of unacceptable research practices in Aboriginal communities has yet to be systematically addressed. Many researchers involved in Aboriginal research continue to employ helicopter-style methodologies, i.e., they fly into communities, gather sought after data, and seldom return to the field to discuss the results of our studies. According to the Royal Commission on Aboriginal Peoples (RCAP):

The gathering of information and its subsequent use are inherently political. In the past, Aboriginal people have not been consulted about what information should be collected, who should gather that information, who should maintain it, and who should have access to it. The information gathered may or may not have been relevant to the questions, priorities and concerns of Aboriginal peoples. Because data gathering has frequently been imposed by outside authorities, it has met with resistance in many quarters (RCAP , Vol 3, Chapter 5, 1996).

RCAP had the foresight to know that something like this, i.e., OCAP (ownership, control, access and possession) was going to have to occur. Thus, research will continue to be a dirty word until we revise these patterns. So, how can we improve upon our research methodologies with Aboriginal communities?

Ethics in Aboriginal Health Research: Tri Council and Beyond

One way in which to work more effectively and respectfully with Aboriginal peoples is to recognize and adhere to Aboriginal protocols and ethics guidelines. Noncompliance with Aboriginal research protocols can result in conflict between communities and researchers. Thus, there is a certain vigilance that researchers need to hold and the phrase “nothing about us without us” captures the need for communities and

researchers to work together through a bi-directional process. Elder Peter Waskaha of Saskatchewan writes:

We had our teachings, our own education system - teaching children that way of life was taught by grandparents and extended families; they were taught how to view and respect the land and everything in Creation. Through that the young people were taught how to live, what the Creator's laws were, what were the natural laws, what were these First Nations' laws...the teachings revolved around a way of life that was based on their values (Treaty Elders of Saskatchewan 2000).

In Canada, the Canadian Institutes of Health Research (CIHR) guidelines for health research involving Aboriginal people was a crucial document in which research philosophy and practice were tied to the recognition of fundamental Aboriginal rights and to the need to promote health through research that falls within Aboriginal values and traditions. The CIHR guidelines outlined principles of community-control and self-determination, changing the terms of consequent discussions about research into Aboriginal health. For example, the CIHR guidelines outline a set of ethical principles referred to as OCAP (ownership, control, access and possession) that shapes research conducted with Aboriginal peoples in Canada. Schnarch calls it "a political response to tenacious colonial approaches to research and information management" (Schnarch 2004, 80). OCAP then is self-determination applied to research. OCAP is a way to participate in an Aboriginal created environment that promotes the pursuit of beneficial research and its ethical application (NAHO 2007).

OCAP includes four important principles. The first principle refers to the collective ownership by Aboriginal communities of information about themselves and

their members. This principle states that a community or group owns information collectively in the same way that an individual owns their personal information. It is distinct from stewardship. The stewardship of care taking of data or information by an institution that is accountable to the group is a mechanism through which ownership may be asserted. The National Aboriginal Health Organization writes:

First Nations claim to ownership of their own data is not some strange new aberration. On the authority of their own institutions and laws, governments and academics have long possessed and owned data without really thinking twice about it. OCAP brings the illegitimate owners into the spotlight. Those who most strongly reject the notion of data ownership tend to have control or possession of considerable volumes of it (2007, 12).

Anne Macaulay characterizes the problem:

The trickiest questions in full partnership surround ownership of the data and publication of results. To date, the researcher has had complete control over data and results, but in a partnership, the community expects control over the data, too. Theory becomes reality when results have negative implications and are seen by the community as potentially damaging (1994, 1889).

The second principle includes the authority to designate who controls or makes decisions about research affecting them. The aspirations and rights of Aboriginal people to maintain and regain control of all aspects of their lives and institutions extend to research, information and data. The principle of control asserts that Aboriginal people, their communities and their representative bodies are within their rights in seeking to control all aspects of research and information management processes which impact them. Aboriginal control of research can include all stages of a particular research project - from conception to completion. This principle extends to the control of resources and

review processes, the formulation of conceptual frameworks, data management and so on (Schnarch 2004).

The third principle of OCAP is access. Aboriginal people must have access to information and data about themselves and their communities, regardless of where it is currently held. The principle also refers to the right of Aboriginal communities and organizations to manage and make decisions regarding access to their collective information. These conditions may be met, in practice, through standardized formal protocols.

The final principle refers to possession. While ownership identifies the relationship between people and their data in principle, possession or stewardship is more literal. Although not a condition of ownership, per se, possession (of data) is a mechanism by which ownership can be asserted and protected. When data owned by one party are in the possession of another, there is a risk of breach or misuse. This principle is particularly important when trust is lacking between the owner and possessor. OCAP asserts that Aboriginal governance and self-government imply jurisdiction and control over a full range of institutions and processes, including research and information (NAHO 2004). OCAP asserts Aboriginal authority to control their own research and information. Information can produce prosperity and can serve as the bedrock for policy and planning. OCAP is about enhancing Aboriginal resources. It is about *nation building*.

Thus, it is important and necessary that the OCAP principles should be addressed in a research agreement, to the degree that their guidance coincides with the priorities and

capacities of the parties involved. Ideally, issues of data ownership are worked out at the beginning with specific mechanisms for dealing with conflicting interpretations or inappropriate use of data established at an early phase of the relationship between the community and the researcher and included in the written agreement between them.

TCPS 2 Chapter 9: Research Involving the First Nations, Inuit and Métis Peoples of Canada

In the fall of 2010, the second Tri Council Policy Statement was released with the updated Chapter 9 entitled “Research Involving the First Nations, Inuit and Métis Peoples of Canada”. This statement applied to the three national research funding bodies: Canadian Institutes of Health Research (CIHR), Social Sciences and Humanities Research Council (SSHRC) and the Natural Sciences and Engineering Research Council (NSERC). Chapter 9 of the Policy Statement is one that has particular relevance in Political Science as it has been brought to the forefront of scholarly debate within the last couple of years. Although ethics and appropriate research have long been a conversation amongst scholars in Indigenous Studies and Indigenous health, only recently has it become a contentious area of discussion amongst Political Scientists. There are those who offer support and praise of the Tri-Council guidelines and subsequently OCAP principles, while others see these guidelines and principles as an obstacle to research and the pursuit of truth. A recent roundtable that I attended at the Canadian Political Science Association at Wilfred Laurier University in May 2011 to discuss research ethics and Aboriginal peoples had standing room only. The broadening interest in this discussion of

methodologies only reinforces the continued relevance and significance of this topic within the discipline.

Chapter 9 is designed to serve as a framework for the ethical conduct of research involving Aboriginal peoples. It is offered in a spirit of respect. It is not intended to override or replace ethical guidance offered by Aboriginal peoples themselves. Its purpose is to ensure, to the extent possible, that research involving Aboriginal peoples is premised on respectful relationships. It also encourages collaboration and engagement between researchers and participants. Building reciprocal, trusting relationships will take time.

This chapter provides guidance, but it will require revision as it is implemented, particularly in light of ongoing efforts of Aboriginal peoples to preserve and manage their collective knowledge and information generated from their communities (TCPS 2, 2010). One of the arguments has been that having two sets of guidelines was confusing. As a result, the CIHR Guidelines for *Health Research Involving Aboriginal People* are no longer CIHR funding policy. Health research involving First Nations, Inuit and Métis people in Canada is henceforth governed by the provisions outlined in Chapter 9 of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS). Those who fought hard to keep the CIHR guidelines on Aboriginal health research, have argued that Chapter 9 is a much softer and weaker document than the CIHR guidelines for Aboriginal health research. For example, while research agreements are strongly encouraged, they are not required. Some scholars (Evans, Anderson, Dietrich, Logan)

assert that, though well intentioned, the TCPS 2 may have the unintended effect of marginalizing health research in communities.

Specifically, the understanding of ‘community’ as presented in the guidelines possesses two key flaws which effectively marginalize the access of communities to such an important bulwark of funding: First, it assumes a certain level of infrastructure simply not present in most communities. As such, the TCPS-2 requires application and reporting criteria unlikely to exist in communities in the ways it (apparently) does in those of First Nations. Second, it assumes a ‘landedness’ to community (like specific First Nations or Settlements) which, though conceptually convenient, fails to account for the formation and survival of communities not so easily recognized according to such criteria.

I do believe that research remains a very important tool and is not inherently bad, as long as it is community-controlled, action-based research. The following themes are evident in both the CIHR Guidelines for Health Research involving Aboriginal People and the updated TCPS Chapter 9:

- *Aboriginal people expect a voice in setting research agendas;*
- *Research should be conducted by and for Aboriginal people;*
- *Researchers should consult with an Aboriginal advisory board and the target community throughout the research process. The university-based researcher and Aboriginal community should agree upon objectives and methods;*
- *Aboriginal community members have powers of observation, critical analysis and intuition that should be harnessed in the research process;*

- *The confidentiality of all research participants and the rights to withdraw at any time must be ensured;*
- *Research should not entail the transfer of ownership from informant to researcher; researchers should merely be trustees of community knowledge;*
- *The results of research must be accessible to Aboriginal communities;*
- *Community advisory boards and research participants should be integrally involved in the evaluation of research processes*

Unfortunately, there still remain some research protocols required by funding agencies and university-based ethics committees that ignore or contradict Aboriginal research protocols. Researchers are often required to write detailed research proposals and prepare outlines of interview questions before we have had the opportunity to develop relationships and consult the communities with whom we plan on working. Academics in psychology, sociology and epidemiology are often required to perform clinical trials, experiments or surveys that entail rigid research plans. However, the Aboriginal health researcher who expects to adhere to the same rigid research plan is not likely to get past the door of an Aboriginal community.

These guidelines concerning Aboriginal knowledge affected the way I thought about the research for this dissertation. The current compatibility between participatory, community-based research purposes and conduct and Aboriginal cultural norms provided a basis for earning respect, that most basic principle for the establishment of any relationship. In the remaining sections of this chapter, I highlight some moments of the

research partnership established for this study and the research design which developed as a result of the collaborative process.

Community-Based, Participatory Research (CBPR)

Community based, participatory research (CBPR) is a practice that has been growing steadily in the field of Political Science and other social science disciplines in both Canada and abroad. CBPR is defined as a “collaborative research approach that is designed to ensure and establish structures for participation by communities affected by the issue being studied, representatives of organizations, and researchers in all aspects of the research process to improve health and well-being through taking action, including social change” (Agency of Healthcare Research and Quality 2004, 3). To expand on this definition, it can be further suggested that CBPR involves 1) co-learning and reciprocal transfer of expertise by all research partners, with particular emphasis on the issues that can be studied with CBPR methods; 2) shared decision-making power, and 3) mutual ownership of the processes and products of the research enterprise. CBPR involves a collaborative partnership in which all parties participate as equal members and share control over all phases of the research process (Isreal et al. 1998, 178). As an attempt to leverage the research expertise of universities in the service of community identified needs, CBPR rests on the premise that communities have a need for high quality research but limited resources with which to conduct or purchase those services while universities house significant amounts of research expertise. CBPR thus provides a mechanism through which resources and needs can be matched. In the health field, CBPR is an

approach that is meant to increase the value of studies for both researchers and the community being studied. This approach is particularly attractive for academics struggling to address the persistent problems of health care disparities in a variety of populations (Horowitz et al. 2009).

Done properly, CBPR benefits community participants, health care practitioners, researchers and policy-makers alike. CBPR creates bridges between researchers and communities, through the use of shared knowledge and valuable experiences. This collaboration further lends itself to the development of culturally appropriate measurement instruments, making research projects more effective and efficient. Finally, CBPR establishes a mutual trust that enhances both the quantity and the quality of data collected (Schulz et al. 1998). The key benefit to emerge from these collaborations is a deeper understanding of a community's unique circumstances, and a more accurate framework for testing and adapting 'best practices' to the community's needs (Bishop 1996). One of the challenges of CBPR is to create balance between academic power/control and voice and community power/control and voice. Thus, when we engage in CBPR, we are called to pay attention to the dizzying multiplicity of elements, many that are invisible, and to facilitate healthy relationships and truly shared research agendas.

Thus, it is important to ask 1) what kind of power do I have/hold? and 2) how can I work to ensure equitable participation during my research? It is also important to point out that in many areas in health promotion, researchers and community advocates are beginning to focus their efforts further by encouraging an increased emphasis on policy

changes that facilitate proactive health choices at the individual level. Communities and community partners are becoming impatient with the gap between knowledge produced through conventional research and the translation of this research into interventions and policies to improve health of various groups, especially marginalized groups and Aboriginal communities. CBPR is well positioned to address such approaches through its ability to mobilize community action. Continued efforts aimed at achieving the best possible balance between research methodologies and community collaboration are critical to advancing the field.

Into the Field: Establishing Partnerships and Collaboration

I knew that the most important element in any developmental process was the quality of the relationship I was able to form with the people with which I worked . Unlike instrumental or merely task-oriented processes, I knew that opting for a community-based, participatory research approach would require a great deal of time, energy and investment of myself as a person not just as a researcher. It takes time to develop relationships and for this reason, I began exploring the possibility of pursuing this research at the end of my first year in the doctoral program.

In the fall of 2009, I contacted Dr. Wayne Warry, a preeminent scholar in Canadian Aboriginal health policy in the department of Anthropology from McMaster University to inquire about where and how to begin my fieldwork in Ontario. Dr. Warry suggested contacting community health directors belonging to Mnaamodzawin Health Services Inc. (MHS), the North Shore Tribal Council (NSTC), a group of seven First

Nations linked by road from Sudbury to Sault Ste. Marie in north-central Ontario. Dr. Warry also recommended working with the Manitoulin Island First Nation communities in Northern Ontario. While research fatigue is growing among community members, First Nations agencies and leadership are under increasing pressure to conduct their own research to provide funding agencies with reliable data to support community-based initiatives. As communities are taking over the delivery of their health services, agencies are also in need of reliable research data on the health status in their communities and the effectiveness of their health programs (Guidelines for Ethical Aboriginal Research in the Manitoulin Area 2003, 4). Dr. Warry noted these communities were potentially interesting for my study because 1) the transfer process in the early 1990s is documented in his book “Unfinished Dreams: Community Healing and the Reality of Aboriginal Self-Government” 2) they have a Health Access Centre that supplements on reserve, federally funded services 3) they are fairly research savvy and 4) some, if not all of the communities were undergoing Transfer evaluation, which would make my project timely.

Immediately following my conversation with Dr. Warry, I began writing to health directors belonging to the NSTC communities to propose a study of Aboriginal involvement in the design and implementation of health policy and programs. Early on in my proposal development, I was encouraged to think about broader community-government networks and relationships in Aboriginal health policy. The province of Ontario is considered a leader in the development of Aboriginal community-controlled health care, therefore, fieldwork in Ontario is extremely important for a study of

Aboriginal health policy and politics. I was rejected outright by one community, unanswered by several others, eventually my e-mail made its way to a health and social services director located in a small reserve located outside of Blind River, Ontario. The health and social services director contacted me by phone and expressed interest in my research. I met with him in Niagara Falls, Ontario where he was attending a meeting on Aboriginal health, to discuss my research and interest in working with his community.

Within a six month window, I made several trips to the community, giving presentations to Chief and Council, community members and the Health and Social Services staff regarding my research. I provided community members with information about the purpose of my project, the process of data collection, the responsibilities, risks or inconveniences, and benefits of participation, assurances of confidentiality and any additional information potential community members required or requested. Despite the endorsement of the community health director, when voted upon by the Health and Social Services committee, the committee was not comfortable in making a recommendation to proceed with my research project. The reasons given were a reluctance to make the decision on behalf of the First Nation, and they felt it may be detrimental to the health and social services future initiatives or community at large.

At the time, the decision was highly discouraging as I had spent a considerable amount of time building relationships with community members. In hindsight, however, I can understand the community's reluctance and this is to be expected with community-based research. In addition, the structural blueprints for this community make it difficult

for a researcher to pursue research projects. The tribal council health director has no authority to bind to a regional research project their respective First Nations communities, who are independent entities. The Council receives such requests for research on a weekly basis and they have to refer such requests to the individual First Nations. While they do not have any one within their agency responsible for research, they would like to establish a research unit if funding was available in the future.

A final factor that swayed the community stems from a negative experience involving a land claim agreement with Blind River, Ontario in the early 1990s. Dr. Warry discusses this situation in his book and explains how the process placed enormous pressure on members of the community. Many community members believed that deteriorating relationships with non-Native communities was the cause of immense stress and contributed to the sudden deaths of twelve community members in a year and a half period (Warry 2007, 46). Warry notes how “the aftermath of the claim is still being felt. Resentment among non-Native people...remains” (Warry 2007, 47). In light of this experience, I believe that the community members were reluctant to engage in negotiations with ‘outsiders’ because of this negative experience. This reluctance was evident when I gave my presentation to the Health and Social Services staff. Many had voiced their concerns about the impact my research would have on issues around ownership, control, access and possession.

Throughout this process, I had also submitted an application to the Manitoulin Anishinaabek Research Review Committee (MARRC). The MAARCs role is to review

research proposals and to provide recommendations to the researchers, First Nation communities and/or Aboriginal organizations. On March 5th and 6th of 2001, Noojmowin Teg Health Centre sponsored a community-based health research conference in M'Chigeeng, a First Nation located on Manitoulin Island, to provide a forum for participants to discuss their experiences with health research on Manitoulin Island. Approximately 45 people attended this workshop, which brought together health workers, community members, elders and local as well as university based researchers and students. Participants brainstormed about what makes research ethical from a First Nations perspective and how the goal of ethical research could be realized and thus created a vision for health research (Guidelines for Ethical Aboriginal Research in the Manitoulin Area 2003, 4).

Following the recommendations from this meeting, a working committee was formed to facilitate collaboration among the following First Nations agencies: Noojmowin Teg Health Centre, Wikwemikong Health Centre, M'Chigeeng Health Services, MHS, UCCM Tribal Council and Kenjgewin Teg Educational Institute. This working committee for health research was to develop ethical research guidelines. Noojmowin Teg was identified as the agency responsible for coordinating this phase, since this health centre already had a research mandate and a full time position for a research coordinator. During the summer and fall of 2001, participants created a vision for ethical health research on Manitoulin Island. A working committee was formed to make that vision into a reality with the Guidelines for Ethical Aboriginal Research

(GEAR) were developed. The First Nations in the Manitoulin District have made significant strides in building community research capacity and engaging in research partnerships with university-based researchers (Maar et al. 2009, 3).

What are the pros and cons of a centralized versus a local research committee?

Unlike the North Shore Tribal Council community that I had been negotiating with earlier in the process, the Manitoulin communities have their own research ethics board. The advantages of having a centralized research ethics board means first that it is more generic and standardized which makes it more predictable and second, that it is detached from individual communities which can have both a positive and negative impact. As of August 2005, MARRC had reviewed approximately fifteen research proposals and had recently held a research conference to celebrate ten years of successful research within their communities.

In agreement with the local research ethics guidelines, I obtained ethics review from the Manitoulin Aboriginal Research Review Committee and the research project was approved by local First Nations leaders and health boards. My main community partner for this project has been Elaine Johnston, Executive Director of Mnaamodzawin Health Services Inc. The four principles of OCAP, namely: First Nations ownership, control, access and possession were adapted to fit the context of the study. With respect to ownership and control, my approach emphasized consensus in all aspects of the research process rather than a power relationship between community and university stakeholder. Access to research results was created in the form of research/progress reports and

community and staff presentations. Raw interview and focus group data were held in the possession of the university researcher and with Elaine Johnston at MHS. A research agreement was put in place with the community partner incorporating these four principles.

Manitoulin is the world's largest freshwater island. It is located within Lake Huron and Georgian Bay in North Central Ontario. A bridge on the north-eastern tip connects the island to the mainland. The closest urban centre, Sudbury, is about 160 km away (Maar 2004). Figure 1 illustrates the seven First Nations communities on Manitoulin Island:



First Nations in the Manitoulin District with estimated Aboriginal on-reserve population size in parantheses: Aundek Omni Kaning (320), M'Chigeeng First Nation (800); Sheguiandah First Nation (142); Sheshegwaning First Nation (360); Wikwemikong Unceded Indian Reserve (2,600), Whitefish River First Nation (352), Zhiibaahaasing First Nation (48).

The largest, Wikwemikong Unceded Indian Reserve, has an on-reserve population of about 2,600 while the smallest community, Zhiibaahaasing First Nation, has an on-reserve

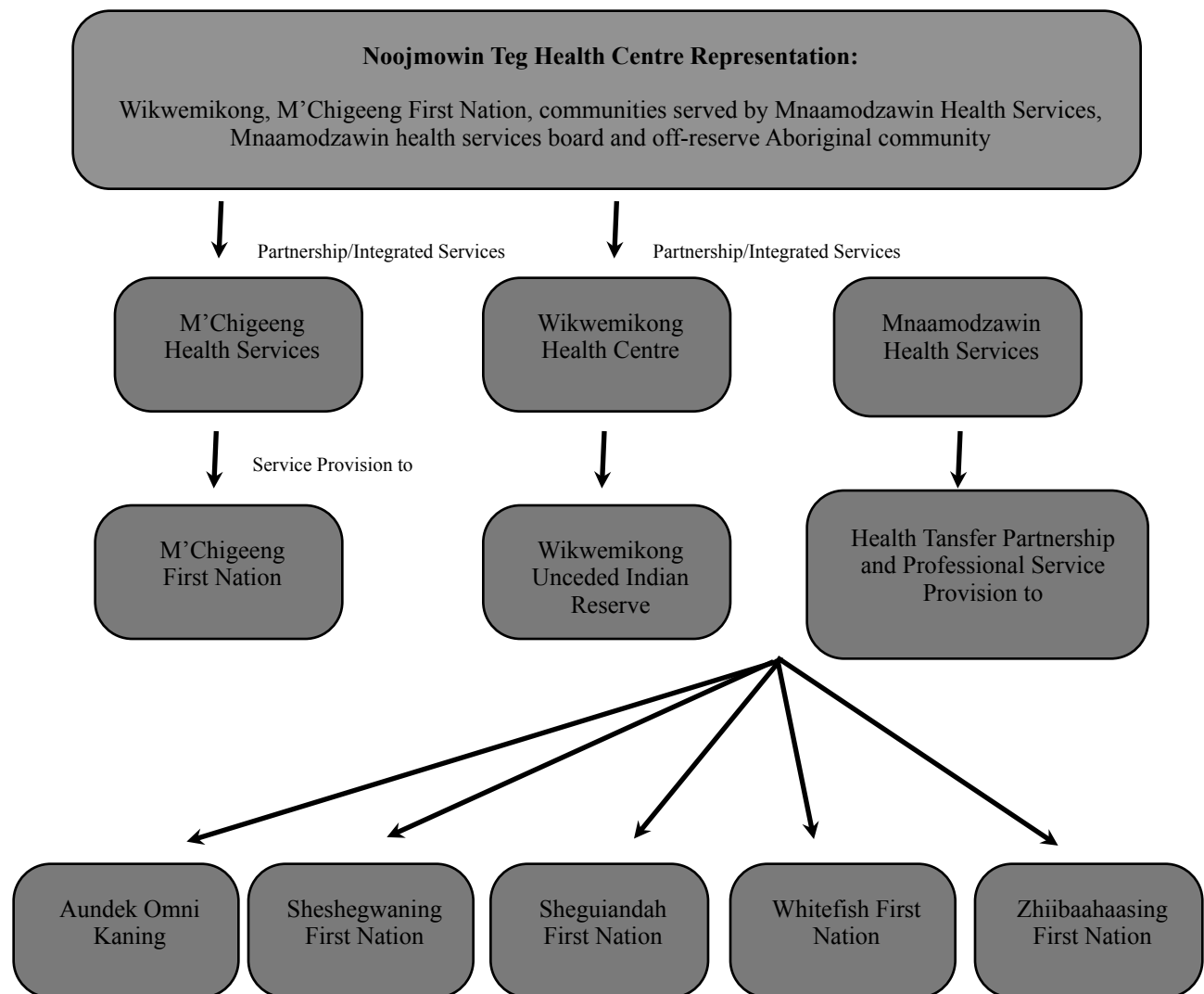
population of less than 50 people. First Nations people account for over one third of the approximately 13,000 local residents and the island's population density is 2.8 people per square kilometer (insert source here...community profile from census 2006). Family physician services are available in several of the larger communities. Most specialized services however are located in the nearest urban centre, at a driving distance of 1.5 to 3 hours from island communities.

There are two regional Aboriginal health organizations. The first organization, Mnaamodzawin Health Services Inc. (MHS), is a regional provider of First Nations community health services. MHS provides services to five First Nation communities – Aundeck Omni Kaning, Sheguiandah, Sheshegwaning, Whitefish River, and Zhiibaahaasing. In order to increase the efficacy of health care services, the First Nations and MHS entered into a transfer agreement arrangement. MHS transfers payments that it receives from Health Canada to each community so essentially they may deliver the following community based programs: First Nation Community Health Representative, Brighter Futures/Building Healthy Communities, and National Native Alcohol and Drug Awareness. These funds enable each First Nation to design and establish these community-based programs,. The funds are allocated according to MHS priorities;. The funds help ensure maintenance of community member health and safety by providing mandatory health programs and they strengthen and enhance the accountability of MHS to community members (MHS Regional and First Nations Evaluation Final Report 2004).

The second one, Noojmowin Teg Health Access Centre (NT) is a regional provider of interdisciplinary primary care services. Both organizations place a distinct emphasis on community-based Aboriginal approaches to care and share a home office. While I have been interviewing participants in both of these organizations about their relationship with government in health policy development and implementation, I have also been hired to assist in updating their community health plans, a process I discuss at length in chapter 4.

Complex and fragmented layers of Aboriginal health services already existed in the Manitoulin district when the Noojmowin Teg Health Centre began operation in 1997. In 1994, the seven First Nation communities transferred the delivery of community health services under the federal health transfer policy with three separate agreements. It was feasible and financially advantageous for the two larger communities to transfer individually while the five smaller communities decided to transfer under one agreement, resulting in the creation of three local health authorities. This decision allowed for the smaller communities to share human resources such as community health nurses, a case manager, a mental health worker and administrative staff under one tribal health organization. Other staff could be employed at the community level, such as community health representatives (CHRs), National Native Alcohol and Drug Abuse Program (NNADAP) workers, and clerical support staff, while ensuring health programs were delivered within the guidelines of the mandatory health programs of the First Nations Inuit Health Branch. In 1996, the three transferred health authorities collaboratively

developed a proposal for a provincially funded Aboriginal Health Access Centre (AHAC) under the Aboriginal Healing and Wellness Strategy which would provide specialized health services on a regional basis. Figure 2 provides a diagram of the health care partnerships and service provision model of the federally-funded community health services and the provincially-funded regional AHAC services.



Source: Maar, Marion "Clearing the Path for Community Health Empowerment.", 2004, 54-65

The program objectives for the AHAC were based primarily on community consultations undertaken during the pre-health transfer needs assessment. When the centre first opened in 1998, it collaborated with two other AHACs already in operation and with the area First Nations Chief and Councils, health staff, and Elders to convene a traditional healing gathering at Dreamer's Rock, i.e., a sacred, spiritual site and meeting place located on Whitefish River First Nation (AHAC Report 2010). Together, the group guided the formation of a Traditional Healing Advisory Committee for Noojmowin Teg, composed of Elders and other representatives from the seven First Nations served on the island, including off-reserve membership. At present, the Noojmowin Teg Health Centre provides specialized, community-based services in extended-practice nursing, psychology, nutrition, traditional Aboriginal medicine, physical activity promotion, heart health, health research and program evaluation to seven First Nations communities in the Manitoulin district. Health programs were created to help reconcile community-identified gaps in services.

Although these health programs are urgently needed within Aboriginal communities, the transfer of health programs, along with the increase in other community-oriented programs causes health services to be in a constant state of fluctuation which creates management challenges. On the positive side, First Nations are able to approach service development creatively and experiment with different community-based and culturally appropriate services to local health needs.

Since 1999, traditional healing and medicine have flourished at the centre. The Traditional Healing Program is administered by a Traditional Program Coordinator who guides the activities of local traditional healers and helpers, in a collaborative approach with the seven community services providers and/or traditional programs. Program staff also harvest local medicines, host workshops and coordinate teachings, support research on traditional healing, and provide program support and advice to other Noojmowin Teg health providers. Community participation in traditional healing programs and services at Noojmowin Teg have increased steadily since 1999. In 2009-10, a total of 717 clients accessed traditional healing programs offered through the centre, up from 220 in 2004 (AHAC Report 2010). One of the challenges that continues to persist relates to the fact that First Nations are required to design and deliver programs that function within confined parameters of governmental funding agencies. Funding agencies' working definitions of holistic and culturally sensitive health services often do not coincide with First Nations' visions for the delivery of health care in their communities.

I compare and contrast the Ontario case study with a second First Nations community in Manitoba that operates solely under the federal health transfer policy. It is important to compare these two communities and their experience with differing Aboriginal health policies to illustrate the strengths, weaknesses and paradoxes that surface from the implementation of locally controlled health programs. I have sought to assess whether additional layers of community-controlled initiatives make tangible differences to community wellness and self-determination, particularly for Aboriginal

peoples living off reserve. A key factor in this research are the political relationships and partnerships between the community-controlled health sector and government, at local, provincial and federal levels.

The Manitoba community discussed in this thesis, Tootinaowaziibeeng Treaty Reserve (TTR), is a signatory to Treaty #4 which was signed in 1874. Treaty No. 4 encompasses southern Saskatchewan as well as a small western portion of Manitoba and south eastern Alberta. Treaty No. 4 contains no health-specific provision. A Medical Officer associated with the Department of Indian Affairs was, however, present at the time the Treaty was signed to provide medical treatment to Indians assembled for the signature (Lavoie 2011). The reserve, whose Anishinabe people originally spoke Ojibway, has a land base of 11,535 acres and is located roughly 400 kilometers northwest of Winnipeg, Manitoba. Tootinaowaziibeeng Treaty Reserve was part of the West Region Tribal Council which services seven First Nation Ojibway Communities but has since decided to become independent of the Tribal Council. There are approximately 1,200 registered members with the band, 550 of whom live on the reserve and 650 off-reserve. The Tootinaowaziibeeng Anishinabe health program has evolved over a period of 30 years, from a Health Centre, founded in 1977 and employing one person under the Community Health Representative Program while during this same time period, a community health nurse attended to the community needs on a one day per week basis. The National Native Alcohol and Drug Program became active in the early 1980s and slowly, the Tootinaowaziibeeng health program began to grow with the challenges and

changes in community health needs and issues. It was recognized as an independent entity from Band Administration in 1994, with the hiring of a full time health administrator. Although the Tootinaowaziibeeng health program continues to fall under the jurisdiction of the band leadership, it currently operates under its own direction, administering its own funding and human resources. One Band Council Member is appointed to hold the Health Portfolio, as an official liaison between the Tootinaowaziibeeng Anishinabe health program and TTR Chief and Council.

Tootinaowaziibeeng Anishinabe health is an organization that accommodates several programs and services for community members, most of which are federally funded. As stated earlier, the Health Program remains under the jurisdiction of the community leadership but handles funding for health programming and services directly through an independent accounting system. The health administration also has the authority to develop various initiatives and programs with regard to health within the TTR. The most recent evaluation of the Tootinaowaziibeeng Anishinabe Health Program reviews all programs, initiatives, the administrative system and program delivery, with a primary focus on the Transfer Program Area, which includes: addiction/prevention services, communicable diseases, emergency response, environmental health services, podiatry care, immunization, mental health and prenatal nutrition. Due to the fact that this is an all-inclusive health program, referrals and follow-up clients' require all service providers/program managers to work together, resulting in the responsibility to provide information on all services available through the Tootinaowaziibeeng Anishinabe Health

Program. This arrangement clarifies how each program complements another through communication and delivery of health care for the membership, population and community, while providing qualitative and quantitative data on the Transfer Agreement Programs funded by the First Nations Inuit Health Branch of Health Canada.

I began my research with TTR in the winter of 2010 by establishing relationships with community members and health staff. I grew up close to the community in Roblin, Manitoba and had pre-existing ties with some community members. When I arrived in March 2010, I did some volunteer work and gave the staff and community members an opportunity to observe, evaluate and get to know me. It was important for me to be part of the concrete, daily activities and struggles of the community. Within a month of when I arrived, I was asked to help analyze and respond to government policy statements and helped facilitate the beginnings of a Community Health Needs Assessment Report and evaluation, a process that communities are required to undergo prior to developing their five year community health plan. The Community Based Health Needs Assessment that I developed with the community consultant involved issuing 126 surveys to youth, families, elders, service providers and leadership and included thirty-three recommendations geared toward priority planning in meeting the health care needs of the community. In addition, I also helped with focus group meetings and forums to receive further information from community members about improving and enhancing the delivery of community based health care. I was later hired as the main consultant to update their five year community health plan. It was at this point that I began to feel that I

was an advocate for the community. After presenting the Community Health Needs Assessment report to the community and submitting it to Health Canada, the community kept me on as a full time consultant and I engaged with others as colleagues rather than research subjects. Part of this position involved working with other community consultants interviewing stakeholders about their perception of how things have changed in the health policy arena. As I worked with the community, I conducted a separate set of interviews and focus groups with Aboriginal and non-Aboriginal stakeholders so I could go deeper into an analysis of the relationships between Aboriginal communities and government in policy development, implementation and evaluation. A detailed research agreement was put in place that clarified and confirmed mutual expectations between the community and the researcher.

Research Approach

This study, drawing on community-based, participatory methodology, uses cultural sensitivity as its primary principle. Qualitative research methods were utilized because they were considered appropriate and sensitive to the cultural differences that exist in Aboriginal communities across Canada. Critics of social science methodology argue that the detached observer approach is inappropriate in Indigenous research (McGillvary and Comaskey 1999). Thus, respect for persons and cultures are important elements built into the method. Respect is acknowledged in each of the steps undertaken to gather and analyze data, validate the findings and present research outcomes in ways

which communities find understandable, accessible, and facilitative of their growth and continued development.

One of the difficulties of working with Aboriginal communities is that the timeframe for earning people's trust and demonstrating respect for community interests is unlikely to fit into a researcher's field schedule. While I had well established networks and considerable experience working with Aboriginal people and communities, it still took several months before I could begin the study to gain necessary community approvals. I visited each community, held meetings and discussions with key community members to outline the purpose of the study and to gain the support and trust of the local community members. It was important that community leaders were involved in the proposed design of the research methods. Considerable lead-time was required with time spent in the field before I could proceed with my study and gain the necessary ethics approvals from community members. Time and expense needed to be directed to early meetings with key community leaders to establish mutual trust and respect and to recognize and understand values on both sides. This mutual respect could only be achieved through multiple visits to the field before my study could commence. It took time, care and patience to build a healthy relationship so that partnerships were developed with each of the communities ensuring their involvement in the research process.

As noted earlier, collaborative arrangements with Aboriginal communities are costly in terms of the time taken to consult in the development of the study as well as the

actual delivery. However, the benefits outweigh the costs for all members in the research study. Some of the benefits of partnerships are outlined below:

Benefits at the community level:

- Builds community capacity and resilience
- Increases community awareness of health policy issues, problems and consultation processes
- Creates joint ownership of the issues and problems
- Demystifies research and academia

Benefits for the researcher:

- Gains a deeper level of access knowledge and information
- Opens possibilities for tapping into tacit knowledge of the people themselves
- Gains trust and acceptance of the community
- Gets community support and encouragement

Methods of Data Collection

I sought to make every effort to ensure that community members were not inconvenienced or offended by the methods used to gather my information. During initial discussions, I provided community members with information about the purpose of my project, the process of data collection, I went over the responsibilities, risks or inconveniences, and benefits of participation; I offered, assurances of confidentiality and any additional information potential community members required or requested.

There are many key Aboriginal and non-Aboriginal stakeholders involved in Aboriginal health policy and politics. I conducted interviews and focus groups with 108

people between November of 2009 and December of 2011. I used a snowball selection process: colleagues suggested initial contacts for me to interview and then, during consultations, participants suggested other important stakeholders to contact. Four main interview cohorts emerged in my study:

1. Aboriginal and non-Aboriginal staff of community controlled health services, including Aboriginal health workers, registered nurses, physicians, policy analysts, program coordinators, managers and health directors;
2. Community members both on and off reserve, including Chief and Council and community elders and;
3. Aboriginal and non-Aboriginal government bureaucrats at the community, provincial and federal levels involved in the development and implementation of Aboriginal health policy and Aboriginal affairs
4. Aboriginal Organizations involved in the development, implementation and evaluation of health policy

Table 1 breaks down the interviews and focus groups by category, number and date:

| Table 1 | | |
|--|----------------------------------|------------------------------|
| Interview Group | # of Interviews Conducted | Interview Dates |
| Federal Bureaucrats (Ottawa and Winnipeg) | 15 | November 2009 - January 2010 |
| Provincial Bureaucrats (Toronto) | 18 | January 2010 - December 2010 |
| Chiefs | 7 | N/A |
| Elders | 4 | N/A |
| Health Service Providers (Manitoulin Island) | 17 | April 2011 - December 2011 |
| Health Administrators (Manitoulin Island) | 12 | April 2011 - December 2011 |

| Table 1 | | |
|--|----------------------------------|---------------------------|
| Interview Group | # of Interviews Conducted | Interview Dates |
| Health Service Providers (TTR) | 8 | January 2010 - April 2011 |
| Health Administrators (TTR) | 10 | January 2010 - April 2011 |
| Aboriginal Organizations (National, Provincial and PTOs) | 8 | N/A |
| Others: Community members, Consultants, etc. | 9 | N/A |

Different interview guides were developed for each of the interview groups (See Appendices A through H for the interview and focus group guides and recruitment instruments).

In a conference on Indigenous research methods that I attended in Palsbo, Washington in the summer of 2010, I was struck by a comment that many Indigenous people are not comfortable in most formal interview settings. In response to the power relationship that develops from such a scenario, researchers are urged to hold informal discussions with community members. It was useful to identify in each of the communities the main negotiators and key persons who were able to provide informed perspectives on the evolution of the community-controlled health regime over the past thirty years. The goal was to focus on the participants' conception of community-

controlled health care and the community-government relationships that shape Aboriginal health policy and politics.

Archival research in pursuit of published and unpublished position papers, and policy documents also formed the foundation necessary in order to begin the process of piecing together the puzzle in each community. For each community selected, a number of secondary sources were also used to document the specific institutional context, policy outcomes (impact on communities), the dynamics of negotiation and the general context within Aboriginal and governmental policy communities.

Ethics approval is absolutely necessary in research involving human subjects. Such approval is and should be difficult to obtain. In their Winnipeg study of Aboriginal women and intimate partner violence, McGillvary and Comaskey noted that,

Consent must be fully informed and freely given. Confidentiality must be completely protected to guarantee both privacy and safety. There must be no pressure on potential respondents to participate. The potential for overt or subtle agency coercion of potential subjects, covert withdrawal of services should participation be refused. And the comfort level of respondents must be considered (1999, 176).

Thus, the McMaster Research Ethics Board approved this qualitative study after much deliberation. A qualitative study in the form of interviews and focus groups was chosen to generate discussion by community members, health professionals and administrators and government officials around community-controlled health care. The goal was to begin to unravel the health policy puzzle by mapping some of the key political stakeholders in Aboriginal health and to reflect upon the processes and institutional structures that shape relations between the Aboriginal community-controlled

health sector and government. Focus groups in particular were felt to be the best way to explore community-controlled health care. They enable discussion by permitting respondents to raise both concurring and dissenting opinions. Although, it is certain that some fear regarding speaking up due to community hierarchies exists, in my experience, this format allows respondents to be the most forthright and follow-up one on one interviews were provided for those who wanted an additional layer of privacy.

Protecting research subjects is of utmost importance in studying sensitive topics. Informed consent, lack of deception, protection of confidentiality, and assurance of physical and emotional safety must be closely considered at every stage – consent and the manner of obtaining consent, place of interview, design of the interview schedule, choice of interviewers and immediate follow-up. Rapport between interviewer and interviewee is necessary to ensure comfort and maximize sharing of information. Thus, throughout the dissertation, whenever I insert a person's narratives into my text, I provide general descriptions of the speakers' backgrounds. Those descriptions are intentionally vague because I do not want to betray the privacy of the people I am interviewing. In small communities, it is difficult to maintain anonymity. All interview participants were asked to read and sign a letter of information and consent form or alternatively provide oral consent in order to permit me to use their narratives in my analysis. Only the narratives of those participants who gave their consent throughout the process are included in this dissertation.

As a requirement of the McMaster Research Ethics Board, advertisement posters for the interviews and focus groups were placed, with permission, in community health centres in both the Tootinaowaziibeeng Health Centre and MHS and Noojmowin Teg Health Access Centre on Manitoulin Island. The focus groups and interviews were audio recorded with participant permission and field notes were maintained. The recording was transcribed verbatim and analyzed by the researcher for themes emerging from the text. During fieldwork, at the end of each day of interviewing and conducting focus groups, a formal debrief was conducted with the community partner of each community to discuss how the data collection was going to go over and any concerns regarding the content of the interviews. This debriefing was an important element of the process as participants often gave sensitive personal data. It was important to discuss this information in the debrief with the community partner. A research agreement between the researcher and the community partner ensured that confidentiality would be adhered to (See Appendix I).

The field notes were compared with the transcription to clarify and ensure completeness. An open analytic approach was used initially to explore the content of the text and themes were drawn from the text. I reviewed the transcripts independently. Then, I identified key passages for consideration and compared my findings and came up with larger conceptual categories that seemed to emerge from the text. The larger categories were then used as a basis for coding the text. I actively reviewed and revised the categories using an inductive and iterative process and sought out passages that contradicted the themes. Disagreements were resolved through discussion with the

community partner and those who participated in the study and the findings were then checked with the participants' ideas to ensure that they were represented appropriately.

In summary, it has been necessary to rethink and challenge every aspect of the research process, from research protocols, to advisory committees, informed consent, methodology, analysis, evaluation, ownership of knowledge, publication, etc.

Dissemination of Research

To honour the knowledge bestowed by my participants, I disseminated the research results with presentations on the preliminary findings at the following events: The American Political Science Association (September 2010), the Canadian Political Science Association Conference at Wilfred Laurier University in Kitchener, Ontario (May 2011); and the Indigenous Health Research Development Program Graduate Student Conference (June 2011 and 2012). A second option will consist of distributing the final dissertation to both communities. There are also a variety of options for publishing results from this research including a book/report comprising both the literature review and the empirical findings as a large single volume; smaller booklets based on specific sections; an executive summary; a website; journal article(s) in peer-reviewed journals and fact or resource sheets.

It is also important to point out that oral rather than written descriptions of research findings would be more culturally appropriate, enhancing the accessibility of the research findings among the community. A culturally appropriate means of disseminating the research findings from this project has consisted of a series of presentations and

workshops. Findings were disseminated orally to community members, enhancing the access and engagement of members with these research findings.

The fieldwork component of my research ended when I left the communities. However, my relationships with colleagues have remained and have progressed and evolved into further studies and opportunities. Furthermore, my role - to unite the community-academic divide by working collaboratively with McMaster University and both communities was embraced by non-Aboriginal and Aboriginal researchers. It is my hope that it will be less awkward to admit to being a university researcher in these, and perhaps other, communities in the future.

As a researcher, my original intention to initiate a reflection process with other participants on these important experiences was fulfilled. Secondly, in pursuing this research, a responsibility to act in solidarity was met by “giving back” to the people involved and to a wider audience, especially the Aboriginal communities with whom I engaged. What remained was to fulfill a third obligation to myself and to the academy: by means of the data collected I sought to engage in a sustained and deeper reflection on these important public policy experiences. As far as this dissertation is concerned, these processes are initiated in this chapter by recounting the story of the research partnership which produced the data. In doing so, I meet a responsibility to provide for accountability and transparency in research practice. With this understanding in place, I turn now to Chapter four which describes the two policies before turning to the last three chapters as case studies.

Researcher's Point of Entry

Finally, I am a person who brings particular knowledge, experiences and values to this research. First, I am an Aboriginal person whose experiences and beliefs cannot be divorced from this research and ultimately this thesis. One such belief is that self-determination in Aboriginal communities is related in important ways to improved health outcomes. As a researcher, I will attempt to be objective to the extent possible, invariably however, my worldview will consciously and unconsciously influence my research approach and my interpretation of data. In this same vein, my past experiences working for a National Aboriginal Organization and for the First Nations Inuit Health Branch will likely influence my interpretation of the data. On the one hand, my familiarity with the organizations and with several of the staff will provide me with access to these case studies. On the other hand, this previous experience may bias me towards an acceptance of established attitudes or administrative practices. However, I believe that my knowledge of Aboriginal health gained while working with several Aboriginal health organizations has enhanced my knowledge, awareness and sensitivity to many of the issues intrinsic in Aboriginal healthcare.

Chapter 4

Towards Healthier Aboriginal Health Policies? An Overview of Aboriginal Health Policies in Canada

When the turtle is scared, it doesn't try to get across the road. It pulls its feet in and thinks carefully about what it is going to do next. The symbol of the turtle is how [the Strategy management] have walked these last ten years.

- Elder Lillian McGregor

Introduction

The purpose of this chapter is to describe the history of Aboriginal community-controlled health initiatives, namely, the federal health transfer policy and Ontario's Aboriginal Healing and Wellness Strategy. These are primary health care services tasked with providing services to an Aboriginal community that is perpetually considered high risk. High risk is usually ascribed to socio-economic marginalization resulting from colonization. Aboriginal services are involved in the delivery of non-commercial social goods and are often tied to an Aboriginal governance structure which is primarily designed by Aboriginal people to promote their political aspirations involving a renegotiation of their relationship with the nation-state (Lavoie et al. 2008). Once I determine a general platform of policies which currently shape community-controlled health initiatives, the remainder of the dissertation takes up the challenge of critically analyzing how government-community partnerships around these policies impede or advance the success of such initiatives, especially in the context of Aboriginal self-determination. This chapter will consider some existing gaps and challenges in Aboriginal public health which are likely to continue despite the transfer of control over some

aspects of these problems. The chapter also notes some gaps related to health which may come to fruition under these policies.

There is a continuous desire by Aboriginal people to develop institutions and processes of government that reflect Aboriginal values and ideas (O'Neil et al. 1997). Such institutions and practices in the health field have developed over the past thirty years and are now endorsed and actively promoted by the federal government as a means of increasing Aboriginal participation in health care, improving access and reducing inequities. This pursuit of more aboriginal participation is common among Indigenous populations in Canada, New Zealand and Australia who have sought to secure more control over community-based health services, in the hope of improving access and responsiveness (United Nations 2002). Becoming directly engaged in this way is seen by Indigenous peoples as an expression of their Treaty right (as in New Zealand) and/or Indigenous rights to self-determination and rights that survived colonization (especially in Canada and New Zealand) (Lavoie et al. 2010). Aboriginal communities in Canada have seized upon the opportunity to become primary health care providers. Health Canada reports that as of March 2008, 83% of eligible First Nation communities are now involved in managing their own community-based health services (Health Canada (FNIHB), 2008). While community members have reported improvements in health outcomes (Lavoie et al. 2005), the significance of these improvements is not known. Similarly, despite international commitments to the ideal of community participation in the planning and delivery of primary health care services beginning with the Alma-Ata

program of the WHO triggered in the late 1970s, empirical studies demonstrating the relationship between community engagement and outcomes remain non-existent. Perhaps as a result, “if some key principle of Alma-Ata has been lost more than another, it is that of community participation” (Lawn et al. 2008, 924).

This chapter examines the emergence of Aboriginal health policies and more specifically, the relationship between policy and implementation in Aboriginal primary health care services in Canada. This focus has proven a fruitful area for understanding policy development. I explore two key policies that have emerged and are the primary focus of this thesis: the federal Health Transfer Policy (HTP) and Ontario’s Aboriginal Healing and Wellness Strategy (AHWS). This chapter examines in more detail whether or not these policies more readily reflect Aboriginal aspirations, Aboriginal-state’s historical relationship or other interests. I argue that although both policies are premised around self-determination in health, AHWS is closer aligned with the vision of self-determination that predates colonization while the health transfer policy is more a product of the last forty years of colonial control as described in chapter two.

Aboriginal Health Conditions

Health and wellness entails much more than physical health, i.e., the absence of infectious and chronic disease (Lavoie et al. 2008). From an Aboriginal perspective, good health is viewed as a state of balance and harmony involving body, mind, emotions and spirit. Good health links each person to family, community and the earth in a circle of dependence and interdependence described by some in the language of the Medicine

Wheel (Lavoie et al. 2008). Reports continue to illustrate that Indigenous peoples around the world still bear a disproportionate burden of physical and emotional illness (Bartlett 2003). In the earlier days, Aboriginal Peoples were not only displaced physically from their land, but also they were made subject to intensive missionary activity and the establishment of residential schools, the purpose of which was to assimilate Aboriginal Peoples into mainstream Canadian society. These assimilationist activities undermined the social and cultural fabric that is central to Aboriginal identity, as they forbade families from sharing their cultural practices (dances, ceremonies, language, songs), many of which tied Aboriginal Peoples to features of their traditional environments, such as water, plants and animals (Richmond and Ross 2008).

Currently, Aboriginal populations continue to experience the health effects related to colonial and post-colonial legacies (Abelson 2005). These legacies undermined Aboriginal peoples' cultures, languages and social structures and resulted in widespread marginalization (Anderson et al. 2006). As a result, Aboriginal Peoples face higher rates of injury and accidental death than their non-Aboriginal counterparts. Aboriginal Peoples continue to report being at an increased risk of infectious disease. Chronic conditions are sometimes called the diseases of modernization, or western diseases, because they arise from lifestyles typical of western industrial nations: reduced physical exercise; an over-reliance on foods of poor nutritional quality because of the limited access to alternatives. Cardiovascular disease, cancer, metabolic disorders (diabetes) and respiratory and digestive disorders are significant problems in Indigenous illness and death

(Richmond and Ross 2008). Thus, the picture of health conditions that emerges indicates that Aboriginal Peoples are increasingly living with chronic conditions requiring access not only to primary but also to secondary and tertiary prevention interventions (Lavoie et al. 2008). The disparities in access that are experienced by the Aboriginal population give the lie to Canada's portrayal of its health care system as one of the best in the world. As Janesca Kydd points out, "The sorry statistics for Aboriginal health also underscore how a health care system designed for the majority of the population does not serve the needs of smaller, more vulnerable portions of the population" (2006, 225).

Historical Developments in Aboriginal Health Policy: Transferring Control of Aboriginal Health – From Idea to Ideal

Jacklin and Warry provide an overview of the major economic and policy trends in Canadian health care which are summarized in Table 2, which provides a national context for the changes in Aboriginal health policy.

| | Table 2 Major Economic and Policy Trends |
|-------------|--|
| Year | Event |
| 1961 | Hall Commission recommends that the federal government cost-share a universal medical insurance program with provinces. |
| 1968 | Federal government adopts the Medical Care Act providing universal medical insurance for Canadians. |
| 1969 | The federal government's White Paper proposes the discontinuation of special services for Aboriginal peoples and the assimilation of Aboriginal people into Canadian society. It also proposes that Aboriginal people receive health services from provincial governments. |
| 1970 | The Red Paper is released by the Chiefs of Alberta, demanding their right to receive health care. |

| Table 2 Major Economic and Policy Trends | |
|---|---|
| Year | Event |
| 1974 | The Lalonde Report is released by the federal government. It suggests a broader definition of health. |
| 1974 | The proposed Indian Health Policy is released, proposed (again) the transfer of Aboriginal health services to provincial governments. |
| 1977 | Bill C-37 - Federal - Provincial health care cost-sharing is replaced with block funding. |
| 1978 | Proposed to reduce non-insured health benefits (e.g. dental benefits, prescription medication, and eye care) for Aboriginal people. |
| 1978 | Funding allocated for health promotion at federal level Health Promotion Directorate. |
| 1979 | New Indian Health Policy created based on the Lalonde Report and the World Health Organization's (WHO) Declaration of Alma Ata. |
| 1980s | Block funding for provincial health care is limited, and more money is invested into Health Promotion. |
| 1981 | A proposal to transfer services to Aboriginal communities is approved. |
| 1983 | The Penner Report is released, calling for administration and policy reforms within current legislation to enhance the movement toward self-government. |
| 1985 | The Nelson Report repeats the tenets of the White Paper and reiterates that the priority of the federal government is to fight the deficit . |
| 1986 | The Indian Health Transfer Policy is announced. |
| 1988 | The Indian Health Transfer Policy is approved by cabinet. |
| 1990s | All federal funding is reduced in order to fight the deficit. |
| 1996 | Health Canada adopts the Population Health Model which focuses on economic development as a means to better health care. |
| 1999 | The Health Transfer Policy is revised. |
| 2001 | The Communities First: First Nations Governance initiative , proposing changes to the Indian Act, is announced. |

Adapted from "The Indian Health Transfer Policy in Canada: Toward Self-Determination or Cost Containment?" (217-218) by Kristin Jacklin and Wayne Warry in Unhealthy health policy: A Critical Anthropological Examination, (eds) Arachu Castro and Merrill Singer, 2004, New York: Altamira Press.

There has been a general shift toward devolution of responsibility for health care to the provinces. Prior to the Health Transfer Policy, there was an agenda to transfer Aboriginal health care responsibility to provincial governments. While the federal government has provided care to the Aboriginal population for multiple reasons: to limit the spread of disease to the non-Aboriginal population and on humanitarian and economic grounds (Jacklin and Warry 2004), the federal government has never admitted to its constitutional responsibility for health care of Aboriginal people. In the absence of accepting this responsibility, the country is left with an arbitrary regime where Ottawa could theoretically withdraw its support at any time.

As noted in chapter two, the discourse around First Nations issues changed throughout the 1970s and 1980s with increasing demands for self-determination on the part of First Nations. The first nation-wide initiative to exercise control over colonial medicine occurred in 1978 when the federal government attempted to reduce the provision of uninsured services (examples include prescription drugs and eyeglasses) to First Nations. This action provoked a forceful reaction from Indian organizations such as the National Indian Brotherhood (now referred to as the Assembly of First Nations) which argued that Treaty rights were being abrogated (Abele et al. 1999).

The National Native Alcohol and Drug Abuse Program (NNADAP) was one of the first federal health programs to be developed to function under the administrative authority of First Nations and Inuit communities in 1975. Contributions are given to communities for prevention services, construction of facilities, training and research.

Expenditure on the program – 16 million in 1982-1983 had tripled in 1986-1987 (Waldram et al. 1995, 94). An evaluation of the program suggested that the NNADAP services did not meet community needs. The review also concluded that NNADAP workers required broader infrastructure support such as training, and recognition by management and external agencies in order to be successful. This can be at least partially attributed to funding. The program is funded for service delivery during regular office hours (9 to 5 Monday to Friday) and at pay scales that are too low to attract qualified individuals (Waldram et al 1995).

In 1979, Joe Clark's Progressive Conservative government put forth the first Indian Health Policy which was intended to restore Indian health through community development, a reaffirmation of the traditional relationship of Indian peoples to the federal government and by improving the relationships within the Canadian health care system. The policy was a two page document that could be best portrayed as a statement of values with one broad based objective:

the goal of Federal Indian Health Policy is to achieve an increasing level of health in Indian communities, generated and maintained by the Indian communities themselves (Health Canada 2000).

The policy, which is still in place today, builds on three pillars:

The first, and most significant, is community development, both socio-economic development and cultural and spiritual development, to remove the conditions of poverty and apathy which prevent the members of the community from achieving a state of physical, mental and social well-being.

The second pillar is the traditional relationship of the Indian people to the Federal Government, in which the Federal Government serves as advocate of the interests of Indian communities to the larger Canadian society and its

institutions, and promotes the capacity of Indian communities to achieve their aspirations.

The third pillar is the Canadian health system. This system is one of specialized and interrelated elements, which may be the responsibility of Federal, Provincial or Municipal Governments, Indian bands, or the private sector. But these divisions are superficial in the light of the health system as a whole. The most significant federal roles in this interdependent system are in public health activities on reserves, health promotion, and the detection and mitigation of hazards to health in the environment.

The most significant provincial and private roles are in the diagnosis and treatment of acute and chronic disease and in the rehabilitation of the sick. Indian communities have a significant role to play in health promotion, and in the adaptation of health services delivery to the specific needs of their community. Of course, this does not exhaust the many complexities of the system. The Federal Government is committed to maintaining an active role in the Canadian health system as it affects Indians. It is committed to promoting the capacity of Indian communities to play an active, more positive role in the health system and in decisions affecting their health (Health Canada 2000).

The policy made no distinction between First Nations persons living on and off-reserve, nor did it lead to the formulation of an implementation strategy with short, medium and long term objectives, either under the Conservative or the subsequent Liberal governments. This document has been further interpreted as providing both a stimulus for the recognition of important traditional medicines and for greater First Nations and Inuit control over the delivery of services (Abele et al. 1999).

Another important report emerged in 1979 entitled the “Report of the Advisory Commission on Indian and Inuit Health Consultation” written by Justice Thomas Berger. Justice Berger provided the first systematic inquiry into Aboriginal dissatisfaction with the health care system. He recommended that Indian and Inuit health be addressed separately, given the very different traditions and problems faced by each group.

Furthermore, he recommended that consultation funding be provided to a National Commission inquiry on Indian Health, a subcommittee of which would be responsible for assisting First Nations communities to develop locally controlled health care systems. It is important to point out, however, that while this recommendation was clearly influential, it was ultimately ignored in the end (Abele et al. 1999).

By the 1980s, the First Nations and Inuit Health Branch of Health Canada was funding a series of “demonstration projects”: short term experimental projects on community self-determination in the area of health care service delivery (Health Canada 2004, 2). In 1981, the federal government implemented the Community Health Demonstration Program (CHDP) in an effort to assess the costs, timing and implications of future transfers of control (Begin 1981). The program was portrayed as an exercise of self-determination and was heavily criticized because it was implemented without prior Aboriginal consultation. The program funded a dismal 31 projects and only seven of these projects directly addressed the transfer of community health services. A specific project in Sandy Bay reserve in Manitoba was given a very critical evaluation. It was suggested that local control was lacking in the CHDP and in the end, this lack of local control prevented the creation of a community-based health development plan (Garro et al 1996).

The Canadian Aboriginal Health Care System

To fully comprehend the emergence of self-determination in the area of health, it is necessary to answer two important questions: Who does what? And, who is responsible for what? The answers to the first question are not always compatible with the answers to

the second question. This is because Aboriginal people in Canada receive health care from a complex and at times contested system of services provided through federal, provincial and territorial governments as well as through Aboriginal organizations (sometimes in partnership with one or other levels of government) (Minore and Katt 2007). The Aboriginal health care system is highly complex because it results from a combination of jurisdictional concerns, constitutional interpretations, policies and established practices (Minore and Katt 2007).

Who does what?

Currently, Health Canada's First Nations Inuit Health Branch (FNIHB) provides distinct health programs for status Aboriginal people, i.e., a person defined as an Indian under the *Indian Act*. FNIHB provides \$500 million per year to five major health programs: Community Health Services, Environmental Health and Surveillance, the National Native Alcohol and Drug Abuse Program, Hospital Services and Capital Construction. A sixth program involves noninsured benefits (so-called because they are not covered by provincial health plans); prescription medicines, dental care and eye care are covered for people with status, regardless of where they live. The federal government also provides services normally covered by provinces, such as physician care in remote communities where they would not otherwise be available. Métis and other Aboriginal people who lack a status card have limited access to federally supported health programs, except for some prevention and promotion efforts (Brownell et al. 2007). It is important to point out that while the federal government is often considered to have primary

responsibility for Aboriginal health, most of the services are provided by either the provincial or territorial governments.

As mandated under the Canada Health Act, 1984, the Canadian Health Transfer provides cash and tax transfers to ensure that predictable and sustainable funding is available to provide all Canadians access to health care (Pal 2001). The provinces have constitutional and legislative obligations to provide health care to its residents. As noted above, most of the services rendered to the Aboriginal population (similar to other residents) are those funded by the province such as hospital care, physician services and home care.

A similar situation exists within Canada's territories where the three territorial governments have responsibilities with respect to health care that are similar to those of the provinces. Aboriginal peoples make up a substantial part of each territory's population: 22.9 percent in the Yukon, 50.5 percent in the Northwest Territories and 85.2 percent in Nunavut (Statistics Canada 2001). Minore and Katt point out that "Because the populations are small and widely dispersed – combined with the fact that funds, facilities and clinicians are limited – the territorial governments concentrate on delivering primary health care services. To meet the need for advanced-level care, they have entered into service agreements with various provincial governments" (2007, 7). An example of this kind of arrangement involves the non-insured health benefits program for First Nations and Inuit people which is administered by the Northwest and Nunavut territorial governments, but it has been transferred and is under the control of First Nations and Inuit

communities in the Yukon. The Royal Commission on the Future of Health Care in Canada concluded that “the territories have established a collective citizenship that emphasizes social solidarity for all groups and cultures, but, at the same time, respects the cultural and ethnic differences of their populations” (2002, 223). However, a month before the final Romanow report was tabled, the president of Inuit Tapiriit Kanatami, Jose Kusugak, had already criticized the work of the commission:

The health care system you are reviewing barely exists in the Arctic. It is so far removed from our needs and our reality that as I read the commission’s interim report I often felt as I was reading about a different country...there is a great gap in the quality of health care between the North and South , and it is visible in two areas: firstly the lack of basic programs and services for northern Canadians, and secondly, the absence of Inuit input when health policy is made (Kusugak quoted in Knopf, 2008).

According to Kusugak, many Aboriginal peoples living in Canada’s territories, including the Inuit, feel powerless and intimidated by the existing health care system since they have little input into the design and provisions of health services.

Certain provinces have implemented health programs designed specifically to meet the needs of its Aboriginal citizens. Ontario is one such province in that it administers the Aboriginal Healing and Wellness Strategy, a nationally recognized initiative that takes a wholistic approach to fostering healthy communities. The Ontario government in partnership with Aboriginal stakeholders also initiates pathology specific services, such as the Ontario Aboriginal Diabetes Strategy and the HIV/AIDS Strategy. Or it provides designated funding within broader initiatives such as the Smoke-Free Ontario Strategy. Additionally, Cancer Care Ontario, with continuing direction from

Aboriginal organizations, has a department devoted to addressing cancer surveillance, awareness and programming needs within Aboriginal communities (Minore and Katt 2007, 8). Similarly, in 2005, British Columbia launched an initiative entitled “The Transformative Change Accord: First Nations Health Plan”. The stated vision of the accord is to improve the health and well being of First Nations to close the health gap with other British Columbians. Despite efforts from other provinces to address Aboriginal health care needs, Ontario remains the only province to date with an Aboriginal specific health policy that targets the entire Aboriginal population, not simply First Nations living on reserves. Other provinces such as Manitoba, Nova Scotia and New Brunswick take the position that “they are not responsible for supporting such targeted programs because Aboriginal people fall within federal jurisdiction and so should be served through federal funding and programming” (MacIntosh 2008, 203).

The collaborative partnerships between the Ontario government and Aboriginal organizations on which the programs operate echo the underlying shift that has taken place across Canada. Going beyond these partnership initiatives, Aboriginal organizations now have primary responsibility for the delivery of health services in many places. Land claim agreements, transfer or integrated agreements and self-government negotiations have created scenarios whereby most First Nations and some Inuit communities are able to take control over the management of local health systems. This development has resulted in Aboriginal communities being able to tailor health services that are specific to their community needs. Accordingly, there has been a change in the range and scope of

the health programs offered and these policies permit communities to engage in greater local administrative control over aspects of health care services (Gregory et al. 1992).

Even with the trend toward Aboriginal control or, alternatively, significant program input, Aboriginal health is still faced with a kind of jurisdictional roulette (MacIntosh 2006). Constance MacIntosh illustrates some of these jurisdictional divisions and how one Cree community of Manitoba found that when communities are given power to come up with their own solutions, that they often become hoodwinked by the federal government. In 1993, the Cree Nation Tribal Health Center issued a 'boil water' order because of high coliform counts. MacIntosh provides one example where the presence of multiple agencies was problematic:

Provincial authorities characterized the problem as an environmental one, that is, contaminated water. Since the water was located on a reserve, which is federal land, Manitoba concluded that Canada was responsible for addressing the situation. Federal authorities, however, characterized the problem differently. Instead of viewing the problem as the environmental contamination of federal land, they described the situation as a public health problem. Further, federal spokespersons concluded that because the Band had taken responsibility for public health programming through the Health Transfer Program, the Band was responsible for solving the problem. The Band argued that the Federal authorities were responsible, as the federal government had constructed the faulty expenses, so repairs would require the Band to pull funding from its primary health care purse (2006, 206 - 207).

After nine months, the federal government agreed to help move the discharge sewage pipe downstream to decontaminate the reserve's drinking water supply, but the problem had to be addressed by Indian and Northern Affairs Canada, rather than by Health Canada.

Canada's Royal Commission on Aboriginal Peoples assessed what had transpired in this community and found that, as a result of jurisdictional divisions, the health governance system had completely failed this community. These divisions are not uniquely an intergovernmental occurrence. Even within the same level of government, Romanow points out that policy sectors function within silos. The Commission thus proposed abandoning the whole issue of jurisdictional assignment. As described by Janesca Kydd, "Romanow suggests breaking down jurisdictional silos by pooling all existing federal and provincial Aboriginal health funding in each province into one envelope. That envelope would then be administered through Aboriginal Partnerships" (Knopf 2008). Constance MacIntosh notes that "this proposal seems to be more promising and could be effective on many fronts" (2006, 209).

Who is responsible for what?

The relationship between the government of Canada and Aboriginal peoples is unique in the sense that it is characterized by a complicated legislative and constitutional regime. Because this regime has resulted in an unequal and fractured manner of delivering services, the outcome has been that of jurisdictional confusion and policy vacuums regarding many aspects of Aboriginal peoples' lives (Macintosh 2006, 193). In Canada, primary health care services for on-reserve First Nations are under federal jurisdiction while primary health care for other Canadians are under provincial jurisdiction. This historical separation of jurisdiction is based on two documents: the Royal Proclamation of 1763 and the Constitution Act of 1867. According to Coates and

Morrison, the Royal Proclamation of 1763 essentially stated that “the Indigenous Peoples of Canada were not conquered and retained title to their ancestral territory. Any encroachment on the part of the settlers was to be approved by the Crown, negotiated through the treaty process and duly compensated” (2008, 107). Following Confederation in 1867, the Crown engaged in treaty negotiations with First Nations throughout the Prairie Provinces. The eleven numbered Treaties are land surrenders agreed to in exchange for reserve land. For First Nations, signing the treaties was an exercise in self-preservation in light of American Indian Wars, the demise of the buffalo and the devastating impact of epidemics (Coates 1999). The federal government has consistently worked on limiting the sphere of influence that the Royal Proclamation and the treaties have had (Borrows 1997). It is also important to point out that the Indian Act which is the principal regulator of Aboriginal life in Canada, sets out in rather limiting ways based on a blood definition imposed on First Nations communities the legal category of Indian, When persons fit the government defined notion of membership, that is, of being an “Indian”, then only those person have the right to live on-reserve and to qualify for certain individual-based benefits (Coates 1999).

Many of the settlers who arrived at the turn of the twentieth century were concerned with the below standard health conditions that were evident on the reserves. The federal government responded by hiring a General Medical Superintendent in 1904 and set up a mobile nurse visitor program in 1922. The first on-reserve nursing station (now called health centers) was set up in Manitoba in 1930 (Waldram et al. 1997). Indian Health was

incorporated into the National Department of Health and Welfare when formed in 1944. Nursing stations were built on most reserves to provide primary health care delivered by nurses. Under the establishment of the national health care system, nursing stations provided free care to Indians on humanitarian grounds.

First Nations continue to argue that access to free health care is a treaty right. The current national health care system was established in 1970 and is a publicly-financed, publicly-delivered system, managed by the provinces under the umbrella of the Canada Health Act. Under the Canada Health Act, public health and primary, secondary and tertiary health care services can be accessed for no cost by the individual. On-reserve services in the form of health centers now complement this system, but they remain separately funded by the federal government. Physicians who are paid by the provinces visit the health centers. Aboriginal patients who are in need of secondary or tertiary care in between health center visits are transported to the nearest provincial referral center. Thus, the development of a national health care system did not end the historical separation of jurisdiction in health care for First Nations peoples.(Waldram et al 2008). MacInotish sums up the situation whereby the issue becomes whether Aboriginal health governance is properly characterized as (1) an Indian matter and so within Federal jurisdiction, (2) a health matter and so within provincial jurisdiction or (3) a federal infiltration into provincial jurisdiction which must be legitimated on a case-by-case basis (2006, 196).

In most cases where the question of jurisdiction arises, both federal and provincial levels of government claim to hold power and the authority to operate a governance regime. However, when it comes to issues involving Aboriginal matters, there appears to be an exception to this rule. Constance MacIntosh refers to Aboriginal legal scholar Kent McNeil who argues that “it is not jurisdiction per se that the governments are trying to avoid, but rather responsibility” (McNeil cited in MacIntosh 2006, 197). It is not surprising to see that most provinces view Aboriginal health as an ‘Indian’ issue and as such within federal jurisdiction and an issue to be addressed through federal funding and programming (MacIntosh 2006, 197). Thus, Ottawa’s position on the jurisdictional question is highly complex. Meanwhile, after years of foot-dragging, provincial governments have accepted that they have legal obligations to their Aboriginal citizens that go beyond making health services available to all residents. This position is reflected in Ontario in a policy document entitled “Ontario’s New Approach to Aboriginal Affairs” which outlines a number of initiatives undertaken on and off reserve in partnership with Aboriginal groups (Ontario Native Affairs Secretariat 2005). The participation of all three levels of government creates a highly complicated and uncoordinated system characterized by gaps in service and overlapping coverage. It also results in funding duplication and inconsistencies. Being an Aboriginal person without status also deprives that person access to certain health care services.

Funding for health care services to Aboriginal communities often comes in the form of program specific envelopes. This situation means that there are different lines of

accountability depending on the program and each program has its own purpose-designed format for processing information. Minore and Katt write, “This generates a great deal of time-consuming paperwork at the local level, which is a source of constant complaint” (2007, 9). It is often difficult to attract and retain staff not knowing whether funding will continue past the fiscal year-end. In addition, in order to receive funding, communities are often required to write proposals and make a case for new and renewed monies. This situation can often lead to administrative complexities and situational uncertainties.

The Health Transfer Policy

Currently, there are three general types of arrangements at the federal level known as contribution agreements for transferring health programming to First Nations communities. Each arrangement has a different level of flexibility and control post-transfer (MacIntosh 2008, 71). The first arrangement known as the Health Transfer policy which was implemented in 1989 was intended to solve twenty years of consultation and discussion between Aboriginal Peoples and government on the more appropriate ways to deal with inequalities existing between Aboriginal Peoples and the rest of Canada (Lavoie 2008). The federal government presented the policy as a positive effort to meet the demands for autonomy and band-level control of health care services (Speck 1989). The Policy offers First Nations south of the 60th parallel a significant opportunity for enhancement of local capacity and culturally appropriate health planning and delivery. In April 1986, an Interim Report from the Sub-Committee on the Transfer of Health

Programs to Indian Control was distributed to the First Nations. In this report, Health Transfer was made to appear very desirable. It was stated that “The Branch is proposing a developmental approach to transfer centered upon the concept of self-determination in health” (Health Canada 1986). It further suggested that communities would determine their own needs and make decisions about how services would be developed and managed, and would be free to take into consideration their own traditional, cultural and practical circumstances (Canada 1986, 6). The Health Transfer Policy had three broad objectives:

To enable Indian Bands to design health programs, establish services and allocate funds according to community health priorities.

To strengthen and enhance the accountability of Indian Bands to Band members. And,

To ensure public health and safety is maintained through adherence to mandatory programs (National Health and Welfare & Treasury Board of Canada 1989).

The submission also stated that:

The Health transfer initiative is consistent with self-government... and serves to reinforce federal policy to increase Indian control of programs for Indian people (National Health and Welfare & Treasury Board of Canada 1989).

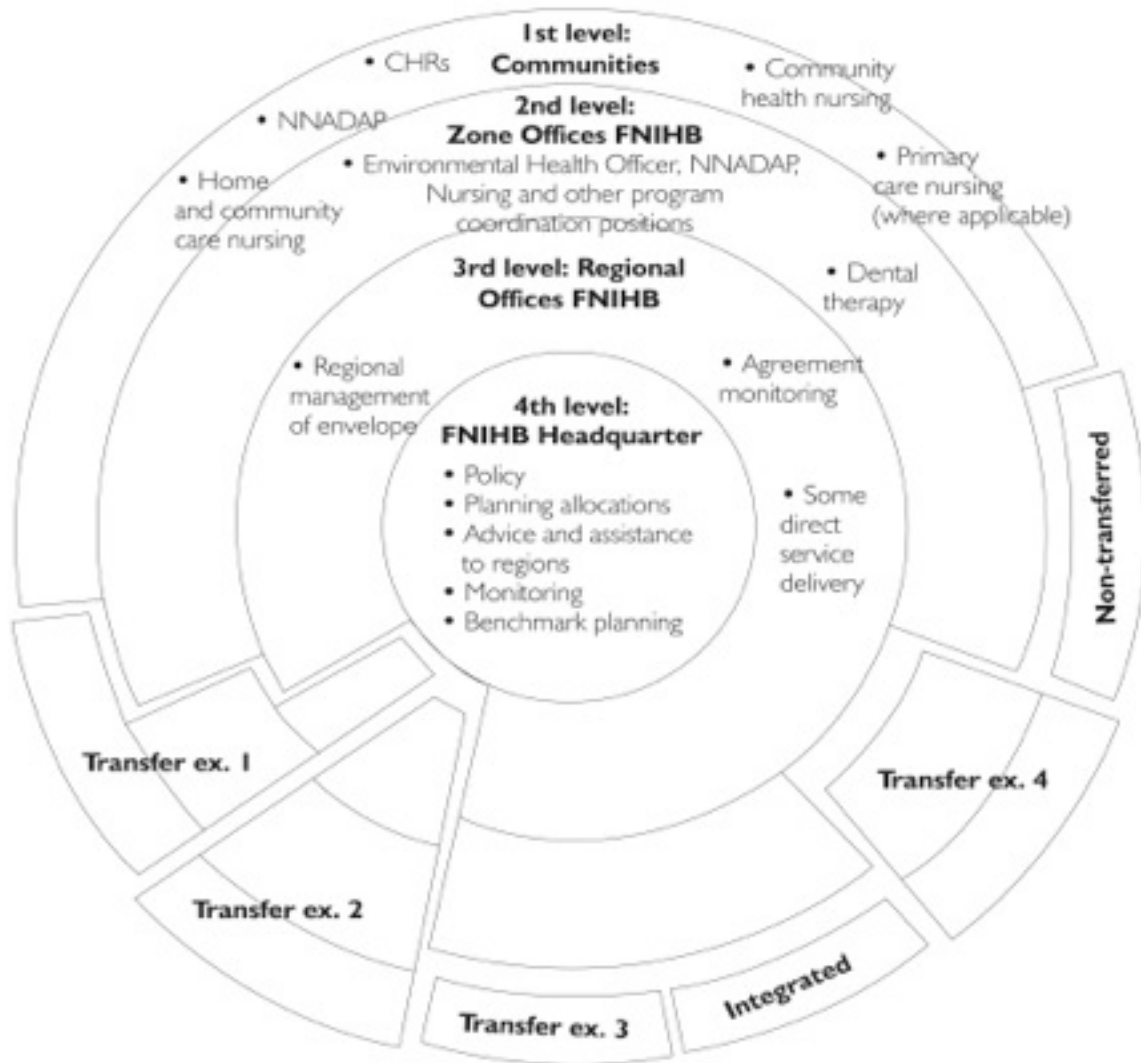
As was the case for the Indian Health Policy, the Health Transfer Policy was and remains defined in a two page document that most closely resembles a statement of intent (Lavoie 2004).

The Health Transfer Policy envisioned the transfer of existing community-based and regional services to a single community/Band or a group mandated by communities/Bands (Health and Welfare Canada 1989). Health transfer enables communities to take on

the administration of a range of community-based and regional programs. The process includes the transfer of knowledge, capacity and funds so that communities can manage and administer their health resources based on their community needs and priorities (Health Canada (FNIHB) 2004). The majority of transfers has occurred in single communities that range from less than 200 to 10,000 residents, with the average being around 500 (Indian and Northern Affairs Canada 2004). The final policy was not as detailed and flexible as suggested in the interim report because it did not include noninsured health benefits (NIHB), dental, environmental health, or training in Transfer (Culhane-Speck 1989, 207). In light of the rhetoric of self-determination that was part of the development and marketing of the Health Transfer, it can be argued that the policy has enhanced local capacity in health governance and administration and has assisted in the initial steps toward self-determination in health care. This conclusion is particularly true if one has a long-term incrementalist view of self-government, a position that the federal government assumes.

Transfer agreements may include any or all of the three tiers of FNIHB healthcare: first level (community - direct service delivery), second level (zone - coordination, supervisory) and third level (regional - consultant, advisory). A fourth level, headquarters services, remains the exclusive purview of FNIHB. As illustrated in Figure 3, these choices resulted in communities selecting a different complement of services, based on local priorities, capacity, community size, and other factors:

Figure 3



Source: Lavoie, Health Transfer Policy. 2007 May; 2(4): 79–96.

The government outlined the steps that bands were required to take in the process of gaining control. These steps have proven to be complicated and frustrating. There are three steps identified in the transfer process. The first is “Pre-Transfer Planning”. This

planning process involves assessing the current state of health care delivery, identifying the most important needs, and examining how the health care budget should be organized to meet these needs. This stage requires the development of a Community Health Plan, a document designed to explain how the community would manage health resources (Warry 2007, 97). Funding to develop a plan is available after a funding proposal has been prepared and accepted by the MSB (now FNIHB). However, there is a two year limit on the duration of funding. The Community Health Plan is then submitted to a review committee, a group with substantial government representation. Included in this committee are the assistant deputy minister of FNIHB, plus the directors general of Program Transfer Policy and Planning and Indian and Northern Health Service. If successful, the community is allowed to move to the next stage of “negotiation”.

The process of negotiation begins with acceptance of the plan by the FNIHB which retains the power to return plans approved by the review committee to the community, for example, where the FNIHB determines that more information on some aspect of the plan is required. Once the plan is accepted by the FNIHB, a Memorandum of Understanding is drawn up, outlining the negotiation process leading up to the Transfer agreement. Once approved, the Transfer Agreement has a duration of three to five years, after which a review of the implementation of the Community Health Plan is undertaken in preparation for a renewal of funding (Smith and Lavoie 2008). Under these agreements, communities may design new programs and redirect resources to areas of high priority, as long as mandatory programs (immunization, communicable disease

control, environmental health) are delivered (Health Canada 2007). Funding is provided based on historical expenditures to which is added some funding for administration. Because of this additional funding, some communities are able to hire a full time Health director from the community. The chief and council of the band become responsible for the plan and all health matters. They are required to keep their community members informed of the progress of the health plan, but are accountable to the minister for executing the terms of the transfer agreement (Waldram, Herring and Young 2006). This model became available in 1989.

In 1994, a second approach was developed whereby FNIHB broadened opportunities for community control by introducing the Integrated Community-based approach. A community that chooses the integrated community-based health services approach gains less control than with the health transfer (Lavoie et al. 2010, 2). The intent was to provide flexible alternatives to the one-size-fits-all transfer model. Table 3, adapted by Josée Lavoie illustrates the main differences between the two approaches.

| Table 3 Comparison of Two Approaches to Transfer Programs | | |
|--|---|--|
| Name of Agreement(s) | CCA-Integrated , Integrated Agreement | CCA-Transfer, Transfer Agreement |
| Duration | Phase 1: Up to 1 year Phase 2: Up to 5 years | 3 to 5 years |
| Description | All transferable programs chosen by the community under a single 3 to 5 year agreement Non-transferable programs under separate contribution agreements | All transferable programs chosen by the community under a single 3 to 5 year agreement Non-transferable programs under separate contribution agreements. |
| Funded Planning Phase | Development of work plan in Phase 1 (12 months) The completed work plan must contain four components of a Community Health Plan | A 21-month planning process resulting in development of 12 components of the 15 required for a Community Health Plan Remaining 3 components are done in the first year of implementation |
| Ability to Move Funding between Programs | Once work plan is in place, cannot reallocate unless prior written approval of FNIHB | Yes |
| Ability to Carry over Financial Resources | No. Unexpended resources must be returned to FNIHB | Yes, for the use on health- related expenditures |

Source: Lavoie, Health Policy. 2007 May; 2(4): 79–96.

Under this approach, communities may not create new programs outside the FNIHB mandated services. However, communities are able to make some program adjustments to reallocate resources and to set up health management structures that receive funding on an on-going basis (Health Canada (FNIHB) 2004).

Although this model provided somewhat less flexibility, several communities opted for this approach because they felt it did not infringe on their treaty rights. Some communities have been concerned that the transfer process pushes communities to accept a model that simply side-steps more important discussions of treaty rights in areas of health (Culhane Speck 1989; Favel-King 1993). Other communities argue that the integrated agreement is lower risk and provides an opportunity to learn how to manage health services before entering into transfer agreements. Furthermore, small communities were not eligible to transfer because of a lack of economies of scale, thus, the integrated model provided them with a new opportunity for participation (Lavoie et al. 2007).

The third type of arrangement allows for the least amount of flexibility and is known as a Consolidated Contribution Agreement - General [“General Agreement”]. Under this agreement, a limited number of specific programs are delivered to communities and it usually has a one year term. The Aboriginal community has no authority to re-direct funding in response to changing needs. Instead, they must follow the blueprint as set out in the contract.

The Health Transfer Policy has received criticism and has generated considerable controversy. Wayne Warry has argued that the health transfer policy can reinforce

inequality between Aboriginal and non-Aboriginal authorities. Through its centralized control over the language of policy, and its power to set the terms of accountability that community agencies and front-line workers must meet, the state bureaucracy influences local conceptions of personal competency and individual morality. As public discourses come to stress accountability and affordability, they simultaneously cast suspicion that these standards are not being met - suspicions that come to rest on communities and individuals (Warry 2007). Canada's Assembly of First Nations (AFN) cautions that the policy reflects assimilationist ideology. Simply stated, the AFN argues that the policy is viewed as a means whereby the federal government would no longer honour its treaty obligations concerning health care and Aboriginal people (Gregory et al. 1992). The AFN also suggests that the policy is an attempt by the federal government to reduce FNIHB costs associated with Aboriginal health care.

A program evaluation conducted in 2005 determined that the HTP had met its stated goals and that mechanisms should be continually made available to First Nations communities and organizations to first, support the flexible development and delivery of community-based services and second, to promote local governance in health policy, programs and priority setting (Health Transfer Policy, Final Report). The evaluation illustrated several shortcomings while offering a number of actions. One area of concern related to inequities that existed in the way First Nations communities are funded: this prompted three recommendations. The first recommendation was to establish a process to develop funding formulae that reflect needs, recognize the unique conditions existing in

each community, reflect the cost of service provision, and are mindful of sustainability.

The second recommendation suggested that all funding agreements should include built-in, automatic yearly index reflecting the cost of living and price and volume increases.

Finally, it recommended the need to take into account the specific needs of small and isolated communities in the formulae-based funding mechanisms. The evaluation emphasized an inequitable reporting burden for First Nations communities. In 2003-2004, First Nations in British Columbia alone submitted an estimated 5, 815 reports to fulfill the First Nations and Inuit Health Branch accountability requirement (Lavoie et al. 2008).

The report recommended that reporting requirements be streamlined by changing the monitoring agreement clauses and how activities and indicators that cannot be aggregated be reported into a cost-effective reporting framework that illustrates the performance of on-reserve services as well as the accessibility of all services.

In referring to programs, the evaluation suggested that FNIHB support First Nations in taking the lead in developing strategic linkages with federal and provincial public health authorities to address First Nations public health needs. It further suggested that investments be made in holistic mental health and wellness as a key area of Health Transfer to reflect a broader and more current understanding of the consequences of multi-generational trauma. (Ottawa, Health Canada (FNIHB) 2005).

The evaluation report was accepted by FNIHB in September of 2005 and the report led to a submission to the Treasury Board Secretariat in March 2006 for the renewal of program authorities. Plans for the implementation of a new and more flexible framework,

building on the strengths of transfer, and addressing some of the shortcoming illustrated in the evaluation, were rolled out this year (Ottawa, Health Canada (FNIHB) 2005).

Other examples of Aboriginal control over health services have emerged, both at the local and regional levels. The Kateri Memorial Hospital Centre (KMHC) was established in 1955 when a local Mohawk elder secured funding from the Mohawk Council of Kahnawake and the Quebec government to continue local hospital operations. Through over fifty years of tumultuous relations with federal, provincial and university (McGill) agencies, KMHC provides curative and preventative services to Aboriginal residents of the Kahnawake reserve and nearby Montreal (Macaulay 1988).

A further example is the Alberta Indian Health Commission (AIHCC) which was established in 1981 to promote provincial First Nations health concerns, together with the Blood Tribe Board of Health as a First Nations health authority in the 1989 Health Transfer Forum (Nuttall 1982). The Labrador Inuit Health Commission (LIHC) was created in 1979, in response to the specific exclusionary policies of the International Grenfell Association which failed to recognize Aboriginal rights. The Labrador Inuit Association refused to witness the signing of the 1986 Canada-Newfoundland Native Peoples of Labrador Health Agreement and established the LIHC instead, focusing on the CHR-delivered health education and promotion (Allen 1990). The Commission is now in the process of negotiating a self-government agreement that will include health services which until now were delivered by the Government of Newfoundland and Labrador.

In summary, I argue that a fourth health sector has developed in Canada because of the demands that have been put forth by First Nations to have increased control over their own affairs. With the increased adoption of self-government, Aboriginal people will assume roles now filled by non-Aboriginal people. Self-government then, should be a major step in breaking through the cycle of poverty, disadvantage and hopelessness. These improvements may be secured if self-government agreements respect and reflect the needs and interests of Aboriginal peoples. It is necessary to point out, however, that while the Health Transfer Policy in particular has provided many opportunities for Aboriginal peoples to pursue their own health care needs, these opportunities have been scaled back due to the administration and delivery of pre-existing services as determined by Health Canada.

In addition, the Health Transfer Policy remains very much a 'work in progress', making it impossible to arrive at any definitive conclusions as to its effects upon Aboriginal health. It has at the very least, however, the potential of benefiting Aboriginal communities considerably, by bringing their health concerns under their own purview (Barron et al. 2001). This positive reading appears to be borne out by the experience of the William Charles Band in Montreal Lake, Saskatchewan. The community leaders arrived at a transfer agreement with Health Canada's Medical Services Branch in 1988 and 1990 respectively (Dion Stout 2000). Although to date there has been no detailed study of the effects of this transfer of control, anecdotal information suggests that the process has benefited this community by making them feel more secure about

their health and by providing services that are responsive to their needs and values (Kelm 2003; Waldram, Herring and Young 2006).

The Aboriginal Healing and Wellness Strategy

In 1994, Ontario became the first province to develop a comprehensive Aboriginal Health Policy (AHP). Wayne Warry has documented the development of the policy in his book “Unfinished Dreams: Community Healing and the Reality of Aboriginal Self-Government”. This policy may be followed by other provincial initiatives that will enhance the role of provinces in Aboriginal health care (Maar 2004). Similar to the health transfer policy, criticisms arise that community-controlled health initiatives will undermine the federal government’s fiduciary responsibilities and provide Health Canada with the opportunity to further limit its role in the delivery of services. Wayne Warry writes,

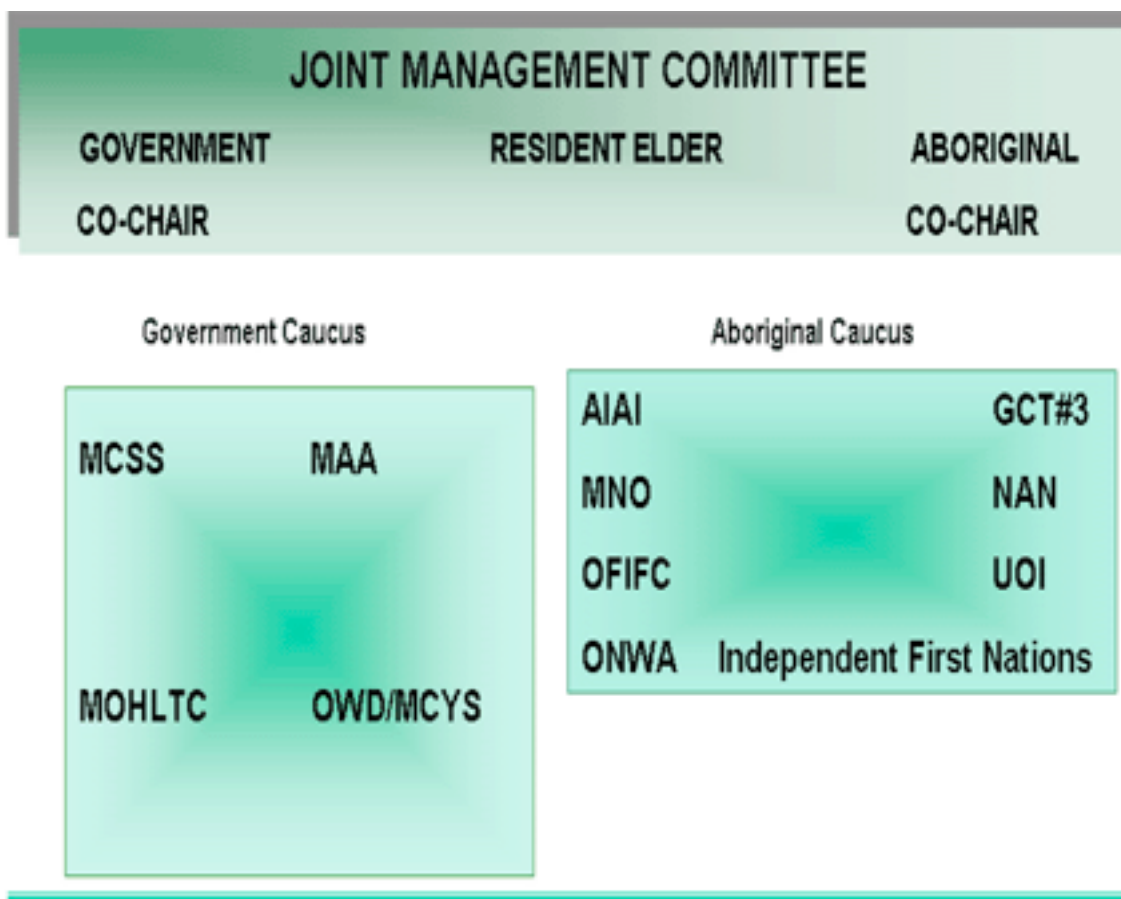
In the absence of any comprehensive self-government agreements or constitutional recognition for health jurisdiction, the federal government is able to restrict, at every turn, its fiduciary responsibility. From an Aboriginal perspective, the reality is that with the introduction of the AHP, communities select from alternative federal and provincial funding opportunities and, at the community level, attempt to integrate and enhance existing services (2007, 123).

The Ontario Aboriginal Healing and Wellness Strategy (AHWS) resulted from the merger of the Aboriginal Health Policy with a major family-healing initiative (Warry 2007). In the summer of 1992, First Nations and Aboriginal political territorial organizations (PTOs) across Ontario conducted extensive consultations with their populations about family violence and health. The information from these consultations

provided community based direction on how to address the health and healing needs of the Aboriginal population in Ontario. Warry describes the consultation process and writes,

The AHWS was the result of sixteen months of consultation with PTOs. At times this was a contentious process, and at many points it appeared endangered as Native political organizations threatened to withdraw their support for the initiative. Without detailing specific arguments, it is fair to suggest that differences arose during the process between urban and reserve Indian organizations, and between coordinating groups such as the Indian Social Services Council – which comprise social services directors- and the health directors about the processes to develop the initiatives and the direction and overall wording of the final policy (2007, 123).

In the end, the Strategy, which is governed by a joint government-Aboriginal steering committee evolved over many sessions and meetings and was formed with the coming together of seven Aboriginal provincial territorial organizations as demonstrated in Figure 4:

Figure 4

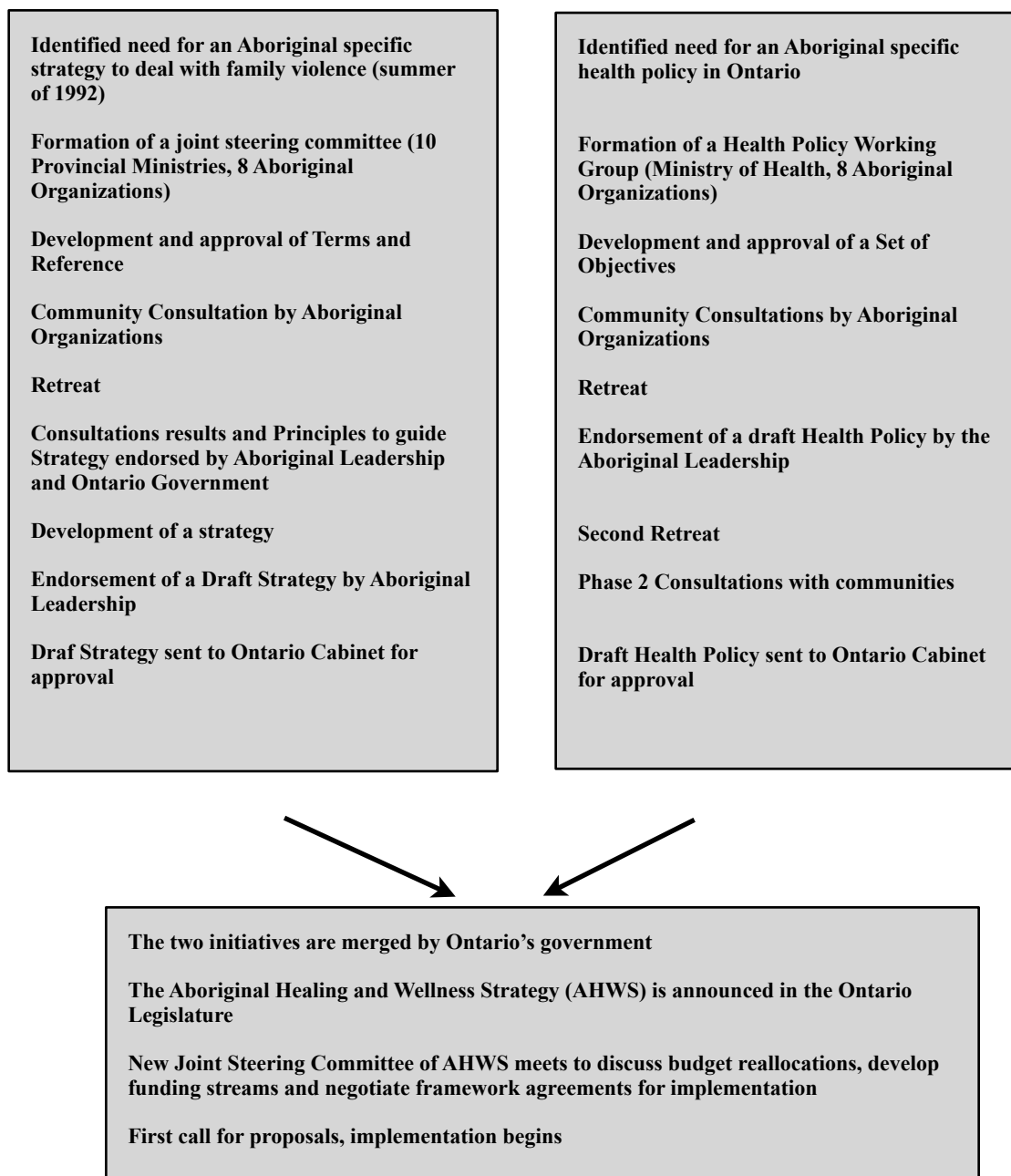
Source: Aboriginal Healing and Wellness Strategy (2007). **About AHWS – Mandate.** Toronto, ON: AHWS. Accessed November 4, 2010 from <http://www.ahwsontario.ca/about/mandate.html>

These included the Association of Iroquois and Allied Indians, Grand Council Treaty #3, Nishnawbe Naski Nation, the Union of Ontario Indians, the Ontario Federation of Indian Friendship Centres, the Ontario Métis Aboriginal Association and the Ontario Native Women's Association; seven independent First Nations coordinated through the Chiefs of Ontario, the ten provincial ministries, including the ministries of the Attorney General, Citizenship, Community and Social Services, Education, Northern Development and

Mines, Housing, Health and Long-term Care, Solicitor General/Corrections and the Ontario Women's Directorate and Ontario Native Affairs Secretariat (AWHS 1997, 4).

Figure 5 outlines the developmental phases of the Aboriginal Healing and Wellness Strategy:

Figure 5



Carrie Hayward worked from 1991-1995 as the Aboriginal Health Coordinator and was involved in the development of the Aboriginal Health Policy component, the Family Healing component and securing government approval for the Strategy. Hayward was hired as the first Manager in 1995, a position she held until 1999. Warry quotes Hayward as stating the following:

Provincial bureaucrats must bring a fundamental respect to their dealings with Aboriginal people – a respect born of the realization that representatives of First Nations should be treated as equal partners in decision-making, and as representatives of distinct Nations. To date, however, the reality is that government officials assume responsibility to decide for First Nations and to act as if Indians were wards of the state. A respect for healthy process also means that bureaucrats must be willing to spend considerable time and effort consulting with individual First Nations. As in the case of Health Transfer, policy or program consultations initially designed to take six months, may take three or four times that period (2007, 123-4).

While this unique partnership between the Aboriginal community and government partners worked for the Aboriginal stakeholders, it clashed with traditional Ministry approaches intended at controlling and claiming ownership over the policy-making process.

In my experience of moving from a national Aboriginal organization to a federal government bureaucratic position, I noticed several inherent differences between the two. First, there was a visible lack of Aboriginal peoples represented at the government level, whereas at the National Aboriginal organization, the overwhelming majority of employees were Aboriginal. Furthermore, within the government ranks, there was a lack of knowledge of Aboriginal communities and culture. Given these two realities, it poses

difficulties for government decision-makers to respond with effective policy solutions for Aboriginal communities and its people. In an interview with Wayne Warry regarding the AHWS, Carrie Hayward reiterates this sentiment and notes “There is an inherent bureaucratic conservatism that sustains the status quo. When this is reinforced by conservative political platforms the chances of innovative policy reform are remote” (2007, 124). Hayward continues to point out that the status quo is simply not working for Aboriginal peoples and that the key change in mindset needs to be government’s willingness to develop policy-making processes that place Aboriginal governments on equal footing with mainstream governments (Warry 2007, 124).

Hayward applauds several ministries and departments for reorganizing their funding arrangements, i.e., Ministry of Health, Community and Social Services, the Native Affairs Secretariat and the Women’s Directorate but is critical of key ministries that have not adopted such re-organizational models. Most notably, she critiques the Attorney General and Solicitor General who did not view Aboriginal health within their mandates and refused to contribute despite AWHS’s focus on family violence and the need for alternative programs. It is my contention as I suggest in chapter 6 that this neglect by government agencies and agendas is indicative of the hands off approach that far too many government agencies apply to Aboriginal issues.

Thirty Three million dollars was initially committed to the Strategy which is only a portion of what was needed to resolve the problems amongst the Aboriginal population and much less than the \$137 million that Aboriginal communities had initially proposed

for the family healing initiative alone. Warry notes, “To place this financial commitment in perspective, at about the same time the AHWS was announced, the NDP government also announced plans to build or expand three urban cancer treatment centres at a cost of \$100 million” (2007, 125).

Sixteen years after its inception, the Strategy currently distributes over forty million dollars to develop many important programs for Aboriginal health care including Aboriginal health access centres, healing lodges, shelters, hostels, crisis teams, urban, First Nation and rural community workers, an information clearinghouse and many other initiatives, including an Aboriginal Healthy Babies Healthy Children program. However, similar to the health transfer policy, the scope of the strategy and the financial resources allocated to its implementation, can be easily criticized. For example, Warry notes that “despite a rising concern over family violence, the strategy contains no comprehensive approach to the creation or delivery of community-based mental-health services; such an initiative awaits further provincial review” (2007, 125).

However, the Strategy does set an important example in that it is built around three complimentary concepts: it is a holistic and inclusive approach (taking into account spiritual, physical, mental and emotional needs of individuals, families and communities), it seeks to address life cycle issues along a continuum of care, and programs and services are designed and managed by Aboriginal organizations and communities. The Aboriginal health policy’s strategic directions attempts to enhance the environment for the development of integrated services through improving access to existing services,

developing new approaches to improve health status and respecting traditional Aboriginal health knowledge and practices. Taken together with federal transfers over health care and other federal initiatives in the area of mental health, the Strategy presents First Nations with considerable opportunities to recognize their unique visions of health-care delivery over the next several years.

The development of Aboriginal Health Authorities (AHAs) at the PTO level has resulted in different models of healthcare delivery. Warry points out that these health authorities may ultimately gain responsibility for allocating funds and evaluating services needed within their regions. He writes, “These authorities should prove to be more responsive to First Nations and tribal council needs than the Ministry. They may develop policy and service-delivery mechanisms to respond to different geographic and cultural needs” (2007, 126). There is a need to think through the philosophy of community ownership and control over health services. It is here where building the capacity of community-based health care delivery systems becomes paramount. In the case of Ontario, the challenge will be to honour the government-to-government relationships so that Aboriginal control over health care can become a reality.

Community-controlled health policies hold great promise for improving Aboriginal public health. They also allow for practical responses as a way of gaining ground with some of the jurisdictional hurdles which are so often compromised as obstacles to success. Based on the findings in the last three chapters of this dissertation, community-controlled health initiatives are far more likely to yield substantive

improvements if they are developed as part of a continuing partnership between communities and government. These partnerships will need nurturing and revisiting as experiences increase and challenges persevere. Governments, at provincial and federal levels have committed to maintaining an active role in the Canadian health system as it affects Aboriginal Canadians. Whether this advocacy role occurs, will be the focus in the final three chapters of this dissertation.

Chapter 5

The Practice and Politics of Community-Controlled Health Care

We have 500 years of stuff that we're working through and people think that we're going to make a difference overnight? If you take two steps forward and you take one step back, you celebrate that one step forward

- Ovide Mercredi

Canada is both one of the healthiest countries in the world, and as I have noted, one with the greatest disparities in the quality of health care across its inhabitants. In 2006, the 1.2 million Aboriginal peoples accounted for 4% of Canada's population. They are the fastest growing segment of the population. Indicators of economic, social and health wellbeing among Aboriginal Canadians compare unfavourably with the Canadian population overall (Adelson 2005; Cooke et al. 2007; Stephens et al., 2006). Aboriginal peoples experience lower life expectancy, higher incidence of chronic diseases, higher rates of infectious diseases, and higher rates of substance abuse, suicide, and addiction, than the non-Aboriginal population in Canada (Adelson 2005; Banerji et al. 2009; Clark and Cameron 2009; Frohlich et al. 2006; Macdonald et al. 2010; MacMillan et al. 1996; McDonald and Trenholm, 2010). The poor health status of this population does not come as a surprise to many living in Canada as Aboriginal health is consistently making headlines in the media. Attawapiskat First Nation in early 2012 is the most recent example in Canada making headlines in that the community has declared a state of emergency.

It is difficult to find documents that reference positive advances made in Aboriginal health. Nevertheless, at least two notable changes have occurred in the

landscape of Canadian Aboriginal health policy and politics in the last thirty years that appear to be more promising. The first is the development of the Canadian Aboriginal community-controlled health sector in the late 1980s with the establishment of the health transfer policy. The second development occurred in the 1990s with the bureaucratization of Aboriginal health and the establishment of mechanisms and processes for the Aboriginal community-controlled sector to collaborate with federal and provincial levels of government. The Aboriginal Healing and Wellness Strategy (AHWS) is a unique experience in policy-making and collaboration at the provincial level.

In order to pursue my interest in critical Aboriginal health policy, I travelled to a total of five communities on Manitoulin Island in Northern Ontario and to one community in north western Manitoba to analyze contemporary relationships between Aboriginal communities and government in the development, implementation and evaluation of health policies and programs. This chapter is based on that community-based health research. The following interview responses demonstrate a theme whereby those at the community level feel that current government policy is reducing the scope of self-determination

In Ontario, I worked closely with the health director of Mnaamodzawin Health Services Inc. (MHS), a non-profit organization that collaborates with community members, political leadership, families and community groups to optimize the health and well-being of five First Nation communities on Manitoulin Island: Aundeck Omni Kaning, Sheguiandah, Sheshegwaning, Whitefish River and Zhiibaahaasing. In Manitoba,

I worked with the health administrator and a community consultant of Tootinaowaziibeeng Treaty Reserve. Although my goal was to conduct interviews and focus groups as part of this research, it was also important for me to be able to foster capacity building among Aboriginal people by enhancing their participation in my research project. Over the course of two years, I travelled to all six of these communities. I spoke with leaders, community members, health care providers and administrators and discussed their health priorities, goals and challenges in the health policy process while simultaneously developing their five year community health plans. Throughout this process, I became amazed by Aboriginal communities' achievements in health. The discouraging information conveyed by the media was contrasted against the many accomplishments in Aboriginal health policy and politics.

In chapter two, I discussed colonialism and its impact on self-determination and how self-determination has evolved over time as a local concern which has since moved in a direction which now lies with the federal government. This development is particularly evident in the area of health. However, in resistance to the renderings of Canadian history dominated by British colonialists, Aboriginal people have begun the process of re-writing and re-claiming their history. This new history begins with Aboriginal people and involves proclaiming ownership over land, describing colonial invasion, violent dispossession and oppression and discusses Aboriginal people's resistance and survival:

Eventually the government is going to get into trouble. Our Aboriginal youth are becoming educated and they are becoming angry. One person can only take so much [Community Member].

While the government of Canada recognizes the inherent right of self-government as an existing Aboriginal right under section 35 of the Constitution Act, 1982, Canadian Aboriginal peoples perceive the legal processes by which to reclaim land and self government to be fundamentally flawed. This colonial historiography continues to shape contemporary politics and trickles down to the community level in its various forms.

My research addressed the following questions: What does Aboriginal control over the health care system mean to Aboriginal people? How is community-controlled health played out on the ground? What historical conditions have contributed to the erosion of Aboriginal control over their health care system? Were Aboriginal communities empowered or disempowered when they took on bureaucratic models and collaborative rather than adversarial approaches to government? How do federally based Aboriginal health policies differ from integrated ones? The following chapter presents Aboriginal and non-Aboriginal responses to those questions. While both policies set out to improve health conditions for Aboriginal peoples, the argument pursued in this chapter suggests that the Ontario policy is far more reflective of self-determination than the health transfer policy. Furthermore, this chapter argues that governance structure and having key champions positioned strategically trumps any type of government policy.

Aboriginal Healthcare and Policy Processes on Manitoulin Island

For many non-Aboriginal Ontario residents, Manitoulin Island is considered a vacation destination with sandy beaches and waterfront cottages, a perfect place for families. For many Aboriginal families on the Island, however, racism, poor health, high unemployment and high rates of suicide are a continuous reminder that colonialism is still dominant within their communities. In my discussions with community members and leaders, many expressed disbelief that non-Aboriginal people, including government bureaucrats responsible for Canadian health policy are simply unaware of the history of Aboriginal peoples. In addition, they have minimal knowledge of current issues in their communities:

There are too many myths out there saying that our people are well looked after and Canadians believe that we are. Clearly, we are not [Elder].

Where is Indian Affairs in all of this? They say it's not our problem and Health Canada? They say here are some trinkets and bells, you'll be fine. The federal government needs to step up. The citizens of this country need to hold the government responsible. We're not merely stakeholders in the country, we're nations...When we signed treaties, we didn't sign kill us...This all points back to one thing and that's colonization [Chief].

Aboriginal communities in the Manitoulin district experience similar health problems to those in Aboriginal communities in other parts of Canada. It is also important to point out that each community has its own distinct health care needs and priorities. Some of the health concerns that were brought up in my research included ongoing issues with diabetes, hypertension, cancer, obesity and poor nutrition, drug abuse (including prescription drug abuse) and violence in all forms. Fluency in traditional languages is also

rare due in large part to residential schools, although there is interest in preserving and reinvigorating what knowledge there is of those languages:

The influence at residential school was so dramatic. They would belittle everything about our people. I can remember when my brother came back home after his first year there and he wouldn't speak our language...he was proud of himself for speaking english and then when I went I modeled my brother and now my kids are upset with me because I can't teach them the language...there is no money for curriculum development and we can't change the system with one First Nation representative in the system...Why do we have to send our people to a non-Indian school to be able to teach our own language?... Restoring our language is one way of becoming healthier [Community Member].

Mental health issues continue to be a major concern, especially amongst Aboriginal youth. I arrived on Manitoulin Island at a time when communities were reeling from the effects of youth suicides. I had spent several weekends in Sudbury, Ontario at various brainstorming sessions with academics, community leaders and administrators prior to my arrival to discuss potential strategies and solutions to some of these problems. For years, communities have been trying to deal with health disparities by designing and implementing culturally-appropriate services within their communities. In addition to the services provided under the health transfer program, the management of other services such as the Canadian Prenatal Nutrition Program, the Aboriginal Head Start Program and the First Nations and Inuit Home and Community Care Program have also been transferred through the First Nations Inuit Health Branch through separate contribution agreements to the First Nations or tribal council level (Maar 2004). These programs are provided in addition to other community-based programs (provincially based programs under AHWS for example). Marion Maar points out that:

A positive aspect of this situation is that First Nations are able to approach service development creatively and experiment with different community-based and culturally appropriate solutions to local health priorities. More negatively, communities are expected to design and deliver programs that operate within the often rigid parameters of government funding agencies. Funding agencies' working definition of culturally appropriate services often does not match First Nations' vision for the delivery of health care in their communities (2004, 58).

The Evolution of the Aboriginal Health System on Manitoulin Island:

Aboriginal health service delivery on Manitoulin Island has a complex history. MHS came into existence in 1995 with the hiring of the first Health Director in 1996 under the administrative umbrella of the United Chiefs and Councils of Manitoulin (UCCM) until a new Board of Directors was appointed in 1998, with full incorporation in 2000. This new health service was first established under the Health Transfer Policy previously introduced in the Canadian Parliament in 1989. The UCCM approved through Board resolution and Band Council Resolutions in the development of a collaborative model involving six First Nations under the UCCM Tribal Council. However, it was determined early on that M'Chigeeng First Nation would apply for their own Health Transfer Agreement with Health Canada. Accordingly, the other five First Nations formed their own partnership and health authority to be called MHS. This group of five First Nations joining together in joint collaborative partnership has allowed the sharing of expertise and ensured efficient use of limited health resources.

During the same period, all seven First Nations in the Manitoulin District determined after a needs assessment in 1995, to apply for new health funding from the Aboriginal Healing Wellness Strategy in 1996 under the supervision of the Provincial

government. This application was for primary health care positions that did not exist under the Health Transfer Funding envelope. Following a needs assessment, it was clear there were critical needs for nurse practitioners, dietitians, traditional healers, and psychology and program evaluation/research positions. The final approval occurred through seven Band Council Resolutions in partnership to form a new health corporation that would become Noojmowin Teg Aboriginal Health Access Centre. This centre would be complimentary to the Health Transfer/Health Authorities inclusive of Wikwemikong, M'Chigeeng and MHS. This new application was funded in 1996, with the hiring of their first Executive Director and Executive Assistant in early 1997. Noojmowin Teg Health Services and MHS are both housed in the same facility which is located on Aundeck Omni Kaning First Nation.

A former health administrator with many years of health experience on the island discusses the evolution and complexities of the integrated Aboriginal health system in the Manitoulin district:

There were a series of suicides in the early '70s in Wikwemikong ... I ended up as part of a multidisciplinary team coming to this community and developing healthcare services...So basically then the healthcare centre was maybe one or two people in a tiny little building. So they've really evolved. They've got lots of staff now. The whole spectrum under their Health Transfer agreement evolved over the '70s and the '80s getting into the early 1990s, and all of these communities did their health needs assessments in '92, '93, '94. The health needs assessment was done for Wikwemikong and under the UCCM which would have been the six First Nations and included M'Chigeeng at the time... M'Chigeeng decided "no we want to be part of the Tribal Council but we want our own health authority". So they did their own Health Transfer agreement in '95, '96 in that period.

Mnaamodzawin on behalf of the other five communities, did their needs assessment in '92, '93 in that period and negotiated the first transfer agreement which came under the UCCM in 1995. And so the UCCM as a Tribal Council oversaw the health authority and they had a committee...a health committee of three to five people at the time...They got the transfer for all the fieldworkers which included the Community Health Representative, the Building Healthy Communities, Brighter Futures and the National Native Alcohol and Drug Abuse Program workers...in 1998, '99, Mnaamodzawin began the process of becoming incorporated so that they could be somewhat at arms length from the Tribal Council because Tribal Council wasn't really about program delivery. So they got all five communities to get a BCR [Band Council Resolution] to agree to be incorporated and that was completed in 2000. They became incorporated and elected a board of directors.

At the very same time, Noojmowin Teg Health Services under the Aboriginal Health Access Centres in '95, '96, completed a health needs assessment by looking at primary care and by looking at what resources Health Transfer was not going to fund...it was brilliant...In '97, when it all got approved and funded, they had four nurse practitioners, they had two dietitians, they had a program evaluation researcher and a traditional coordinator.

They evolved from 2000 to now, eleven years and lots of growth. The health authority and Wikwemikong, they've all grown tremendously as well as Mnaamodzawin, but still fragmented in many ways because the Health transfer had a bit of an anomaly. So, Health Transfer will set up a structure where they were accountable for the delivery of health services but Mnaamodzawin as a corporation transferred part of it to the bands where most Health Transfer are directly with the band, not a separate corporation. So it's rather unique, it's innovative [Former Health Administrator and Consultant].

As a result of these various adaptations, Aboriginal community dynamics have become highly charged. The boards of Aboriginal organizations and health services have their own ideas about what is best for their community and organization. These sorts of difference are not necessarily a negative quality as it often reflects the passion felt by health administrators toward their organizations. However, since the inception and development of these two primary health care organizations, there has been some

instability. High turnover rates, weak leadership, and competition over funding have made it difficult to move forward at times:

It's been a bumpy road. Changing leadership, political changes with elected officials changing every two years has had an impact. You can't move ahead as fast because you start moving forward and then with each election you're moving three steps backwards for a while and then moving ahead again. But it has evolved, there are good things. I think some of the things under Health Transfer with joint funding from different sources both provincial and federal have a huge impact but then it always seems to collapse over time [Health Manager].

Some individuals who come here don't have a good health background, a good understanding of government, a good understanding of writing proposals, partnerships, being responsible...what is our accountability for delivering healthcare services? If you're the health authority, you should be working with parallel services to advocate that we do get really good services from AHWS or visiting doctors. So there are all these little pieces out there but sometimes they end up doing their own thing and working in silos and sometimes having too many resources can become problematic [Non - Aboriginal consultant].

I think we could be even further ahead if there hadn't been so many changes in the administrative leads. Over a five year period, I think there were six EDs so there was always dissent [Consultant].

Representing Aboriginal communities in negotiations with government bureaucrats also becomes problematic because of the diversity within and between communities. One example of such difficulties are the tensions that led to the dismantling of the Joint Management Committee, a provincially based committee in Ontario that was composed of various Aboriginal organizations, leaders and government officials that presided over decisions as they related to AHWS. This tension is reiterated from a government perspective in chapter six and is echoed by a community health administrator:

Sitting on the Joint Management Committee and sitting at that table, it was an absolute zoo and so nobody really knew what they were doing...all of this hard dialogue and discussion with the PTOs [Provincial Tribal Organizations], all the unorganized Native communities and the Métis and the Indian Friendship Centres and they were all at the table and they all hated each other or were in competition for dollars and they still are [Health Administrator].

Community-Controlled Health Care on a Monday Morning

When I first arrived on Manitoulin Island, I was immediately shuffled into health planning sessions with MHS. Our goal for the next several months was to travel to each community and develop their five year community health plan, a process I discuss at length in chapter three and one that is required under the health transfer process. Representatives from MHS were vehement that their boards take direction from their local community members. They felt strongly that processes for grassroots input are critical to their organizational structures. There was still the feeling from some community members, however, that they are not using the organizations to their full potential while some of the five communities felt a detachment from the organization:

There is still a lack of understanding of what MHS services do. Consequently, there are multiple programs and workshops happening at the same time and attendance is low as a result [Health Service Provider].

We're classified as a semi-isolated community by Health Canada and so we're always the last community picked to have workers come to our community to do workshops or events with our youth...we get the slim pickings [Health Service Provider].

At each session, our presentations and discussions focused on the following topics: What is your dream for health services in your community? What would the health system look like at the local level? What is your vision in five years? Is there something different that

should work? The question that generated the most debate, however, was prompted by a community member who asked: “What would it look like for our First Nations to take over our own health care from Health Canada. What would it *really* look like?”

In Chapter four, I noted that the concept of community-controlled health care was gradually popularized after the establishment of the Indian health policy in the 1970s, the health transfer policy in the late 1980s and the Aboriginal health policy in Ontario in the early 1990s. The concept of community-controlled healthcare has been taken up by social scientists, health researchers and by government to some extent as a guiding mechanism of research. From the perspective of a Political Scientist, the diverse ways in which community control and community-government collaboration are defined by Aboriginal and government bureaucrats is captivating. The dynamics between these concepts becomes highly complex, especially in Ontario where the Aboriginal population is so diverse. This diversity can create tensions related to contemporary Aboriginal identity.

During our planning sessions, Aboriginal participants illustrated the importance of community control with the following remarks:

Community control means charting our own destiny but I think in doing so because we live in a communal society, it should be community-driven, not just leadership driven [Chief].

Community-controlled health means that an awakening has taken place among First Nations people about what they need to do to improve our health, so the solutions are coming from them and they are coming forward now. It means waking up and being educated, having capacity and finding our own solutions [Health Administrator].

The descriptions of community-control are philosophies, ideals and mandates.

Translating these into action and what actually happens on the ground, however, are dependent on a number of factors, some operating within the communities themselves while others external to the communities. Tensions result when the community's definition of community-control comes head to head with the practice of community-government collaboration. This tension is partly due to the fact that the government comes to the table with its own interpretation of what community-control should mean. This tension is further discussed in Chapter six. As a result, communities continue to have feelings of anger and mistrust towards government:

You look at the level of dependency...the government has created this dependency relationship for First Nations. And we can't do anything unless it's government funded or if it's this or if it's that [Aboriginal Advocate - Aboriginal Organization].

I've been involved in a couple of land claim negotiations in our community and the government supplied some funding in advance for lawyer fees. The government pays \$200 an hour for the lawyer which is the same rate they were giving in 1994. We see the same things in health and it's not about to change anytime soon [Chief].

Because the government gives us funding, we're expected to make a difference. And one of the things that I've noticed is that because we're committed and we have passion so we're trying to make a difference that we do more with less and we do it all the time. And so we've kind of set ourselves up that because we can do more with less that the expectation from government is that we'll continue to do that [Health Administrator].

What I've noticed with government is that it always becomes a money issue and not what kind of benefits or what kind of things happen in the community that have moved you forward...With the Attawapiskat crisis, the government says 'I'm going to put in a third party manager' and the Minister basically said when the

Chief walked in the door that this is non-negotiable. So he wasn't even willing to think outside the box; he was like this is the way it is [Health Manager].

The people that are closer to the communities have a better understanding. The policymakers who are distant from the communities have no idea [Health Administrator].

You really need to have a good grasp on things like proposals and you need to be on top of things and be aware when opportunities come up to get funding from the government for a particular project and to jump on it...but you need to ask, how do you create a health system based on projects anyway...That's always a challenge [Community Consultant].

One of the things that I saw that was really problematic under Health Transfer is that you have to go through all this screening and crazy paper exercises, plan after plan, evaluation after evaluation...Even under Health Transfer some of the dollars are too small. They haven't grown with the times...Health Transfers have been there for sixteen years and how much have they grown, maybe ten percent. And the population has doubled. When you first set up Health Transfer you might have had eighty-seven people in one community and now there's a hundred and thirty [Health Administrator].

Not only is there tension with government officials, but this tension also exacerbates at the community level amongst community members. In my discussions and interviews, assimilation and colonization were themes that were constantly brought up:

If you look at the policies of assimilation and all those things, it's based on what can they do to get the land; we were the first people on this country and what did the people that came from Europe - what did they do to get that land and develop their policies and violence. And so it has perpetuated because we have been violated and what happens is we tend to become the violators as well, so lateral violence [Health Administrator].

When you look at the issues in communities, it's about identity, who we are, when you get into the addictions, the alcohol, the drugs, issues around violence, not having self - worth about my job, housing issues - these are all deep rooted issues and to think that you're going to eradicate all of this just like that, that's crazy [Community Member].

I would be telling people that we don't get along, we fight. We're really wounded, we're hurting, we're not cooperating, we're not communicating, we're not networking. All this reporting and evaluation points to that. We need to have a goal for the agency, how we're going to improve that, how we're going to heal with Noojmowin Teg even though we disagree on our approaches we need to heal because we have clients walk through these doors [Health Administrator].

As I was driving to the next community to begin the next planning phase, one of the consultants that I was working with described this process as one of internal colonialism. She identified the problem as one whereby government allocates a minimal amount of services, money and resources to Aboriginal people which pits them against one another in the search for funds. It also creates, she added, the perception that they cannot function without infighting amongst themselves. Taiaiake Alfred writes, "This harm has resulted in the erosion of trust and of the social bonds that are essential to a people's capacity to sustain themselves as individuals and as collectivities" (2009, 52).

Non-Aboriginal people who work in the community-controlled sector are also in a precarious position because of the colonial history and continued relationships they have with the non-Aboriginal population. Non-Aboriginal people are welcomed into communities as health administrators, workers or consultants but they need to be able to contribute to the organizations in which they work:

Yes, I believe Aboriginal people should be the lead but if you're not able to get an Aboriginal person, I'm only too willing to come in and do my part to help but you shouldn't disrespect me because I'm there and I have a certain culture or whatever my background is. I'm here for the purpose because you hired me...a good part of it for me is that we're all in it together, all races, all cultures [Consultant].

Given the substantially lower levels of pay under health transfer and AHWS, the decision for non-Aboriginal people to work with Aboriginal communities and their organizations is usually a testament to their commitment to the Aboriginal health sector.

After a busy day of health planning, I sat down with a group of health managers to conduct a focus group and I asked them what a Monday morning looked like for them. They talked about some of the challenges they experienced under the community-controlled health process. They told me that while health programs are urgently needed within Aboriginal communities, the rapid evolution of Aboriginal healthcare on the Island has brought about changes that can get in the way of the development of integrated health services. Many of the managers spoke of funding challenges and the rigidity of reporting requirements or program goals that often vary tremendously between funding streams and provide challenges to the provision of integrated services. Their argument is that policy and programs take too much of a top down approach:

The government still doesn't understand that we have the health authority for five First Nations. They still go communicate with these five First Nations individually and we don't know that they're communicating with them and then the five First Nations think they're getting money where we don't even know if our organization is getting money. So, it gets confusing and First Nations get upset with us.[Health Manager].

A challenge that we're going to have is that the Union of Ontario Indians receives the funding for the board of directors. None of our programs cover the board of directors. It comes directly from the Union to us and then we administrate the budget. So that right now it is up in the air because apparently they've been told that cuts are coming and they don't know where it's coming from and we haven't been advised...And then our plans are due March 31st, hopefully we don't get told March 1st that we're not getting any money for the next fiscal year. If so, then we have to do some juggling with budgets. So that's a challenge...The new challenge

is Health Canada will tell us at the end of March, you're getting this funding and you have until March 31st to spend it, so we have to spend it in less than a month and when we buy an item, we have to make sure it's delivered before March 31st [Health Manager].

Or they say that you have suicide money. Well what suicide money? Tell us where in our budget that we get suicide money. And they say well no, it's the mental wellness part of the project. Well, that's not us. That's another agency [Health Manager].

Our chemo patients have to go under a different set of paperwork and it has to be a contract driver because that contract driver has to be paid under the same contract. So if there's a complication, then I have to get different paperwork for that client and say if I wanna transfer them and they have an appointment, I have to get the paperwork from the doctor and they're having dialysis in Sudbury because they have to see the vascular surgeon about something. So, it's under a different system for non-insured health benefits to cover their medical transportation. And if they want to spend the night - well, that's another process altogether [Health Manager].

Government bureaucrats however go to great lengths in order to emphasize the strides they have made in terms of making it easier for community health administrators to manage their reporting:

We're looking at performance measures, performance outcomes and data elements and we're looking to streamline all of those...one of our programs - Aboriginal Healthy Babies Healthy Children...had 140 data elements that people were responsible for reporting on and now we've whittled it down to fourteen or fifteen...with our new system rolling out, it'll be less information that we're asking for, more user-friendly to assist the partners [non-Aboriginal bureaucrat].

Although the way that community controlled health care is conceptualized has changed over the past many years, the model of how community control is practiced on the ground continuously evolves. Others find that there are definite advantages and that the current integrative model is indeed effective. Health services have become

increasingly holistic; services of traditional healers, nurse practitioners and dietitians are all provided at the community level. These services present a contrast to most communities elsewhere in Canada without additional health services in place. It is possible for communities to reclaim power back from government. Change is unavoidable as each generation of Aboriginal leadership will bring a different perspective to activism and advocacy.

While many barriers need to be overcome in the provision of integrated services in Aboriginal health on Manitoulin Island, in my discussions and interviews, I found that there are positive processes occurring at the community level:

I think we're making progress and there is a method to the madness. We are starting to build capacity. We're focusing on infrastructure and addressing social problems and things like health. We're working on fixing housing and extending water lines to make sure that people live in a healthy environment. We're starting to pay more attention to keeping a healthy environment in the homes, in the offices. Even the land, we have clean ups. We're starting to focus more on economic development, creating business opportunities and now we're focusing on our cultural, social and spiritual development and strengthening the governance component and we're having a lot of success. You can network and build best practices and find out who's doing things that are great. You need to be able to open up your eyes and see that there's a better world out there [Chief]

When I look at statistics and I look at the numbers from previous years, like for foot care problems, we're down a massive amount. Like we've had a lot of diabetes, with ulcers, amputations. We've had our first amputation, it was a toe, in three years. That's a very positive thing. And our wounds were really, really high at one time. We have less than five...It's the prevention, that they have the foot care services, they have the PSWs [Personal Support Workers]. The PSWs are trained. The nursing services, the educational and knowledge is increasing a lot and with non-insured health benefits, because we're one of the pilots, we have access to wound care products a little bit faster than anyone else in all of Ontario [Health Manager].

I think community-controlled healthcare is waking us up and saying we need to look for our own solutions. If anything, it's teaching us something about being innovative in regards to how we're going to push for more self-determination [Health Administrator].

What I've noticed is that we're looking at things and saying okay, how can we do more with less, how can we look at other kinds of opportunities, you know, can we look at pilot projects, can we do some research or stuff outside of government since we know that they're not going to be there for us, so let's look at some other options [Health Administrator].

Marian Maar has pointed out that partnerships between the primary healthcare organizations on the island and the local federally-funded health authorities is contributing to local health empowerment in many ways (2004, 63). An empowered First Nation model is driving these communities to a more cooperative and integrated system. This is allowing each First Nation to develop their own creation for learning, to rethink the dimensions of their health care work. It is allowing each community to look at their own work and needs through a different lens that is consistent with the Aboriginal traditional ways in partnership with the western health models so that their citizens have clear choices and options.

In chapter two, I made the argument that governance can be treated as a vehicle towards self-determination and can be a critical factor when crises occur in a community. This argument begs the question as to what constitutes good governance for an Aboriginal community? Although there is no single model that can be applied to every community, the Manitoulin example highlights the need for champions in both leadership and community-based roles. This idea of having champions was brought to my attention by a

consultant who had been working in the area for many years. While strong leadership is critical for a community to flourish, what is equally valuable is having champions in the formal and informal system. When the system is working at its best, it involves identifying who the champions of that community are and empowering them into roles within the community that will enhance the wellbeing of the community. Therefore, it's not up to leadership per se, i.e., Chief and Council to make the difference, but it is up to them to find these champions and delegate roles and responsibilities to them:

It's about people who have a passion, people who believe and that you believe at the grassroots level...It might be a grassroots person, it might be somebody in the health centre, it might be an elder, a youth member [Consultant].

I think the Chiefs here are doing a really great job in terms of moving us toward self-determination. We're working towards that and have been doing it for a very long time. They are saying that we are First Nation, I am First Nation, this is a First Nation community and we're going to stay First Nation; you're not going to wipe us out [Elder].

I think the PTOs [Provincial Territorial Organizations], the Union of Ontario Indians and the AFN [Assembly of First Nations] should turn into grassroots organizations...Council still has a lot of control and it's important to look at the whole system and how it can work together [Community Member].

The government is still a bureaucracy, yes, and I think the bureaucracy often doesn't get it right, but I think the more Aboriginal people that you have working in the system, the better. I think government is improving and Aboriginal managers are coming into positions from the grassroots up; they understand the importance of developing policy frameworks that really make sense [Director of Aboriginal Organization].

The importance of champions is not only about community empowerment, but it is also an effective way to deal with crises when they occur. The importance of champions and a good governance structure was evident during the recent increase in youth suicides on

First Nations communities on Manitoulin. Years ago on Manitoulin Island and in current communities elsewhere in Canada, a suicide would be looked upon as a dark mark for everyone involved. However, due to the governance in the Manitoulin area, particularly the health authorities on the Island and the champions fulfilling their roles, they were able to organize supports and shoulder the load to avoid the hysteria of such an epidemic. Additionally, a local Chief took proactive measures to avoid future catastrophe by pushing the federal government to create a national suicide prevention strategy, liaising with Aboriginal leaders, pushing the province to cultivate its strategic direction with respect to enhancing its mental health and addiction services over the next ten years. He wanted to ensure that these changes include the development of a provincial suicide prevention plan:

The system under the authority can organize support systems around each crisis and if it's integrated the power is better because then you can share the load to cover for that first couple of weeks until things calm down. Leadership is asking how do we celebrate the good things because we're only celebrating the bad things...That's one of the things that I really like about this leadership. He's making suicide public. Like he said 'I had an epiphany, why aren't we celebrating our youth' instead of saying 'oh you were out on the streets last night smoking, or drinking'. And now he's saying, 'wow, you're special' and of course in our Ojibway culture some of the most sacred gifts are children and the community raises the child. So I think that's his thinking behind all of this [Community Member].

When you're told over and over again that you don't belong, it wears on you. I don't want to see this continue. Harmony, healing and hope, that is our goal, but if you don't have willing partners in the federal and provincial governments... People need to wake up and say, 'we're the settlers here, let's respect these people', It hasn't gone away, this 'Indian problem.' We've never said go away, you people, go back to Europe...We're handcuffed to the 170-200 reports they [the government] has us do annually. We're stuck doing reports to justify the government, not to justify

the people, and we've bought into it. We've been strangled by bureaucracy [Chief].

While the health structure on Manitoulin Island is unique and does not parallel with many communities across Canada, the way they have identified champions, utilized them and approached crises in a proactive manner, is something that all communities should strive towards:

I've always found no matter who I speak with, I can get people excited. And all I'm doing is getting people excited about what I see or what I think might improve quality of life. It doesn't matter if it's a government person, even if I can get bureaucrats excited, at the end of the conversation, they might say 'there is going to be no money, but I like what you're saying'...I'll give an example of a champion I have known for many years. She's in government and I would ask her about people I could approach at a regional or provincial level as I was concerned about a particular health issue and not enough funding being available. She would put me in touch with regional physicians or people from a health organization and when I think about that growth, it has been unbelievable [Consultant].

The various narratives presented above represent the very essence of community-based, participatory research. Looking at the actions of these communities from afar using traditional approaches and frameworks, it is possible that one could interpret the relationships between communities and government and draw similar conclusions. However, because of the first hand interactions and access I was given within these communities, I was able to see not only how governance structures can enhance the effectiveness within a community but how pivotal champions within that structure are in shaping the policy landscape.

In the past ten years, the communities and leadership on Manitoulin Island have witnessed the value of partnership. Through this partnership, they have received over a

quarter million dollars from health organizations to run pilot programs that were developed and designed for the client by the client, a true model of self-determination in health. The idea of partnership and agency has now grown to all seven Manitoulin districts:

So they're good, bureaucrats are good even provincially here in the system for these communities. It's different dollars not what they need or what they want sometimes, but it does work. You've got to reconcile people are people, we're all in this together and you've got to make their job easier or give them some knowledge that might help them in their day to day work, in their briefings [Health Manager].

I think in some areas we're developing partnerships. The Cancer Care Ontario asked for the Sudbury Regional Hospital cancer care unit to look at screening for certain types of cancer. And so what Sudbury Regional Hospital has done is developed a working group and so it involves Aboriginal groups and we're part of this, of the development of the framework and we're hiring two coordinators and we're involved in the hiring of those two individuals. They're going to come into the community. So we're looking at a working group, sub-working group of professionals to work with these coordinators...I think we're involved in some of these groups so right from the proposal stage to the implementation stage and we're involved in looking at the evaluation. So that to me is a partnership in decision-making...we see the proposal and we're involved [Health Administrator].

This Aboriginal community's relationship with government could be viewed as a different type of activism. This type involves a model of power that takes into account the broader social context within which power relationships are established and maintained. This approach is in contrast to earlier activism in the 1960s with the creation of the National Indian Brotherhood (NIB) for example, now the Assembly of First Nations, needed by Aboriginal people for sustained mobilization. The NIB established a base for the dissemination of information, large-scale structural support for strategic organization of activities and a degree of unity to the efforts and perspectives of Aboriginal people

across Canada (Long 1997, 155). Aboriginal communities and their organizations are now using their leaders, organizations and their champions to exercise political agency through relationships with other wielders of power. MacIntosh points out that “many community final reports/self evaluations of transfer indicate that community health improvements were in part the result of partnering or otherwise forming new relationships with provincial agencies...Provinces have extensive experience in designing, delivering and evaluating public health programming...as well, the jurisdictional fragmentation caused by federal/provincial split in health provision for First Nations is in practice effectively minimized” (2008, 99). While power imbalances will continue to exist, there are many sites of power in that no single structure or institution is considered politically supreme.

I am now going to turn to my second case study in rural Manitoba. Like Manitoulin Island, this community has the health transfer process in place but in contrast there is limited provincial policies available or partnerships and this difference from the Manitoulin situation limits what the community and its leaders are capable of accomplishing.

Aboriginal Healthcare and Policy Processes on Tootinaowaziibeeng Treaty Reserve:

Tootinaowaziibeeng Treaty Reserve (TTR) is situated 400km northwest of Winnipeg, Manitoba and 38km east of Roblin, Manitoba. TTR is also immediately situated adjacent to the provincial Duck Mountain forestry, and 24km westward of the Municipality of Grandview, Manitoba. It is considered a rural reserve and geographically speaking is not close in proximity to any major city centres. Roblin and Grandview each

have a population of under 2,000 residents. The TTR overall population is 1283 (On/Off Reserve) with 616 residing on reserve, and 661 residing off reserve. The health funding from FNIHB Health Canada is specific to the on reserve population only.

Tootinaowaziibeeng Health Centre administers a variety of Community Health Programs and Services to the community through two types of health funding agreements with First Nations and Inuit Health, Health Canada of the Manitoba Regional Office. These agreements include the federal health transfer agreement as well as separate contribution agreements from FNIHB. As noted above, the health transfer process, as an expression of the Federal Indian policy, is intended to ameliorate the significant health disparities between Aboriginal people and non-Aboriginal people in Canada by a strategy of community controlled planning and delivery (Macintosh 208). As reviewed in Chapter four, the health centre at TTR was founded in 1977 as a one person operation. As complications arose within the community in the late 1980s and early 1990s, the TTR health administration grew to deal with these issues as well and signed a health transfer agreement in 1993, one of the first communities in Manitoba to sign. It re-signs every five years as per rules of transfer.

TTR has experienced many health concerns within their community including issues with their youth, drug and alcohol abuse, increases in chronic disease and mental health concerns. Many TTR residents do not have access to adequate shelter for their needs. They defined these needs as housing that would protect them from the harsh climate, that would foster human dignity and emotional well-being and that would

support (rather than undermine) health. Housing on TTR is viewed in the communities as a serious issue of health, justice, human rights and Indigenous rights. While the community experienced TB epidemics in the early and mid- twentieth century, they have not experienced any recent cases. But they have expressed concern regarding the potential for crowded housing to promote possible future epidemics of infectious diseases, including TB and influenza. There are significantly more permanent residents per house than the Manitoban average of 2.9. Crowding is exacerbated by the frequency of overnight temporary visitation from family and friends, which is common in First Nation communities. Languages spoken are English and Ojibway. The majority of the population, however, is versed in English as TTR is experiencing an alarming language (Ojibway) decline.

TTR is currently one of seventeen bands in Manitoba under a co-management system. This situation occurs when Aboriginal Affairs and Northern Development forces the band to hire an outside accountant or consultant to help keep the books in co-operation with the Chief and Council. Band councils still have signing authority but can make financial decisions only with the agreement of the co-manager, who is paid from band funds.

My interest in working with TTR began in December 2010 when I approached their community with the desire to pursue my PhD research on Aboriginal health policy. I grew up in a surrounding Manitoba community and it was important for me to conduct my research close to my roots. Since December 2010, I have worked closely with Ms.

Gloria Cameron, a community member and contractor, to put together a Community Health Needs Assessment (CHNA) for TTR residents. This assessment looks at community health care delivery through involvement of their youth, families, elders, service providers and leadership. The CHNA is a highly important document that the community can use to their advantage to improve and enhance the delivery of community based health care, while incorporating existing health delivery approaches that are already working to support community health and wellness strategies. Additionally, I have helped the community with focus group meetings and forums to receive further information from community members. I have been able to pursue my PhD research while developing a highly positive partnership with TTR in an effort to help the community with their goals of improving the overall health of their community. As part of this project, I was able to hire a youth research assistant from TTR to help me with my ongoing work within the community. After a year of working with TTR, I sat in on community-government meetings and wrote responses to government policy through the critical lens of the Aboriginal community. I felt very strongly that I was not only there as a researcher and consultant, but that I was an advocate for the community.

When I arrived at TTR, one of the things that I was reminded of was that significant life events bring communities together. The Tootinaowaziibeeng Anishinabe Health Centre provides an important sense of community for TTR residents. It is uncommon to have conversations with elders, youth, health workers or administrators about Aboriginal health services without someone at some point drawing attention to the

health centre as a meeting place for community members. When I walked into the health centre each morning, I often found TTR residents cooking in the kitchen or having coffee with one another. The health centre is where most health programs and workshops take place within the community. As one TTR resident told me, it's not just a place of healing but a meeting place. The community centre was burnt in a fire several years ago and the health centre is now considered the hub of the community:

I really despise going to the doctor in Roblin because I don't like the way I am treated but I like going here because it gets me out of my house. For some people it's a healing place but for many of us it's more of a social and cultural place even though it's the health centre. I can catch up with my friends who I haven't seen in a while...it's a place where we can come together [Community Member].

The idea of the Aboriginal community as a social construct is now firmly embedded in our understanding of Aboriginal history and culture. Stereotypes and images of First Nations' life sprang from European assumptions and values more so than they did from the reality of the Aboriginal existence (Coates 1999, 25). Most Aboriginal communities defined themselves as "the people" and had a powerful sense of attachment to their specific surroundings, had accurate understandings of contiguous Aboriginal peoples and had sufficient direct and indirect contact with more distant groups to form reasonably accurate understandings of cultural differences and similarities. The State represents an extreme situation of imposed homogeneity (Castells 1999, 270). Politeness, peacekeeping and respecting cultural difference are celebrated as the founding values of Canadian society. However, Canada has been largely built on the denial of the historical/cultural identities of its constituents to the benefit of that identity that is better suited to

the interest of the dominant social groups at Confederation. Castells stipulates that once a nation has become established through territorial control of a given state, the sharing of history does induce social and cultural bonds as well as economic and political interests among its members (1999, 270). In Canada, Aboriginal peoples were not included in the history, memory or collective consciousness of its constituents. The uneven representation of social interests, cultures and territories in Canada skewed the national institutions toward the interest of the originating elite and their geometry of alliances, thus opening a way for institutional crises. Not surprisingly, Aboriginal people are wary of outsiders:

People in Roblin have no idea what things are like here. They're ignorant. They go to church and pray for people in Africa yet we experience third world conditions right here 20 minutes down the road. We are a community in crisis. People are hungry. There is a lot of poverty here. Every morning, people are off to the food bank and the government set programs are hard to run when things are this dire. It's unrealistic to teach and run workshops on the Canada Food Guide when there are none of the four food groups to put on the table [Health Service Provider].

There never seems to be an answer or clarity on the exchange between settlers and First Nations so how can we reconcile with them and how can we trust them if they still continue to do what they're doing? [Community Member].

Similarly, conflict and issues around trust also arise within and amongst community members. Conflict can arise when one family network moves in to force out another. This often occurs in small communities:

No one in the community is capable of working together even though we have lots of wonderful people with skills and talent. Addiction to hard drugs, prescription drugs and street drugs have emerged as a serious problem within this community over the last five years. The problem is that the community is not on board to deal with issues so the only way to fix the problem is to get outside intervention because people here don't trust one another. It's tough though because they don't

trust anyone from the outside either. The fact remains that we can't fix this ourselves...People are dealing with crap from the past, residential schools and all of that. We have tried to run workshops that could be useful, but because of personal, family or political conflicts, people won't participate. I have seen situations where someone has showed interest in a program, but when they find out who is running it, they won't attend. The bottom line is that many of these people are addicts and don't think they need help and telling them that they do need help makes the problem worse. Current government programs are not equipped to deal with the severity of the issue [Health Service Provider].

A few years ago, we were a prosperous community, we were the success story of Manitoba. We had a strong leadership and a solid Chief and Council. Those who were around at the time are deeply saddened by what they see happening in the community. The friction that exists among the people here prevents us from forming groups and committees that could be helpful to the health of the community. Once upon a time, we had a health committee made up of 15 people that met and made decisions about the health priorities of the community and currently no such committee exists [Health Administrator].

When I began my position as a consultant with TTR, one of my first tasks was to put together a health committee and a terms of reference. The health administrator and I drafted a letter inviting community members to sit and participate on the committee. Almost immediately, conflicts arose as to who could and couldn't sit on the committee, what the roles and responsibilities would entail. Several members of the TTR leadership were worried that the committee would have full say over health matters. Once we overcame certain hurdles, we were able to get a committee in place and had three successful meetings discussing community health goals and dreams. However, it was only a matter of time before the committee was dissolved.

On occasion, government offices and bureaucrats are pulled into these community conflicts. In Manitoba, the Community Liaison Officer (CLO) oversees the health funding

agreement that she has with Chief and Council of TTR through the Manitoba Regional Branch of FNIHB. The CLO acts as a filter between the government and the community and is the face of the government that the community sees:

The liaison program piece is a bullshit position. They come in and they're there to administer your program that you've already developed and then they see how it's run from the community side of things and respond accordingly but it's the authority perspective that Health Canada has with these types of arrangements that basically takes a community and puts them back in the dark ages [Health Administrator].

While the role of the CLO is to advocate on behalf of the community and to help with capacity building to a certain extent, she continually reminded me that her allegiance ultimately lies with the government. She recalled a recent instance in which she was drawn into a community conflict:

I know the community gossip. I've been working with Manitoba First Nations for over a decade and so people tell me things. I got a call a few weeks ago because the current health director was worried about being pushed out of his position and replaced by someone else because of family conflicts... this stuff happens all the time. There is too much political infighting and a lack of work ethic...they need to figure things out and deal with it themselves. I can't drive five hours from Winnipeg every time something happens [Non-Aboriginal bureaucrat].

As a consultant and researcher, I often felt drawn into community-government conflicts. As a consultant, I made several trips to the FNIHB regional office in Winnipeg for meetings to discuss the community's five year health transfer renewal. At one meeting I attended, I arrived early and took my seat at one side of the boardroom table. Several minutes later and to my discomfort, government officials arrived and sat next to me. When the community members arrived, they were forced to sit across from us. A senior

bureaucrat arrived at the meeting late and to my disbelief and to the community's disbelief began the meeting by telling community members that one of their health programs that was offered through a pilot project was going to be cut because they were not meeting the program goals and objectives. When he was done with his explanation, he could have sat next to the community members and instead chose to pick up a chair from their side, put it on the government side and sit next to me.

The practice of community control in Aboriginal communities under transfer relies upon systems and structures that are similar to mainstream bureaucracy:

The community programs that are doing well in Manitoba are running well because they are acting more like FNIHB...they are becoming more and more political and bureaucratic [non-Aboriginal bureaucrat].

Similarly, many community members have expressed their disdain towards Aboriginal organizations and the degree to which they have morphed into government agencies.

These peak, advocacy bodies such as the Assembly of Manitoba Chiefs and the Assembly of First Nations represent the interests of the organizations but not the interests of Aboriginal communities:

You have Chiefs for example that go pass resolutions, vote on a resolutions or participate actively by voting for a national Chief or a grand Chief and yet, when does that ever come back to the community? I've never seen a Chief take those components back to the community for them to discuss and then to get the guidance from there to move forward. And that's the way it should be...And then you have the AFN and the AMC having some big meeting and we all know what the result's going to be...Instead, they should divide the money up from these meetings and send it to the communities for health programs [Community Member].

Looking at the protection of treaty rights, the AFN doesn't want to do it. They said they have a health commission on the existing structures. Well the existing structures are there and the AFN is writing a commission or they'll have it on health care delivery systems within communities. Well where were you when Health Canada was granted the authority in the area to deal with the needs of the community? Where were you then? [Health Manager].

Many elders within the community who paved the way in the 1960s and 1970s have feelings of anger and cynicism towards Aboriginal organizations and government. They see the younger generation who work for these organizations as sell outs. A common criticism is that the meaning behind community control is undermined by the practice of Aboriginal people collaborating with and even working within government:

My nephew went and worked for the government and I couldn't understand why he left [the community] We need educated people here... We're losing our people to government [Elder].

What struck me about this conversation was that in contrast to earlier activism in which individuals were independent political protestors, contemporary Aboriginal political activism invests power in government departments or Aboriginal organizations. These departments and organizations have opportunities to interact with each other and enter negotiations with other professional bodies creating new governance structures.

Much of the literature on health transfer speaks to the positive nature of transferring varying aspects of governance responsibilities from federal hands to Aboriginal ones. When asked about community control and whether health transfer has had positive impacts on the health of the community, I received the following responses:

I have a great deal of faith and I think that our community is strong and everybody's moving at a different pace and growing and developing. Some

communities are very clear about where they want to go and other are moving in that direction [Health Service Provider].

I think our community is highly resourceful and we don't want the status quo, we want to have good health and access to services just like any other Canadian. That's all we want. Getting there has been a long road for us, it can be troubling and not clear because there are just so many other things going on [Community Member].

Community-controlled health for us is being self-determined and when you're completely governed on your own. Maybe we haven't reached that but I think these are exciting times, I think these are very exciting times [Health Administrator].

To me, community control means severing all ties with government, especially FNIHB [First Nations Inuit Health Branch]. It would mean having our own mint, generating our own money and having the power to actually design and implement our own culturally-based health services...Transfer doesn't exactly do that [Consultant].

Others are not as optimistic about the health transfer process and feel that the health transfer process perpetuates a system of state run operations. Under health transfer, the government also sees the Aboriginal health programs and operations as its own:

As soon as we received the health building, then the asset component changed, so it actually quite literally says that even though they went through the construction phase and all that sorta stuff, with the building itself, in the next year's agreement it states in there that that building is an asset of Health Canada's [Community Member].

The government is all over the map, they speak of self-determination and health, but there's nothing cohesive with self-determination because health transfer is a set agreement. But yet they call it a partnership. So in other words, it's horse shit [Community Member].

Realistically, FNIHB is not dealing with the issues, they're dealing with what's on the table already so they're accepting that as a starting point when it shouldn't be. So if people understand what's there, then you might have more vocal support behind those issues [Health Service Provider].

The reporting is awful. Let's say you take mental health and Brighter Futures and established your own psychologist for abuse and substance abuse and you've combined that, so you take all those pieces and put them together...Okay now you try and take that and report that back..Health Canada doesn't accept it because they've gotta take that program you've adopted and it's been modeled and sits in the community. If you wanna go for the new transfer agreement you have to rip that program apart, to report on it. Because you've got data in here and you have to combine with data over there and you know who's responsible for taking that. So now, you've gotta develop a whole information system to accommodate that cluster reporting [Health Administrator].

The health programs should be able to service off reserve membership as well. Because it is your membership so in my opinion somebody should be going after Health Canada for the residency requirement of on versus off reserve. You're not allowed to sequester opinions from off reserve people, that's discriminatory. There's an inherent bias in the system [Consultant]

We have to always remember that FNIHB is the banker, that's where we get our money from and until that changes, they are going to continue to influence our future (Health Service Provider).

Much of the past and current literature views Aboriginal peoples and their communities as a homogenous group in the context of Aboriginal-State relationships. The narratives above prove this view is simply not the case. Community-based, participatory research permits scholars to obtain a clearer view of the complexities and tensions within communities, and to see how different these can be from one community to another especially as these differences relate to self-determination and health. By conducting in depth, on the ground analysis, the strengths and weaknesses of these policies are unearthed in ways that expose the localized 'messiness' of self-determination that otherwise would not have been so visible. Reverting back to the argument made in Chapter 2, this methodology does not begin with externally defined hypotheses but builds

a capacity for scholars to “live along” with members of the community and permit them to frame the problems that they face and the hypotheses about how these problems might be addressed.

A further concern that many communities face is that of co-management. As discussed previously, co-management occurs when a band's finances are in disarray, at which point, Ottawa steps in to remedy the situation with a government-based advisor. A growing concern is that government sets out unrealistic goals and objectives for Aboriginal communities and when those benchmarks aren't met, the government solution is co-management. The reality is that often the community was set up for failure. Government is increasingly requiring more and more data that demonstrate the successful rate of programs, particularly in the area of health. These success rates dictate whether or not programs get funded or cut and thus, a tremendous amount of pressure is placed on the communities to make their programs successful. As noted above, this occurred to TTR while I was pursuing my research. First, this structure of governance makes it trying to maintain goals and objectives when elections occur every two years. There may be competing visions among various administrators. Further to that, the AMC Grand Chief has argued that it's tough to improve governance and financial management when bands hold elections every two years, meaning chiefs often don't have time to make real changes. As a result, the AMC is pushing for four-year terms to make bands more stable.

Second, this structure places an unfair burden on the community by creating an additional layer of tension by having to appease government officials with every step. An

optimal model for communities is one that would be much more in line with self-determination where community members feel a sense of empowerment rather than the need to hit these statistical benchmarks and goals set out by the government. A feasible argument could be made that communities under co-management have a higher likelihood for crises to occur due to the constraints and pressures of the said system. A community with a good governance structure that does not have outside forces tearing away at the fabric of the community is less likely to have these crises and more likely to be better equipped to deal with them when they do occur.

One further impediment at TTR is a lack of current partnerships. When I look at how the communities on Manitoulin Island are working with one another and many are benefiting in the process, I see the potential for the same types of partnership occurring at TTR. Forming partnerships has been a successful outcome of several Aboriginal communities across Canada in the last decade which is particularly true for small communities. Communities are forming relationships with provincial agencies and creating cross-jurisdictional linkages with other communities which helps both on and off reserve residents and helps close gaps for all involved (MacIntosh 2008). This cooperation is critical in the area of health because of the best practices shared and the cost effectiveness and improved public health programming that result:

Quite frankly if you look at municipal structures, provincial structures...they're doing outsourcing, they're doing privatizing and that sorta stuff, well why not have a partnership in place that could bring some new health programs or some economic development that could benefit the community [Community Member].

We have started the process of having a nurse practitioner come in from Grand View to run women's health clinics which is a very positive thing. We really need to set aside our differences and start from the basic building blocks to make our community healthy again. We need to learn to partner with each other before we can expect to develop partnerships outside of the community [Health Service Provider].

You've got to say that this will not happen overnight, it's baby steps. There's always a better way, a more efficient way. Let's really listen, are these the top three goals for our community for this year? Let's figure out how to implement them...As players change, the goals are going to change and you're always going to have uphill issues. It's redoing things, re-educating, being respectful of the new players, helping each other out. The reality is that people are always going to have to play catchup whether it's local...band politics, provincial government or central government. It's all the same [Consultant].

Through the use of these powerful narratives from community members, Elders, Chiefs, healthcare providers and many others, I have been able to provide readers of this dissertation a sense of Indigenous voice and authenticity to this project. To me, this approach involved employing an Indigenous Paradigm, that is, a new perspective to research by challenging and deconstructing dominant values, worldviews and knowledge systems. As an alternative to more traditional theoretical approaches, these narratives offered a new set of tools for analyzing the dynamics/tensions of joint policy development. With this analytical capability, I am able to show the deeper structure of the process which produced these dynamics. I purposely used the words of participants to tell their story. Unlike quotes and frameworks from other scholarly writing, these narratives from the participants that I used throughout my dissertation are integral to the telling itself of the story and then providing insights about how particular policies work in the given communities. Aare argues that the analysis, interpretations and reporting of

Aboriginal stories within the context of research is not about the generalizations of experiences but about the experiences themselves, based on personal and social stories that give meaning to the phenomenon (2003, 5)

I end this chapter with an anecdote from another community-government meeting that I attended. The first distinct difference from the previous meeting with government bureaucrats was that the meeting took place at the TTR band office as opposed to FNIHB. Secondly, the seating arrangement was different in that there were no visible alliances. Whether or not it was coincidence or purposeful, the arrangement certainly made for a more engaging meeting. Having the meeting on TTR territory gave the members of this meeting a confidence and sense of empowerment that allowed for a vision to be put forth. Keira Ladner writes “Indigenous governance ‘traditionally’ was by and large, viewed in terms of creating peace and living together the best way possible (as people and as nations)” (2009, 89). At the conclusion of the meeting, I had a moment to speak with the Chief about my research, he showed me his copy of the Red Paper:

When I attend one of these meetings, one that involves government, I bring a copy of this. It’s a reminder of what we as First Nations have achieved and what we stand for [Chief].

The current type of community activism taking place is an intricate system connecting Aboriginal communities with the mainstream and with each other. It requires an eradication of boundaries and allows for the fluidity of processes and roles whereby it’s conceivable that Aboriginal communities can work with surrounding agencies, governments and communities in ways that years ago wasn’t acceptable. There is no

single model of government-community collaboration. In Manitoulin Island, the model that appears to be working is that of champions at various levels whereas in TTR a strengthened partnership throughout the community is necessary before further advances can be made. While these two models are not identical, they do have a similar landscape that in the end will improve community wellness.

Chapter 6

Aboriginal Health Policies and Government Structures and Practices

Is there a chance for First Nations health service delivery agents and communities and tribal councils to give forthright feedback that actually results in additional money? No there isn't. So it's not a reciprocal kind of accountability there. And until it is, it's an unequal holding of power

- Non-Aboriginal bureaucrat

Aboriginal Issues on the Federal Agenda

While the previous chapter discussed challenges of Aboriginal representation and self-determination at the community level, the purpose of this chapter is to evaluate the federal government's responsibilities around Aboriginal health policy. In addition, I investigate the responsibilities of provincial governments in Ontario and Manitoba and the bureaucratic institutions in which Aboriginal community-controlled health structures interact. I explore the practices of government, the ways they function, both internally and in relation to other institutions. I also examine the historical progression of Aboriginal health issues at federal and provincial government agendas and analyze Canadian Aboriginal health policies as a reflection of the political, economic and social systems from where they came. The argument presented in this chapter is that although government has made strides in increasing participation of Aboriginal people and communities regarding their health care, the reality is that there is a tension and disconnect between communities and government. This tension is a result of continued distrust and colonial tendencies which manifest into impassible communication. From the government interviews presented in this chapter, the majority of the respondents believe that a neutral and responsible form of governance is being utilized in Aboriginal health

policy and as seen in the previous chapter, this dichotomous to the views of those working at the community level.

The federal government plays a significant role nationally in providing broad directions for policies and programs that reflect national values. The leadership of the federal government in the implementation of the Canada Health Act of 1984 or in responding to the SARS outbreak are cases in point. As I discussed in chapter three, broadly speaking, Aboriginal issues at the federal level are the responsibility of the department of Aboriginal Affairs and Northern Development (formerly Indian and Northern Affairs Canada). Indian health was initially included under Indian Affairs. It, was moved to the Department of National Health and Welfare (now known as Health Canada) in 1945, a year after its creation, where it has remained ever since (Lavoie 2010, 17). Elsewhere in Canada, the emerging welfare state embraced a comprehensive structure of benefits, pensions, disability allowances and general provisions for social, economic and health security. Federal and provincial governments embarked on a course of legislation to provide new services and benefits to Canadians. For the first time in Canadian history, First Nations and Inuit were brought under the shelter of the new welfare umbrella.

By the 1960s, the department of Health and Welfare began gearing up for another round of expansion and program development. Seven different services were brought together in a new Medical Services Branch. First Nations and Inuit health services were lumped in with six other services, dealing with client groups ranging from public

servants, to civil aviation personnel, to immigrants, mariners and patients requiring quarantine. This odd mixture of services continued right up until the turn of the twenty-first century with the creation of today's First Nations and Inuit Health Branch in Health Canada (?). On a more positive note, federal and provincial governments were forging new partnerships that were having some positive impacts on the delivery of health services to First Nations and Inuit. The branch was also placing a renewed emphasis on preventative medicine. Large scale, intensive immunization programs were introduced to deal with measles, mumps, polio, tetanus and diphtheria. It was at this time that First Nations and Inuit began to take on increasingly important roles as service providers in their own communities. Policies and programs were being developed in an attempt to echo the obvious links between culture, health and healthcare delivery.

By 1979, after consultations and public debate, the 1979 Indian Health Policy was introduced by the Department of Health and Welfare. In announcing the new policy, the department underscored the special relationship of Indian people to the federal government, a relationship which both the Indian people and the government are committed to preserving:

The priority at the time was to get First Nations input into questions about programs, funding and the best way to come to terms with the economic factors that stood in the way of communities progressing. The role of each community was key [former non - Aboriginal bureaucrat].

As discussed in chapter 2, the new policy was based on three pillars:

- community development, both socio-economic and cultural/spiritual, to remove the restraints of poverty

- the traditional trust relationship between Indian people and the federal government;
- the inter-related Canadian health system, with its federal, provincial, municipal Indian and private-sector components.

This was really about First Nations and Inuit communities taking over all aspects of the administration of their community health programs at their discretion...and with the support of FNIHB [formerly the Department of National Health and Welfare]. In the early 80s, we piloted a series of community health projects to provide both the department and First Nations with important planning information to help facilitate First Nations control [non - Aboriginal bureaucrat].

Remarkably, the 1979 Indian health policy focused on “Indian communities,” not reserves, and thus put forward the idea of community membership which extended beyond the on-reserve population. Constance MacIntosh notes that:

it foregrounded the need to address socio-economic development, and support Aboriginal community control, if health was to improve. However, over the next decade, implementation models and government discussion documents adopted a focus upon a more limited population, on-reserve status Indians. The broader context of addressing health determinants and general capacity building was side-lined by a focus upon one element, transferring control over the delivery of public health services (2008, 70).

As the push for greater community control over healthcare continued, policy frameworks, authorities and resources were developed that would allow the department to transfer health administration responsibilities to communities. To support these efforts, a subcommittee was established to oversee the transfer of health programs to Indian control. Its members included First Nations representatives who had experience with healthcare. From the perspective of some First Nations activists who sat on the subcommittee, the transfer of healthcare posed a threat to Aboriginal self-determination,

while others supported the transfer because the Aboriginal rights agenda was considered solid enough to withstand this change:

By this point, the idea of participation was on the agenda and I don't think that anyone could say that our people shouldn't have a say...there was a commitment there to develop health specific processes within the context of our communities [Aboriginal employee of a National Aboriginal Organization].

In March 1988, the government approved a health transfer policy that allowed the department to enter into multi-year agreements with First Nations communities. Under that policy, the federal government argued that communities that wished to participate could determine both the nature and timing of that control. They were also free to develop their own community health plans, as long as the plans met certain standards. These included the provision of public health and treatment programs, and effective financial controls to make chiefs and councils accountable to other members of the community. However, a counter-argument came back:

You're threatening self-determination...I would say that many communities have structural systems in place that push Aboriginal self-determination. So no one institution is the institution of self-determination. Self-determination is about the way you see your power and relationship to the government. Community-controlled health care, which was being under-funded, are also incredibly important, in fact they are critical to expressions of self-determination [Former Chief].

This new transfer policy as argued by some, went a long way toward indigenizing the First Nations healthcare system and that the benefits outweighed many of the risks:

Under transfer, they had some innovative programs, they started off by doing some very good stuff. There was still a burden of illness of course, but there were a lot of things that worked and there were a lot of things that were preventing disease. The morbidity of illnesses communities received... with some of these

people under other structures outside of transfer, like having their leg amputated, or getting heart disease and other multiple problems is something that I really noticed as I often got contracted out to some of these communities [Consultant].

With health transfer, communities received a fair amount of money so they were able to hire some personal support workers, nurses, etc. to enhance their federal budgets. It also gave communities greater input into health programs [Aboriginal bureaucrat].

Health transfer provided a certain amount of flexibility of program design and moving funds between program areas and priorities in communities...These programs allowed for enough design to fit the circumstances, like culturally relevant kinds of services and that sort of thing. As long as they have enough funding for things like giving elders a role in the community - where there's suicide prevention - and things where youth are at risk, then, health transfer is doing its job [non-Aboriginal bureaucrat].

When you have Aboriginal people delivering their healthcare service, it makes a tremendous difference in the health outcomes because you're able to communicate in a culturally confident, culturally safe way. In my community, most of the people that are in healthcare are Aboriginal people...are First Nations from out of that community...nurses, administrators, directors, etc. [Director of Aboriginal Health Organization].

It was known as the Department of Indian Affairs and Northern Development until 1966. Prior to that (1867-1966) Indian and northern affairs administration was handled by various departments throughout the years, including the Office of the Secretary of State, Citizenship and Immigration, Mines and Resources, and Northern Affairs and National Resources. While some of its programs and services are arguably health related, the Department of Indian and Northern Affairs mandate is not health focused. There continues to be a great deal of confusion surrounding jurisdiction and the willingness to take responsibility for issues:

When I was at the Treasury Board Secretariat we were preaching horizontal management. I mean, the people who created the horizontal Aboriginal expenditure framework at the Treasury Board Secretariat were my team and I. And so I've been preaching that since I've been here [at FNIHB] with very limited success. But everybody has recognized, you have to rely on INAC for many more things. And they're finding in provincial Tripartite Health Agreements, when it comes to things like long term care, INAC has a piece of the puzzle, we have a piece of that puzzle and the provinces have pieces of that puzzle. And we are all in concert on that...And sometimes First Nations have to watch Health Canada and INAC saying, well no that's yours to do. Well no, I thought that's yours to do. Yeah, but I'm not funded to do that. Yeah, but I'm not funded to do that either. And so, it can even be within the federal government, inter-ministerial misunderstanding and conflict about what we can and cannot do [Non-Aboriginal Bureaucrat].

Jurisdiction is such a big forum in terms of what the hell we've got to do here, what's tribal jurisdiction, what's provincial jurisdiction, what's First Nation jurisdiction, where there's going to be areas of agreed to shared jurisdiction. That hasn't been ironed out and that's why it's causing a lot of our problems in every area. And sorting this out will help a lot. The other thing is, you know, is this 'I'm the government; I'm here to help' mentality, that's a bunch of bullshit [Chief].

The Department manages the structures and provisions that are linked to the Indian Act.

At present, the Honourable John Duncan was made Parliamentary Secretary to the Minister of Indian Affairs and Northern Development (as of 2008). Perhaps the most interesting development for Aboriginal Canadians is that Mr. Duncan who was previously in charge of Indian and Northern Affairs, continues as minister but his department is now known as Aboriginal Affairs and Northern Development. His portfolio covers a broad spectrum of issues: economic development, comprehensive and specific land claims and self-government agreements; oversees implementation of claim settlements; delivers provincial-type services such as education, housing, community infrastructure and social

support to Status Indians on reserves; manages land; and executes other regulatory duties under the *Indian Act*. Some Aboriginal leaders have questioned whether Mr. Duncan is simply a modern-day Indian Agent or if he is in fact an Agent for change.

Aboriginal health issues, in contrast, fall within the jurisdiction of the department of Health. As of October 2008, the position of Minister of Health has been held by an Aboriginal Canadian woman, Leona Aglukkaq. Ms. Aglukkaq's appointment as Federal Minister of Health has raised expectations for the government's agenda for Aboriginal health in this country. As I discussed in Chapter three, Health Canada's First Nations and Inuit Health Branch (FNIHB), oversees Canada's First Nations and Inuit Health system. In April 2000, as part of a major departmental realignment, Health Canada announced that the activities of the Medical Services Branch would now, "focus exclusively on Aboriginal health issues and the delivery of health services to First Nations and Inuit communities". Programs with a non-Aboriginal focus that had previously been under the branch's purview would be transferred to other branches in the department. Meanwhile, to reflect the new focus, the organization would be called the First Nations and Inuit Health Branch (FNIHB). As the re-focused branch moved forward with an organizational realignment aimed at addressing more clearly defined strategic priorities, the federal government was taking steps to close the gap between Aboriginal peoples and other Canadians in key quality of life indicators, including health.

In April 2004, just weeks after taking office, Prime Minister Paul Martin convened the first ever Canada-Aboriginal Roundtable involving the federal, provincial and

territorial governments, Aboriginal organizations and experts to discuss ideas for stronger, healthier and more economically self-reliant Aboriginal peoples and communities. The purpose was to strengthen relationships between Canada and Aboriginal peoples and to establish clear goals moving forward in a relationship of collaboration and partnership:

The process took about 18 months. I was heavily involved in it. We were starting the process of changing the way government does business but, unfortunately...the government was defeated...But because we stepped back from what was I think the interesting change where, if you can get the federal house in order, and the different pieces of the puzzle the federal government was financing to actually begin to harness, rather than doing their own things in ministerial stovepipes [Senior Non-Aboriginal Bureaucrat]

In September, the roundtable was followed by a meeting of First Nations and leaders of the Assembly of First Nations, the Inuit Tapiriit Kanatami, the Métis National Council, the Congress of Aboriginal Peoples and the Native Women's Association of Canada. That meeting led to agreement on:

- the need to work together to develop a blueprint to improve the health status of Aboriginal peoples, and to report on their work within one year
- increased federal funding for First Nations and Inuit health systems, based on a reasonable rate of growth to support general program improvements to meet the needs of First Nations and Inuit; and
- federal funding for a series of measures to address urgent and critical health issues for Aboriginal peoples in Canada

This last point included:

- \$200 million over five years to help improve access to streamline health delivery;
- \$100 million over five years to address human resources needs involving Aboriginal healthcare; and \$400 million in upstream investments in prevention and promotion

aimed at diabetes, maternal and child health, early childhood development, and youth suicide prevention.

Since coming into power in 2006, the Conservatives have been criticized by Aboriginal leaders for failing to commit to funding the 1.3 billion Blueprint on Aboriginal health that was part of the Kelowna Accord of First Ministers in 2005. The Kelowna deal promised to tackle the health gap between Canada's Aboriginal people and the rest of the country which “resulted from more than 2 years of planning and negotiation by federal, provincial, territorial and national Aboriginal governing bodies” (Smylie and Anderson 2006, 603). The Kelowna deal placed special emphasis on promoting Aboriginal control and self-determination over health policies (Webster 2006). The Conservative federal government, however, has remained dismissive of the Accord:

the Conservative government's decision to dismiss the Kelowna Accord had a detrimental impact on Aboriginal communities that had hoped for better health services, such as kidney dialysis. We appealed to the government in 2006 but it resulted in short term boosts for the health budget...The demise of the Kelowna Accord was devastating and forced provincial and territorial governments to cancel health service improvements because they were worried that the federal government would refuse to offer financial support. It truly was devastating for those of us who put our heart and soul into these negotiations. The fact was that the government took the \$5 billion and put it into military spending...Their priorities were clearly out of whack... The Conservatives promised more than \$10 billion for new equipment, largely to support Canadian troops in Afghanistan [Former Health Director of Aboriginal Organization].

Federally, it's always about money and lack of money. There's never enough money. If they had gone with the Kelowna Accord, I think that really would have helped [non - Aboriginal bureaucrat].

Joffe points out that, “as a result of continued pressure from the leaders of provincial and territorial governments and national Aboriginal organizations, significant funding for long

neglected Aboriginal housing, education and training was included as part of a large economic “stimulus” budget for Canada. This budget was announced in Parliament by the federal government on 27 January 2009” (2010, 154-155).

Even more recently, the 2011 federal budget has boasted that:

Since 2006, the Government has taken action to support families and help meet the needs of all Canadians, including...Investments to support priorities in First Nations education, child and family services, water and housing and First Nations and Inuit health (federal budget 2011).

The Governor General of Canada, David Johnston read the throne speech which claimed that the federal government was committed to Aboriginal issues stating that:

Canada's Aboriginal peoples are central to Canada's history which is based on mutual respect, friendship and support, and our government has made it a priority to renew and deepen our relationship. The contribution of Canada's Aboriginal peoples will be important to our future prosperity. Concerted action is needed to address the barriers to social and economic participation that many Aboriginal Canadians face. Our government will work with Aboriginal communities, provinces and territories to meet this challenge. It will help open the door to greater economic development by providing new investments in First Nations Land Management. It will promote access to clean water and the deployment of clean energy technology in Aboriginal and northern communities (Speech from the Throne 2011).

However, the 2011 June Status Report of the Auditor General of Canada (AG Report), Sheila Fraser tells a different story. Chapter 4 of the report highlights the ongoing appalling conditions on First Nation reserves, the stark contrasts between conditions of First Nation reserves and other communities, and the federal government's repeated failures to address adequately the deplorable conditions on First Nation reserves. While Aboriginal Affairs and Northern Development Canada released their joint work plan with

the Assembly of First Nations in June 2011, people will need to see significant improvements on reserves and a drastic change in their relationship with First Nations:

Is there a chance for First Nations health service delivery agents and communities and tribal councils to give forthright feedback that actually results in additional money? No there isn't. So it's not a reciprocal kind of accountability there. And until it is, it's an unequal holding of power, and therefore all the things that flow from that [non-Aboriginal bureaucrat].

There is no partnership in the legal sense of the word. We are not kicking in anything. This is us setting the funding levels and parameters while allowing the recipient a little more self-control when it comes to health [non-Aboriginal bureaucrat].

We are the minority in the white man's house. The white man has worked hard to assimilate us and keep us off our land. We want recognition of rights to our land...Why do we have to go through the process with them of recognize, settle and deal? Restoring Indian control and allowing our own people...giving us our fair share is what we deserve...The Federal government speaks the language, but they won't walk the talk [Aboriginal Elder].

Personal relationships and timing, rather than formal political processes and structures are important elements that impact one's capability to sway government decisions about what should be on the health agenda:

A person can try to put in place structural ways of doing things, however, it is the ability to put an argument forward to someone else, someone of importance and have that person listen to you, a person of authority and who can seriously impact another person, that is in fact how real change occurs [non- Aboriginal bureaucrat].

Furthermore, government bureaucrats place importance on having the "right" people in place to advocate on behalf of Aboriginal peoples:

I think it's important to have a person in place who has the right personality...a person who is sympathetic to the needs of Aboriginal peoples and with compassion for example....Or if we had a person for whom this was a great

priority...Or a person with a more reformist agenda...All of these factors can impact how much we can get done around here [non-Aboriginal bureaucrat].

However, access to an important government bureaucrat does not necessarily guarantee that one's interest or aspirations are advanced in Cabinet:

While ministers are powerful people, the fact remains that they are career politicians and therefore are anything but innovative...they tend to continue on with policies of previous governments and much of what they end up introducing during their terms in office serves their own interests [employee of National Aboriginal Organization].

We can't go back to the Department of Finance and say, you know, we thought we had a program integrity gap that was this size; it's actually this size. And we're sorry we didn't tell you before, but as these agreements come close to needing to be renewed, we have lots of additional information, and we didn't have it before that time and here it is, and don't you agree? And the Department of Finance and Treasury Board Secretariat are going to go, there's a worldwide economic collapse and the biggest deficit we've ever had, this is not a good time to ask for this, go away [non-Aboriginal bureaucrat].

Almost sixteen years after the health transfer agreement was first introduced, the federal government published a report evaluating First Nations' management of Aboriginal health programs. Dr. Josée Lavoie and her colleagues who belonged to the Aboriginal Health Research Centre in Manitoba were granted the federal contract to evaluate the health transfer program in 2005. It is difficult to determine whether the health status of the Canadian Aboriginal population has actually increased since the onset of the transfer process in the late 1980s.

Constance MacIntosh points out that:

They had intended to conduct a comparison between communities with and without Transfer Agreements over time. Upon requesting this comparative data from FNIHB, however, the researchers were advised that this type of analysis

would not be possible because the data is simply not available. Although FNIHB retains data for non-transferred communities and imposed very specific reporting requirements on transferred communities (which fulfill its reporting requirements to the Treasury Board), the collected data largely reflects administrative matters. Of all the communities that have completed their three to five year term under a Transfer agreement and have submitted their final reports, only about 20% include some sort of longitudinal outcome analysis and only 36% actually refer back to the public health goals outlined in their community health plans (MacIntosh 2008, 90).

This lack of systematic information is one of the main challenges in determining how the federal health transfer program has influenced Aboriginal health outcomes:

The biggest challenge for us is that we don't have any stats to pull up yet the government expects stats in order to keep getting funding. We don't know what type of problems there were at time of intake. We don't know how many clients see physicians or how many see a clinician. So we don't really have that. And how many clients did we have this year with suicidal ideation? We couldn't pull that out [Aboriginal Health Service Provider].

If you're trying to transform systems, the first thing you look for is not going to be an improved health outcome. It'll be some proxy for that, or some proxy for a system change that will ultimately give you a better health outcome or a better experience. When you are using the system, that's probably a better measure in terms of a better experience in the system. And how that contributes to better health, is the better logic model I think [non - Aboriginal bureaucrat].

Even if health is improving under the health transfer process, the burdens that communities are required to undergo in terms of administrative responsibilities are perceived as unreasonable by some and highly complex:

I was attending government meetings once a month and just before my holiday, I went to a meeting and they advised us that changes were coming with health transfer reporting. So the challenge now this year is that I'll be doing six reports as opposed to one report. Also with the block health transfers, the difficulty coming is that the government talks about the flexibility of the new transfer approach when really it's a huge hassle. They've given us a template that gives us line items

where we have to put in our dollars. So there's no accountability...We are puppets and we're told what to do and how to do it [Aboriginal health administrator].

A growing body of research suggests that socio-economic factors determine health. Czyzewski defines social determinants of health as “environmental causes of ill health that affect populations. They point to evidence that highlights higher susceptibility to illness and disease as a product of particular socio-economic and physical environments” (2011, 1). Evidence suggests that factors such as education, income, housing isolation, poverty, unemployment and household structure among other factors, are critically important for a healthy population. The Romanow commission has argued that policy sectors function within silos. Thus Aboriginal health is often dealt with independently from the very social services that are determinants of health. A tension that becomes evident is government health-policy makers' emphasis on community empowerment, community development and social determinants of health on the one hand while simultaneously dictating rational resource allocation and output based funding on the other. In the context of health policy reform, community empowerment results in government offering communities a choice between social equity and economic efficiency. While FNIHB describes itself as a supporter and proponent of culturally appropriate services and traditional modes of medicine, bureaucrats within these departments often rationalize budget expenditure for health issues that fall within narrowly-defined classifications:

When we talk about gaps, the other key thing, that is an awful challenge for the health sector is within Health Canada. Within FNIHB, you have your hands around just health system stuff. You don't have your hands around social

determinants involved. And some of the key drivers of health is poverty, and crowding and water quality. You know? And a whole bunch of other things that Health Canada doesn't have its hands around. You don't have those levers. And yet we have the expectations. We've actually changed in our authority, with little exercise, change the statement for some of our strategic objectives, so we don't keep getting criticized for not closing the health gap. But we don't have the levers to do that. And I think that's the problem when you work in silos [Senior non - Aboriginal bureaucrat].

Those in the Aboriginal health sector and in government who are more critical of policy processes argue that while government bureaucrats consult on an ad hoc basis with Aboriginal communities, there remains a lack of commitment and responsibility when it comes to Aboriginal self-determination in health. Aboriginal controlled health policies are problematic because services are not funded equitably compared to provincial services; the funding often does not account for a growing population; and there is cost shifting and administrative fragmentation by federal and provincial bodies, which provides for an overall limiting structure from which to offer the necessary holistic, responsive services that communities need and want (Lavoie, 2003 345). The health of Aboriginal peoples is essential to self-determination which involves personal and community power and control over decision-making (NAHO 2001, 18). This is especially important where Aboriginal peoples and communities "have historically lacked control over their social health" (Warry 1998, 65). In order to more fully understand this situation, it is necessary to unravel some of the values that underlie government health policy by examining specific examples in Manitoba and Ontario.

Evaluation of Aboriginal Health Care in Manitoba:

The following section considers some existing gaps faced by government officials in Manitoba which have emerged in response to Aboriginal health policies, particularly challenges that occur in relation to transferred communities. The analysis in this thesis is obviously a selective one; there are many other “gaps” which could have been included. As a result, it is intended to contribute to the initiation of a broader discussion about the future of Aboriginal health policy under the health transfer process at the government level and some of the challenges they encounter.

Manitoba has the highest proportion of Aboriginal people relative to provincial population among the ten provinces of Canada. A total of 175,395 Aboriginal people lived in Manitoba, representing 15% of the provincial population. First Nations in particular comprise approximately 11% of the total Manitoba population with 51,546 living off-reserve and 84,262 living on-reserve (FNIH SVS Population 2010). Manitoba is second only to Ontario in terms of total on-reserve population and in total First Nation population. Manitoba has 63 First Nations, including six of the 20 largest bands in Canada. Slightly more than one third of Manitoba's Aboriginal people are Métis. The province includes the largest number of Métis people per capita in Canada with the majority living in southern Manitoba, including the city of Winnipeg. The Manitoba Centre for Health Policy found higher mortality rates in the Métis population compared to the rest of Manitobans. As well, the prevalence of physical illnesses (and some mental illnesses) was higher (2010, XLII). According to the most recent census data, 6,900

Aboriginal people in Manitoba could not be classified as either Status Indians or Métis. Of these, 6,300 indicated North American Indian identity but not registration under the Indian Act (non-Status Indians). The rest were Inuit or indicated multiple Aboriginal identities but not registration under the Indian Act.

Overall, the story of the health of Manitoba's First Nations people is not a good one:

The Manitoba Region faces a number of challenges in the delivery of health services to First Nations in Manitoba. First of all, we have a high number of remote and isolated communities and many of them are not accessible by road. Over 60 per cent of First Nations people living on-reserve in Manitoba live in remote, isolated or semi-isolated communities. We also have over 10,000 clients that must travel by water, either by boat, helicopter or ice road to access health care and most health care services are centralized in Winnipeg. What this means is that many clients must travel long distances for tests and to see specialists - some clients have to travel 12 to 16 hours roundtrip [Aboriginal bureaucrat].

Consistent findings across many studies have indicated that First Nations face substantially greater mortality and morbidity rates and poorer self-rated health compared to other Manitobans. They can expect to live eight years less than other Manitobans and the rate at which they die young is especially troubling. They are three times more likely to be hospitalized for injury (Martens et al. 2005). Diabetes amongst First Nations in Manitoba (and Aboriginal peoples more generally) is the highest in the country:

Chronic disease, especially diabetes continues to plague our communities...Aboriginal people have been forced to undergo unnecessary foot amputations because Health Canada will not fund foot care...The federal government has spent millions of dollars on amputations and this is only going to increase...I guess that's the cost of doing nothing [Aboriginal health service provider].

A recurring theme throughout this dissertation revolves around jurisdictional ambiguity and the lack of clarity on the roles and responsibilities of the federal and provincial government with respect to health services to Aboriginal peoples. Despite the high numbers of Aboriginal peoples living off-reserve, the province of Manitoba continues to take the position that they bear no responsibility for supporting health programs because Aboriginal people fall within federal jurisdiction and thus should be served through federal funding and programming. Although the Manitoba government is required to provide equal access to health care services under the Canada Health Act for all residents of Manitoba including First Nations living on reserves, it continues to take the position that the federal government is responsible for certain health services to First Nations people who are Status Indians under the Indian Act. As a result, some health services not covered by the Canada Health Act but otherwise provided by the provinces through the Regional Health Authorities may or may not be provided to First Nations communities (Boyer 2003).

These disputes create ongoing tensions that translate into complex program fragmentation, problems with coordinating programs, under-funding, inconsistencies, service gaps and lack of integration (Webster 2005). Additionally, policies fail to adequately address the health care needs of the Métis or First Nations and Inuit people who are either not registered or not living on reserve/traditional territory (UNICEF Canada 2009). Such inadequacies have also resulted in much jurisdictional debate about who should pay for health services in particular contexts:

We have a mandate to participate in discussions, but it's not a mandate to enter into a self-government agreement... Legally, we view health as a federal government responsibility...the province is really afraid of federal offloading, particularly with regard to First Nations issues on reserve. So there's a real fear of that. But I think provincially, we do totally support other initiatives such as economic development, but there is a lot of complexity around health... [Aboriginal bureaucrat].

Josée Lavoie writes:

According to provincial and territorial policies, non-status or non-registered First Nations have the same rights to access to programs and services such as health care, income assistance, and education as any other Canadian resident as provided for by their province or territory of residence. Because non-registered First Nations are considered a "provincial or territorial jurisdiction," First Nations communities do not receive funding to extend services to them. In theory, the jurisdictional carving is neat (2008, 110).

However in practice, because of Bill C-31 (legislation that regulates Indian status), jurisdictional issues are anything but neat. They are often "compounded by generations of First Nations not eligible for registration, who may be born on reserve, and share the culture, language, practices, and needs of their cultural peers, but who are denied access to the same culturally appropriate services, including the right to live on reserve, as a result of a bureaucratic provision" (Lavoie 2008, 110-111). Substantial documentation corroborates the fact that the long standing conflict between provincial and federal governments has negatively impacted Aboriginal peoples and has resulted in the patchwork of fragmented services which exists today. Despite the entrenchment of Aboriginal and treaty rights in section 35 of Canada's constitution, the federal government refuses to acknowledge the impact of health as it relates to Aboriginal and treaty rights (Boyer 2003):

When discussing health discrepancies with Health Canada, we as First Nations need to use the Canada Health Act to our advantage, we need to use section 35 of the Constitution to our advantage which has stayed silent and we need to use the Canadian Human Rights Act. Why aren't we doing more with these documents? [Community Member and Consultant].

Table 4 provides an overview of health programs and services provided by federal and provincial jurisdictions to First Nations people in Manitoba.

Table 4

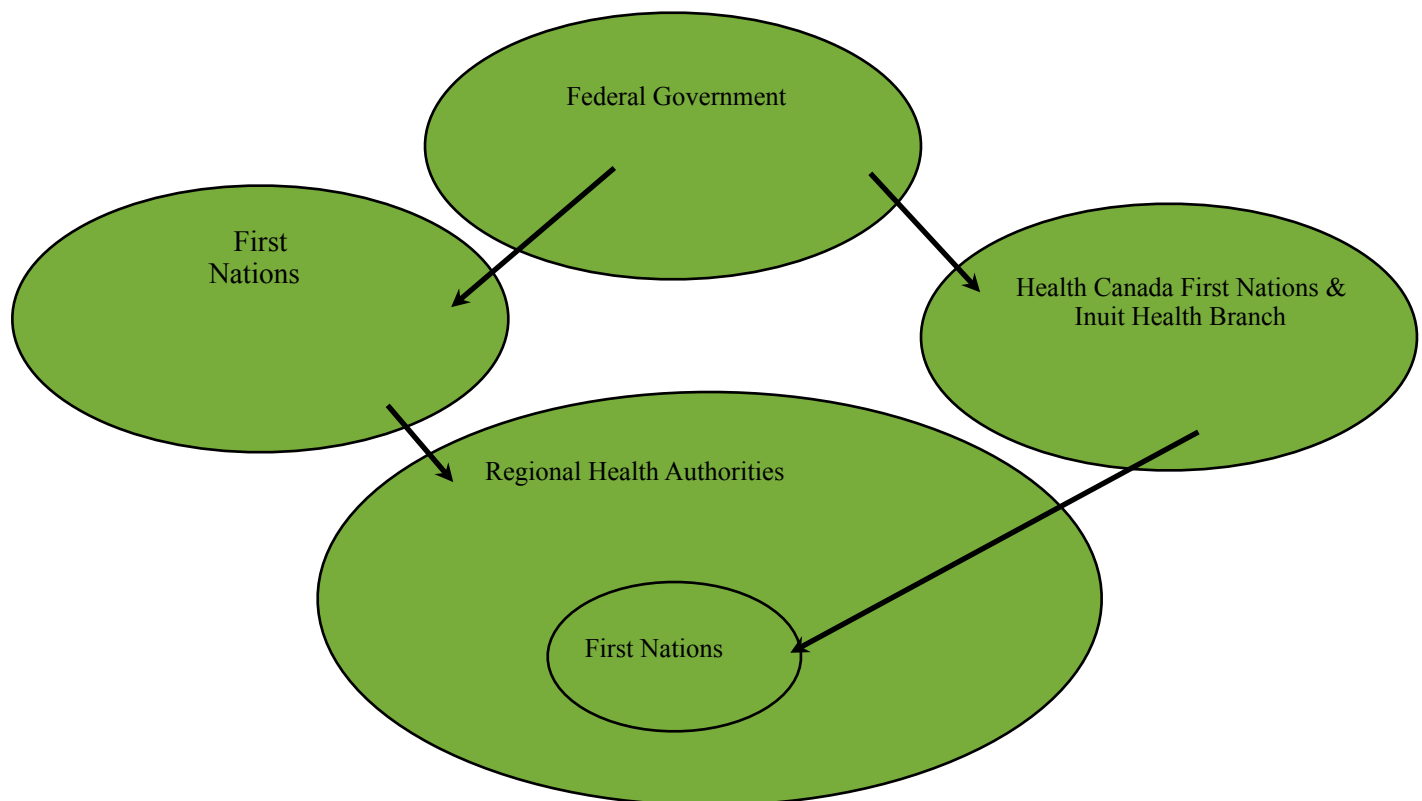
Health services available in Manitoba

| | | |
|---|---|--|
| First Nations people living on reserve | Community health services: Public health nursing, Community Health Representative, National Native Alcohol and Drug Abuse Program, HIV/AIDS, FAS/FAE, Canada Prenatal Nutrition Program, Brighter Futures/Building Healthy Communities, Aboriginal Diabetes Initiative, dental health promotion, tuberculosis, Non-Insured Health Benefits program. Some hospitals in northern locations. Emergency and non-urgent treatment services in remote and isolated communities in addition to the above. | Physician services and hospital services as covered under the <i>Canada Health Act</i> , First Nations People can generally access other provincial services in off-reserve locations. |
| First Nations people living off reserve | Aboriginal Head Start, Aboriginal Diabetes Initiative, HIV/AIDS, Non-Insured Health Benefits Program | |

Source: Romanow Final Report, FNIHB and Lemchuk-Favel L. and Jock R. (2004) 'Aboriginal Health Systems in Canada: Nine Case Studies.' *Journal of Aboriginal Health*

Similarly, Dr. Catherine Cook provides a framework to understand the current First Nation health delivery in Manitoba (2003). Figure 6 demonstrates how First Nation communities are situated on a federal land base geographically but also within provincial health authorities.

Figure 6



Source: Catherine L. Cook, 2003, *Jurisdiction and First Nations Health and Health Care*. Winnipeg: University of Manitoba.

Areas of Consensus

To a large degree, jurisdictional issues which impact accessibility and comprehensiveness stem from decades of a “tug of war” match over which level of

government is responsible for services. One extreme example of this “tug of war” between differing levels of government is centred around Jordan River Anderson, a young child from Manitoba’s Norway House Cree Nation, who was born in 1999 with a rare neuromuscular disorder, requiring him to receive care from multiple service providers. He became the centre of a jurisdictional funding dispute between the province and the federal government over who should pay for his home care which prevented him from leaving the hospital to receive care in a family home. Jordan eventually died before his situation could be resolved.

Frustration over these types of jurisdictional disputes have so enraged Aboriginal leaders and children’s advocates that a Private Member’s Motion (M-296) was introduced in the House of Commons. The motion stipulates “in the opinion of the House, the government should immediately adopt a child-first principle, based on Jordan's Principle, to resolve jurisdictional disputes involving the care of First Nations children,” and received unanimous support in Parliament. The intent of this child-first principle is to ensure that the necessary care for a First Nations child is not delayed or disrupted by a jurisdictional dispute. Despite consensus being reached on Jordan’s Principle in the House and its endorsement by several provinces, no real progress has been made on implementing it.

Cross-jurisdictional coordination forums have also emerged between Aboriginal organizations, Aboriginal leaders, and Aboriginal and non-Aboriginal bureaucrats from provincial and federal levels of government as a way to navigate through some of the

hurdles discussed above. Josée Lavoie describes these forums as functioning “as committees, not formal organizations, which bring together stakeholders in Aboriginal health...their roles vary but can generally be defined as information sharing and coordination” (2010, 31). Discussions between differing levels of government have occurred around various areas of health:

In terms of integration in the health area, I can give you an example, where it's not a huge media worthy outcome, but certainly involves stuff around Jordan's Principle. In the case of Manitoba, the idea of case assessments and case reviews came about that were done jointly, and the MOU between INAC and Health Canada, that has indicated, you know, if we aren't sure, we'll settle later, but Health Canada will pay and INAC later...So there's an MOU which actually sets out in one of these cases, here's who'll go first, there's who'll go second and we'll settle it later, but we won't wind up in front of a client pointing fingers at each other. We've had lots of what-if kinds of discussions. But at least in Manitoba there have been some active discussions about how do you integrate what is happening and how do you put aside the jurisdictional uncertainties or conflicts [non -Aboriginal bureaucrat].

In 2003, the Manitoba Inter-Governmental Committee on First Nations Health was established to identify priorities and coordinate approaches to improve First Nations health in Manitoba. The committee's membership brought together representatives from the Assembly of Manitoba Chiefs, Manitoba Keewatinook Ininew Okimowin, Southern Chiefs Organization Inc., First Nations and Inuit Health Manitoba Region, the Public Health Agency of Canada, Manitoba Health, the Manitoba Department of Aboriginal and Northern Affairs, Family Services and Housing Manitoba, Manitoba Finance, and Indian and Northern Affairs Canada:

I was asked to participate in one of these meetings from a departmental perspective to influence how a policy was being developed...I believe the only

way you can bring about any kind of policy change and have input is to involve the people that it's going to influence. It's a way for us to come to some sort of common approach over a particular issue and say so, how can we realistically turn daily struggles in our different jurisdictions, knowing full well, that we're all different, have different situations and see if we have similar thought processes about where things are heading...I think it's a positive thing [Non-Aboriginal bureaucrat].

Not everyone is as optimistic regarding the effectiveness of these forums. Many Aboriginal community advocates as well as Aboriginal and non-Aboriginal government bureaucrats are skeptical of the productiveness of intergovernmental, interdepartmental, and interagency collaboration. There is a need to protect one's bureaucratic territory which can interfere with people's attempts to coordinate and collaborate. Political tensions also occur every five years as health strategies and funding mechanisms are renewed. Disagreements take place as to who has the authority to make policy decisions, who is accountable for the health outcome of the population and how much money is available:

We meet, and meet and meet, but nothing seems to get accomplished...the process is really a facade...we sit around a table and discuss things, but nothing comes out of it...it's a waste of time [non-Aboriginal bureaucrat].

These joint forums between various levels of government, Aboriginal organizations and political leaders often appear as though they are autonomous political entities. However, it became clearer to me as I began to piece together the puzzle of Canadian Aboriginal health policy that there is still significant overlap and interdependence among these participants. Josée Lavoie notes that cross-jurisdictional coordination forums "While encouraging, these mechanisms are not empowered to

change legislation and adopt policies. Their effectiveness...may nevertheless be constrained by existing legislation, policies and budgets that are decided at the national and provincial levels. Still, these developments are steps in the right direction” (2010, 32). While many view these forums, committees and Memorandums of Understanding as new forms of partnerships that are occurring between the Aboriginal health sector and government, others still see these processes and those who participate in them as meaningless:

I was at one of those meetings once and there was a lot of drama going on and the objectives just weren't being followed. And there were major assumptions being made and so for myself, I would have said, you know, just get past all that, just get to what the client, you know, the project client needed...And I think sometimes it's easy to get into drama with government and I know that because I used to do it myself, I would envision myself yelling. I would say now, there is more discussion but there's still a dance that goes on and there's still a back and forth and it's still adversarial...There is a bottom line in terms of how much we're going to give in to government...because if I'm to go over the line then I may be saying I'm no longer First Nation [Aboriginal Consultant].

First Nation communities receive funding from the federal government (the First Nations Inuit Health Branch at Health Canada) for community-based programs in health promotion and prevention and some primary care services, including drug and alcohol prevention. In addition, the Brighter Futures and Building Healthy Communities programs of Health Canada are aimed at addressing some of the social services needs of First Nations communities in the areas of mental health supports, healthy babies, child development, parenting skills, and injury prevention. FNIHB has also established home care programs on reserve. While its headquarters are located at Health Canada in Ottawa,

they also have numerous regional branches across the country. The role of the FNIHB-

Manitoba Regional branch has various roles:

We're in charge of delivering programs and services to First Nations in Manitoba with the hopes of improving health status. We provide services in areas of communicable disease control, injury prevention, immunization, etc. via transferred service provision...Our goal is to really try and develop positive working relationships between First Nations and our branch [non-Aboriginal bureaucrat].

Ministers at the provincial level reiterate the importance of meeting face to face with their

Aboriginal partners:

We're moving the yardstick and have a stronger Aboriginal relationship. Aboriginal groups come here - that didn't happen very much before. So I think that relationship has improved. Now, Chiefs and other Aboriginal leaders have ready access to Ministers [Aboriginal bureaucrat].

Similarly, some Aboriginal bureaucrats employed with the regional branch of FNIHB

consider themselves in a more appropriate position than their non-Aboriginal colleagues

to monitor the pulse in local communities:

I don't look like your traditional government bureaucrat. My hair is long, I don't dress a certain way and I think people here have come to respect that...they respect me. I think communities have come to respect me too. I know what is going on there on a day to day basis and the problems they're facing because I've also faced them...I travel to some of the rural and remote communities just to check on them and I attend their health fairs and treaty days so that they see and interact with a government face [Senior Aboriginal bureaucrat].

When it comes to transfer, there are actually lots of opportunities but communities are just not taking advantage of them and I'm not sure why that is, I think a lack of understanding probably has something to do with it...but there's lots of flexibility with transfer and it's just a matter of taking the time to understand the process and what it entails...I have meetings with people who say "well there's not enough money to do this and there's not enough money to do that and we need more money and you cut my program" and I say "but there is, you just need

to do this”...because I’m Aboriginal, I think it’s easier to have some of these conversations...they tend to listen to me [Aboriginal bureaucrat].

However, other government bureaucrats are more direct and are quick to point out the on-the-ground difficulties that are occurring at the community level:

From what I see, communities do not want to work together and help each other out. We try and work with bands however there are too many turnovers and a lack of education...The question becomes how do you build partnerships with people who don’t partner? [non-Aboriginal bureaucrat].

The problem is that communities want to be nice to everybody and so they keep unqualified people, family members who are not competent. No one wants to ask the hard, tough questions: Why are you still here? And what do you do all day? [non-Aboriginal bureaucrat].

I think success comes from having a tight governance structure and having the community members buy into it...If the governance structure isn’t in place, everything falls apart [non-Aboriginal bureaucrat].

When it comes to self-determination, so many Manitoba communities want what British Columbia has, but they don’t realize that it took many, many years of hard work to get to where they are currently at and I’m not sure the communities here want to put in the work [non-Aboriginal bureaucrat].

Some of the values invoked by government bureaucrats are those of appropriation, paternalism and subordination. It became clear to me as I spoke with government bureaucrats about some of their frustrations that these sentiments often come from offices and from mid-level bureaucrats far away from the communities in the balance. Several government officials that I spoke with as part of this research admitted that they had never set foot in an Aboriginal community:

I am definitely aware of the appalling conditions on reserves, don’t get me wrong, I know things are bad and I would never say that I’m an expert on Aboriginal health issues...my job here is to work on contribution agreements

and review proposals, I'm not required to go to the actual reserves [non-Aboriginal bureaucrat].

I can recall sitting in a government boardroom as a consultant with both government bureaucrats and community members discussing the community's five year health plan and being appalled at how little decision-making power the community had with regard to their own future. What appeared to be happening was that community members were trying to tailor their community health plan and health needs to a government checklist that the community had no part in creating. This type of paternalism is seen all too often in the relationship between government and Aboriginal communities.

Health policy in a colonial context demonstrates the extent to which social, economic, historical and political factors shaped government policies and programs. In Canada, Aboriginal health policies came about as a result of the colonial attempt to control Aboriginal peoples' lives. The government took aggressive measures to minimize the spread of diseases in Aboriginal communities. They were acting not out of concern for the overall wellbeing of the Aboriginal population but for the concern of the health and economic interests of the colonialists. They did so by introducing contagious diseases like smallpox, the banning of the Beothuk, or the atrocity that occurred in the residential school system (Czyzewski 2011). Czyzewski argues that these discrepancies reflect the "protracted effects of land dispossession and sedentarization on cultural continuity, access to traditional economies, as well as physical separation from mainstream monetary economies" (2011, 3). This notion of history, especially in the inter-dealings between government and communities is often overlooked by bureaucrats as they tend to only

focus on present day circumstances and on the internal colonial conflicts that are occurring as a result of past history:

I was with one of the Chiefs in Manitoba and, you know, really we've gone through a lot at the Tribal Council level here about what we should be advancing, what is, you know, the governance model, justice models, health models, economic development, you name it. And we came to the conclusion that we're not going to make any real tangible focus on any of these sectors until we heal ourselves - there is a healing in our community that needs to take place first [Chief].

While health transfer initiatives are urgently needed in Aboriginal communities across Canada, this process often brings about changes by government that can interfere with community goals and aspirations. Service provisions must be constantly renegotiated with all of the appropriate stakeholders as new programs become available while others are removed. Healthcare workers are also constantly in flux adding to the stress of their already demanding jobs. Funding under the health transfer process also has an impact on the self-determination process. Funding and reporting requirements or program objectives vary considerably between funding streams which becomes very demanding to the provision of health services. As I sat in community health planning sessions between government and community health administrators and leaders throughout this research, I listened as communities were told again and again that cuts were coming. If they were unable to demonstrate program success, the program would be eliminated. Government policy-makers have become more outcome oriented and attempt to quantify Aboriginal health issues by turning them into concerns about overcrowding, asbestos in houses and water contamination. Public health solutions can then be empirically evaluated,

photographed and even publicly displayed. This approach becomes highly problematic as communities and governments have very different perspectives on measures of health.

There has also been greater government demands for financial reports as communities are continuously audited which is a source of much frustration for administrators and health service providers. One could make the argument that this collection of information which includes constant reporting and includes establishing a community health needs assessments and community health plan every five years is a mechanism in which the government flexes its control over Aboriginal communities. In no other part of Canadian society are health administrators required to follow these types of processes:

I think when it comes to funding, they're using the funding for the purposes that we fund, but we recognize that that particular worker might be involved in other initiatives that kind of supplement the work that they're doing...our money is cut and very detailed and very closely monitored as well [non-Aboriginal bureaucrat].

Some communities find that the money they've been transferred hasn't been enough and a tribal council comes forward and says we need money, you're stuck with FNIHB saying okay, well we'll try to use some year end program integrity money. We can't give you a five year fix, but we can give you patches of money but we have to be careful because we have a whole country to look after [non-Aboriginal bureaucrat].

There isn't a lot of inter-program flexibility and the ability to move money, however, if you meet certain minimum standards for your program, then you can economize and move monies around...we saw a lot of that happen on an emergency basis when H1N1 hit. And people sort of did a bit of a cash cow moving of money from a whole of different contribution agreements, the clause in there allows you to do that [Senior non-Aboriginal bureaucrat].

Ultimately, financial audits and reporting that is required by government is a mechanism that they use to justify their budgets to Cabinet. At the end of the day, it's the government in power that has the ability to decide whether the money has been used appropriately and whether Aboriginal health is a priority that is worth investing in. Clearly, with all of the recent cuts that have been made to Aboriginal health and their corresponding organizations in 2012, Aboriginal health is not being treated as a priority.

Evaluation of Aboriginal Health Care in Ontario:

In contrast to health transfer, the AHWS partnership was designed to engage in joint policy development - an approach that moved far beyond the more traditional "input" or "consultation" that government provides to Aboriginal peoples. It unites not just "different" but historically opposed groups, the colonizer and the colonized. AHWS offers a highly interactional and process-oriented approach as joint policy development challenges the more traditional technocratic and linear approaches to health policy and planning. On the actual program and management level, the AHWS partnership operates on the principle of interdependence which not only allows for the needs of diverse communities to be met but also ensure that programs are community-driven and can operate provincially, regionally and/or locally.

There are almost 300,000 Aboriginal people, or First Nations, Métis and Inuit, in Ontario. According to the 2006 Census, the total population of Aboriginal people in Ontario rose from 188,315 in 2001 to 242,495 in 2006 - an increase of 29 per cent resulting in Ontario having the largest Aboriginal population in Canada. The Aboriginal

population in Ontario experiences a disproportionate burden of many infectious and chronic diseases, increased injury rates and mental health disorders. The off-reserve Aboriginal population constitute approximately 70% of the total Canadian Aboriginal population. They suffer from lower levels of education, lower levels of household income and higher rates of smoking compared to their non-Aboriginal counterparts. As a result, the Aboriginal population in Ontario has a lower health status than their non-Aboriginal counterparts.

As noted throughout this thesis, one way to reduce the health gap between the Aboriginal and non-Aboriginal population is to develop culturally sensitive public policies (Shah 2005). Several coordination mechanisms have surfaced across the provinces to enhance Aboriginal participation in identifying health priorities, designing strategies, and coordinating approaches to improve Aboriginal health (Lavoie 2010). The most comprehensive example is Ontario's Aboriginal Healing and Wellness Strategy (AHWS). AHWS is the single largest Aboriginal initiative undertaken by a province in Canada and involves a unique partnership between on- and off-reserve Aboriginal organizations and provincial ministries in Ontario. The goal is to reduce family violence and improve health outcomes in Aboriginal communities.

The Ontario government acknowledged that mainstream programs were not effective in addressing the issues of high rates of family violence and poor health status in Aboriginal communities. Thus, AHWS began with the development and design of the Aboriginal Family Healing Strategy. It arose as a result of the courage of a number of

Aboriginal organizations working at grassroots and provincial levels to recognize family violence as a major issue affecting Aboriginal communities across Ontario. In 1989, the Ontario Native Women's Association disseminated a report entitled "*Breaking Free: a Proposal for Change to Aboriginal Family Violence*" which highlighted the urgent need for culturally appropriate services to end domestic violence in Aboriginal communities. The report documented that 80% of Aboriginal women and 40% of Aboriginal children in Ontario were victims of family violence. This evidence resulted in action from the Ontario Women's Directorate (OWD) who released a report in 1990 entitled "*Violence Against Women: Wife Assault Prevention Initiatives*" which identified the need for a specific Aboriginal Family Violence Strategy. In 1991, the Aboriginal Family Violence Joint Steering Committee (government and Aboriginal partners) was formed to address the issues in the above reports by creating a framework to develop a strategy that promotes healing and positive lifestyles for Aboriginal people in Ontario.

By 1993, Ontario began to rethink the province's approach to Aboriginal health services and programming more generally by moving toward an overall Aboriginal health policy. The Aboriginal health policy was adopted after extensive community collaboration and consultation with more than 5000 people in over 200 communities, including mental health and correctional facilities. It was one of the most elaborate series of consultations ever carried out with Aboriginal people in Canada (Maar 2004). A final report was disseminated in 1993 entitled "*For Generations to Come: The Time is Now – A Strategy for Aboriginal Family Healing*" and subsequently a new policy was presented

a year later by the Ministry of Health entitled “*New Directions: Aboriginal Health Policy for Ontario*. This policy was unique in the fact that:

- 1) It was a collaboration between government and Aboriginal partners;
- 2) It was designed specifically to address the health and wellness needs of Aboriginal people in culturally appropriate manner;
- 3) Programming/services would be designed, developed and delivered by Aboriginal communities.

Impressed by the concept, the Royal Commission on Aboriginal People recommended AHWS as a service-delivery model that other jurisdictions should consider in addressing Aboriginal healing and health. Subsequently, the Aboriginal Healing and Wellness Strategy Phase I was formally established in 1994:

I have so many great memories related to the AHWS but the best memory I have was at a health fair at Queen’s Park to raise awareness of the Strategy. Many of the specialized programs came and set up booths to profile their successes. The Six Nations Maternal and Child Centre even brought the first baby delivered by a traditional midwife. I can remember looking around and it really hit me for the first time what all of the Aboriginal community efforts and provincial funding were accomplishing and the emerging impact of AHWS [Former Health Administrator of AHWS].

AHWS is unique in Canada, and has become a source of innovative expertise in Aboriginal healing and health services across North America:

AHWS is really about here’s the money, design a program based on your needs...I think that’s the uniqueness of AHWS, I don’t know of any other program in Canada that actually provides that [Senior Aboriginal Bureaucrat].

Until April 2011, the AHWS was managed by a Joint Management Committee (JMC) which included an inter-sectoral governance approach employing a consensus model for decision-making (Maar 2004). The JMC had an annual budget of \$33.3 million dollars and consisted of two representatives from each of the eight Aboriginal umbrella organizations in Ontario representing all Aboriginal People. These included non-status Indians, Inuit, Métis and women as well as ten government Ministries and departments which was eventually reduced to four ministries (Aboriginal Healing and Wellness Strategy, 2007). Unfortunately, due to political tensions amongst government ministries and their Aboriginal partners, the JMC was recently dismantled in April of 2011 after eighteen years of service.

The purpose of AHWS is to fund and support the development of community-based health and mental health care services in a culturally-based and holistic environment. The goal is to improve Aboriginal health status and reduce family violence in Aboriginal communities across Ontario (Maar 2004). Marian Maar points out that “AHWS programs emphasize community-driven, culturally appropriate services; accessibility to primary care and a continuum of services; and general improvements to access to western and traditional medicines” (2004, 55). To help fulfill its objectives, AHWS funds various types of Aboriginal community-based health initiatives in Ontario. These initiatives serve both on and off-reserve populations and include Aboriginal Health Access Centres (AHAC). First announced in 1995, AHACs were closely modeled after Ontario’s Community Health Centres (CHCs), whose wide range of services and supports

had become the preferred mechanism to improve the health and well-being of communities in Ontario facing various barriers in accessing health care. By 2000, all ten were operational.

Since their introduction, AHACs have made an important contribution to health and well-being in Ontario. From clinical care services, to integrated chronic disease prevention and management, family-focused maternal/child health care, addictions counseling, traditional healing, mental health care, youth empowerment and other programs, AHACs continue to serve as a key gateway to overall family and community health and development (AHAC Report 2010). As part of the process, AHWS-funded projects are committed to having Aboriginal Elders and Traditional people participate as an integral part of their approach to healing and wellness (AWHS Traditional Healing Guidelines 2002).

. The shift to self-determination in health care means that Aboriginal health organizations and government are dealing with increased administrative change. Furthermore, community health administrators at the local level are faced with the challenge of developing Aboriginal models of care and administering these models within the often-conflicting backdrop of the current government public health models of care. This challenge can be a daunting one. While political leadership and health organizations typically have mandates to work towards self-determination in health with an emphasis on the well-being of their communities, these two sectors are often at odds with each other and with government ministries as they try to navigate through the health policy

puzzle. Despite many of the challenges, AHWS can be considered as a positive example of a successful government-community partnership. Unlike health transfer, AHWS success is due in large part to the extensive consultations and relationship-building amongst various stakeholders so that programs were designed with and by communities. It is also important to consider that any health policy outcome will only be as good as the energy and resources put into the initial developmental phase.

“Partnerships” and Consensus Decision-Making

The idea of partnerships in public health has grown in popularity over the past few years and is not unique in Aboriginal health. Since the 1990s, the term “partnership” has been a popular buzz word amongst government ministries and their departments. AHWS is an interesting example of a unique form of partnership between government, communities and organizations. It is important to note that the term partnership in the AHWS context involves various sets of social relations. In addition to the emergence of Aboriginal-government bodies, the relations also include Aboriginal organizations working together across diverse histories of oppression and cultural differences and government ministries which rarely cooperate across mandates and budgets. Early on, AHWS took “partnership” to heart as the *modus operandi* in their attempt to reconcile Aboriginal and non-Aboriginal actors in the Aboriginal health sector. Consensus was the lynchpin in the development and implementation of the strategy and consensus decision-making provided a way to deal with the heterogeneity without homogenizing or diminishing different perspectives. In my discussions with government officials,

references to compromise, understanding and reaching middle-ground were often mentioned:

There were some decisions that were really hard to reach consensus on and our sense of consensus was different from everyone else, so that people would try really hard to come to an agreement together, but if not, they wouldn't hold back a decision. They would kind of state their opposition to it - give some kind of rationale and then indicate whether or not they would let it go, so that there was no kind of bitterness or anything [Aboriginal bureaucrat].

Consensus decision-making is sort of the Aboriginal way of doing business. You bring people together, you talk, you share your differences, but at the end of the day...people rallied and made decisions that continued to support the programs and the delivery of those programs [non-Aboriginal bureaucrat].

In his research on consensus government in Canada's North, Graham White writes, "Consensus government is congruent with Aboriginal values...On the question of what 'consensus' entails in reaching a decision, the overwhelming view was that it did not mean unanimity or near-unanimity. It did mean respectful exchange of ideas and open-mindedness" (2009, 62). With AHWS, consensus-based planning resulted in more effective and comprehensive planning and encouraged the establishment of partnerships among Aboriginal organizations to run programs that serve several communities in a given area.

Given the complex cultural and political dynamics operating when diverse groups and interests attempt to develop policy together, dialogue and decision-making using consensus continues to be considered very effective. Practically speaking, consensus requires several rounds of discussion and intense listening over longer periods of time.

As various government officials commented, this process facilitates greater understanding which can result in better decisions:

We've had a very supportive relationship with our partners and I believe that will be ongoing. It's remarkable, Ontario really is, I think, a very good province to be working in the public service for, because our relationships with the Aboriginal partners are really different...I also think that the perspective that we take on dealing with all of our partners is, equitable and fair...And making sure that when decisions are made, that all partners have some kind of input of information along the way, so that all of that is taken into consideration before decisions are made [Aboriginal bureaucrat].

It's a very interesting relationship between the Aboriginal population and the province. AHWS has had its challenges - and there have been significant challenges - at the end of the day, the organizations have come together and focused on what was important; it was the delivery of services to people in their communities. And at the eleventh hour, people rallied around that and that's what made this model unique [non-Aboriginal bureaucrat].

We have an intra-ministry working group which is very successful. Ministries are working together more closely. I think the ministry now has a better relationship with Aboriginal organizations. As a ministry, we are ensuring that there is collaboration. An example is through the Aboriginal crisis line - there was lots of consulting and engaging with Aboriginal leaders at the community level from the outset. A representative from the ministry went to the Aboriginal community to get their feedback and leadership from the community came to Toronto - it was a very collaborate process [Senior non-Aboriginal bureaucrat].

While consensus decision-making has been a useful process under AWHS, it has also been criticized by some senior-bureaucrats as being inefficient, particularly with regard to the dismantling of the JMC in April of 2011. The JMC was made up of representatives from First Nations, Provincial-Territorial organizations, independent First Nations, off-reserve organizations representing non-status, Métis and women and four provincial ministries.

All AHWS policy, program and funding decisions were determined by the JMC:

First Nations felt it wasn't an appropriate table to be at because it wasn't representative of their reality - personality conflicts ensued and many issues came up that were not negotiable...It's very difficult to have a pan -Aboriginal group at the table [Senior non - Aboriginal bureaucrat].

So moving forward, the decision was to dissolve the JMC and enter into direct funding relationships with the signatories of AHWS...The First Nations were at a stalemate. They're not happy with the decision and we can't even have discussions right now with them because they want their own JMC and they don't want anyone else there. They want their own distinctive-based approach. And for us, we're not increasing money in these economic times. So we're not prepared to increase administration money to create another bureaucracy. We need to have a conversation around governance structures [Aboriginal bureaucrat].

For us, the dismantling of the JMC has been a learning experience in how you deal with relationships - players change, it's a reality [non-Aboriginal bureaucrat].

Several bureaucrats also discussed a trend that is occurring in Ontario which is the infighting that is occurring between different Aboriginal groups across the province. This development also makes collaboration challenging, particularly around the First Nations side as their issues are so vast:

So I think what happened is when AHWS was established, the Joint Management Committee was set up between different groups of people. And so when initial allocations were decided in terms of who was going to get what, the meetings became dysfunctional. It was some of the most dysfunctional meetings I've ever attended. The infighting amongst Aboriginal groups, in particular the First Nations wanting a government to government relationship - and they didn't want to sit at the table with the Métis - so it became very, very toxic and difficult to move things...They were stressful for everybody who was sitting at the table [Senior Aboriginal bureaucrat].

Ultimately, we want to be able to lay out what the plan is, right? We want to do service contracts, we want to do an overarching agreement. We want to talk about best practices. We want to talk about evaluation. We want to talk about what's going to happen to the money within the JMC... how can we best use that? We

want to have those conversations jointly...but everyone is steaming right now, it's really unfortunate. First Nations are going to miss out in terms of having input because other groups formed a coalition and alliances, they've already organized themselves. They're trying to position themselves for more money, but...you know, they're being savvy about it. Whereas First Nations, through some of the Grand Chiefs are starting to call me to see what's happening and I'm like, your technicians are giving you bad advice...Let's sit down and have a conversation and figure out how to move forward [Senior Aboriginal bureaucrat].

I think the province is also going to need to look at who are the Métis, who represents them, and where are the historical Métis communities? We're going to be setting up a table with MNO [the Métis Nation of Ontario]. MNO will say well, we're everywhere, you have to consult with us. The province may not have that position. So, we need to kind of figure out those key questions. I think it's going to be some policy work that we'll really have to look at. And also, what are the rights? Is it just harvesting...you know if they don't have a land base, well what is it? [Aboriginal bureaucrat].

Although the idea of the JMC was a step forward in the way of building stronger partnerships between government and Aboriginal peoples, the government perceives the fighting as a set back for Aboriginal peoples, particularly First Nations. From a community perspective, it is illogical to take part in the government's pan-Canadian solution of having all Aboriginal peoples sitting at one table as it makes it challenging for each nation to pursue their own agenda in light of their unique history and challenges with various levels of government. Many Aboriginal leaders view this requirement of bringing First Nations, Métis and Inuit together as a further tool of power over Aboriginal people. As a result, this infighting is having a negative impact at the community level and constrains the development of an Aboriginal community controlled health care system because governments are unwilling to negotiate in any other fashion.

“Accountability” is another bureaucratic buzz-word. Those who work for Aboriginal leaders and organizations are eager for government bureaucrats to take responsibility for Aboriginal health and to hold their end of the bargain. They also want government bureaucrats to involve them in policy processes so that their priorities and health needs will be addressed. For their part, many government bureaucrats see it as a priority to improve Aboriginal health and they are open to new consultative processes But trust remains a significant barrier encountered by the two parties:

We have literally had a year and a half of meetings for First Nations to try and come up with a model to negotiate. We thought we had gotten somewhere. And after 12 hours of negotiations, they came up with a new model that wasn't even what we were talking about. They want their own process, their own governance model. They want the money to flow through them...There's no accountability [non-Aboriginal bureaucrat].

When you blend politicians and technicians in a room - everybody's kind of got different interests. So it becomes challenging in terms of who to trust. The second you blend the politics and the technical it becomes a challenge. And you can't really say no to Chiefs because a lot of Chiefs are technical too because they wear many hats. So that's part of the challenge I think [Aboriginal bureaucrat].

In addition, government bureaucrats also point to some of the on the ground challenges that are occurring:

It's hard to get full time workers that will stay in the long term and the turnover is really high, because once they go to mainstream, there are a lot of higher paying jobs available. There's a challenge of working in a First Nations community, in small communities, because you know everybody and you may be working with family members...there's also the geography...for some of the northern communities, it's a huge challenge and they run out of money after three or four months, because of the cost of traveling... at our end, we haven't put a lot of money into supporting some of the older programs in a number of years, so our partners have to be really creative with their funding sources as well, they would

take federal and provincial money, they combine it all together, have one dedicated worker that reports back [Aboriginal bureaucrat].

From a technical point of view, the other thing we're doing is looking at performance measures, performance outcomes and data elements and we're looking to streamline all of those, so we have a lot of work going on around streamlining data...one of our programs - and I always use this program as an example, because I was just shaking my head when I looked at the data element for Aboriginal Healthy Babies Healthy Children...communities had 140 data elements that they were required to fulfill which is ludicrous. So we've whittled it down to like fourteen or fifteen [non-Aboriginal bureaucrat].

Despite some of the challenges discussed above and regardless of the top-down nature of government, bureaucrats are eager to provide examples that identify situations in which policy and programs have been initiated by Aboriginal communities. They want to show that these initiatives result in what they see as successful health outcomes at the local level. Government rhetoric is often self-congratulatory and tends to inflate the significance of its action with respect to Aboriginal people:

We're really optimistic that we've overcome a lot of the challenges that potentially could have been very difficult for us to manage...I'm not patting ourselves on the back, but we're able to do some great things because we got out there from the very beginning and we started talking to people and we were very transparent about what we were doing and why we were doing it and more importantly, how they would benefit from some of the changes. We're also listening to them in terms of priorities for spending and whether it's across the board salary and wage increases, which they haven't had since '94, or you know, enhancement to programs where geographically they incur huge costs because of travel and so on and so forth [non-Aboriginal bureaucrat].

Everybody has agreed that AHWS itself, in terms of taking a bunch of pots of money, creating one envelope and allowing people to design a birthing centre or a traditional healing program and the other programs under AHWS is unique - FNIHB would never agree to something like that [Aboriginal bureaucrat].

There is lots of valuable work taking place on the ground. The growth of the AHACs [Aboriginal Health Access Centres] has been amazing and the maternal child health at Six Nations is a success in terms of programming and service delivery models [non-Aboriginal bureaucrat].

I think the strategy itself has been very successful because it hasn't kind of been here's a government box and here's a pillar, you need to fit within the criteria. It's been, you assess what your community needs are, and you develop programs. And all of the assessments that have been done on AHWS have been very, very favourable...Clients are happy [Aboriginal bureaucrat].

Similarly, there are many government documents that promote bottom-up approaches to Aboriginal health planning. As I conducted government interviews for this research, many bureaucrats were quick to provide or refer me to reports and documents centred around positive relationships with their Aboriginal partners. One such document that was referred to me was called "Ontario's Approach to Aboriginal Affairs" - a contextual piece from which senior management and the ministries take their direction. This document is premised on a partnership between the province and many sectors including the Aboriginal community controlled health sector. Disputes over whether policy processes are bottom-up or top-down add to the complexities of current Aboriginal health politics. In chapter five, I discussed the direct role that Aboriginal community advocates now play in the government policy process, a role that many years ago was non-existent. As evidenced from the discussion above, many, but not all government bureaucrats are supportive of this redistribution of power towards Aboriginal leaders, organizations and community health administrators.

An emerging concern with which the Ontario government is going to have to grapple in the future is that of jurisdiction. Jurisdictional concerns could become problematic and start to weigh on Aboriginal-government relationships:

We're being bombarded on jurisdictional issues...the problem is that governments and First Nations have different opinions about treaties. And what was agreed to in treaties and treaty interpretation and how do we start to address treaty interpretation. We have tried to set up a treaty commission within Ontario, however, the challenge has been the diversity within Ontario [Senior Aboriginal bureaucrat].

A further trend that is emerging within Ontario is that the federal government is looking more towards the provinces to deliver provincially based services:

The provinces are going to have to make decisions and think hard about whether or not they are prepared to do that [Senior Aboriginal bureaucrat].

The federal government doesn't have the same direct role it had in the past in delivering services, in reporting on services because a lot of the municipalities, provinces and even those at the community level can handle it. If they've been given the funding, they have the capacity and they've grown that capacity - they have enough funds to develop their capacity. Why can't they do that? Within that system, First Nations communities can take a hand in delivery, which puts a First Nations stamp on culturally appropriate services and continuum of services. And so you have the chance for that fusion. So you've got integration, aggregation, complex systems that require complex and well-trained managers, at the same time as local control of certain aspects of this. The federal government doesn't really fit here [Senior non-Aboriginal bureaucrat].

Although many communities across Ontario continue to be autonomous, negotiations continue with federal and provincial partners with regard to the enormous health status problems that continue to plague most communities. Resolution of outstanding resources and discussions concerning jurisdiction will continue to be on-going.

These strongly held beliefs over what community controlled health care means to Aboriginal peoples, their organizations and government have at times led to an impasse as there appears to be little common ground that any party is willing to move forward on. As these tensions continue, it is difficult to envision a scenario where self-determination will land on the discussion table. The reality is that governments are enablers of Aboriginal health policy and until this relationship is bridged, Aboriginal people will continue to live in substandard conditions far below that of the non-Aboriginal population.

Chapter 7

Piecing the Puzzle Together: Government, Self-Determination and Reconciliation

We owe the Aboriginal peoples a debt that is four centuries old. It is their turn to become full partners in developing an even greater Canada. And the reconciliation required may be less a matter of legal texts than of attitudes of the heart.

-Roméo LeBlanc

In this conclusion, I address several questions that have emerged consistently in my study. Does the legacy of colonization render impossible any future reconciliation process between government and Aboriginal peoples? Does the concept of path dependency make it impossible for government and Aboriginal peoples to move toward a relationship of co-existence due to unequal dynamics of power? Based on the themes discussed throughout this dissertation, one can be optimistic about the future relationships around Aboriginal health. In the two policies examined, it becomes evident that the provincial-based strategy is far more conducive in offering key stakeholders a voice in shaping the development, implementation and evaluation of health policy. The question remains what does reconciliation and self-determination mean in the context of Aboriginal health policy? How do government bureaucrats and Aboriginal communities see partnerships with one another? What does the future hold for government-Aboriginal relationships?

In response to these questions, I argue that even though the landscape of Aboriginal health policy and politics has undergone a significant transformation in Canada, Aboriginal and non-Aboriginal people have yet to overcome a history of distrust

that extends over 500 years. Because of this distrust, I argue that Aboriginal communities will not be receptive to any policy that is initiated by government. Reconciliation is possible, but only when decisions and partnerships are initiated from within communities.

What is the government's official position on Aboriginal self-determination? With an acute sense for the interviewee's reaction, I often asked this question at some point during most interviews with non-Aboriginal and Aboriginal government bureaucrats. It is important to note how the temperature can rise so suddenly in climate-controlled government offices when such questions are posed. Their answers about self-determination waver between expressions of support for Aboriginal community empowerment and expressions of concern about how much control can realistically be handed over to Aboriginal people. Government bureaucrats are quick to acknowledge the importance of culturally appropriate health care and for health policies to be managed by Aboriginal people. In February of 2011, I attended the Ontario Public Service Aboriginal Forum where a minister spoke of ensuring there is an inclusive process where people across organizational levels have opportunities to be listened to and to provide input. Government bureaucrats make such statements in the spirit of practical reconciliation and to appease the frustrations of Aboriginal peoples. Unfortunately, such statements do little to address the larger issues of self-determination from an Aboriginal perspective.

Sheryl Lightfoot, for example, observes that such compliance is often concentrated in "soft rights," such as rights to language and culture, while systematically denying

“hard rights,” such as rights to land (2010, 62). This approach is evidenced by a senior bureaucrat when she discusses the government’s position on self-determination:

While we do focus on improving social outcomes, improving relationships, resolving land claims all of which end up helping communities move towards self- determination, we do not have an official government policy on self-determination. We do have a mandate to participate in discussions with regard to self-government negotiations. We do support economic development , being able to have your own revenue, making decisions for yourself, being able to choose how to spend your money and resource benefit sharing...but no, we do not have an official position on self-determination. We don’t see that as our responsibility [non-Aboriginal bureaucrat].

As a result, many Aboriginal people express concern and suspicion that reconciliation and partnerships in Aboriginal health are a false front. Although governments promote Aboriginal community-controlled health care, government bureaucrats seem threatened by the notion of self-determination.

Other government bureaucrats are more supportive of partnerships with Aboriginal people and have a stronger understanding of Aboriginal peoples’ visions of self-determination and have helped them pursue Aboriginal community-controlled health initiatives:

The things we’ve been doing in terms of programs and administratively borrow from the evidence and logic of the inherent right of self-government, i.e., communities that are ready for self-governance or self-government, have better attributes and have much healthier members in a whole number of ways. Whether it’s because of self-government or whether it’s because they live along a self-government path or because a number of things are right at the time is a bit of a question. It’s sort of a chicken or egg question. What we’ve done through the funding agreements since the 1980s a number of government branches especially this one [FNIHB] have recognized - that if you want to have your public sector meet your needs, you’re the best people to figure that out and not somebody far away in the national capital [Senior non-Aboriginal bureaucrat].

For Aboriginal communities, the argument has been that the process of self-determination needs to be initiated by the community. Forms of governance cannot be imposed upon the community, as it has been over the past 210 years. A project based on self-determination will mean the community will be involved with the decision-making, planning, implementation and evaluation of that project. The ultimate aim is for total community control. A greater awareness of the social and political issues influencing the health status of Aboriginal people is necessary to provide sensitive, culturally appropriate health care services in a context of self-determination.

The Politics of Reconciliation

Political movements of the last 30 years helped create a significant degree of pan-Indian identity (although cultural differences in some places mean tensions remain in place). The sharing experience of political protest and organization, the growing influence of the AFN, a dramatic increase in Aboriginal cultures among the mainstream society as a whole and an increase in the confidence among young Aboriginal people helped generate a growing sense of being Aboriginal (Coates 1999, 34). A sense of peoplehood is diverse yet Aboriginal peoples were frequently forced to act as a single political unit. Aboriginal consciousness allowed for Pan-Indianism to emerge along social and political organizations. The growth of Aboriginal organizations and movements in helping Aboriginal people retain their culture and identities reinforced links among Aboriginal people across Canada.

With the establishment of the National Indian Brotherhood and the categorical rejection of the 1969 White Paper, the widespread support for activities to reject the White Paper allowed for the social construction and avowal of common motives and identities among movement supporters. This collective identity represented a transfer from the colonial external construction of a Pan-Indian identity under policies and laws, such as the Indian Act, to an appropriation of it for political movements and social reform. Many laws and policies that are employed and enacted affect all Aboriginal peoples (or many) and therefore, Aboriginal communities needed a sense of solidarity to fight what could have impacted many of them.

The concept of reconciliation took on a life of its own with the establishment of the Royal Commission on Aboriginal Peoples (RCAP) in the 1990s. No longer was strategic organization of activities the only outlet to reconcile differences. RCAP allowed for a new form of advocacy. This form included a Statement of Reconciliation expressing Canada's regret for past actions that had resulted in damage to Aboriginal peoples and communities. It also set out an agenda for the development of a new partnership between the federal government and Aboriginal peoples. The agenda centred on four objectives: renewing the partnership; strengthening Aboriginal governance; developing a new fiscal relationship; and supporting strong communities, people and economies.

Thus, it gradually became fashionable for policymakers in health, education, Aboriginal Affairs, and other sectors to work together. As discussed in Chapter One of this dissertation, partnerships became the framework for relationships between

governments and Aboriginal communities. Government bureaucrats discuss the importance of partnerships:

I think a partnership is the method for setting the strategic direction and the processes for policies and programs. And practically, that can mean joint identification of needs and priorities - in what order things need to be funded or reorganized and then the roles and responsibilities for achieving that...We are committed to working in collaboration with Aboriginal people to explore and develop new processes that build our relationships and where Aboriginal partners will continue to have input into government planning, policies and investment opportunities. I believe that is the sort of partnership that we are trying to implement [Non-Aboriginal Bureaucrat].

Federal, provincial/territorial and local governments develop public health policy in collaboration with health professionals as well as community-based organizations. A fairly broadly-defined concept, “partnerships” refer to many types of collaborative relationships:

I see partnerships as involving both sides coming to an agreement. It means Health Canada working in unity with us and coming to a position so that you can move forward in a way that makes everyone happy. To me, that’s what a partnership is. Some government officials that we work with view partnership as being ‘You’ll do it my way because there is only one way’. They [the government] believe that we should be grateful for what they are giving us. That’s not a partnership. [Health Service Provider].

The bureaucrats that I see that go onto First Nations land will get a gift that symbolizes a relationship with the Crown; it’s a personal gift; for our communities, gift giving is very consistent with our values [Consultant].

By the late 1990s, partnerships became the framework for relationships between government and Aboriginal communities. Reconciliation was used by government departments to promote the doctrines of Canadian unity and partnerships were invoked as a key mechanism to reconcile Aboriginal and non-Aboriginal Canadians. Despite these

bureaucratic initiatives, Aboriginal critics of reconciliation point out that the Canadian public - and by extension government - has not let go of the vestiges of colonialist mentality. For example, Canada was the only country on the 47-member Human Rights Council to vote against the United Nations Declaration on the Rights of Indigenous Peoples at the General Assembly in September of 2007. Paul Joffe has noted that “*The Declaration* constitutes a major step towards addressing the widespread and persistent human rights violations against Indigenous peoples worldwide. It is the most comprehensive and universal international human rights instrument explicitly addressing the rights of Indigenous peoples” (2010, 123). In a letter to the Assembly of First Nations in June 2006, however, Prime Minister Stephen Harper characterized Canada’s objective in terms of “promoting harmony and reconciliation” but claims that the text falls short. In November 2010, Harper’s government finally endorsed *the Declaration*. Grand Chief of the Assembly of First Nations, Shawn Atleo has stated that “It signals a real shift, a move forward toward real partnership between the First Nations and the government”. Similarly, Indian Affairs Minister John Duncan said in a statement that in endorsing the document the government was recognizing its importance to Aboriginal Canadians” (Ibbitson 2010).

The many contradictions of the reconciliation process are also captured in the Canadian media. Prime Minister Stephen Harper’s apology to residential school survivors in 2008 evoked a mixed reaction among Aboriginal Canadians to the concept of an apology. Some think it is important while others feel it was insincere and meaningless.

For example, several community members that I spoke with about the apology felt that at a time when the Prime Minister could have demonstrated a true commitment to forging a new relationship with Aboriginal people, he chose not to work with their leaders or residential-school survivors to develop the apology. The apology would have been much more meaningful to the Aboriginal community if he had chosen to walk the walk instead of talk the talk of reconciliation.

The day after the Harper apology, Indian Affairs Minister Chuck Strahl repeated the government's position that it prefers to work on practical matters in Canada rather than endorse "flowery words" of a declaration of principles (Joffe 2010, 156). Thus, from a non-Aboriginal standpoint, reconciliation seems to be more about mitigating colonialist guilt than resolving discriminatory practices, past and present.:

The apology was a political statement and it wasn't intended for the survivors and no amount of money made up for what happened. The apology was an empty statement and it needs to be affirmed with action about what residential school did to our people. Apologies mean nothing unless you can show you're sincere
[Residential school survivor]

Reconciliation in Aboriginal Health

As demonstrated throughout this dissertation, the Canadian government has championed practical reconciliation. In the eyes of successive governments, practical reconciliation is equated with partnerships in which non-Aboriginal and Aboriginal Canadians work amicably toward specific, realizable goals and objectives. Health has become a key area of such practical reconciliation. Under community controlled health policies, Aboriginal and non-Aboriginal people involved in Aboriginal health politics are

pioneers of intersectoral and intergovernmental policy collaboration. Their efforts yield tangible, quantifiable outcomes. Examples of their achievements include: 100% success rates of immunization programs, lower rates of hospitalization, decreases in rates of infectious disease and better chronic disease management. In all of these developments, however, there is an expectation by government bureaucrats, public health policymakers and others that Aboriginal peoples and their communities accept mainstream values that do not radically challenge non-Aboriginal people's conceptualization of reality.

In contrast, Aboriginal people view reconciliation as an opportunity to reinterpret Canada's colonial history and to recognize Aboriginal peoples' rights as Aboriginal Canadians. Aboriginal political advocates argue that reconciliation and Aboriginal self-determination must go hand in hand. Reconciliation should bring about changes to bureaucratic structures and should challenge non-Aboriginal peoples' values. The government's emphasis on reconciliation is experienced by community health workers as essentially patronizing:

Publicly they [the government] say that they are committed to Aboriginal health and care about us and that they support us but in our last evaluation with them, they closed down our files and froze our funding...after a year of paperwork, they told us that our transfer report to them was not very comprehensive and not easily readable. The fact that they can just close our files and freeze our transfer funding...it's wrong [Healthcare Provider].

They [the government] say, we recognize culture and tradition but they really don't because they say, 'well, you can do what you want in regards to culture and tradition'. I say 'well, no you can't'. Their thought is well, hire a Native person and you have culture. If you can't hire a Native person, because there are not a lot of Native nurses around then you have to hire a non-Native nurse and they're not sensitive to the culture. And so when you look at the issue of suicide as an

example, I want to bring our traditional people, but the problem is there is no funding for that because they're [the government] prescriptive [Health Administrator].

I wouldn't call them partnerships. I would call them more flow of dollars. And so it's not necessarily a partnership because to me, a true partnership means that we're both working together towards the same goals and it's not a true partnership because they expect us to develop these community health plans and all they're doing is flowing the dollars so they're not working with us on these issues, it's more of a financial accountability...so it's not a true partnership...I've also had this discussion with the Local Health Integration Network and I've challenged them and said you guys are just a flow through dollars. I think the funders have these buzzwords, partnership and relationship. all of these things, but they don't practice what they preach, you know, they say this is a partnership but it's not. It's a flow through, it's pure and simple; that's what it is [Health Manager].

It comes as no surprise that governments limit the degree of Aboriginal communities' independence with respect to the design, delivery, and evaluation of health services.

Government departments are held accountable to Cabinet and ultimately to the Canadian public for the money that they spend. Aboriginal health expenditures are therefore scrutinized closely by governments.

A former policy analyst with the National Health and Welfare & Treasury Board of Canada discusses how he too was indebted to the division between practical and impractical reconciliation:

We understand that it's hard to make the change from a past paternalism in health to develop some sort of strategy that provides better health care to Aboriginal peoples. However, this raises questions about whether the answers rest on principles of self-determination or community control. It's better to just say that these principles can be unreasonably different to put into practice...Aboriginal communities stated early on that community control meant that health would be tailored and defined to their particular community health needs. This was contradictory and somewhat unhelpful to us at a time when the needs of Aboriginal communities were so

great and when Aboriginal health was in the spotlight [Senior non-Aboriginal Bureaucrat].

A tension is created between outcomes and processes. There is a desire on the part of the government for health outcomes that will stand up to public scrutiny. At the same time, they know that they must work amicably with Aboriginal communities. Government departments and bureaucrats are constantly seeking ways to establish practical partnerships with communities. But at the same time, they try to avoid more complex discussions of Aboriginal self-determination.

This tension can be further illustrated with the demise of the Kelowna Accord in 2006. The Kelowna deal promised to tackle the health gap between Canada's Aboriginal people and the rest of the country which “resulted from more than 2 years of planning and negotiation by federal, provincial, territorial and national Aboriginal governing bodies” (Smylie and Anderson 2006, 603). The Kelowna deal placed special emphasis on promoting Aboriginal control and self-determination over health policies (Webster 2006). The Conservative Federal government that assumed power in 2006 has remained dismissive of the Accord. A tension exists whereby Aboriginal political advocates call for self-determination and control over health policies. In contrast, non-Aboriginal government bureaucrats take advantage and toy with the notions of Aboriginal empowerment as a means to an end. And governments do not endorse self-determination.

While the Aboriginal health policy arena has undergone major reconstruction in Canada, Aboriginal peoples continue to place themselves in historical continuity with 500

years of struggle against colonization and oppression. They see current government policies as fracturing Aboriginal identities on both a personal and collective level:

I don't expect the federal or provincial government to change, you know. They're continually trying to exert jurisdiction, they are continually trying to capitalize on our resources, totally disregarding our relationship to the land in terms of trading relationships and our Aboriginal rights. So we're in for, you know, ongoing struggles, things are going to move slowly [Chief].

Governments continue to exert control, keep us uneducated; that's why they cut back on the education planning...How do they dare steal our voices? They don't deal with the treaties; they don't deal with land claims. How do governments still continue to exert control on our kids? Give us \$25 for a \$100 job. There are just so many situations where things aren't going to change because they have no morals [Director of Aboriginal Organization].

Next Steps in this Research

Is there a need for future research to examine how effective health research is as an instigator of change? How can community-based research be translated into policy?

Collaborative research that brings together university researchers, Aboriginal communities and government bureaucrats is less common in the social sciences in large part because the translation from research to policy is that much more unclear. Although collaborative work could be used as a way to back up applications for community-based projects or to provide data for submissions that put pressure on policy-makers and government, university researchers have been unsuccessful in transferring their findings to health policy settings. The number of projects and community health programs that have had an impact on the health status of Aboriginal people illustrates a serious gap in Canadian public health.

There are many factors that influence the translation of research into policy. There is a need to choose allies carefully with the goal of getting research into the hands of people who can use it, make sense of it and turn it into policy options. There is also a need to think about long terms goals and how to get ideas into the policy system. There are decision-makers that can come and go, however, policy makers are forever. There will always be people inside government that need ideas and options and want to share their knowledge and expertise. They can identify challenges and eventually become champions. There is a need to explore these ideas further and to research new avenues to make this litany of research translate into policy. It is my hope to attain a better understanding of how to make this research applicable for Aboriginal communities in the larger policy process.

Final Word

Thirty years ago, Aboriginal people were choosing illness and death rather than deciding to face the mainstream health care system out of a fear that they would encounter racism and discrimination. Subsequently, community controlled health policies were developed to combat some of these issues. Although many communities have faced challenges under these policies, the achievements have been extraordinary. Formal and informal means now exist for Aboriginal communities to have a voice in the health policy process. More importantly, Aboriginal issues have finally entered the Canadian public consciousness.

It is not surprising that reconciliation and self-determination in Aboriginal health progress at a very slow rate when one is up against the apathy of neo-colonial institutions, structures and practices. Having worked with a government department, a nongovernment Aboriginal organization as a consultant, and now as a researcher in Aboriginal health, I am left with a sense of pride when I think about the many challenges and outcomes that are faced by these communities on a daily basis and the unbelievable accomplishments that are being made by individuals at every level, from the community level, to the highest level of policy advocacy. Often, positive developments that occur between government and communities are overshadowed by ongoing crises within Aboriginal health. Perhaps it is time to set the record straight by recognizing the many accomplishments in Aboriginal health, however small or large they may be.

My research compared health governance structures of Aboriginal communities in both Ontario and Manitoba. Although many challenges continue to face these communities including geography, isolation, addictions and the possibility of a crisis occurring at any time, the communities on Manitoulin Island have provided a unique model of healthcare. In addition to the federal health transfer programs, these communities also have access to provincially funded AHWS programming with the establishment of the Aboriginal Health Access Centre, Noojmowin Teg in addition to other programs and services on individual reserves.

In 1990, Sally Weaver predicted that a paradigm shift in policy-making was “inevitable” because old paradigm 'solutions' would become less tenable. New paradigms

would emerge from forging relationships with Aboriginal communities that gave them the lead voice for analyzing their own situations. New paradigms would emerge that reveal the “outmoded analysis of the state's obligation to Aboriginal peoples” (1990, 8). Weaver identified joint policy-making forums and joint management systems as part of that new thinking (1990, 14). AHWS programming reveals that such an approach is quite possible. The AHWS policy process calls our attention to the importance of policy development, to epistemological issues in relation to that development, and to the dynamics of social processes in policy-making that can facilitate social change.

These services in turn complement what the federal government offers through transfer and other contribution agreements. A few of the strategies include the blending of mainstream, rural and urban health services with First Nations based health services; integration at the First Nations level including community health services and community sectors such as education and housing; as well as continuation of the partnership between non-Aboriginal community health services and traditional healing strategies. The flexibility to work with organizations and the communities in the surrounding area have allowed First Nations to empower themselves when there are a plethora of factors working against them. Finally, their ability to identify and utilize champions in and around their community enhances their governance structure. Possessing such a structure, in turn, assists community wellness on a day to day basis and can thwart crises when they do occur.

In contrast, communities that are limited by less conducive structures of governance, co-management for example, are less likely to have the same level of community empowerment or the same ability to deal with crises. TTR, like many communities in Manitoba and elsewhere, have struggled with the constraints put on them by the federal government. Furthermore, in Manitoba the same level of support and opportunity does not exist as there is no provincial strategy in place that addresses the health gaps created by health transfer. Thus, the few programs that are available to First Nations in Manitoba through the provincial government, are so highly vied for, that many communities are left with the bare minimum when it comes to health services. Community-controlled health policies may be improving health outcomes, but these policies will not lead to self-determination on their own. When exploring factors that enhance or constrain the development of Aboriginal controlled healthcare systems, having a policy that focuses on “process rather than plan” is very important. Such a dynamic opens doors to creative change and a governance structure that enhances community empowerment through the use of champions both internal and external to the community. In effect, such policies become models that help clarify the link between self-determination and community wellness.

My research with all six of these communities illustrates ambitious health policies that have provided Aboriginal people a deciding voice in the way health services are provided to them and their communities. It demonstrates two main reactions: resistance and accommodation. As noted above, a key factor in the process of change is the

transmission of ideas. As they spread from one community to another, some ideas will be easily accepted while others will lag behind. The important thing is that positive changes will continue to occur. From the perspective of Aboriginal peoples, this is only somewhat comforting as they are still faced with the reality of ongoing crises that are taking place in their communities on a day to day basis. A continued push toward self-determination will further the plight of Aboriginal peoples towards improved health and community wellness.

My hope is that this research has contributed to the Political Science literature in the following ways: I have employed a community-based, participatory research approach, one that very few political scientists have used in studying Aboriginal health policy. This research is part results being generated by a small, but growing new cohort of scholars moving in this direction. In the process, we hope that we are enriching political scientists awareness of alternative research designs and methodologies. As such, this dissertation research is demonstrating to political scientists the importance of understanding local knowledge and understandings of Aboriginal peoples in conceiving research projects.

Second, by using community-based participatory research, I was able to open up a dialogue within the respective policy communities about the health care policies of the Government of Canada and of the Province of Ontario. I also added to understandings about what community members understood by such terms as “self-determination” and “self-government”. As a result of these discussions, I was able to draw conclusions about respective health policies that will be helpful to these communities as they continue to

participate in broader discussions among Aboriginal peoples about governance and well-being. In adopting this methodology, I constructed as best as I could the presentation of the discourses and analyses of policy strengths and weaknesses gained through narratives from community members themselves. The Indigenous paradigm utilized in this dissertation is one that moves beyond more traditional political science analytical lenses and approaches. The narratives embedded throughout the dissertation are part of this process of giving voice and authenticity to community members and of permitting them to construct their own analyses of well-being, self-determination and self-governance as they live their daily lives and frame their hopes for policy change. The discourse presented by community members suggests that these concepts have important relevance and meaning to them.

Finally, the discourse and narratives that form part of the empirical account of this research are in the language, i.e., the very different kinds of language used by different parties in discussing health policy and self-determination. Fleras writes:

Politicians and First Nations often employ similar words but still speak a different language. Terms such as self-government and sovereignty are essentially Anglo-Saxon terms that rarely reflect the experiences of Aboriginal realities. Consider the concept of autonomy. For many, autonomy conjures up images of secession and dismemberment; for Aboriginal peoples, autonomy resides in the restructuring of their relationship with Canada to secure control over (a) self-government; b) treaties; (c) land claims; (d) economic development; (e) service delivery; and (f) culture, language, and identity. Not surprisingly, central authorities perceive autonomy in terms of municipal-level, self-governing, administrative structures under provincial jurisdiction. In contrast, Aboriginal views of self-government and autonomy are defended on grounds other than crown authority, as self-contained and inherent, not delegated (1996, 150).

In short, without an understanding and willingness to engage directly with communities to learn the content of Aboriginal difference, Western understandings and worldviews remain partial and hegemonic. In the absence of such engagements, there is a risk of creating misunderstandings and conclusions that could fuel ethnocentrism. Without the kinds of community engagements identified in this thesis, the danger remains that dialogues with Aboriginal communities will continue to be interpreted through Western frameworks and concepts.

I leave the reader with an Aboriginal health administrator's vision of future community-government relationships. She told me this story on my last day on Manitoulin Island:

When Matthew Coon Come [former AFN Chief] was campaigning, I had the opportunity to go to the election with him in Ottawa and Ovide Mercredi [former AFN Chief] gave the last speech and what he said was that when he became the national chief, the elders approached him and told him not to take this job as national chief. The elders gave him three flags each of a different colour. The elders told Ovide to listen to his heart and needed to involve the people wherever these flags were placed.

Elders and young people helped him place the first yellow flag in the northwest territories. The second green flag was placed in BC because of the vast vegetation and forest. The last flag was a red flag and he first thought of taking it down to Mexico but his heart said no so he kept it.

Once Ovide was the advisor to the National Chief, he told me the story again and I gave him tobacco and told him that he needed to do something with that flag. He said I will go smoke my pipe as you have given me tobacco and I think there is still meaning attached to this last flag. Ovide decided that he needed to go back to his own community to be Chief and that's where he currently is. That red flag, Ovide still has. He hasn't given it to anyone. That tells me that something is coming in our future. What that is, I don't know. I have hope, even though I know it's tough

economic times, but I also believe that we as First Nations people are very spiritual beings and I think that is what has kept us being resilient throughout the whole 500 years of issues that we've faced and we're still here. I think that our spirituality is the key to who we are and where we're going and that red flag is representative of that.

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Appendix A

For: Aboriginal and non-Aboriginal Health Staff & Service Providers

DATE:

LETTER OF INFORMATION / CONSENT

A Study about the impact of community-controlled health care on Aboriginal communities

Principal Investigator:

Chelsea Gabel
Ph.D. Candidate
Department of Political Science
McMaster University
Hamilton, Ontario, Canada
(905) 633-9487
E-mail: gabelc@mcmaster.ca

Faculty Supervisor:

Dr. Alina Gildiner
Department of Political Science
McMaster University
Hamilton, Ontario
(905) 525-9140, ext. 27417
E-mail: gildina@mcmaster.ca

Research Sponsor: Canadian Institutes of Health Research (CIHR)

Study Goals, Purpose and Objectives

The goal of my research is to better understand how health policies come to fruition and how they are implemented and evaluated. Additionally, I am interested in the interactions between Aboriginal communities and governments in these processes. I am particularly interested in the Health Transfer Policy and the Aboriginal Healing and Wellness Strategy. My research examines four important questions:

1. How are the concepts of community control and community-government collaboration defined by Aboriginal and non-Aboriginal stakeholders in the health policy arena?
2. How is community-controlled health acted out on the ground?

3. Were Aboriginal communities empowered or disempowered when they adopted bureaucratic rather than adversarial approaches to government?
4. How and to what extent do models of Aboriginal self-determination influence the formulation of Aboriginal health policy?

I will be gathering the views of four groups:

1. Aboriginal and non-Aboriginal staff including Aboriginal health workers, registered nurses, physicians, policy analysts, program coordinators, directors and executive officers.
2. Community Members including Chief and Council, Elders
3. Aboriginal Organizations
4. Aboriginal and non-Aboriginal government bureaucrats at the provincial and national levels involved in the development and implementation of Aboriginal health policy.

Data Collection, Analysis and Results

The main data collection instrument will be in person, semi-structured interviews, employing a short guide of open-ended questions and topics for discussion. Data collected in the course of this study will be used solely by the researcher to compile a Ph.D. dissertation.

Analysis and reporting will be conducted by the Principal Investigator and will involve input from participants.

Procedures involved in the Research

If you agree to participate in this research, your participation will involve an interview at a mutually convenient time and location. I expect the interview to last about 1 hour. With your permission, I would like to audio record and keep notes through the interview. I will ask you questions such as the following:

1. What were the main reasons why the community wanted health services transferred?
2. What were some of the difficulties negotiating transfer?
3. Were you satisfied with the result of the negotiation?
4. What may have been your main concerns?
5. What have been some of the benefits that you have witnessed since the community transferred?

6. What have been some of the major challenges/problems for the community that you have witnessed since transfer?
7. Describe your interactions with government officials and whether or not you feel that you have a voice?
8. Are the structural arrangements for funding effective? Why or why not?
9. How will the new health transfer policy impact the current arrangements?
10. How does the policy contribute to the broader goal for Aboriginal self-determination?
11. Do you feel that you are being treated as an equal partner in decision-making?

Once I have completed my preliminary analysis, I will send you a copy if you wish, and would be happy to receive your comments and reactions.

Potential Harms, Risks or Discomforts:

The interviews may raise issues that you feel strongly about. You do not need to answer questions that you do not want to answer or that make you feel uncomfortable. Additionally, you can withdraw (stop taking part) at any time. I describe below the steps I am taking to protect your privacy.

Confidentiality

Your participation in this study is confidential. I will not use your name, nor any information that would allow you to be identified. However, we are often recognizable in the stories we tell, the references we make and the views we express. Please keep this in mind through the interview. Names will be assigned codes by the researcher and will not appear in the final dissertation.

In-person interviews will be conducted and responses will be audio-recorded or hand-written. Key informants have the option to decline the audio recordings if they prefer. Recordings will be transcribed and coded by the researcher.

I will be the only one with access to the data for this study. All of my notes will be stored securely in a locked filing cabinet in my office. Once I have completed my research I will shred all of my notes.

Consent

Each study participant will be required to give signed or oral consent at the beginning of interviews. See attached informed consent form.

Participation and Withdrawal

Your participation in this study is voluntary. It is your choice to be part of the study or not. If you decide to be part of the study, you can decide to stop (withdraw), at any time, even after signing the consent form or part-way through the study. If you decide to withdraw, there will be no consequences to you. In cases of withdrawal, any data you have provided will be destroyed unless you indicate otherwise. If you do not want to answer some of the questions you do not have to, but you can still be in the study.

Languages

Efforts will be made, within reason to translate documents into the language of the community or the participant. The researcher will also provide plans for collecting oral consent. Some segment of written documents and consent forms could also be made available in languages used in the community. Interviews designed for a community or individual whose first language is not English will be handled on a case-by-case basis with the researcher and participant.

Cultural Protocols

The researcher will work closely with the community partner and community members to respect and accommodate cultural protocols and practices associated with the communities where interviews are conducted. The researcher will be prepared to adjust the data collection techniques accordingly.

Potential Benefits

Your participation will allow you to tell your personal stories and to voice your opinions and concerns related to Aboriginal health care in Ontario. It will contribute towards a better understanding of the processes and institutional structures that affect relations between the Aboriginal community-controlled health sector and government in the development, implementation and evaluation of health policy.

If any portion of the interview process adversely affects the participant, termination of the interview session will be considered and the decision of the recipient respected. The participants will have ample opportunities to withdraw from the project or debrief at any stage during or after the interviews.

Honoraria

Honoraria of \$50 will be offered to study participants at the beginning of each interview in respect for sharing their time and wisdom. It is the participants' choice to accept or refuse the honoraria. In the event that a participant terminates the interview session before all questions are asked, the honorarium will still be offered. In addition to cash honoraria, gifts (e.g. tobacco) may also be offered, as appropriate to the cultural custom of the participant.

Questions about the Study

If you have any questions about the study, please feel free to contact me by telephone at 905-633-9487, or by e-mail at chelsea.gabel@gmail.com. You may also contact my research supervisor, Professor Alina Gildiner by e-mail at alina.gildiner@gmail.com.

This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance. If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

McMaster Research Ethics Secretariat
Telephone: (905) 525-9140 ext. 23142
E-mail: ethicsoffice@mcmaster.ca

CONSENT

Please complete this page, sign it and give it to Chelsea Gabel, the principal investigator of the study. Or, you may choose to give oral consent and I will complete it for you.
Thanks!

I have read the information presented in the information letter about a study being conducted by Chelsea Gabel, of McMaster University and I understand:

- It is my choice to take part in this research study.
- If I take part, I do not have to answer all the questions.
- After I start the interview, I can decide to stop.
- I can decide if the interview is voice-recorded or not.
- I can request an interpreter be present during the interview.
- Study information will be combined into a Ph.D. dissertation.
- My name will not be shared with anyone (except the interviewer).
- I will be offered a gift of thanks for participating in the interview.

I _____ agree to be interviewed for this research study.

Print your name

Sign in ink Date

Interpreter:

I request an interpreter to be present during the interview: ☐ Yes ☐ No
_____ Initials

Recording:

I agree to the use of a voice recorder during the interview: ☐ Yes ☐ No
_____ Initials

I agree to the taking of hand-notes during the interview: ☐ Yes ☐ No _____ Initials

Follow-up Contact:

I would like to receive a summary of the study's results. ☐ Yes ☐ No _____ Initials
(if yes, give contact information below)

I can be contacted at: _____

(postal address, telephone number and/or email address)

Oral Consent:

Date: _____ Time: _____ Place: _____

Researcher's Signature: _____

Appendix B

For: Government Officials

DATE:

LETTER OF INFORMATION / CONSENT

A Study about the impact of community-controlled health care on Aboriginal communities

Principal Investigator:

Chelsea Gabel
Ph.D. Candidate
Department of Political Science
McMaster University
Hamilton, Ontario, Canada
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E-mail: gabelc@mcmaster.ca

Faculty Supervisor:
Dr. Alina Gildiner
Department of Political Science
McMaster University
Hamilton, Ontario
(905) 525-9140, ext. 27417
E-mail: gildina@mcmaster.ca

Research Sponsor: Canadian Institutes of Health Research (CIHR)

Purpose of the Study

The goal of my research is to better understand how health policies come to fruition and how they are implemented and evaluated. Additionally, I am interested in the interactions between Aboriginal communities and governments in these processes. I am particularly interested in the Health Transfer Policy and

the Aboriginal Healing and Wellness Strategy. My research examines four important questions:

1. How are the concepts of community control and community-government collaboration defined by Aboriginal and non-Aboriginal stakeholders in the health policy arena?
2. How is community-controlled health acted out on the ground?
3. Were Aboriginal communities empowered or disempowered when they adopted bureaucratic rather than adversarial approaches to government?
4. How and to what extent do models of Aboriginal self-determination influence the formulation of Aboriginal health policy?

Procedures involved in the Research

If you agree to participate in this research, your participation will involve an interview at a mutually convenient time and location. I expect the interview to last about 1 hour. With your permission, I would like to keep notes through the interview. I will ask you questions such as the following:

1. What is the government's official position on Aboriginal self-determination?
2. How do you feel that [the policy] contributes to the broader goal for Aboriginal self-determination and health?
3. What have been some of the major challenges or criticisms that you have encountered in dealing with this policy (either from community members, health staff or others)?
4. How do you define community control as it pertains to health?
5. Do you feel that you are being treated as an equal partner in decision-making?
6. How will the new health transfer policy impact the current arrangements?
7. What does the future hold for relationships between governments and Aboriginal communities?

Once I have completed my preliminary analysis, I will send you a copy if you wish, and would be happy to receive your comments and reactions.

Potential Harms, Risks or Discomforts:

The interviews may raise issues that you feel strongly about. You may also worry about how others will react to what you say. You do not need to answer questions that you do not want to answer or that make you feel uncomfortable.

Additionally, you can withdraw (stop taking part) at any time. I describe below the steps I am taking to protect your privacy.

Potential Benefits

You are not likely to benefit from this research directly. Your participation will contribute, however, towards a better understanding of the processes and institutional structures that affect relations between the Aboriginal community-controlled health sector and government in the development, implementation and evaluation of health policy.

Confidentiality

It is up to you whether you want to participate openly or confidentially. If you prefer to participate confidentially, I will not use your name, nor any nor any information that would allow you to be identified. However, we are often recognizable in the stories we tell, the references we make and the views we express. Please keep this in mind through the interview.

I will be the only one with access to the data for this study. All of my notes will be stored securely in a locked filing cabinet in my office. Once I have completed my research I will shred all of my notes.

Participation and Withdrawal

Your participation in this study is voluntary. It is your choice to be part of the study or not. If you decide to be part of the study, you can decide to stop (withdraw), at any time, even after signing the consent form or part-way through the study. If you decide to withdraw, there will be no consequences to you. In cases of withdrawal, any data you have provided will be destroyed unless you indicate otherwise. If you do not want to answer some of the questions you do not have to, but you can still be in the study.

Information about the Study Results

I expect to have this study completed by approximately June of 2011. If you would like a brief summary of the results, please get in touch with me after that date or indicate at the end of this letter how you would like the summary sent to you.

Questions about the Study

If you have any questions about the study, please feel free to contact me by telephone at 905-633-9487, or by e-mail at chelsea.gabel@gmail.com. You may

also contact my research supervisor, Professor Alina Gildiner by e-mail at alina.gildiner@gmail.com.

This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance. If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

McMaster Research Ethics Secretariat
Telephone: (905) 525-9140 ext. 23142
c/o Office of Research ServicesE-mail:
ethicsoffice@mcmaster.ca

Appendix C

For: Aboriginal Organizations

DATE:

LETTER OF INFORMATION / CONSENT

A Study about the impact of community-controlled health care on Aboriginal communities

Principal Investigator:

Chelsea Gabel
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Research Sponsor: Canadian Institutes of Health Research (CIHR)

Purpose of the Study

The goal of my research is to better understand how health policies come to fruition and how they are implemented and evaluated. Additionally, I am interested in the interactions between Aboriginal communities and governments in these processes. I am particularly interested in the Health Transfer Policy and the Aboriginal Healing and Wellness Strategy. My research examines four important questions:

1. How are the concepts of community control and community-government collaboration defined by Aboriginal and non-Aboriginal stakeholders in the health policy arena?

2. How is community-controlled health acted out on the ground?
3. Were Aboriginal communities empowered or disempowered when they adopted bureaucratic rather than adversarial approaches to government?
4. How and to what extent do models of Aboriginal self-determination influence the formulation of Aboriginal health policy?

Procedures involved in the Research

If you agree to participate in this research, your participation will involve an interview at a mutually convenient time and location. I expect the interview to last about 1 hour. With your permission, I would like to audio tape the interview. I will ask you questions such as the following:

1. Please describe your current role.
2. What does Aboriginal self-determination mean to you?
3. Do you feel that Aboriginal health policies contribute to the broader goal for Aboriginal self-determination and health?
4. Does your organization have an official position on self-determination?
5. What have been some of the major challenges or criticisms that you have encountered in dealing with Aboriginal health policies (either from community members, government officials or others)?
6. What are some of the successes in Aboriginal health that you have seen?
7. What does reconciliation mean to you in the context of Aboriginal health?
8. Do you feel that you are being treated as an equal partner in decision-making?
9. What does the future hold for relationships between governments and Aboriginal communities?
10. Is there anything else that you would like to add?

Once I have completed my preliminary analysis, I will send you a copy if you wish, and would be happy to receive your comments and reactions.

Potential Harms, Risks or Discomforts:

The interviews may raise issues that you feel strongly about. You may also worry about how others will react to what you say. You do not need to answer questions that you do not want to answer or that make you feel uncomfortable. Additionally, you can withdraw (stop taking part) at any time. I describe below the steps I am taking to protect your privacy.

Potential Benefits

You are not likely to benefit from this research directly. Your participation will contribute, however, towards a better understanding of the processes and institutional structures that affect relations between the Aboriginal community-controlled health sector and government in the development, implementation and evaluation of health policy.

Confidentiality

It is up to you whether you want to participate openly or confidentially. If you prefer to participate confidentially, I will not use your name, nor any information that would allow you to be identified. However, we are often recognizable in the stories we tell, the references we make and the views we express. Please keep this in mind through the interview.

I will be the only one with access to the data for this study. All of my notes will be stored securely in a locked filing cabinet in my office. Once I have completed my research I will shred all of my notes.

Participation and Withdrawal

Your participation in this study is voluntary. It is your choice to be part of the study or not. If you decide to be part of the study, you can decide to stop (withdraw), at any time, even after signing the consent form or part-way through the study. If you decide to withdraw, there will be no consequences to you. In cases of withdrawal, any data you have provided will be destroyed unless you indicate otherwise. If you do not want to answer some of the questions you do not have to, but you can still be in the study.

Information about the Study Results

I expect to have this study completed by approximately June of 2011. If you would like a brief summary of the results, please get in touch with me after that date or indicate at the end of this letter how you would like the summary sent to you.

Questions about the Study

If you have any questions about the study, please feel free to contact me by telephone at 905-633-9487, or by e-mail at chelsea.gabel@gmail.com. You may also contact my research supervisor, Professor Alina Gildiner by e-mail at alina.gildiner@gmail.com.

This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance. If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

McMaster Research Ethics Secretariat
Telephone: (905) 525-9140 ext. 23142
c/o Office of Research ServicesE-mail:
ethicsoffice@mcmaster.ca

CONSENT

I have read the information presented in the information letter about a study being conducted by Chelsea Gabel, of McMaster University. I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested. I understand that if I agree to participate in this study, I may withdraw from the study at any time. I have been given a copy of this form. I agree to participate in the study.

Signature: _____

Name of Participant (Printed) _____:

1. ...Yes, I would like to receive a summary of the study's results. Please send them to this email address _____ or to this mailing address _____.

.....No, I do not want to receive a summary of the study's results.

2. I want my identity kept confidential.

...Yes

... No, I prefer to be identified.

Appendix D

PARTICIPANT INFORMATION FOR FOCUS GROUP

Letter of Information for Community Members

Date:

Title of Study: Towards Healthier Aboriginal Health Policies? Navigating the Labyrinth for Answers

Principal Investigator: Chelsea Gabel, PhD Candidate, Department of Political Science, McMaster University. Tel: 905-870-9487; E-mail: gabelc@mcmaster.ca

You are being invited to participate in a research study conducted by Chelsea Gabel from McMaster University. While making the decision about whether or not you want to be part of this research study, I urge you to read and understand what is involved and the possible risks and benefits. This form gives full information about the research study.

What is this study about?

I am conducting a study about the impact of community-controlled health care on Aboriginal communities. The goal of my research is to better understand how Aboriginal health policies come to fruition and how they are implemented and evaluated. I am particularly interested in learning more about the impact of the Health Transfer Policy and the Aboriginal Healing and Wellness Strategy and how programs born out of these initiatives impact community members living on and off reserve.

What is your participation like?

Your participation in this study is voluntary. If you volunteer to participate in this study, you will be asked to do the following:

You will be asked to participate in a **focus group interview**. The interview you are being asked to take part in will be moderated by Chelsea Gabel, a PhD Candidate at McMaster University. It will include between 10-12 members of the Aboriginal community, all of whom were recruited through an Aboriginal organization. The focus group will be audio recorded so that I do not miss important information.

The total time commitment will be 1 ½ hours.

Consent

Each study participant will be required to give signed or oral consent at the beginning of interviews. See attached informed consent form.

You can withdraw from the study at any time without consequence.

In cases of withdrawal, any data you have provided to that point will be destroyed unless you indicate otherwise. Your decision whether or not to participate will not affect you in any way.

Will you be paid for participating?

Honoraria of \$50 will be offered to study participants at the beginning of each interview in respect for sharing their time and wisdom. It is the participants' choice to accept or refuse the honoraria. In the event that a participant terminates the interview session before all questions are asked, the honorarium will still be offered. In addition to cash honoraria, gifts (e.g. tobacco) may also be offered, as appropriate to the cultural custom of the participant.

What are the questions you will be asked during the interview?

In the focus group interview, I am interested in learning about the experiences and views of Aboriginal peoples living both on and off reserve and their experiences with Aboriginal health care. In particular, I would like to know what community-controlled health care means for an Aboriginal person.

The following are example questions:

1. Do you feel that health service delivery in your community is reflective of the community's wants and needs?
2. What have been some of your main concerns?
3. By living on-reserve/off-reserve, what advantages/disadvantages do you have in comparison to those who live off-reserve/on-reserve?
4. What does self-determination and health mean to you?
5. Are there ways to ensure that community member's voices are heard in terms of shaping health service delivery?
6. What recommendations would you offer to improve the current health system in your community?

What may be the risks and benefits for you to participate in this study?

It is not likely that there will be any harm associated with this study. Some participants may feel intimidated or overwhelmed by other participants whose knowledge levels are higher, or who are especially vocal in expressing their views. Keep in mind that the focus group interview is not a test, and that there are no right and wrong answers. I am interested in learning about your personal experiences and views.

Focus groups involve the discussion of views and experiences with the researchers as well as with other members of the community. While the researcher promises not to divulge the personal information or identity of participants, I cannot guarantee that the other participants will respect each other's privacy in the same manner.

However, some ground rules and terms of consent will be clearly communicated at the beginning of the focus group interview. These include: 1) Respect the viewpoints of the other participants; 2) There are no right or wrong answers – every person's view matters; 3) No insults will be tolerated; 4) Respect the privacy of other participants – please do not identify participants or discuss the opinions expressed by other participants, outside of our meeting here today.

With regards to benefits, your participation will allow you to tell your personal stories and to voice your opinions and concerns related to Aboriginal health care in Ontario.

How will your confidentiality be ensured?

The researcher will treat what you say in the focus group as confidential, and I will ask all participants to do the same. Nevertheless, I **cannot guarantee complete confidentiality for your focus group participation**. All written records and transcripts will be kept in a locked filing cabinet at my research office to which only I have access, and will be destroyed after completion of the research project. Names will be assigned codes by the researcher and will not appear in the final dissertation.

If you would like to know the results of this study, what should you do?

If you would like to receive information about the results of the study, please indicate this on the attached consent sheet. I would like to receive your comments and reactions.

What if you have more questions or would like to get more information about this study?

If you have questions or require more information about the study itself, please contact me:

Chelsea Gabel (Email: gabelc@mcmaster.ca Tel: 905-870-9487)

This study has been reviewed and approved by the McMaster Research Ethics Board. If you have concerns or questions about your rights as a participant or about the way the study is conducted, you may contact:

McMaster Research Ethics Board Secretariat

Telephone: (905) 525-9140 ext.23142

c/o Office of Research Services

E-mail: ethicsoffice@mcmaster.ca

CONSENT

Please complete this page, sign it and give it to Chelsea Gabel, the principal investigator of the study. Or, you may choose to give oral consent and I will complete it for you.
Thanks!

I have read the information presented in the information letter about a study being conducted by Chelsea Gabel, of McMaster University and I understand:

- It is my choice to take part in this research study.
- If I take part, I do not have to answer all the questions.
- After I start the focus group, I can decide to stop.
- I can request an interpreter be present during the interview.
- Study information will be combined into a Ph.D. dissertation.
- My name will not be shared with anyone (except the interviewer).
- I will be offered a gift of thanks for participating in the interview.

I _____ agree to be interviewed for this research study.

Print your name _____

Sign in ink Date _____

Interpreter:

I request an interpreter to be present during the focus group: ☐ Yes ☐ No
_____Initials

Follow-up Contact:

I would like to receive a summary of the study's results. ☐ Yes ☐ No _____Initials
(if yes, give contact information below)

I can be contacted at: _____

(postal address, telephone number and/or email address)

Oral Consent:

Date: _____ Time: _____ Place: _____

Researcher's Signature: _____

Appendix E

Focus Group Script

Chelsea Gabel

Towards Healthier Aboriginal Health Policies? Navigating the Labyrinth for Answers

Welcome

Thank you for meeting with me today. This focus group will last for an hour and a half. Please help yourself to snacks and refreshments throughout the focus group.

Who is carrying out the study?

My name is Chelsea Gabel and I'm a PhD candidate in the Department of Political Science at McMaster University. I am Métis from Rivers, Manitoba...

What is this study about?

I am conducting a study about the impact of community-controlled health care on Aboriginal communities. The goal of my research is to better understand how Aboriginal health policies come to fruition and how they are implemented and evaluated. I am particularly interested in learning more about the impact of community-controlled health initiatives and how programs and services born out of these initiatives impact community members living on and off reserve.

In this focus group, I will be asking you questions about health care in your community.

Explain that the participants have the right to withdraw from the session at any time.

Your participation is completely voluntary. You are not under any obligation to take part, and you can stop taking part in the focus group at any time. All the information that you give will be stored and used anonymously.

Introduce the Participant Information sheet and ask participants to read it (I will also read it out loud)

Please read the Participant Information form. If you have difficulty reading or understanding the form, please let me know and I will talk you through it. After we have gone through the form I would ask that if you want a copy of this focus group discussion that you write your name and email and/or mailing address on

the sheet that is being sent around. After I have distributed your compensation and you have given either oral or written consent, we can get started.

Introductory Questions: Participants introduce themselves

Ask all participants to introduce themselves:

The following are open-ended questions to facilitate the discussion:

Opening Questions:

1. Do you feel that health service delivery in your community is reflective of the community's wants and needs?
2. What have been some of your main concerns?
3. By living on-reserve/off-reserve, what advantages/disadvantages do you have in comparison to those who live off-reserve/on-reserve?
4. What does self-determination and health mean to you?
5. Are there ways to ensure that community member's voices are heard in terms of shaping health service delivery?
6. What recommendations would you offer to improve the current health system in your community?

Closing Questions:

Of everything we discussed, what is the most important to you?

Is there anything in this discussion that we missed?

Closing Comments:

Does anyone have any comments or questions before we bring this session to an end?

In closing, I would like to thank all of you for coming out to join this group today. And most importantly I would like to thank you for your participation in this discussion group.



Appendix F

Recruitment Poster for Community Members

Participants Required for Research on a Study about the Impact of Community-Controlled Health Care on Aboriginal Communities

My name is Chelsea Gabel. I am Métis from Rivers, Manitoba. I am currently a Ph.D. candidate at McMaster University in the Political Science department. I am looking for participants who reside either on or off reserve and who are willing to take part in a study about the impact of Aboriginal health policies on Aboriginal peoples. I am interested in whether you feel empowered or disempowered by the current health services and programs and if you feel the community is achieving its vision of self-determination with regards to health care. As a participant in this study, you will be asked to participate in a focus group that discusses the items mentioned above. I expect the focus group to last about 1.5 hours. With your permission, I would like to audio record the focus group. If desired, the focus group questions will be provided prior to the meeting. You will receive \$50 for your time and knowledge and refreshments will be provided.

For more information, or to volunteer for this study, please feel free to contact me by telephone at 905-870-9487, or by e-mail at chelsea.gabel@gmail.com. You may also contact my research supervisor, Professor Alina Gildiner by e-mail at alina.gildiner@gmail.com.

This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance. If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

McMaster Research Ethics Secretariat
Telephone: (905) 525-9140 ext. 23142
c/o Office of Research Services
E-mail: ethicsoffice@mcmaster.ca



Appendix G

Recruitment Poster for Health Staff

Participants Required for Research on a Study about the Impact of Community-Controlled Health Care on Aboriginal Communities

My name is Chelsea Gabel. I am Métis from Rivers, Manitoba. I am currently a Ph.D. candidate at McMaster University in the Political Science department. I am looking for

Aboriginal and non-Aboriginal staff of community-controlled organizations and Aboriginal health services, including health workers, registered nurses, physicians, policy analysts, program coordinators, managers, directors and executive officers to take part in a study about the impact of Aboriginal health policies on Aboriginal communities. I am interested in the interactions between Aboriginal communities and governments in these processes. As a participant in this study, you will be asked to participate in an interview at a mutually convenient time and location. I expect the interview to last about 1 hour. In

addition to taking notes, I will also be audio recording the interview. If desired, the interview questions will be provided prior to the interview. You will be given \$50 for your time and wisdom and refreshments will also be provided.

For more information, or to volunteer for this study, please feel free to contact me by telephone at 905-633-9487, or by e-mail at chelsea.gabel@gmail.com. You may also contact my research supervisor, Professor Alina Gildiner by e-mail at alina.gildiner@gmail.com.

This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance. If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

McMaster Research Ethics Secretariat
Telephone: (905) 525-9140 ext. 23142
E-mail: ethicsoffice@mcmaster.ca

Appendix H

SCRIPT FOR ORAL CONSENT

This script will be adapted for the intended role of the person from which consent is sought.

At the start of the focus group meeting:

This will be read aloud to the participant(s) in English (by the PI) or in the local language (by the translator):

If you agree, I would like to ask you questions concerning health care in your community so that I can be introduced to this knowledge and include it in my Ph.D. research dissertation.

I will not record your name or any identifying information, and I will not disclose in any way your identity in future publications, conference presentations and academic reports. I will be audiorecording this focus group session.

I will be giving a payment of \$50 and a small gift to show my appreciation for your contribution. Please help yourself to refreshments and snacks throughout the session.

The participant(s) will then be encouraged to ask questions for clarification or further information. After this, the PI or translator will continue:

Do you agree to this arrangement, and that I may ask you these questions?

Focus group participant will each be asked this in turn, and only those who answer 'yes' will remain in the focus group. This will be recorded and witnessed by another participant. Next the PI or translator will ask for permission to use direct quotes.

If you agree, I will use direct quotations from your responses in this focus group in writing and presenting my study results.

The participant(s) will then be encouraged to ask questions for clarification or further information. After this, the PI or translator will continue:

Do you agree to this arrangement, and that I may use direct quotations?

Focus group participants will each be asked this in turn, and only those who answer 'yes' will have their contact information recorded so the PI can contact them in the future if a direct quotation is to be used. This will be recorded and witnessed by another participant.

At the end of the focus group meeting:

At the end of the focus group meeting, the participants will be asked the following:

Because you have contributed to the development of my Ph.D. research by sharing your knowledge and ideas concerning Aboriginal health care in Ontario, I would like to contact you after I have completed the preliminary analysis.

You will be asked to reflect on the quotations selected and whether they fit the context and respect your identity. I would also welcome any comments about the thematic descriptions and summaries.

I will contact you by telephone [give approximate timeframe].

The participant(s) will then be encouraged to ask questions for clarification or further information. After this, the PI or translator will continue:

Do you agree to this arrangement, and that I may contact you by telephone in the future to ask you these questions?

Focus group participants will each be asked this in turn, and only those who answer 'yes' will have their contact information recorded and will be contacted in this next stage of the research. This will be recorded and witnessed by another participant. Oral consent will again be sought when these participants are contacted by telephone for their follow-up interview.

Appendix I

PhD Dissertation Title: Towards Healthier Aboriginal Health Policies? Navigating the Labyrinth for Answers

Research Agreement

Chelsea Gabel of McMaster University, a PhD Candidate in the department of Political Science and Public Policy agrees to conduct her research with the following understandings:

1. The purpose of this research project, as discussed with and understood in the community of [], is for Chelsea Gabel to conduct research for her PhD dissertation on the implementation and evaluation of Aboriginal health policy.
2. The scope of this research project (that is, what issues, events or activities are to be involved and the degree of participation by community residents), as discussed with and understood in this community is to:
 - i) To conduct in-person, semi-structured interviews and focus groups with a) Aboriginal and non-Aboriginal staff including health workers, registered nurses, physicians, policy analysts, program coordinators, managers and health directors; b) Community members (including those living on and off reserve, Elders and Chief and Council in order to further my learning about about the relationship between the Aboriginal community-controlled health sector and government in the development, implementation and evaluation of health policy
 - ii) My learning will also come from listening to , observing and interacting with those who partner in this research. I will work closely with community members to respect and accommodate cultural protocols and practices within the community and am prepared to adjust my data collection techniques accordingly.
3. I would like to place small posters up in the health centre advertising my study and those who wish to participate can contact me directly. Prior to each interview and/or focus group, I will provide lunch and/or refreshments. My hope is that our talks will be relaxed and light hearted where we can laugh and where everyone feels welcome.
4. The development of this project is based on sincere communication between community members and researchers. All efforts will be made to incorporate and address local concerns and recommendations at each step of the project. At the end of

this project, the researcher will participate in community forums to discuss the results of the analysis with community members.

5. Information collected is to be shared, distributed and stored in these agreed ways:

- An individual consent form will be read by the interviewer to the respondent.
- A copy of the consent form will be left with the respondent where the address and contact information of the researcher can be used at any time, should the participant wish to contact the researcher for additional information.
- The interviews are confidential and in no instance will the name of a respondent be attached to a record.
- Both the researcher and the community contact person will have access to the data

6. Before the distribution of the final report, or any publication, the community will be consulted once again as to whether the community agrees to share this data in that particular way.

Funding, Benefits and Commitments:

Funding:

The main researcher has received funding and other forms of support for this project from: The Canadian Institutes of Health Research (CIHR).

Benefits:

Scientific presentations in peer-reviewed publication and conferences will be made. The final report will be reviewed by community members prior to publication. Scientific presentations will be made and articles published after discussion with respective community leaders.

The benefits likely to be gained by the community through this research project are:

- i) Educational
- ii) Informational
- iii) Financial

Commitments:

The community's commitment to the researcher is to:

- i) Recommend capable and reliable community members to collaborate or to be employed in this project
- ii) Keep informed about the progress of the project, and help in leading the project toward meaningful results

The researcher's main commitment to the community is to:

- i) Inform the community about the progress of the project in a clear, and timely manner.
- ii) Act as a resource to the community on health care and health priority related questions.

The research agrees to interpret the research project in the following circumstances:

- i) If community leaders decide to withdraw their participation
- ii) If the researcher believes that the project will no longer benefit the community

Date:

(Signature of Main Researcher)

Name: Chelsea Gabel

Position: PhD Candidate in Political Science (McMaster University)

Date:

(Signature of Community Contact Person)

Name:

Position:

Adapted from the Canadian Institute for Health Research. (2007). CIHR guidelines for health research involving Aboriginal people. Ottawa, ON: Canadian Institute of Health Research, 1-46.