The National Aboriginal Health Organization, an Aboriginal-designed and -controlled body, will influence and advance the health and well-being of Aboriginal Peoples through carrying out knowledge-based strategies.

The Journal of Aboriginal Health (JAH) is owned by the National Aboriginal Health Organization (NAHO). The JAH’s Editorial Board, Guest Editor, Peer Reviewers, and staff strive to provide Aboriginal health research excellence with community relevance. Published twice a year, each issue will identify a theme and solicit appropriate papers from a variety of perspectives under the direction of a Guest Editor. By sharing success stories and new research, the JAH will not only contribute to the critical thinking and learning process around Aboriginal health issues, but also build information exchanges, networks, and partnerships. Ultimately, the JAH will lead to improved health and increased capacity and participation in health care fields of Aboriginal Peoples.

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Contact
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Journal of Aboriginal Health
National Aboriginal Health Organization
56 Sparks St., Suite 400, Ottawa, ON K1P 5A9
Phone: (613) 237-9462 Toll free: 1-877-602-4445
Fax: (613) 237-1810
E-mail: vst-denis@naho.ca, Web site: www.naho.ca

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Cover Image
The Journal of Aboriginal Health launches with an issue dedicated to the
theme of governance of Aboriginal health. Study after study proves that
Aboriginal Peoples’ health is better when we work together and steer our
own course to wellness.

Dustin Janvier of LaLoche, Sask., looks back while canoeing with his
partner during the 2000 Summer Youth Camp-Out at Marrison Lake.
    Photograph submitted by LaLoche Community Development Corp.
Welcome to the first issue of the *Journal of Aboriginal Health*. In early development almost three years ago, guided by the original consultation reports about the role of a national Aboriginal health institute, the National Aboriginal Health Organization (NAHO) became aware that there was a void in the availability and accessibility of health information and outcomes of Aboriginal health research. To remedy this, NAHO’s Board of Directors and staff decided to produce a research journal focusing on Aboriginal health. NAHO is an Aboriginal-designed and -controlled body that strives to influence and advance the health and well-being of Aboriginal Peoples by sharing and distributing knowledge on Aboriginal health issues.

The *Journal of Aboriginal Health* will share success stories in Aboriginal health, discuss issues and opportunities, and provide the latest information and research of interest to First Nation, Inuit and Métis Peoples. It will publish in-depth analysis of health research and issues with full citation of sources; facilitate informed discussions on new research, recent publications and projects; and explore health determinants from an Aboriginal viewpoint.

This *Journal* is a tool for community members including traditional healers, Aboriginal health and social service care practitioners and organizations; tribal, treaty, regional, and national political organizations; Aboriginal and other Canadian health scholars and researchers; people who influence and determine Aboriginal health research and policy including Canada’s federal/territorial/provincial and Aboriginal politicians, public servants, consultants, think tanks, and foundations; and finally, anyone with an interest in Aboriginal health in Canada. Readers can use the *Journal* to share their work, experience and knowledge. They can also use it to refine and/or expand their thinking around Aboriginal health and Aboriginal Peoples.

The goal of the *Journal* is to cultivate a dynamic community of those with interest, creative ideas, or a concern with Aboriginal health matters through information exchange, networks and partnerships. This dynamic community will contribute to the critical thinking and learning process. Ultimately, we envision that the *Journal of Aboriginal Health* will lead to improved health and increased capacity and participation of Aboriginal Peoples in the health care delivery and policy settings in Canada.

Each issue of the *Journal of Aboriginal Health* will feature a theme. The *Journal* Editorial Advisory Board and staff will draw upon a Guest Editor who has expertise in the theme area and an established network of contacts in the field so they may solicit appropriate papers to cover as many perspectives as possible.

John O’Neil is the Guest Editor for this issue focusing on the governance of Aboriginal health. O’Neil is the Senior Investigator with the Canadian Institutes of Health Research, Head of the Department of Community Health Science and Director of the Centre of Aboriginal Health Research at the University of Manitoba. O’Neil was able to draw on those resources and others to bring together an interesting mix of research papers dealing with the governing structures of various Aboriginal health centres, systems and research units. On page 4, he gives a broad overview of this inaugural issue in his editorial.

Due out later this year, the second issue of the *Journal of Aboriginal Health* will focus on population health and determinants of health. Kimberly A. Scott, the principal at Kishk Anaquot Health Research, is the Guest Editor for that issue.

A Guest Editor is responsible for acquiring and evaluating papers. This issue has articles written by Josée Lavoie, Laurel Lemchuk-Favel/Richard Jock, Marion Maar, Brian Schnarch, Brenda Elias/John O’Neil/Doreen Sanderson, and Marlene Brant Castellano. They conducted the research and the often equally difficult process of writing and rewriting the paper to share their observations.

A Guest Editor also sends the papers for peer review by others who are experts in the field. This is a process to identify the strengths and weaknesses of a paper, soundness of arguments, correctness of research methods, accuracy of facts, relevance to the *Journal of Aboriginal Health*, readability, and more. Two peer reviewers with different backgrounds read each paper. One has a scholarly background in the theme to ensure academic excellence while the other has a community background to ensure the paper is relevant to and readable by frontline workers. Constructive comments are provided to the author who then has an opportunity to make revisions that will make the paper as strong as possible.
An Editorial Advisory Board oversees the entire process. This dedicated group of people includes Gail Valaskakis, Marlene Brant Castellano, Linda Day (Senior Research Analyst and Projects Manager at the Institute of Aboriginal Peoples’ Health), Judith Bartlett (NAHO Chairperson), Richard Jock (NAHO Executive Director), and Melissa Lazore (NAHO Communications Director). They are responsible for the overall look and feel for this issue of the *Journal for Aboriginal Health* and for setting future publication directions including upcoming themes and guest editors.

The Canadian Medical Association was also helpful in making this publication become a reality by offering advice and design expertise.

NAHO’s Communications Editor Virginia St-Denis provided excellent co-ordination of the entire publication. She helped ensure the papers used accessible language so as many people as possible could benefit from the information. As many of the papers state, research should not only benefit researchers and academics, but it must benefit the community. St-Denis was assisted by NAHO’s Communications Unit and was supported by all NAHO staff.

On behalf of all those involved, we hope you enjoy this first issue. We welcome your letters and feedback so the *Journal of Aboriginal Health* can continue to develop and meet the needs of its readership. We also hope you will become a future part of this publication by sharing your research, experience, creativity, and knowledge.

Yours in health,
Judith Bartlett, MD, CCFP, M.Sc.
Chairperson
NAHO Board of Directors

Richard Jock, BA, M.Ed
Executive Director
NAHO

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The Journal of Aboriginal Health is also available online in English and French

To download a free pdf file, or to find out more about the *Journal of Aboriginal Health* including writing guidelines and the latest call for papers, please go online to:

http://www.nahoa.ca/english/communications_journal.php
t is both a privilege and a pleasure to be offered the opportunity to be the Guest Editor of the first issue of the *Journal of Aboriginal Health*. This journal promises to fill a significant gap in the knowledge base that is available to Aboriginal communities, researchers and government agencies. They share the responsibility for improving health conditions in Aboriginal communities. The theme of this first issue - health governance - signals the importance the National Aboriginal Health Organization places on focusing attention on the most fundamental determinants of health outcomes.

The concept of health governance has substantial implications for Aboriginal health along several dimensions. In this issue, we consider health governance to refer to the extent that individuals or communities have control over the conditions that impact their health. There is increasing recognition that control is an important determinant of health independent of poverty, physical environment and other social determinants of health outcomes. The widely referenced Whitehall studies\(^1\) have provided (fundamental or essential) evidence to suggest that individuals who feel they have a higher level of control over the conditions of their work life have better health regardless of income levels. In Canada, M.J. Chandler and C. Lalonde\(^2\) have produced provocative evidence that lower suicide rates are found in First Nations Peoples 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. Although additional work is needed to confirm these findings, this evidence suggests self-determination and local governance in First Nations communities is related in important ways to improved health outcomes.

The concept of governance in Aboriginal communities is also fundamentally connected to the destructive impact of colonialism on the capacity of communities to be self-governing. The history of colonialism in the Aboriginal context is a long history of assault from Euro-Canadian political, economic, religious, and educational institutions on the social and cultural integrity of Aboriginal communities. Sometimes overlooked in this discussion is the role of health care institutions as contributors to the colonization process.\(^3\) Health care institutions may be as important an instrument of colonization as residential schools, the economy or the *Indian Act* in terms of their impact on self-determination. The analysis of this potentially destructive relationship is particularly challenging because of the inherent beneficence in the medical enterprise. Saving lives is a more difficult subject for a critical analysis of exploitation and oppression than are many of the other institutions that have impacted historically on Aboriginal Peoples.

The subject of this first issue of the *Journal of Aboriginal Health* is not new to the academic and community discourse around health and health services. Aboriginal communities have been involved in a determined effort to restructure this colonial relationship over the last two decades.\(^4\) Indeed, much of the Royal Commission on Aboriginal Peoples Report *Gathering Strength* was devoted to providing examples of efforts to increase local governance in the health care sector.

This issue further contributes to this discussion, drawing particular attention to growing confidence in collaborative models that reflect partnerships with other sectors (e.g. provincial governments, universities, regional health authorities, etc.) and to the importance of gaining control over the evidence to health policy process. More specifically, the process of defining the health status and health care needs of communities in the context of competition for resources for health care is examined in several of the papers in this issue.

The first paper by Josée Lavoie entitled Governed by Contracts: The Development of Indigenous Primary Health Services in Canada, Australia and New Zealand alerts us to the fact that this is not a uniquely Canadian concern. Indigenous Peoples in other colonized countries such as Australia and New Zealand are struggling with similar problems. Lavoie outlines the ideological context that impacts health services for Indigenous Peoples in these three countries. She points out that a comparison of the specific economic and administrative arrangements that emerge in different jurisdictions are significant determinants in how self-determination is realized.

The second paper by Laurel Lemchuk-Favel and Richard Jock is entitled Aboriginal Health Systems in Canada. It provides a useful overview of the history of health service development in Aboriginal communities in Canada and a comprehensive review of policies, systems and services in the Aboriginal health service sector. The authors
describe a series of case studies of Aboriginal communities that have undertaken the development of community-controlled health care by asking what works.

The Marion Maar paper Clearing the Path for Community Health Empowerment is a detailed examination of one model of an integrated approach to Aboriginal health care, where Aboriginal provincial and federal programs and resources have been brought together to increase local control over and access to health services.

This issue of the *Journal of Aboriginal Health* then shifts to several papers that examine the growing prominence of the issue of including health information systems in considerations of governance of health systems. Brenda Elias and her co-authors of The Politics of Trust and Participation describe an emerging relationship in Manitoba among First Nations and university researchers that addresses the impact of a pathologizing health information discourse on First Nations communities that is focused on building a new health information system supportive of self-determination in health care.

The last two papers address critical ethical issues related to governance in health care research. Brian Schnarch provides an overview of the Ownership, Control, Access, and Possession process. Called OCAP, it has emerged as a key value that is driving First Nations health information development at the national level.

The paper by Marlene Brant Castellano entitled Ethics of Aboriginal Research provides a perspective on ethics that is based on her long and distinguished academic career that included serving as the Director of Research for the Royal Commission on Aboriginal Peoples. Brant Castellano provides an insightful overview of ethical issues in health research. She directs our attention to the increasing recognition in Aboriginal communities that control over research is also critical to achieving self-determination in health care.

Together this collection of papers provides important insights into critical aspects of the governance project in Aboriginal health care. Self-determination in health must be recognized as part of a broader decolonization history directed towards the promotion of better health outcomes. This issue does not pretend to provide an exhaustive review of governance in health care. It is nonetheless a fundamental collection for communities, governments and health researchers looking for insights in their efforts to achieve this goal.

John D. O’Neil, Ph.D.
CIHR Senior Investigator
Professor and Head
Community Health Sciences
Director
Centre for Aboriginal Health Research
Rm. 715, 7th Floor
Buhler Research Centre
University of Manitoba
715 McDermot Ave.,
Winnipeg, MB R3P 3P4
Tel: (204) 789-3677; 789-3434
Fax: (204) 975-7783; 789-3905
oneilj@ms.umanitoba.ca

ENDNOTES
Governed by Contracts: The Development of Indigenous Primary Health Services in Canada, Australia and New Zealand

Josée G. Lavoie, PhD Candidate
London School of Hygiene and Tropical Medicine
Health Policy Unit

Abstract

This paper is concerned with the emergence of Indigenous primary health care organizations in Canada, Australia and New Zealand. In Canada, the adoption of the 1989 Health Transfer Policy promoted the transfer of on-reserve health services from the federal government to First Nations. In Australia, Aboriginal Community-Controlled Health Services first appeared in the 1970s because of community mobilization. It aims to provide some access to free health care to Aboriginal People. A more recent model, the Primary Health Care Access Program, aims at guaranteeing Aboriginal access to comprehensive primary health care services under the authority of Regional Aboriginal Health Boards. In New Zealand, Maori providers emerged because of the market-like conditions implemented in the 1990s. This study compares the policy and contractual environment put in place to support Indigenous health providers in Canada, Australia and New Zealand, using a case study approach. Results show that the contractual environment does not necessarily match declared policy objectives, especially where competitive models for accessing funding have been implemented.

Key Words
Primary health care, policy, self-determination, Indigenous People, health care financing, fourth sector

INTRODUCTION

This paper is concerned with the emergence of a fourth sector in Canada’s, Australia’s and New Zealand’s health care systems. The health care literature generally acknowledges the government, the private sector and non-profit, and non-government organizations (third sector) as the three sectors involved in the delivery of health care services. A fourth sector has now emerged with distinctive features. It includes Indigenous primary health care services. It is funded with public dollars to provide services to an Indigenous constituency that is considered high risk because of colonial policies and socio-economic marginalization. Like the third sector, Indigenous services are involved in the delivery of non-commercial social goods. In addition, Indigenous health services are often tied to an Indigenous governance structure; are primarily designed by Indigenous groups to serve the needs of that group; and to promote their political aspirations involving a renegotiation of their relationship with the nation-state. Key features include increased responsiveness to local Indigenous needs; increased opportunities for employment; and increased cultural expression in health care delivery. The sector developed over the past 30 years. It is now endorsed and actively promoted by all three governments as a mechanism to improve Indigenous participation in health care, increase access and reduce inequities.

Indigenous People appear to have seized upon the opportunity to become primary health care providers. In Australia, Peter S. Hill et al.1 report that the number of Aboriginal-controlled health organizations has grown to more than 120 since they first emerged in 1971. Health Canada reports that 71 per cent2 of eligible communities - representing nearly half of the eligible First Nation population - are now engaged in
delivering on-reserve primary health care services. Another 13 per cent is exploring this possibility. In New Zealand, the Ministry of Health reports that the sector grew from 23 providers in 1993 to 240 in 1998.

This paper explores the context in which Indigenous health policies emerged and the relationship between policy and implementation in Indigenous primary health care services in Canada, Australia and New Zealand. The paper begins by exploring key conceptual issues. This is followed by a case study of each Indigenous health care sector, emphasizing historical, legal and administrative factors. Each case study is based on an extensive review of literature and key documents, following the methodology described by Robert K. Yin and Barbara McPake and Anne Mills. The Canadian material is supplemented and put into context by the author’s 10 years of working for Indigenous-controlled health services. The Australian and New Zealand material was gathered during fieldwork done between June 2001 and April 2003. Each case study begins by providing some historical context, then exploring issues of jurisdiction, policy and financing as they affect the fourth sector. The discussion section provides a more detailed analysis of the relationship between health policy objectives and the Indigenous health sector. A final conclusive section summarizes key findings and proposes areas for further international comparative research.

THE NON-PROFIT AND INDIGENOUS SECTORS:

Framework for Comparison

Despite significant differences, Canada, Australia and New Zealand share a remarkable number of similarities, making them amenable to comparative analysis. Over the past decade, numerous studies have emerged analysing the political and legal space Indigenous Peoples occupy in all three countries. Epidemiological comparisons have also been pursued.

All three countries share a history of colonization by Britain, leading to the development of a comparable political and legal context. This legal framework emerged because of historical legal documents having currency today and/or because of international pan-Indigenous representations that led to the ratification of international agreements ratified by all three countries. This is summarized in Table 1. This framework establishes that the Indigenous Peoples of Canada, Australia and New Zealand have rights that go beyond that of other minorities. This has led to the development of different concepts of citizenship, where Indigenous Peoples can secure group-specific rights (more evident in issues of land and resources) that other citizens cannot.

In health care, these group-specific rights resulted in the development of different jurisdictional responsibility and policies. For example, in Canada, First Nations affairs have been under federal jurisdiction since Confederation. First Nation health has been under the federal department of health (Health Canada) since 1944. Health care for other Canadians is under provincial jurisdiction. In Australia, Aboriginal affairs were initially under state jurisdiction along with other Australians. However, the failure of the states to provide adequate services led to the emergence of the Aboriginal Community-Controlled Health Services (ACCHS) movement. It shifted Aboriginal health from states to the Commonwealth Government in the early 1970s and finally to the Commonwealth Department of Health in 1995. In New Zealand, Maori health and health care have been included under the authority of the Ministry of Health and delegated to the purchasing authority of the day. The New Zealand government has continuously recognized a treaty-based partnership relationship with Maori. This has been expressed in a commitment to “by Maori for Maori” health services.

As shown in Table 2, the current health policies of all three countries reflect a commitment to primary health services “for Indigenous People by Indigenous People.” Both Canadian and New Zealand policies make clear reference to the legal framework explored in Table 1. In all three countries, policies also emphasize the need to address the health inequalities experienced by Indigenous People in comparison with their national counterparts (see Table 3). Indigenous People understand these inequalities as the result of historical and present policies that limit their ability to exercise control over their own affairs. At a time when equity theory dominates the health care literature, all three governments portray the development of Indigenous

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EDITOR’S NOTE

In New Zealand, Maori is typically spelled with a macron accent (straight horizontal line) above the letter a. However, most Canadian computer keyboards and printers cannot print this symbol. For that reason, this article spells Maori without the accent.
Table 1: Foundation for Indigenous Relations in Canada, Australia and New Zealand

<table>
<thead>
<tr>
<th>International Covenants ratified by all three countries</th>
<th>Canada</th>
<th>Australia</th>
<th>New Zealand</th>
</tr>
</thead>
<tbody>
<tr>
<td>• 1957 International Labour Organization Convention no. 107 and Recommendation no. 104 stipulates that indigenous peoples have rights separate from those of other minorities.</td>
<td>• Legal doctrine of terra nullius, literally uninhabited land</td>
<td>• 1840: Treaty of Waitangi</td>
<td></td>
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<tr>
<td>• 1966 International Covenant on Civil and Political Rights (ICCPR), ratified by Canada in 1976, Australia in 1980 and New Zealand in 1978. Article 27 guarantees the right of minorities to practice their religion and speak their language.</td>
<td>• 1975 Racial Discrimination Act</td>
<td>• 1975: The Treaty of Waitangi Act (establishing the Waitangi Tribunal to hear grievances and rule on disputes between Maori and the Crown)</td>
<td></td>
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<tr>
<td></td>
<td>• 1992 Mabo case ruling rejects the validity of terra nullius, thus confirming the existence of Aboriginal land rights that precede and survived colonization.</td>
<td>• 1982: All Maori references disappear in the 1986 Constitutional Act</td>
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<td></td>
<td>• 1763: Royal Proclamation</td>
<td>• 1990: New Zealand Bill of Rights Act</td>
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<tr>
<td></td>
<td>• 1867: Constitutional Act</td>
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<td></td>
<td>• 1876: Indian Act (amended in 1985).</td>
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<td></td>
<td>• 1870-1920: Treaties</td>
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<td></td>
<td>• 1982: Constitutional Act is amended. Section 35 recognizes Aboriginal People’s Inherent Right to Self-Government</td>
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<td></td>
<td>• 1982: Charter of Rights and Freedoms</td>
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<tr>
<th>National Legal Basis</th>
<th>Canada</th>
<th>Australia</th>
<th>New Zealand</th>
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<tr>
<td>• 1763: Royal Proclamation</td>
<td>• Legal doctrine of terra nullius, literally uninhabited land</td>
<td>• 1840: Treaty of Waitangi</td>
<td></td>
</tr>
<tr>
<td>• 1867: Constitutional Act</td>
<td>• 1967 Constitutional amendment making Aboriginal Affairs a Commonwealth jurisdiction.</td>
<td>• 1852: Constitutional Act allows for Maori specific provisions</td>
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<tr>
<td>• 1876: Indian Act (amended in 1985).</td>
<td>• 1975 Racial Discrimination Act</td>
<td>• 1975: The Treaty of Waitangi Act (establishing the Waitangi Tribunal to hear grievances and rule on disputes between Maori and the Crown)</td>
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</tr>
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<td>• 1870-1920: Treaties</td>
<td>• 1992 Mabo case ruling rejects the validity of terra nullius, thus confirming the existence of Aboriginal land rights that precede and survived colonization.</td>
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<tr>
<td>• 1982: Charter of Rights and Freedoms</td>
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ii Based on Health Canada, Indian Health Policy 1979 (Accessed 2001), (Health Canada Medical Services Branch, 2000); and Health Canada, Transferring Control of Health Programs to First Nations and Inuit Communities, Handbook 1: An Introduction to all three approaches (Health Canada, Program Policy Transfer Secretariat and Planning Health Funding Arrangements, 1999).

iii Based on: Australia Aboriginal and Torres Strait Islanders Commission, “ATSIC health policy” (ATSIC National Policy Office, 2001); and National Aboriginal and Torres Strait Islander Health Council, National Aboriginal and Torres Strait Islander Health Strategy, Consultation Draft (NATSHC, 2001). The Aboriginal and Torres Strait Islander Commission (ATSIC), a statutory body of the Commonwealth Government has a responsibility to monitor health delivery and advise the Minister for Aboriginal and Torres Strait Islander Affairs on its effectiveness. ATSIC holds an advisory role to the federal Department of Health and Aging (DHA) who assumed the responsibility for the administration of Indigenous health in 1995. DHA and ATSIC relationship is defined in a memorandum of understanding.

Table 2: Health Policy Frameworks in Canada, Australia and New Zealand

<table>
<thead>
<tr>
<th>Policy/Strategy Foundation</th>
<th>Canadaii</th>
<th>Australiaiii</th>
<th>New Zealandiv</th>
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</table>
|                            | The Indian Health Policy recognizes three pillars:  
|                            | • Community development in First Nation communities;  
|                            | • The traditional relationship of the Indian people to the federal government communities to achieve their aspirations; and  
|                            | • The Canadian health system. | The Aboriginal Health Policy hinges on nine principles. Of particular relevance to this analysis include a commitment to:  
|                            | • Address health inequalities;  
|                            | • Community control of primary health care services as a preferred method of service delivery; and  
|                            | • Localized decision-making. | The 2000 New Zealand Health Strategy acknowledges that the Crown is a Treaty partner with Maori. This stems from decisions of the Waitangi Tribunal, the Court of Appeal and the Privy Council. It acknowledges that the Treaty guarantees cultural protection for Maori, meaning Maori will have an important role in implementing health strategies for Maori. |

| Policy Objectives | To achieve an increasing level of health in Indian communities, generated and maintained by the Indian communities themselves. | To ensure Aboriginal and Torres Strait Islander Peoples enjoy a long and healthy life enriched by a strong living culture, dignity and justice. | People will be part of local primary health care services that improve their health, keep them well, are easy to get to, and co-ordinate with ongoing care. Primary health care services will focus on better health for a population and actively work to reduce health inequalities between different groups. |

| Implementation Mechanism(s) | The 1986 Health Transfer Policy,  
|                            | • Promoting the transfer of on-reserve primary health services to First Nation control; and  
|                            | • Ensuring appropriate funding be in place, allowing community-based assessment, hiring capacity to draft operational plans and negotiating.  
|                            | The Health Transfer Policy makes no provision to promote increased First Nation participation in all levels of the Canadian health care system. | The draft Aboriginal Health Strategy recommendation on nine key areas. Two notable key areas include:  
|                            | • A commitment to support the delivery of comprehensive primary health care to Aboriginal and Torres Strait Islander communities, particularly through support for Aboriginal community-controlled services; and  
|                            | • Supporting Aboriginal and Torres Strait Islander participation on management of all health services. | The Maori Health Strategy details the direction for Maori primary health care development, highlighting three threads:  
|                            | • Rangatiratanga, meaning whanau, hapu, iwi and Maori aspirations to have control over the direction and shape of their own institutions, communities and development as a People.  
|                            | • Building on the gains, highlighting improvements in Maori and whanau ora outcomes, service uptake and Maori participation throughout the health and disability sector.  
|                            | • Reducing inequalities in health care. |
health providers as the preferred mechanism to address health inequalities. The Alma-Ata declaration and the Ottawa Charter are often cited.\textsuperscript{14}

Little attention has been paid to the Indigenous primary health sector. An appropriate analytical framework has been lacking. This paper builds on the assumption that the literature on the third sector can inform an analysis of the Indigenous health sector, to some extent. The third sector is defined as “a body of individuals who associate for any of three purposes: (1) to perform public tasks that have been delegated to them by the state; (2) to perform public tasks for which there is a demand that neither the state nor for-profit organizations are willing to fulfill; or (3) to influence the direction of policy in the state, the for-profit sector, or other non-profit organizations.”\textsuperscript{15} A board of directors made up of elected community members generally manages these organizations. H.B. Hansmann writes, when “customers are so situated that the costs to them of exercising effective control over the firm are unacceptably large… the solution is to create a firm without owners - or, more accurately, to create a firm whose managers hold it in trust for customers.”\textsuperscript{16}

The relationship between the government health authority (Ministry of Health, its delegate or “the purchaser”) and the third sector (“the provider”) hinges on two key elements: the conduct of the relationship through contract and the separation of service recipient and the provider.\textsuperscript{17} These two elements constitute what John Stewart\textsuperscript{18} calls “governing by contract.” The strength of this approach lies in the tendency for the provider to associate more closely with those to whom the services are provided. This potentially leads to significant learning in how to best provide services. Considerable attention has been paid to the role the non-profit sector can play in meeting the needs of vulnerable populations.\textsuperscript{19} However, the closer relationship between provider and client is only useful if the learning that occurs

<table>
<thead>
<tr>
<th>Table 3: Health Inequalities in Canada, Australia and New Zealand</th>
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<tbody>
<tr>
<td><strong>Canada</strong></td>
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<tr>
<td>First Nations Male</td>
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<tr>
<td>Non-First Nations Male</td>
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<td>First Nations Female</td>
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<tr>
<td>Non-First Nations Female</td>
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<tr>
<td><strong>Australia</strong></td>
</tr>
<tr>
<td>Aboriginal Male</td>
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<tr>
<td>Non-Aboriginal Male</td>
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<td>Aboriginal Female</td>
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<tr>
<td>Non-Aboriginal Female</td>
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<tr>
<td><strong>New Zealand</strong></td>
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<tr>
<td>Maori Male</td>
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<td>Non-Maori Male</td>
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<tr>
<td>Maori Female</td>
</tr>
<tr>
<td>Non-Maori Female</td>
</tr>
</tbody>
</table>

Where no numbers exist for Female, the number for Male covers both genders.

\textsuperscript{vii} For 1991: Trovato, “Aboriginal mortality in Canada, the United States and New Zealand.”
through this relationship can be shared back with the purchaser and incorporated in the contractual relationship. This is an important qualification. Richard G. Frank and David S. Salkever write, “Government appears to both promote and mistrust non-profit organizations in the health sector.”

From the government perspective, the mistrust is based on having limited control over the provider while remaining accountable for the appropriate expenditure of public funding and the overall quality and effectiveness of the services delivered. From the provider’s perspective, the mistrust comes from a limited ability to influence or structure the contractual environment to access resources in a way that better fits the population served and service delivered.

The Indigenous sector shares many of the above characteristics with the non-profit sector. However, there are important differences. The definition provided above must be extended to reflect the fact that Indigenous organizations are extensions of the tribe/band/community governance structure, engaged in the exercise of self-administration. In general, these organizations clearly express Indigenous aspirations for self-determination, building on international and national legal documents explored in Table 1. They are invariably engaged in the process of cultural translation; of western medical ideology, systems, procedures and information to their membership; and of member’s behaviours, beliefs, values, and needs to the health care system.

Interestingly, Canada, Australia and New Zealand have legitimized the fourth sector’s aspirations and role in their respective health policy. The implementation of these policies has at times erred away from their stated goals through barriers embedded in the contractual environment or limitations of the scope of services transferred to the fourth sector. The following case studies explore in more detail the complex environment from which the Indigenous health sector emerged and now operates.

**CANADA:**

**The Challenge of Fragmented Jurisdictions**

In the Canadian context, primary health care services for on-reserve First Nations are under federal jurisdiction. Primary health care for other Canadians, as well as secondary and tertiary health services, are under provincial jurisdiction. This historical separation of jurisdiction is based on two documents - the Royal Proclamation of 1763 and the Constitutional Act of 1867. There was considerable colonial activity in North America in the 18th century by Britain, France and Spain. The Royal Proclamation, which marked the end of the Seven Years War, was an attempt to create an alliance with the Indigenous population to ensure the sovereignty of the British Crown. But it also aimed to contain a westward expansion from the American colonies. It essentially stated that the Indigenous Peoples of Canada were not conquered and retained title to their ancestral territory. Any encroachment on the part of settlers was to be approved by the Crown, negotiated through the treaty process and duly compensated. This document constitutes the rationale for the treaty process that was to ensue.

Following Confederation in 1867 and the push to create a sustainable agrarian economy, the Crown engaged in treaty negotiations with First Nations throughout the Prairie Provinces. The 11 numbered Treaties are land surrenders agreed to in exchange for reserve land. They were calculated at 128 acres per family of four at the time of signature, as well as other provisions such as rations in time of famine, medicines and agricultural implements. For First Nations, signing the treaties was an exercise in self-preservation in light of the American Indian Wars, the demise of the buffalo and the devastating impact of epidemics. Since that time, the federal government has actively worked on limiting the sphere of influence of the Royal Proclamation and the treaties. The Indian Act defines in rather limiting ways the legal category of Indian, which determines the right to live on-reserve and to qualify for certain individual-based benefits.

The settlers who arrived at the turn of the last century were concerned the appalling health conditions that prevailed on reserves would lead to the spread of epidemics. The federal government’s answer was to hire 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 centres) was set up at Fisher River in Manitoba in 1930. 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. Until the establishment of the national health care system, nursing stations provided free care to Indians, on humanitarian grounds. The current national health care system was established in 1970. It is a publicly-financed, publicly-administered and at least partially privately-delivered system, managed by the provinces under the umbrella of the Canada Health Act.
secondary and tertiary health care services can be accessed at no cost to the individual. On-reserve services in the form of health centres now complement this system, but remain separately funded by the federal government. Physicians paid by the provinces visit the health centres on a regular basis. Patients requiring secondary or tertiary care in between visits or in an emergency are transported to the nearest provincial referral centre. The development of a national health care system did not end the historical separation of jurisdiction in health care.

In 1969, the liberal government of Prime Minister Pierre Elliot Trudeau attempted to abolish this historical separation. This was in part a response to the Hawthorn Report, the first comprehensive survey of on-reserve social and economic conditions. It reported dismal conditions and recommended an end to care taking policies in favour of economic development. The government’s answer was outlined in the 1969 White Paper calling for repealing the Indian Act, eliminating the reserve system and transferring the land to First Nations subject to provincial legislation. This plan was rejected by First Nations and eventually withdrawn on the strength of the Royal Proclamation.30 These events entrenched the historical separation, but also gave momentum to discussions of self-government. The 1982 Constitutional amendment saw the inclusion of Section 35. It affirms Aboriginal and treaty rights flowing from the 1763 Royal Proclamation and the right of Aboriginal Peoples to participate in Constitutional and other debates affecting them. This has become interpreted as an open door for Aboriginal self-government. However, what self-government actually means remains a matter of debate. The 1993 Aboriginal self-government policy limits the powers of First Nations wanting to engage in this process to semi-municipal powers. Also, it appears to be more readily associated with an attempt at cutting administrative costs than meeting First Nations political aspirations.31 The federal government further claims that self-government will reduce the government’s fiduciary (trustee-like) obligations in areas First Nations have assumed responsibility.32 First Nations have not embraced this policy.33

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 the rest of Canada. It builds on the 1979 Indian Health Policy that recognized three pillars: community development, the traditional relationship of the Indian People to the federal government, and the Canadian health system. The first transfer was completed in 1988, apparently in anticipation of the release of the policy. Services targeted for transfer are defined by the federal government. They include mandatory services such as communicable disease control, environmental health and treatment services (in health centres located either off the road system and/or at least 60 km from the nearest referral centre). Medical and Hospital Insurance Services are excluded, as well as Non-Insured Health Benefits that includes medication, medical transportation, eye care, and dental care. More recently, the federal government introduced two alternatives to accommodate different aspirations and levels of development.

Various concerns have been raised over the years. It appears First Nation services are not funded on an equitable basis compared to provincial services when existing health inequities and cost of delivery are taken into account. For example, Pran Manga and Laurel Lemchuk-Favel documented that the combined 1991/92 federal and provincial expenditures for a comparable set of services (excluding transportation costs) for Ontario First Nations was only 8.6 per cent higher than that of other Ontarians. In Manitoba, the combined expenditure for First Nations was only 0.8 per cent higher. These analyses considered actual expenditures, not needs. When need is considered, they suggest the optimal level of per capita expenditure on health services is actually 6.8 per cent lower for Ontario First Nations than for other Ontarians. Another study, by John Eyles, Stephen Birch and Shelley Chambers, show an actual shortfall of more than $700 per capita for First Nations living in the remote Sioux Lookout area of Ontario, equal to an under funding of 45 per cent compared to provincial services. These analyses contrast sharply with the official wisdom on the subject. The 1993 Royal Commission on Aboriginal Peoples shows the 1992/93 combined per capita expenditures from federal and provincial governments for Aboriginal health is $2,282 compared to $1,652 for Canadians - a 38 per cent difference.

Another concern is part of the funding is calculated based on First Nations living on-reserve at the time of the signature of the transfer agreement. There is no provision for population increase or for funding non-First Nations people who may use these services. Other transferred funding is based on historical expenditures and varies from one Health Canada region to the next. New initiatives, such as Aboriginal
Headstart, are introduced on a competitive basis rather than needs, disadvantaging small First Nations with limited access to technical expertise in grant application.

The provincial health systems are planned and reformed independently from the federal-First Nation systems. This creates opportunities for cost shifting between both governments or for gaps in service to emerge, leaving First Nations in a substandard or no care situation. By virtue of being a federal jurisdiction, First Nations have only a marginal, if any, role in provincial health care reforms.

In summary, the Canadian fourth sector has emerged because of First Nation demands to have more control over their own affairs. Although the Health Transfer Policy has created opportunities for self-administration, these opportunities have been limited to the administration and delivery of pre-existing services as determined by Health Canada.

AUSTRALIA:

From Integrated to Separated Services

Until the 1992 Mabo decision, the history of Australia’s settlement hinged on the obscure legal concept of terra nullius, literally uninhabited land. Sir Joseph Banks, who had been on the Endeavour with Captain Cook in 1788, reported to the Crown that the continent was uninhabited, except for a small population of Indigenous People along the coast. Banks believed they were unable to negotiate the purchase of land with the Crown. In contrast with the Canadian treaty process, it was this belief in terra nullius that justified Australian settlers in taking land without negotiation or compensation. This invariably led to the displacement of Aboriginal People - first on the coasts, then progressively in the interior. By the 19th century, depopulation from diseases and frontier violence associated with land grabs had taken their tolls and small Aboriginal groups were left to camp on the edge of European settlements, increasingly depending on them for survival. As a result, comparable policies of segregation and containment to protect Aborigines from European excesses were being designed in all states and territories. A reserve system was implemented “as places of refuge where the dying remnants of the Aboriginal population could live their lives.”

Since the creation of Australia in 1901 was a coming together of separate colonies wanting to retain considerable autonomy, Aboriginal affairs remained the realm of the states.

By the 1960s however, attitudes were shifting at all levels of the Australian society, leading to legislative changes to end discriminatory practices. Voting was extended to Aborigines in 1962. Constitutional changes in 1967 gave the Commonwealth government the authority to make laws in relation to all Aboriginal People, including the right to enumerate them in the annual census. Aborigines were now visible citizens of their own country. Since then, the government worked towards consolidating its responsibility for Aboriginal affairs. The Commonwealth Office of Aboriginal Affairs was established in 1968. By 1972, the Labour Party was elected to office and self-determination became the official policy. Commonwealth expenditures on Aboriginal Affairs doubled. By 1973, the Commonwealth government offered that state ministers assume full responsibility over Indigenous affairs, including policy and planning. The Department of Aboriginal Affairs (DAA) was finally given the central authority over Aboriginal policy.

In the early 1970s, the government’s version of self-determination was described as creating opportunities for Aboriginal communities to decide the pace and direction of their future development. Eventually, self-determination crystallized as self-management of governmental plans and projects for Aborigines including input in planning, development and implementation. From 1972, the DAA initiated direct grants to Aboriginal organizations, giving life to what Tim Rowse calls “the Indigenous sector.” Self-determination in matters of health care came to mean the transfer of funds from the government to the burgeoning Aboriginal Community Controlled Health Services (ACCHS) movement. Their emergence in the early 1970s captured the imagination of many academics, professionals and community activists, Aborigina and non-Aboriginals alike. It created much hope that community-based decision-making was the solution to improving Aboriginal health.

At that time, Aboriginal access to health care services was limited by a number of factors. Services were available in some mission settlements, but for a majority of Aborigines living in remote environments, access to treatment was sporadic and linked to the Royal Flying Doctor Service. Elsewhere, economic limitations made access impossible because of a lack of transportation. When transportation was available, direct charges for hospital and physician care added difficulties. The situation was not resolved by the creation of the national health care system in 1984. It can still be problematic. The government funds and administers Medicare (the national health...
insurance system), administers the Pharmaceutical Benefits Scheme and provides grants to non-government organizations for health-related projects. It also finances health services provided by the states/territories through the Medicare Agreements. The system is funded through general federal taxes to the Commonwealth and provides access to primary, secondary and tertiary care. Access fees are waived for low income Australians, but this is linked to a registration process that acts as a barrier to access for some Aborigines. In areas where there is no general practitioner, state and territorial governments may have opted to set up clinics staffed by nurses, thus financing activities that are generally paid for by the government for the general population. Gross inequities in access to primary health care remain.

The first ACCHS was set up in the urban centre of Redfern (a suburb of Sydney), New South Wales, in 1971. Fitzroy (near Melbourne), Victoria, followed in 1973, and Perth, Western Australia, in 1974. These services operated under the direction of an Aboriginal Board of Directors, offered primary health care and functioned with volunteer staff (including physicians, nurses and community staff). It initially secured rent and other necessities with in-kind donations. The goal was to provide accessible and appropriate health services. Some have expanded over the years, while others have retained their original clinical care focus. While born as a community initiative, the movement has been continuously mentioned in government strategies, a Royal Commission and a national inquiry as the most effective way to deal with the health inequalities existing between Aborigines and other Australians. Recognizing the need for a common voice, ACCHS supported the creation of the National Aboriginal and Islander Health Organisation in the mid 1970s, which became the National Aboriginal Community Controlled Health Organisation (NACCHO) in 1992. State and territorial bodies emerged after that. The movement has grown remarkably since it first emerged with ACCHS in each state and the territory, operating in both urban and remote environments. New member organizations are added every year.

Funding for the ACCHS remains problematic. Since 1968, the responsibility for Aboriginal health shifted six times between departments. The DAA extended its grants program to ACCHS in 1972. But the funding was proposal driven and allocated annually. This was still the case when DAA's successor, the Aboriginal and Torres Strait Islander Commission (ATSIC) was given this responsibility in the early 1990s. Despite the establishment of a national health care system financed largely through taxes, funding for ACCHS was limited. It remained disconnected from mainstream funding for health services allocated to the Commonwealth Department of Community Services and Health and by extension, to state governments. This issue led the ACCHS sector to lobby for Aboriginal health funding to be moved to the Commonwealth Department of Health. This was completed in 1995 under the Office for Aboriginal and Torres Strait Islander Health (OATSIH). ACCHS can now access limited core funding, supplemented by Medicare, if they can recruit a general practitioner and project funding is secured on a competitive basis.

The Primary Health Care Access Program (PHCAP) was announced in the 1999/2000 Commonwealth budget. It builds on the experience of the Aboriginal Co-ordinated Care Trials. These were implemented in the mid 1990s in four Aboriginal sites to test the impact of pooling state/territorial and Commonwealth health funding on the development of comprehensive Aboriginal-controlled primary health care services. PHCAP has three objectives: to increase the availability of appropriate primary health care services where they are currently inadequate; to reform the local health care system to better meet the needs of Indigenous people; and to empower individuals and communities to take greater responsibility for their own health. The plan is to carve out Australia into regions and to set up regional Aboriginal health boards to act as fund holders. The funding will pool money previously spent by the territory or state on primary health care of Aboriginal People in the region and Medicare funding calculated on a per capita basis, adapted for needs and remoteness. Although implementation is just beginning, there is high hope that PHCAP will significantly improve Aboriginal access to appropriate primary health care. But there are concerns that the historical lack of investment in Aboriginal education and community infrastructure development may create considerable obstacles.

In summary, Aboriginal community-controlled health services emerged in Australia because of the Aboriginal community organizing against the lack of access to acceptable and affordable primary health care services. After years of lobbying, Australia has finally generated a plan to address the still-dismal access to primary health services. The plan deploys an ambitious and appropriately-funded program that places Aboriginal Peoples in control of Aboriginal primary health care resources, recognizing existing in-
equities, needs and costs associated with remoteness in different regions. The PHCAP is now the most-comprehensive, innovative and exciting model set in place in all three countries.

NEW ZEALAND:

Interpreting Treaty Obligations

Although Maori experienced the sustained presence of missionaries since 1815, New Zealand was the last of the dominions to be annexed and settled. However, there were less than 2,000 Europeans in New Zealand when Britain officially claimed sovereignty in 1840. According to Malcolm Nicolson, by the 1830s and 1840s, it was widely acknowledged in Europe that contact with Indigenous cultures had detrimental effects on their health. While the reasons for such effects were debated, the experience of frontier violence by settlers in Australia left little doubt as to some sources. It appears that it was the British government’s intention to minimize the horrors experienced in its other colonies. The Crown’s answer was to adopt a policy of amalgamation of Maori into the colonial legislative and governmental framework. This approach is embodied in the Treaty of Waitangi, which was signed in 1840 between the Crown, the government’s intention to minimize the horrors experienced in its other colonies. The Crown’s answer was to adopt a policy of amalgamation of Maori into the colonial legislative and governmental framework. This approach is embodied in the Treaty of Waitangi, which was signed in 1840 between the Crown, the governor and about 500 Maori chiefs. The treaty includes only three articles, written in broad terms and in English and Maori. Partly because of differences in translation, Maori understood the treaty as an instrument of protection that would not affect their sovereignty. Maori chiefs had no legal authority or mandate to surrender the sovereignty of the iwi (tribe) or hapu (sub-tribe). Yet, this is how the Crown interpreted the Treaty of Waitangi.

The Constitutional Act of 1852 established a representative parliament and tied the right to vote to land ownership. Maori owning property could vote in accordance with Treaty rights and the policy of amalgamation. The Native Department (later to become the Department of Maori Affairs) was set up in 1861. Under the authority of the Governor and the Imperial government, it was to establish an effective government presence in Maori areas and undermine the appeal of Maori chiefs. The Maori Representation Act of 1867 reserved four Maori seats in the legislature to ensure some representation. That was the result of pressures from the Otaki chiefs. This was meant to complement the representation Maori could secure through general voting. However, after 1893, people of more than 50 per cent Maori descent were excluded from the general seats into a token representation. Although the Maori preferred the establishment of a separate Maori parliament, they were ignored. The overall goal of the policy of racial amalgamation was to integrate Maori while buying up land and ensuring the peaceful settlement of New Zealand. By the 1850s and ‘60s, relations between settlers and Maori were deteriorating. Settlers saw the progressive policy of amalgamation as unduly sympathetic. The colonial authorities and missionaries’ efforts to educate Maori were perceived as wasted on a dying race. But the main source of tension was land, title to which was protected under the Treaty of Waitangi. From 1860 to 1868, this led to large-scale land wars and Maori land confiscation.

The New Zealand Department of Public Health was set up in 1900. Maui Pomare, the first Maori doctor, was appointed as the Maori Health Officer. Maori Councils (runanga) took on the role of assisting the department in health and sanitation initiatives. Hospitals were set up using colonial funds in Auckland, Wellington, Wanganui, and New Plymouth. These were non-segregated and fully accessible to both Maori and Europeans, a phenomenon that Nicolson believes was unique in the history of British colonial administration.

The 1970s proved a time of rapid change. In 1975, the Treaty of Waitangi Act was passed by parliament. It removed the implementation of the treaty from the realm of policy while providing an advisory mechanism, the Waitangi Tribunal, to assist in resolving disputes. Later, the Tribunal ruled that the Treaty of Waitangi apply to both iwi and other Maori (urban, pan-iwi) communities as long as they could demonstrate their exercise of tino rangatiratanga (self government).

During the 1970s and early ‘80s, Maori became increasingly vocal about the need to link culture and health. This led to a number of Maori initiatives including conferences, health promotion campaigns, and community health initiatives. This included the 1984 Hui Whakaoranga, the first national Maori health planning workshop, that recommended increased Maori participation. Maori argued that health could be described as taonga, and therefore is protected under Article 2 of the treaty. The New Zealand government rejected this interpretation. The government argued that its responsibility in health care was the same for all citizens.

Article 3 of the treaty guarantees the same rights for all citizens, including health. This has provided a
solid base for Maori to argue for “a fair share of society’s benefits,”78 including health. The 1988 policy statement Te Urupar Ari Rangapu79 made an unprecedented and never-repeated commitment for the Crown to enter into partnerships with iwi. It was mandated and funded to deliver services on the Crown’s behalf. Iwi were to be formalized as legal corporations under the short-lived Runanga Iwi Act of 1990. However, the Act was repealed the same year it was passed. The Ministry of Maori Development, more commonly known as Te Puni Kokiri, replaced the Department of Maori Affairs in 1992. Maori staff began working in specialist divisions in the areas of health, education, training, and economic resource development. A Board of Health Standing Committee on Maori Health was set up in 1984 to provide advice on policy. A Ministerial Advisory Committee on Maori Health replaced it in 1989. Both initiatives were short lived and had limited success. However, they eventually led to the current structure of the Maori Health Directorate. It was put in place in 1993.80 The commitment to a partnership between the Crown and iwi, which implies the collaboration of representative bodies of comparable status and relevance, had been diluted considerably.

New Zealand’s national health care system was first set up in 1938 through the Social Security Act. It provided universal access to general practitioners, hospitals, pharmaceutical, and maternity services. It remained unchanged until 1980 when an economic downturn and rising cost led to the introduction of cost-cutting measures. Major reforms were again introduced in 1991. This led to the “big bang” approach to health care reform, the introduction of the purchaser-provider split and the expedient privatization of the delivery of health services at all levels.81 Implementing this plan required the collapse of the 17 Area Health Boards (1983-1993) and the creation of four Regional Health Authorities. The authorities were given the job of purchasing services from independent providers.82 Maori received this with a mixture of apprehension and hope. Maori organizations anticipated that opportunities might develop for greater involvement in service delivery. However, at the same time, such participation would imply a support of the commercial overtone of the reform: “Tino rangatiratanga and its promise of greater Maori autonomy could be construed as offering implicit support for privatization or at least for reduced State provision of services.”83 Opportunities materialized because of the second reform. This led to the collapse of the four Regional Health Authorities (1993-1998). The national Health Funding Authority (HFA) was created to continue the purchasing process with national standards. Maori providers emerged and flourished under the HFA.

However, the rapid growth of the Maori health sector has had its problems. Policies for contracting were inspired by a competitive model that required the fragmentation of public health activities into sub-contractual units.84 The result has been the growth of Maori providers funded through a multitude of smaller contracts, each with its own specification, deliverable target and reporting requirement. Many contracts are volume-based (with payment based on a maximum number of intervention and funding capped at that level) or paid on a fee-for-service basis.85 The administrative cost is considerable.86 A cursory review of the Maori Health Directorate funding 2000/01 database conducted October 2001 showed that 40 Maori providers received direct funding from the Directorate.87 The number of contracts per provider ranged from one to 35 and averaged $110,000 Cdn per year. This seems remarkably small considering the administrative work each contract carries, both for the Maori Health Directorate and the Maori provider.

The HFA was short-lived (1998-2000). It was replaced by 21 District Health Boards (DHBs). The competitive ideology has been displaced in favour of co-operation. One main objective of the current reform is to rationalize the primary health care delivery sector, where providers proliferated. This created a high level of fragmentation in service delivery. The implementation of the Primary Health Care Strategy88 requires the DHBs to promote the development of Primary Health Organisations (PHO). These organizations are funded on a per capita basis to purchase and/or provide primary health care services to an enrolled population. The goal is to create a mechanism that will bring together general practice clinics and providers under a co-ordinating community-based authority as well as ensure the planning and delivery of comprehensive primary health care services.

Depending on the direction taken in the development of the PHO, Maori providers may see their funding coming from yet another authority, this time a PHO of which they may be a stakeholder. It is yet unclear whether Maori providers will continue to exist as an independent provider. Regional differences are anticipated, reflecting differences in policy interpretation by the DHBs rather than local Maori provider wishes.

Despite acknowledging the document in its official policies, the Crown has adopted a narrow view of the Treaty of Waitangi. It could be argued that the lack of
a national Maori political organization is giving the Crown more latitude in its interpretations. A treaty-based health policy has yet to emerge. With each reform, the new purchasing authority(ies) received guidelines\textsuperscript{89} to ensure the continued inclusion of Maori and Maori issues at three levels:

• Partnership: working together with \textit{iwi, hapu, whanau} (extended families) and Maori communities to develop strategies for Maori health improvements and appropriate health and disability services.

• Participation: involving Maori at all levels of the sector in planning, development and delivery of health and disability services.

• Protection: ensuring Maori enjoy at least the same level of health as non-Maori and safeguarding Maori cultural concepts, values and practices.\textsuperscript{90}

In summary, policy statements in New Zealand invariably refer to the Treaty of Waitangi. However, Maori providers remain vulnerable to shift in policies that delegate the implementation of a treaty partnership to local health authorities. This model echoes the Australian ACCHS model, which is now being abandoned. New developments may result in progress for Maori providers, or Maori providers becoming swallowed by general practitioner-led PHOs. This last possibility would reflect poorly on the fit between policy and implementation in New Zealand.

\section*{POLICY AND IMPLEMENTATION}

Despite similarities, Canada, Australia and New Zealand have developed different relationships with their Indigenous health sector. This reflects the differences in the political space Indigenous Peoples occupy in each country and ideology in health that defines the place of the non-government sector in health service delivery. For example, in Canada, the Health Transfer Policy has focused exclusively on on-reserve services and on the elimination of health inequalities. In contrast, both Australia and New Zealand have gone further and included a commitment to increase Indigenous participation at all level of the health care system. While broader in scope and noteworthy for Canada, both Australia and New Zealand\textsuperscript{91} have committed considerably less resources and support to provider development. These differences have affected the contractual environment, the range of services that can be offered by Indigenous providers and the Indigenous level of participation in shaping health policy. Each of these themes will now be explored in more detail.

\section*{Contractual Environment}

A different contractual environment has emerged for providers, as shown in Table 4. The Health Transfer Policy and PHCAP both emerged from a separate jurisdictional model and reflect a closer relation between the purchaser and the provider. Although both remain a top down approach reflecting asymmetries in power, the closer relationship provides an opportunity for the purchaser to learn and adapt the contractual environment based on the provider’s experience. In the cases of the ACCHS and Maori providers, Indigenous organizations must access funding through multiple sources that are competitive and proposal-driven. The resulting contracts are notably short term and fragmented to a level that limits a productive purchaser-provider relationship.\textsuperscript{92} The administrative cost of this system, for the provider and the purchaser, is considerable. It yields few administrative benefits or any substantial transfer of learning from the provider back to the purchaser.\textsuperscript{93} In the case of New Zealand, one also wonders how continuous fluctuations in purchasing health authorities can possibly reflect the partnership itemized in policy documents.

\section*{Range of Services}

The services Indigenous organizations can offer vary depending on access to funding and jurisdiction. In Canada, on-reserve services offer primary health care delivered by a team of nurses with an extended scope of practice, community health representatives and addiction workers. The scope of the work includes treatment and rehabilitative care,\textsuperscript{94} public health and health promotion. Physicians visit the communities, but are not employees of the community and remain funded provincially. Off-reserve services are also out of bounds. As nearly 40 per cent of the First Nation population actually live in urban centres, the Canadian policy effectively limits the sphere over which First Nations can extend their influence and therefore their primary health care services. The federal-provincial dual jurisdiction restricts First Nations ability to influence provincial health systems, including services that are used by on-reserve First Nations such as secondary and tertiary care facilities. This model is closely related to the emerging PHCAP, with the exception that Aboriginal Health Boards are funded to hire their own physicians. In contrast to the above, the ACCHS and Maori health providers may offer any services for which they can secure funding. Although this may appear to be a more flexible model, few providers can offer a comprehensive pri-
### Table 4: Fourth Sector Jurisdiction and Financing

<table>
<thead>
<tr>
<th></th>
<th>New Zealand Maori Providers</th>
<th>Australia ACCHS</th>
<th>Canada Health Transfer Policy</th>
<th>Australia PHCAP</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Per Cent of the Total Population</strong></td>
<td>14.50&lt;sup&gt;viii&lt;/sup&gt;</td>
<td>2.20&lt;sup&gt;ix&lt;/sup&gt;</td>
<td>1.45&lt;sup&gt;x&lt;/sup&gt;</td>
<td>2.20&lt;sup&gt;xi&lt;/sup&gt;</td>
</tr>
<tr>
<td><strong>Jurisdiction for Indigenous Health</strong></td>
<td>Undifferentiated</td>
<td>Undifferentiated</td>
<td>Separate</td>
<td>Historically undifferentiated, now separate</td>
</tr>
<tr>
<td><strong>Historical Dimension</strong></td>
<td>Privatization of the health care system in the early 1990s, ideology of competition, promotion of entry of providers into market-like conditions.</td>
<td>Community mobilization and creation of clinics with volunteers and donated facilities in the early 1970s. Some core funding since 1995.</td>
<td>1986 Health Transfer Policy emerged in response to First Nations demands for increased self-governance.</td>
<td>PHCAP emerged in 2000 following pressures by Aboriginal Peoples and the Northern Territory Government for more equitable financing.</td>
</tr>
<tr>
<td><strong>Access to Funding</strong></td>
<td>Fragmented, administratively costly and unresponsive</td>
<td>Fragmented, administratively costly and unresponsive</td>
<td>Single main contract, some opportunity to compete for complementary funding, continuous funder-provider relationship</td>
<td>Single main contract, some opportunity to compete for complementary funding, continuous funder-provider relationship</td>
</tr>
<tr>
<td><strong>Contract Environment</strong></td>
<td>Static contractual environment</td>
<td>Static contractual environment</td>
<td>Some negotiation</td>
<td>Some negotiation</td>
</tr>
<tr>
<td><strong>Contract and Source of Funding</strong></td>
<td>Majority of funding comes through the district health boards. Other funding comes from the Ministry of Health because of treaty responsibilities. Providers report considerable differences in process depending on the source of funding.&lt;sup&gt;xii&lt;/sup&gt; Access to funding is fragmented in multiple small contracts.</td>
<td>More stable annual core funding plus project funding since 1995. Most funding remains proposal driven.</td>
<td>Contracts signed for 3-5 years. Mainly Aboriginal-specific funding from Health Canada with some opportunities for funding from other sources.&lt;sup&gt;xiii&lt;/sup&gt; Core funding based on per capita-historical expenditures, capped from the time of signing. Project funding and new initiatives generally introduced on competitive basis.&lt;sup&gt;xiv&lt;/sup&gt;</td>
<td>Pooling of federal and state/territory primary health care funding under one three-year contract, including pre-existing clinics, Medicare (capitation formulae adjusted for needs and remoteness).&lt;sup&gt;xv&lt;/sup&gt;</td>
</tr>
</tbody>
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<sup>xii</sup> New Zealand Te Puni Kökiri, Maori Provider Views of Government Funding, Key issues from the literature and interviews, (2000).


<sup>xv</sup> Australia Commonwealth Department of Health and Aged Care Office of Aboriginal and Torres Strait Islanders Health Services, Primary Health Care Access Program (Accessed 2002), (OATSIH, 2002).
mary health care service because of their limited access to funding and the many separate contracts required to enable a comprehensive service.\textsuperscript{95}

**Participation in Policy**

In all three countries, the government-purchaser retains a great deal of control over the policy environment and defines the level of participation Indigenous People may have in the system. In Canada, the Assembly of First Nations has an established relationship with Health Canada and sits on planning meetings advising on the development of initiatives. Regionally, First Nations have opportunities for input through their regional political organizations. Some provincial services provide translation and cultural liaison services to better serve the Indigenous population. Health boards may include First Nation representation. But the level of input is quite limited and not formally linked to the First Nation governance structure. In Australia, the National Aboriginal Community Controlled Health Organisation (NACCHO) had decisive influence over moving the Aboriginal health funding from the Aboriginal and Torres Strait Islander Commission (ATSIC) to the Commonwealth Department of Health. The planning of the PHCAP has included both NACCHO and state/territorial Aboriginal political organizations. In New Zealand, the purchasing organization(s) of the day receive clear policy guidelines to ensure Maori involvement at the board level and in service delivery. The purchasing organization(s) of the day is also required to develop a treaty-based relationship with local iwi. But Maori participation at the policy level has been limited to individual Maori being hired in high-level positions. There is no recognized pan-Maori body to independently advise at a government level. This situation, therefore, only weakly reflects policy statements of a partnership between the Crown and iwi.

**CONCLUSIONS**

In Canada, Australia and New Zealand, Indigenous primary health care services emerged at the juncture between an Indigenous commitment to self-determination and ideological influences in national health care systems. Despite this apparent convergence of interest, governments carefully continue to define, with or without an official policy, the sphere over which Indigenous People can exercise some influence despite paying lip service to Indigenous self-government (Canada), Aboriginal self-determination (Australia) or the Treaty of Waitangi (New Zealand).

This paradox has been recognized. Indigenous Peoples have been concerned that all three governments may be capitalizing on the discourse of self-determination to off-load services onto the shoulders of poorly-resourced Indigenous health services. The Australian context has generated a considerable amount of literature supporting this argument. This has led to debates and research on equity in Aboriginal health financing, which has been matched only to a very limited extent in Canada. The proposal-driven process of accessing funding, currently in place for ACCHS in Australia and embedded in the competitive funding model for Maori providers in New Zealand, is remarkably adept at shifting the responsibility for accessing appropriate funding to the providers. This makes inquiries of equitable access to funding unlikely. It is impossible to gauge whether services funded under a competitive model are indeed appropriately funded for what they are asked to provide or whether the sector experiences barriers in securing funding when compared to mainstream providers.

It is apparent in Canada and Australia that the Indigenous health sector is a vehicle for the pursuit of aspirations that transcend a biomedical concept of health. In Canada, this is expressed in First Nations taking the opportunity to exercise some control over the use of the medical surveillance discourse\textsuperscript{98} and in joint Assembly of First Nations-Health Canada forums. In Australia, NACCHO has been central in debates over Aboriginal health. By contrast, the representation of Indigenous People is much stronger in New Zealand, where Maori participation has been encouraged either as independent service providers or as individual Maori participants on public boards. At 14.5 per cent of the overall population, Maori can use the democratic process, as well as their treaty relationship with the Crown, to maintain their place and voice their needs in the larger society. In contrast, Aboriginals and First Nations, making up two and three per cent of the overall population, require other mechanisms to ensure visibility. Separate jurisdiction may very well assist them in that task.

Despite these differences, Indigenous organizations in all three countries are attempting to redesign western health care knowledge and processes to better fit Indigenous health concepts, social arrangements and needs. Although health policies and official government literature promotes this goal, the barriers associated with the contractual environment, especially with the ACCHS and Maori provider funding models, remain daunting. It is a postulate of this paper that pan-Indigenous comparative health research can inform
policy development and implementation. To date, only one study has focused on Indigenous health services financing with case studies from Australia, Norway and Canada. International Indigenous health policy analysis has tended to focus on Australia and the United States or Canada. More work is required to assess the impact of competitive (ACCHS, Maori providers) as opposed to relational (Health Transfer Policy, PHCAP) contractual environments in providers’ ability to deliver effective services; evaluate how contractual different arrangements may favour or impede the implementation of Indigenous models of health service delivery; and the extent to which findings can be generalized to other countries.

ACKNOWLEDGMENTS

The policy analysis presented here is part of a larger research project undertaken in partial fulfillment for a PhD with the London School of Hygiene and Tropical Medicine Health Policy Unit. Although the insights are my own, I am indebted to a large number of people who have provided their time and support. The Foundation Alma and Baxter Ricard of Canada funds the research. I would like to thank the Australian National University National Centre for Epidemiology and Population Health, the Darwin-based Menzies School of Health Research, the Massey University Te Punamawa Hauora in Wellington, New Zealand, and the University of Manitoba Centre for Aboriginal Health Research, Winnipeg, Canada, for their support. A special thank you to my supervisors Lucy Gilson and Stephen Jan for their insightful comments on an earlier draft.

ENDNOTES

2. This figure includes 46 per cent of communities under the Health Transfer Policy, 23 per cent under the Community-Based Health Services Agreements and two per cent under the Self-Government Agreement for a total of 427 communities (2000 figures).
5. A Maori provider is defined as an independent Maori health organization with a Maori governance and management structure.
11. The specifics of national documents are explored in the case studies.
14. The Alma-Ata Declaration was adopted by delegates attending the World Health Organization-sponsored 1978 International Conference on Primary Health Care in Alma-Ata, Russia. The resolution made a commitment to community-based and community-driven primary health care as the preferred mechanism to alleviate health inequalities. The Ottawa Charter was adopted by delegates attending the First International Conference on Health Promotion in Ottawa in 1986. The resolution builds on the Alma-Ata declaration and reaffirms a commitment to community participation in primary health care and health promotion.
17. The terminology adopted here has currency in international health system and economic literature. It defines the system in terms of role and money flow. The purchaser is often the Ministry of Health. However, that role can be delegated to health boards if they are fund holders given the task of pay-
ing independent service providers like general practitioners. Providers can be a medical practice, Indigenous health organization, private hospital, etc. They are contracted by the purchaser to deliver specific services. Although the terminology is at times associated to an ideological commitment I do not subscribe to, and an approach that has not delivered the benefits anticipated, the terminology remains useful as it separated roles and clearly reflects asymmetries in power. See Geoff Fougere, “Transforming Health Sectors: New logics of organizing in the New Zealand health system,” *Social Science and Medicine*, Vol. 52, (2001), p. 1233-1242.


21. Pan-Indigenous organizations such as tribal councils (Canada), pan-tribal organizations (New Zealand) and regional Aboriginal health boards (Australia) have emerged, not because local governance is no longer relevant, but rather to expand access to resources.

22. I am making what I think is an important distinction between self-administration, being the administration of government-defined programs and other public tasks, and self-determination, which in the Indigenous literature invariably includes the power to define what relevant programs and tasks are and how they should be delivered.


26. Specifically, from the turn of the last century until 1985, a First Nation woman who married a man who was not First Nation lost her Indian Status. The same applied to children from this marriage. In contrast, a non-First Nation woman who married a First Nation man gained Indian Status. This discriminatory provision was repealed from the *Indian Act* with the adoption of *Bill C-31* in 1985. As the legislation stands now, First Nations people who are descendents of a treaty signatory and never lost their Indian Status are eligible to be registered as an “Indian” under the *Indian Act* article 6(1). Those who lost status by marriage or other discriminatory means prior to 1985 are eligible for registration under the *Indian Act* article 6(2). Both 6(1) and 6(2) classification categories imply full status and Aboriginal rights. Children of parents classified as 6(1) are classified as 6(1). Children of a 6(1) parent and 6(2) parent are classified 6(1). Children of a 6(1) parent and a non-status parent are considered 6(2). Children of parents classified as 6(2) are considered 6(1). Finally, children of a 6(2) parent and non-status parent are considered non-status and therefore the responsibility of the provinces.

27. Waldram, Herring and Young, *Aboriginal Health in Canada*.

28. First Nations People continue to argue that access to free comprehensive health care is a treaty right. Access to health care was brought up in the negotiations of Treaties 6, 8 and 11. However, it was incorporated in the final text of Treaty 6 only, under the Medicine Chest Clause. The current federal government’s position stems from the 1966 Supreme Court of Saskatchewan ruling on the Johnston case. It ruled that health care for First Nations is a matter of policy rather than a right and is subject to the whims of the Minister of Health. Waldram, Herring and Young, *Aboriginal Health in Canada*.


33. This policy appears to be moving forward slowly in the Yukon Territory and British Columbia.


35. Lionel Bird and Meredith Moore, “The William Charles Johnston v the Crown appeal) of 1969, although more recent court cases, namely Johnston v Crown in the right and is subject to the whims of the Minister of Health. Waldram, Herring and Young, *Aboriginal Health in Canada*.


37. These are services that Health Canada offers outside the umbrella of Medicare (insured services) and have been made available free of charge (although terms of admissibility have been changing) to Status and Treaty Indians, and Inuit. Indigenous People argue that these services are an Aboriginal right entrenched in the Medicine Chest Clause of Treaty 6. However, the federal government argues that these services are offered on humanitarian grounds. This position is supported by the *Johnston v Crown Supreme Court ruling* (in appeal) of 1969, although more recent court cases, namely Sparrow and Sioui, indicate that this early ruling may not hold to more contemporary interpretations of treaty rights. There is some experimentation currently occurring with Non-Insured Health Benefits Program.

38. Under the Integrated Community-Based Health Services model (1994), First Nations can choose to sign one contribu-
tion agreement to administer selected community health services. The self-government option provides an opportunity for First Nations to reconcile all federal government funding agreements under one framework agreement. Canada, Health Canada, Transferring Control of Health Programs to First Nations and Inuit Communities, Handbook 1: An Introduction to all three approaches (Health Canada, Program Policy Transfer Secretariat and Planning Health Funding Arrangements, 1999).


41. Canada, Royal Commission on Aboriginal Peoples, Volume 3 - Gathering Strength. (Royal Commission on Aboriginal Peoples Royal Commission on Aboriginal Peoples - Final Report, 1996). Interestingly, this report merely reflected Health Canada stated expenditure data and overlooked entirely the analysis by Manga and Lemchuk-Favel that had been commissioned for the report.

42. Service delivery in the Far North is expected to be much more expensive than the rest of the country. It is not clear whether the figures include Métis and off-reserve First Nation Peoples.

43. John W. Elias and Deanna J. Greyeyes, Environmental Scan of Mental Health Services in First Nations Communities in Canada for the Assembly of First Nations (Prince Albert, Sask., 1999).


45. According to this recent ruling, Aboriginal People may have lost sovereignty and thereby must comply with Commonwealth and state legislations, but they may not have lost title to (some of) their land, if continuous occupation can be proven.

46. According to Henry Reynolds, frontier conflict was usually small scale, but lasted a long time. He reports that between 1788 and the 1920s, about 2,000 Europeans were killed compared to 20,000 Aborigines. Oral histories collected by Deborah Bird Rose and Richard Trudgen in the Northern Territory suggest that the violence against Aborigines may have lasted longer. Their work invalidates the popular Australian belief that Aborigines did not resist invasion. Henry Reynolds, “New Frontiers,” Indigenous Peoples’ Rights in Australia, Canada and New Zealand, Abby L. Bloom, ed. (Canberra: Oxford University Press, 2000).


50. Tim Rowse, Indigenous Futures: Choice and development for Aboriginal and Islander Australia (Sydney: University of New South Wales, 2002).

51. These centres were initially called Aboriginal Medical Services (AMS). This terminology is still widely used today. The contemporary term is Aboriginal Community Controlled Health Services (ACCHS), which I use throughout the text.


56. David Scrimgeour, Community Control of Aboriginal Health Services in the Northern Territory, Menzies Occasional Papers, (Alice Springs, 1997).


60. The movement has yet to be supported by a national health policy. The reason for this lies in the murkiness of the Australian health jurisdiction. ATSIC is responsible for monitoring health delivery and advises the Minister for Aboriginal and Torres Strait Islander Affairs on the effectiveness of strategies implemented by the Commonwealth Department of Health, who assumed the administration of Aboriginal health in 1995. ATSIC has an official Aboriginal health policy. Its influence on the Department of Health is defined in a memorandum of understanding and remains advisory. Australia
Aboriginal and Torres Strait Islanders Commission, ATISIC Health Policy (ATISIC National Policy Office, 2001). The Northern Territory and states continue to generate their own Aboriginal health policies.

61. Scrimgeour, Community Control of Aboriginal Health Services.


63. Australia Commonwealth Department of Health and Aged Care Office of Aboriginal and Torres Strait Islanders Health Services, Primary Health Care Access Program (OATSIH, 2002).

64. The term Maori is a prevalent, although contested, self-referent for the Indigenous population of New Zealand. Like the terms Aborigines and First Nations, Maori glosses over tribal distinctions.


67. The English version of Article 1 provides for a transfer of sovereignty to the British Crown. Article 2 ensures the continuation of property rights. Article 3 guarantees rights equal to other New Zealand citizens. The Maori translation of Article 1 did not convey a transfer of sovereignty, but that of administrative authority (kawanatanga). Article 2 translated “full and undisturbed possession” as tino rangatiratanga, which implies the full recognition of the authority of the chiefs. It also translated “other properties” as taonga katoa, which implies cultural as well as material properties. Durie, Whaiao: Maori health development. The full texts of the Treaty, along with a transliteration of the Maori text, can be found at http://www.govt.nz/aboutnz/treaty.php3.

68. Ward and Hayward, “Tino Rangatiratanga; Maori in the political and administrative system.”

69. Representatives were to be elected by Maori men, but could be non-Maori.

70. Armitage, Comparing the Policy of Aboriginal Assimilation.


73. Nicolson, “Medicine and Racial Politics.”


77. Durie, Whaiao: Maori health development.

78. Durie, Whaiao: Maori health development.


80. Durie, Whaiao: Maori health development.

81. The purchaser-provider split refers to the separation of the funder, purchaser and provider functions within the health care system. Because of this approach, the government health provider function (government-owned and -operated hospitals, clinics and public health departments) become either privatized or sub-contracted to the non-profit sector. Governments retain a limited role of funder/purchaser and regulator of services. Proponents of this approach hope for improvements in performance and operational efficiency, a minimization of conflicts of interests and increased responsiveness to consumer wants and needs because of the competitive market-like environment. Andrew Podger, “Reforming the Australian Health Care System: A Government perspective,” Health Affairs (May/June 1999), p. 111-113. Sweden, the United Kingdom and New Zealand have adopted this approach. It resulted in “the overlay and interweave [of] market mechanisms into largely publicly funded and publicly provided health systems.” The result has been mixed. New Zealand now appears to be shying away from this approach. (Geoff Fougere, “Transforming Health Sectors: New logics of organizing in the New Zealand health system,” Social Science and Medicine, Vol. 52, (2001), p. 1233-1242.). However, the terminology still permeates the system.


83. Durie, Whaiao: Maori health development.

84. Although competition was definitely the leading ideology, two measures were put in place in the HFA to ensure that Maori providers would be able to access health service delivery funding and compete with other providers. A first measure was the creation of the Maori Provider Development Scheme. It is a proposal driven scheme that funds capacity and infrastructure development. A second measure was practice rather than policy based. It recognized Maori providers as preferred provider for contracts for which performance had been satisfactory (Wayne McLean, Personal Communication, 2003).

85. Both funding formula favour individual-focused interventions rather than a whanau (family-centred) or hapu (sub-tribe, or community) approach favoured by Maori. Mason Durie, Maori Ora: The Dynamics of Maori Health (Oxford: Oxford University Press, 2001).

86. New Zealand Te Puni Kokiri, Maori Provider Views of Government Funding, Key issues from the literature and interviews (2000).

87. This is in addition to funding secured from other sources, Minister of Health, Te Puni Kokiri, district health boards, etc.


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Numerous studies, inquiries and statistics accumulated over the years have demonstrated the poor health status of Aboriginal Peoples relative to the Canadian population in general. This state of affairs has led to charges of neglect, indifference and even genocide against the federal government and Canadian society by Aboriginal groups and their supporters. The debate on Aboriginal health services has focused on their current availability, adequacy, accessibility, effectiveness, and sensitivity to community needs. While there are several books on particular aspects of Aboriginal health and health care in Canada, a comprehensive historical review that is national in scope and combines the methodologies and perspectives of epidemiology, history, and anthropology has not been available until now.

Aboriginal Health in Canada is about the complex web of physiological, psychological, spiritual, historical, sociological, cultural, economical, and environmental factors that contributed to health and disease patterns among the Aboriginal Peoples in Canada. Authors James B. Waldram, D. Ann Herring and T. Kue Young explore the evidence for changes in patterns of health and disease prior to European contact and since then, up to the present. They discuss medical systems and the place of medicine within various Aboriginal cultures and trace the relationship between politics and the organization of health services for Aboriginal Peoples. They also examine popular explanations for Aboriginal health patterns today and emphasize the need to understand both the historical-cultural context of health issues and the diversity of circumstances that give rise to variation in health problems and healing strategies in Aboriginal communities across the country. An overview of Aboriginal Peoples in Canada provides a very general background for the non-specialist. Finally, contemporary Aboriginal healing traditions, the issue of self-determination and health care, and trends in Aboriginal health issues are examined.

Waldram is a professor in the Department of Native Studies at the University of Saskatchewan. He and N. Dyck are the editors of Anthropology, Public Policy and Native Peoples in Canada. Herring is an associate professor in the Department of Anthropology at McMaster University. She and Leslie Chan are editors of Strength in Diversity: A Reader in Physical Anthropology. Young is a professor in the Department of Community Health Services in the University of Manitoba’s Faculty of Medicine. He is author of The Health of Native Americans and Health Care and Cultural Change.
The Aboriginal People of Australia, Canada and New Zealand became minorities in their own countries in the 19th century. The expanding British Empire had its own vision for the future of these peoples, which was expressed in 1837 by the Select Committee on Aborigines of the House of Commons. It was a vision of the steps necessary for them to become civilized, Christian and citizens – in a word, assimilated.

Comparing the Policy of Aboriginal Assimilation provides the first systematic and comparative treatment of the social policy of assimilation that was followed in these three countries. The recommendations of the 1837 committee were broadly followed by each of the three countries. However, there were major differences in the means that were used. Australia began with a denial of the Aboriginal presence. Canada began establishing a register of all Status Indians. New Zealand began by giving British citizenship to all Maori.

The policy of assimilation is traced through five principal phases:
- a period of initial contact when the power relationships necessary to carry out the policy were established;
- a period when the policy was passive and Aboriginal People were expected to die out or merge with the immigrant populations;
- a period of aggressive policy when specific social policies were introduced to suppress Aboriginal institutions;
- a period of integration when it was thought that the policy could be achieved through disregarding the Aboriginal existence; and
- the present period when the policy is being reversed as Aboriginal Peoples re-establish control of their own social policy.

As well as providing comprehensive and comparative data on the conduct of the policy of assimilation, Comparing the Policy of Aboriginal Assimilation provides a series of accounts of the reasons given for the policy in each period. These lead to an analysis of the origins of the policy within the immigrant societies of the British Commonwealth and the reasons for its persistence. In the end, the policy of assimilation is shown to be primarily an expression of the racist and colonial nature of the immigrant societies. Today the Aboriginal societies are reasserting themselves. There are some grounds for hope that a plural form of social policy can be brought into effect that accommodates the need to respect differences between the Aboriginal and immigrant societies.

Andrew Armitage is a professor in the Department of Social Work at the University of Victoria.
Aboriginal Health Systems in Canada: Nine Case Studies

Laurel Lemchuk-Favel  
M.H.A. FA VCOM  
and  
Richard Jock, B.A., M.Ed.  
National Aboriginal Health Organization

Abstract

This paper investigates Aboriginal health systems in Canada, in urban and rural First Nations communities, Inuit communities and Métis Settlements. A summary of the primary strengths and challenges of Aboriginal-controlled health systems is presented. Strengths include holism, synergy of western and traditional health philosophies, focus on primary care, collaboration with provincial services, integrated health service delivery, and administrative reform. Aside from the challenge of health status, Aboriginal health systems must contend with small community size, remoteness, lack of human resources including Aboriginal health professionals, a growing and aging population, inadequacy of funding accompanied with non-sustainability of the system, and jurisdictional barriers. Through nine case studies, successful approaches are presented to providing effective, responsive and culturally-appropriate community health services. These case studies underscore the diversity in Aboriginal health systems necessary to accommodate vast differences in cultural expectations, health service needs, jurisdictional complexity, and geographic location.

Key Words

Aboriginal, health systems, case studies, First Nations communities, Métis Settlements, Inuit communities

INTRODUCTION

This paper focuses on Aboriginal health systems existing in urban and rural First Nations communities, Inuit communities and Métis Settlements. Why are Aboriginal-specific health systems needed? The answer is complex and encompasses health needs of Aboriginal Peoples, cultural uniqueness, federal and provincial roles in health service delivery, and the physical geography of many Aboriginal communities. There are exciting and promising initiatives in Aboriginal health systems described in this paper. They are succeeding in overcoming jurisdictional, cultural and other barriers. This paper provides an answer to the questions federal committees and other groups often sincerely ask: What works? What changes can be made to the health care system to improve the health and well-being of Aboriginal Peoples?

This document is an excerpt from a larger paper on Aboriginal health systems commissioned by the National Aboriginal Health Organization in which all profiled communities agreed to their participation as case studies. This wider report also addresses Aboriginal health usage and expenditures, health system recommendations from the Royal Commission on Aboriginal Peoples, provincial health system reform, and international perspectives on Aboriginal health systems.¹

STRENGTHS OF ABORIGINAL SYSTEMS

Aboriginal communities – whether located on-reserves, in northern reaches of the country or in urban cores – have inherent resources that are proving to be attributes in designing effective and cost-efficient health services. Communities that have been successful in creating responsive, sustainable, accessible, and client-focused health systems share many common characteristics:
• self-empowerment;
• holistic approach;
• synergy of traditions and western health philosophies;
• primary care;
• collaborations with provincial services;
• integrated health services delivery; and
• administrative reform.

Self-Empowerment

Aboriginal ownership and control of health services can contribute to a climate of self-empowerment in the community and can improve access to services through a supportive, culturally-appropriate environment. Thought provoking research into youth suicide among British Columbia’s First Nations communities provides convincing evidence of the impact of Aboriginal control of institutions and other measures to preserve cultural continuity in dramatically lowering youth suicide rates. In B.C., First Nation community suicide rates vary from 800 times the national rate to zero. This research evaluated six markers of cultural continuity:

1. land claims or steps to secure Aboriginal title to traditional lands prior to the establishment of the province-wide settlement process;
2. achievement of self-government allowing economic and political independence within their traditional territories;
3. band-controlled education services;
4. band-controlled police and fire protection services;
5. health services - divided between bands that had funding for permanent health care providers in their community and those that relied on temporary clinics, fly-in providers or out-of-community health services; and
6. presence of a facility designated for cultural use.

The research found that for communities where all of the measures of cultural continuity were present, no suicides occurred in the five-year study period. The suicide rate for those communities that possessed none of these factors was 137.5 per 100,000. A minimum of three factors was necessary to significantly lower the suicide rate. Taken individually, the reduction of relative risk provided by these factors ranged from 20 per cent (police and fire services) to 85 per cent (land claims).2

Holistic Approach

The Aboriginal concepts of holism and wellness are similar to a broad health determinants approach. Holism should not be regarded as just another health determinant as it is a philosophy embracing all life processes, whether they are physical, mental, spiritual, or emotional components. The concept of holism is integrated into community program design, from the level of patient care to administrative integration of health and social services and integrated planning with housing, training, justice, and corrections, schools and other community-based services.

The Aboriginal Healing and Wellness Centre in Winnipeg uses a health promotion framework where well-being is pursued through attaining balance of the spiritual, emotional, physical, and intellectual aspects of a child, youth, adult, or Elder as individuals, members of families, communities, and nations, and within the cultural, social, economic, and political environments.3

Synergy of Traditional and Western Health Philosophies

Traditional (also referred to as Indigenous) healing practices, which encompass physical, spiritual, emotional, social, and mental well-being, may be synergistically combined with western medical approaches to develop uniquely Aboriginal approaches to health services. Traditional and western practices each have their own strengths and weaknesses. Community preferences with regards to each will vary. Health centres in Ontario, which provide culturally-appropriate primary care to urban and rural Aboriginal populations, have the option of including traditional healers on their multidisciplinary team. A recent evaluation found clients most often accessed health promotion services related to traditional knowledge and skills (and nutritional and dietary issues) over a variety of other subjects including substance abuse, specific diseases or illnesses, stress management, depression, or empowerment. The majority of respondents reported that these services had helped them “a lot.” Urban-based health centres were more likely than rural health centres (which serve First Nations living on-reserve) to have included a traditional component to their health services.4 There may be a variety of reasons for this, such as the availability of traditional healers outside of the structured health system.

Not all communities may wish to include traditional healers in their health systems. In an innovative Health Transition Fund project involving primary care reform in the Eskasoni First Nation, a traditional component was not included or requested by the community.5 Some Aboriginal Peoples recognize the value of
traditional culture even though specific healing approaches may not be desired. The 1997 First Nations and Inuit Regional Health Survey, which polled about 10,000 adult respondents in First Nations and Inuit communities, found that more than 80 per cent of respondents answered positively to the question “Do you think a return to traditional ways is a good idea for promoting wellness?”

Primary Care

The health system is organized around primary care and features multidisciplinary teams and linkages to external health resources. Access to adequate, culturally-appropriate primary care is still an issue in many communities. In these cases, the current approach to move resources from treating illness to promoting healthy lifestyles and preventing disease may be premature as primary care services may never have had a chance to make a significant difference because of under funding or low usage.

A prominent feature of primary care reform is the move from fee for service to salaried forms of physician remuneration. The multidisciplinary team can also include nurses, nurse practitioners, nutritionists/diabetes educators, pharmacists, psychologists, social workers, traditional healers, etc. Various models of primary care will be explored more thoroughly in case studies of the Eskasoni First Nation and urban Aboriginal health systems.

Collaborations With Provincial Services

Working linkages exist with external health authorities and solutions to jurisdictional issues are proactively sought. Provincial health systems are an integral part of the Aboriginal health system. Under the Canada Health Act, provincial governments are the administrators of physician and hospital services. All parties, be they Aboriginal, provincial or federal, have the same objective: to use limited health dollars to the greatest effect in order to improve the health system. Health usage studies have shown that Aboriginal Peoples are high users of provincial physician and hospital services. These studies are powerful evidence in favour of provincial collaboration in Aboriginal health systems. A later section of this paper will look more thoroughly at health care usage and expenditures of Aboriginal Peoples.

Good working relationships between Aboriginal and non-Aboriginal systems need not be more than instituting effective referral mechanisms and sharing of patient information as required. The success of instituting collaborative relationships will depend on the attitudes and open-mindedness of all parties who have put aside jurisdictional differences to work on common solutions to health issues.

Integrated Health Service Delivery

Partnerships are created among communities where feasible to achieve economies of scale. This may involve community-based services or, in the case of large tribal council affiliations, secondary and tertiary services such as dental health, medical officer of health, nursing supervision, and environmental health services. In many cases, this has allowed these latter services to be delivered directly by Aboriginal Peoples as opposed to federal or provincial offices. Even so, the need for community capacity development and local service delivery must be balanced with the economic considerations of larger affiliations and centralization of services.

Administrative Reform

The health system is accountable to both the community and the funders. In an optimal situation, administrative structures are lean and the number of funding agreements has been reduced so as to allow flexibility in allocation of resources and minimize paperwork. This may seem like common sense, but for First Nations communities receiving funding from several federal government departments involving multiple program areas, funding arrangements are still not routine. The administrative burden can be minimized through the merging of programs.

Health System Challenges

Aboriginal systems must deal with similar issues to those seen in all health systems, including the prioritization of programs in a climate of scarce resources, accommodating wage increases of the workforce, rationalizing services to achieve workable economies of scale, and shifting from a disease model to one that is based on health promotion and disease prevention. In addition, there are a set of challenges in the environment that largely define the Aboriginal situation:

• health status;
• community size;
• remoteness;
• human resources;
• Aboriginal health professionals;
• demographics;
• funding; and
• jurisdiction.
Health Status

Table 1 provides an overview of the Aboriginal health environment from the perspective of broad health determinants. This data has been gleaned from Statistics Canada Census and surveys, Health Canada indicators, Indian and Northern Affairs Canada administrative databases, and research studies. The picture is one of a population experiencing a disproportionate measure of illness, mortality, injury, addictions, and family violence. There are also overcrowded conditions, often inadequate housing and community infrastructure (water and sewage), with lower levels of employment, average income, and education. Simply put, Aboriginal Peoples rate significantly lower on virtually every measure of health and well-being when compared to the general Canadian population. Although not exclusively, these measures are heavily weighted on physical health and do not adequately cover the spiritual, mental, so-

Table 1a: First Nations and Inuit

Selected Health Status Measures

Mortality

The 1993 age standardized mortality rate for First Nations People was 10.8 deaths per 1,000 compared to 6.9 deaths per 1,000 for the Canadian population.ii

Life Expectancy

In 2000, First Nations and Inuit: males 68.9 years (7.4 years less than Canadian males); females 76.6 years (5.2 years less than Canadian females)ii

Chronic Diseases

First Nations on-reserve to Canada ratio of age-adjusted prevalence for diabetes in 1997: 3.3 (males) and 5.3 (females); for heart problems: 3.0 (M) and 2.9 (F); for cancer: 2.0 (M) and 1.6 (F); for hypertension: 2.8 (M) and 2.5 (F) and for arthritis/rheumatism: 1.7 (M) and 1.6 (F).iii

Selected Health Behaviours

Smoking

62% of First Nations People on-reserve smoked in 1997, which was double that of Canadians. Rates for First Nations under 30 years of age were more than 70%.iv

Alcohol Use

In 1991, 73% of First Nations respondents to the Aboriginal Peoples Survey said alcohol was a problem in their communities and 59% said drug abuse was a problem.v

Selected Health Determinants

Unemployment Rate

On-reserve First Nations had an unemployment rate of 29% in the 1996 Census, almost three times higher than the non-Aboriginal rate (10%). The Inuit rate was 22%.vi

Income

First Nations People’s average income is lower than Canadians at any age or educational level. On-reserve First Nations People’s income levels were only half that of Canadians in the 1996 Census.vii

Educational Attainment

In the 1996 Census, 63% of First Nations People completed secondary school compared to 79% in the Canadian population. More than four times as many Canadians possessed a university degree in the Census than First Nations (14% compared to 3% respectively). Most Census educational attainment indicators for Inuit were lower or comparable to First Nations.viii

Water Systems

41.4% of First Nations and Inuit communities had piping to centralized water treatment plants in 1999-2000.

Community Sewage Systems

33.6% of First Nations and Inuit communities had at least 90% of their homes connected to community sewage disposal systems in 1999-2000.

Shelter

56.9% of First Nations dwellings on reserve were considered adequate in 1999-2000. In addition, 19% of on-reserve dwellings had more than one person per room, compared to 2% for Canada as a whole.ix

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### Table 1b: Aboriginal Population (Excluding First Nations on-reserve)

#### 2000-01 Canadian Community Health Survey (preliminary results)

##### Selected Health Status Measures

**Self-Rated Health Status**
42.4% of Aboriginal People reported very good or excellent health compared to 61.2% of non-Aboriginal people.

**Diabetes**
The prevalence of diabetes was two times that of non-Aboriginal Canadians (8.7% versus 4.3% respectively).

**Restrictions in Functional Status**
40% reported limitations in physical ability compared to 26.0% among non-Aboriginal people.

**Major Depressive Episodes**
Almost twice as many Aboriginal People reported an occurrence of a major depressive episode as non-Aboriginal people (13.3% versus 7.3%).

#### Selected Health Behaviours

**Smoking**
More than half of the Aboriginal population were smokers (1.9 times the non-Aboriginal rate). The largest difference in light daily and occasional smokers.

**Obesity**
As defined by the body mass index, 24.2% of the Aboriginal population were obese compared to 14.1% of the non-Aboriginal population.

**Alcohol Use**
Although Aboriginal People were less likely to report being weekly drinkers, and more likely to be former drinkers, over three times more Aboriginal people were assessed as being alcohol dependent than non-Aboriginal people (6.0% versus 1.8% respectively).

##### Selected Health Determinants

**Educational Attainment**
Aboriginal Peoples were less likely to graduate from high school (43.8% versus 23.1% for the non-Aboriginal population did not graduate) and less likely to be post-secondary graduates (32.5% versus 50.8% respectively).

**Work Status**
38.1% of Aboriginal People worked the whole year compared to 53.2% of non-Aboriginal people.

**Low income**
Based on total income and number of persons in the household, 27.3% of Aboriginal Peoples were evaluated as having a low income compared to 10.1% of non-Aboriginal people.

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ii Canada, *Department of Indian Affairs and Northern Development, Basic Departmental Data 2001* (Ottawa: Minister of Indian Affairs and Northern Development, 2002).

iii *First Nations and Inuit Regional Health Survey National Steering Committee, First Nations and Inuit Regional Longitudinal Health Survey* (Ottawa: First Nations and Inuit Regional Health Survey Steering Committee, 1999).

iv *First Nations and Inuit Regional Health Survey National Steering Committee, 1999*.


x Draft data provided to the National Aboriginal Health Organization from Statistics Canada, May 2002. All rates age-standardized. The definition of Aboriginal Peoples in the Canadian Community Health Survey included North American Indian, Métis and Inuit/Eskimo. This survey was not administered in First Nations communities, therefore included only the Aboriginal population not living on-reserve, including all communities in the territories. The 1991 APS is the most recent source of Métis-specific health data. It found for Métis aged 15 and older: 59% reported excellent or very good health, 43% reported at least one health problem; 27% reported high blood pressure; 25% bronchitis, 16% heart problems and asthma, 13% diabetes. Métis women were more likely than men to report one health problem and 54% of the Métis population were smokers.
Aboriginal Peoples lived in seven of the country’s 25 environments. The 1996 Census reported that 171,000 served First Nations, urban Inuit and non-status Indians. The Aboriginal population that also includes off-reserve Indians are located in larger urban environments as part of centres of 1,000 to 2,000 people. However, the majority are small and remote. There are eight Métis Settlements in Alberta, which comprise about 5,000 people. Métis may live in rural areas removed from small centres of 1,000 to 2,000 people. Poor health status by itself does not mean that the health system has failed to meet the needs of a population. Certainly, health services as a whole is only one of the many pieces of the puzzle that influences the health of a population. It is arguably of lesser importance than socio-economic factors such as income, education, lifestyle, and employment; the environment; and genetic predisposition.

For the majority of the Aboriginal population, however, the mainstream Canadian health system has often been inaccessible in physical terms (due to distance and jurisdictional divisions between federal and provincial governments) and also in cultural and psychological terms. Barriers to service involve language, cultural appropriateness, the scarceness of Aboriginal health providers, and lack of community involvement in the administration of health services. One effect of this is that health needs may be ignored until they become so serious as to require emergency attention. Lack of knowledge of the language and local culture of the Aboriginal community has obvious ramifications on simple communications between health provider and client. Health promotion efforts, not a flagship program of the mainstream health system by any means, have a limited target audience as Aboriginal Peoples in need may not be known by health system workers, or the health message may not be couched in terms that are compatible with Aboriginal culture.

**Community Size**

Aboriginal communities tend to be small. For example, 43 per cent of First Nations communities in the provinces and Yukon have populations of 400 or less. A further 34 per cent have populations between 401 and 1,000. For Inuit, Dene and Métis communities in the territories, community size is inversely related to the proportion of Aboriginal Peoples in the population. Communities that are virtually all Aboriginal are small and remote. There are eight Métis Settlements in Alberta, which comprise about 5,000 people. Métis may live in rural areas removed from small centres of 1,000 to 2,000 people. However, the majority are located in larger urban environments as part of the Aboriginal population that also includes off-reserve First Nations, urban Inuit and non-status Indians.

Small community size is not an issue in urban environments. The 1996 Census reported that 171,000 Aboriginal Peoples lived in seven of the country’s 25 Census metropolitan areas: Winnipeg (45,750), Edmonton (32,825), Vancouver (31,140), Saskatoon (16,160), Toronto (16,100), Calgary (15,200), and Regina (13,605). These populations are a mixture of all three Aboriginal groups. For example, in the 1996 Census, the Métis component of the population varied from 18 per cent in Toronto to 54 per cent in Winnipeg. The challenge for urban environments is the lack of a focus from which a community can be identified and a health system built. Friendship centres have played a significant role in providing a meeting place for the Aboriginal population. They have become involved in federally funded health programming such as urban Aboriginal Head Start and diabetes health promotion. As health services to the entire population, including Aboriginal People, are under provincial jurisdiction in these cities, it has been the exception, rather than the rule, that provincial governments have provided resources for Aboriginal health services. There have been varying levels of involvement within and among provinces, regions and territories in dealing with Aboriginal health issues. This involvement varies from Aboriginal representation on regional health boards to the rare allocation of health resources for Aboriginal-specific programs and services. The section on Urban Aboriginal Health Services, which follows, illustrates the success that these few Aboriginal urban-based initiatives have had in designing health services that have provided supportive, culturally-appropriate care and in the process become virtual communities. In these cases, the characteristics described above for Aboriginal health systems apply, and prove that “Aboriginal community” is a mind set, a culture, not a physical piece of geography.

In today’s fiscal environment, economies of scale are necessary considerations in creating program efficiencies. This would suggest that communities, particularly small ones, must work together to share resources. In some areas, co-ordinating services can impose additional costs to the system, such as in remote environments that have fly-in-only access. There, multicommunity co-ordination faces challenges such as securing sufficient transportation resources for travel of health professionals to multiple communities.

Desire for autonomy may not always be set aside in the spirit of reducing costs or challenges of geography dealt with by pooling resources. For example, in British Columbia it is estimated that six per cent of the First Nations population in communities are too distant from other communities to facilitate intercommunity approaches to health services.
Remoteness

Remoteness is an issue when delivering health service in many Aboriginal communities. For 35 per cent of First Nations communities, physician services are more than 90 km away. About three out of five of these communities do not have road access and must rely on either scheduled or special flights to bring in health professionals and take out patients requiring specialized services, emergency care or other hospital-based treatments. Dealing with remoteness is the rule, rather than the exception, in the territories. In Nunavut, for example, where most Inuit communities are located, 21 of 25 communities rely on visiting physicians. Ensuring a continuity of care between community and larger secondary and tertiary health systems is an issue with all Aboriginal health systems, but compounded in a remote environment.

Recently, British Columbia has set standards on how far patients must travel to receive medical care. There, 98 per cent of patients in any health area will be guaranteed 24-hour emergency services within one hour’s travel time or 50 km from their home and acute care services within two-hours’ travel time or 100 km. Generally, communities that are small and distant from emergency services are Aboriginal. Therefore, if there is a two per cent segment of the population that falls outside of the standards in a health region that is geographically large and has a concentrated urban area, this population will likely be Aboriginal. As such, this standard could be interpreted as biased against equitable Aboriginal access to services.

Interestingly, research in Saskatchewan has challenged the concept that health status is directly related to proximity to acute care. Mortality patterns were analyzed in communities before and after 1993 reforms that closed 52 small rural hospitals. Mortality rates decreased in communities where hospitals closed, even those due to life-threatening events such as heart attack and motor vehicle accidents. As well, residents’ perceptions of their own health or their family’s health were consistent with this lowered mortality data. First Nations mortality patterns were not specifically identified due to issues with identification of residence. Although this study has raised more questions than it answered, it shows that a simple causal relationship between immediate access to acute care and health status does not exist. There are likely a multitude of factors that could influence health status, such as access to better care in larger hospitals, dependencies and patterns of care in small hospitals that result in worse outcomes, or even movement of people with severe health problems to larger urban centres.

The Saskatchewan work did not look specifically at remote communities where emergency services are in place and access to acute care is via air transport. However, it raises the intriguing possibility that perhaps the most effective secondary and tertiary acute care already exists via the large urban hospitals that receive patients from remote communities. Furthermore, a focus on improvements to these communities’ health systems could be better directed to primary health care and health promotion initiatives. This hypothesis would require further investigation to validate. Even so, it does have some support from recent research on Manitoba First Nations health and health care usage. One of its findings was that two tribal councils in the northern areas of the province have the highest rates of referrals to specialists, compared to other tribal councils including those near Winnipeg and Brandon. One of these two northern tribal councils also has the highest life expectancy of all First Nations in the province.

Human Resources

Staff turnover and recruitment of qualified personnel are major issues for small or remote communities. Working conditions can be burdensome, particularly if there are no back-up systems for staff. Achieving equity with provincial wages has been a perennial issue for health systems operating on fixed budgets. About 45 per cent of the 223 nursing positions in northern isolated First Nations communities (in the provinces) were vacant or filled on a temporary basis in 1999. In the north, nurse shortages are critical and threaten the existence of some health centres. Most northern nurses are recruited from the south with turnover and burnout a common issue aggravated by 24-hour call, lack of sufficient supplies, and isolation from family and friends. Strategies involving the recruitment of immigrant physicians to alleviate staff shortages can bring other issues such as different cultural norms that prevent male physicians from seeking assistance from female nurses in the primary care team.

The distinction between north and south can be somewhat fluid, with north generally relating to the territories or to northern areas of provinces where Aboriginal communities are often semi-isolated, isolated or remote by Health Canada standards. These standards use a categorization based on distance from physician services and type of transportation access.
Semi-isolated communities possess road access, but are more than 90 km away from physician services. Isolated communities have scheduled flights, good telephone services, but no year-around road access. Remote communities are without scheduled flights or road access and possess minimal telephone or radio service. Semi-isolated communities can also be found occasionally in sparsely populated and/or mountainous areas in central to southern parts of provinces, such as in British Columbia, Manitoba and Ontario. Just providing a higher salary does not always solve the problem of recruitment and retention in northern or geographically challenging areas. The James Bay and Northern Quebec Agreement (JBNQA), a land claim settlement affecting the northern Cree and Inuit in Quebec, explicitly recognizes the challenges in health professional recruitment. It states that the province is obligated to “recognize and allow to the maximum extent possible for the unique difficulties of operating facilities and services in the North.” In implementing this, factors to be addressed include attractive working conditions and benefits, opportunities for education, employment and advancement of Aboriginal Peoples, and sufficient resources to cover the high costs of developing and operating health and social services in the north. In addition, the province’s collective agreement with nurses allows nurses to take a one-year leave to work in the north, with a second year optional, without losing seniority.

**Aboriginal Health Professionals**

A major part of breaking down barriers to health care in Aboriginal populations is to make health services more familiar and non-threatening. A second factor is to tailor the service so it reflects, or at least is understanding of, a culture’s norms. Aboriginal Peoples in front line health delivery have tangible positive effects on access to primary care. The Ontario Health Access Centres evaluation found that the use of Aboriginal Peoples as service providers was seen to provide a powerful statement of belonging and self-determination. Respondents to the survey said Aboriginal workers were very important in their sense of comfort and the quality of delivered services. They were perceived as understanding people’s needs better and as being more competent in grasping the nuances of people’s circumstances. This is not to say that there are not many excellent non-Aboriginal health professionals who are knowledgeable about Aboriginal culture and are warmly received by a community.

The Royal Commission on Aboriginal Peoples (RCAP) recommended an intensive effort be directed to ensuring that 10,000 Aboriginal Peoples were trained in health professions over the next decade. Progress in increasing the Aboriginal workforce has occurred, albeit slowly. A recent study has reported that 0.7 per cent of first-year students in Canadian medical schools in 2000 were Aboriginal, despite Aboriginal Peoples making up four per cent of the Canadian population. This number (seven Aboriginal students in total) is considerably lower than earlier reports of Aboriginal physician student numbers (see below). Possible explanations could include the design and coverage of the survey, which excluded Quebec, and the participation rate by Aboriginal respondents in this survey.

Aboriginal Peoples in all health professions are a scarce commodity. Educational attainment can serve as an indicator of a population’s professional makeup. In 1996, only three per cent of the First Nations population (aged 15 years and older and not attending school full time) and four per cent of the Métis population possessed a degree, compared to 14 per cent in the general population. The Inuit population fared even more poorly at just more than one per cent. This is also reflected in public school educational attainment. The 1996 Census showed 39 per cent of Inuit had not completed Grade 9 compared to 25 per cent of First Nations and 17 per cent of Métis.

The Aboriginal Nurses Association of Canada currently has a membership of about 300 registered nurses, licensed practical nurses and registered nursing assistants. Not all Aboriginal nurses are members of this organization. The Canadian Public Health Association (CPHA) in a brief to RCAP in 1993 estimated that there might be as much as 3,000 Aboriginal registered nurse graduates in Canada.

There are no recent figures available for the number of graduated Aboriginal physicians. In 1996, the Native Physicians Association in Canada reported that there were 67 Canadian Aboriginal physicians with a further 33 in medical school. RCAP estimated, based on earlier reports of 51 self-identified Aboriginal physicians, that the ratio of Aboriginal physicians to Aboriginal population was about 1:33,000 compared to a corresponding ratio of 1:515 in the non-Aboriginal population.

Data is even more limited on Aboriginal representation in other disciplines, such as health administration, population health, health policy and research, sociology, psychology, anthropology, justice, social work, and education. In the 1993 CPHA submission
to RCAP, three Aboriginal dieticians and 70 Aboriginal dental therapists were reported in Canada.

Demographics

It is generally accepted that the annual growth rate of Aboriginal Peoples exceeds the general Canadian population, the latter which has only grown by four per cent in the five-year period between the 1996 and 2001 Censuses, or an average of about 0.8 per cent annually. It has been more than a decade since projections on the entire Aboriginal population were completed by both RCAP and Human Resources Development Canada. RCAP projected that the annual Inuit growth rate for 2001 would be somewhere between 1.6 per cent and 2.2 per cent depending on the assumptions employed. For rural Métis, the rate would be between 1.6 per cent and 2.4 per cent, whereas urban Métis rates were predicted to be between 1.2 per cent and 1.6 per cent. More recent projections (1998 to 2008) are available for First Nations. The growth rate of on-reserve First Nations People has been estimated to be three per cent annually, with those living off-reserve possessing a growth rate of one per cent. A portion of this difference is due to anticipated migration of First Nations People from cities to their communities.

All Aboriginal Peoples have a large youth cohort or baby boom generation. The maturing of this youth cohort combined with increases in life expectancy suggests that Aboriginal population aging will have a greater impact on the health system than what is anticipated for the general population. For example, it has been predicted that the 65 and older segment of the general population will increase by 0.78 per cent annually in 1999-2000 to 1.24 per cent annually by 2019-2020, or by 1.5 times. The most recent First Nations population projection has projected that First Nations People aged 65 and older will increase by 2.09 times over the same time period (from an annual 4.25 per cent increase in 1999 to 8.89 per cent in 2021) or 40 per cent more than the Canadian population.

In certain regions, the higher growth rate of Aboriginal Peoples has been credited with changing demographics of the population as a whole. The age profile of Manitoba and Saskatchewan 2001 Census results were heavily influenced by the high fertility of their Aboriginal populations. Saskatchewan had the second lowest medium age of all 10 provinces at 36.7 years. The significant numbers of Aboriginal Peoples in the Northwest Territories and Nunavut resulted in these territories having the lowest medium age in Canada in 2001 and the highest proportion of their population aged younger than 20.

Funding

Federal funding is provided for health programs and services in First Nations and Inuit communities. For some, however, the amount of funds is limited by the presence of transfers to territorial governments or land claim agreements. All First Nations People and Inuit, regardless of territorial transfer or other agreements, are eligible for new federal programs such as the Aboriginal Diabetes Strategy (ADI), First Nations and Inuit Home and Community Care Program (HCC), Aboriginal Head Start (AHS), and the Canada Prenatal Nutrition Program (CPNP). Métis are eligible for ADI and AHS funding.

Sustainability of funding for community health services in First Nations communities in the provinces and the Inuit communities in Labrador is currently an issue. The base funding envelope of the First Nations and Inuit Health Branch (FNIHB) for both community health programs and the Non-Insured Health Benefits (NIHB) program has been limited to three per cent annually since 1996-97. The NIHB program consumes about 50 per cent of the total budget and provides pharmaceutical, vision, dental, medical transportation, and medical supply benefits to First Nations People. This program routinely exceeds the three per cent funding cap. This has made it difficult to divert new resources to established community health programs. This has meant that the core community programs of nursing, community health representatives (CHRs) and the National Native Drug and Alcohol Abuse Program (NNADAP) have had to deal with population growth and cost-of-living increases within a static budget for four years. The 2000 federal budget provided some short-term relief with a commitment of $50 million annually over the next two years. FNIHB is now reviewing the issue of financing and how to ensure sustainability in the First Nations and Inuit health system. Health Canada has recently received an adjustment to its base: 7.7 per cent for the NIHB program and three per cent for community health programs.

As health services for Aboriginal Peoples outside of First Nations and Inuit communities are considered the jurisdiction of the provincial governments, the development of Aboriginal health services in this environment is dependent on provincial funding. Provinces certainly include Aboriginal Peoples as prioritized target groups in overall strategies and may include Aboriginal representation in certain health ini-
tiatives. It is rare that a provincial government will divert resources to Aboriginal-specific programs, and much more rare that funding will be provided to Aboriginal groups to develop comprehensive primary care services. As will be covered below, Ontario, British Columbia and Manitoba have all invested to varying degrees in urban Aboriginal health centres. In addition, Métis-specific health initiatives that receive provincial funding are described: the Métis Settlement Health Project, the Métis Nation of Ontario Health Services Branch, and the Métis Addictions Council of Saskatchewan Inc.

Jurisdiction

Table 2 provides an overview of the health programs and services that are provided by federal, provincial and territorial jurisdictions to Aboriginal Peoples. The split of services among these jurisdictions is complex and an interaction of ancestry (type of Aboriginal group), place of residence, legislation, and land claim agreements.

For Aboriginal Peoples where the federal government has acknowledged a policy role in health (i.e. First Nations and Inuit), Aboriginal-specific health systems have evolved. These systems are in communities that are on First Nations and Inuit land and where provinces have no jurisdiction over on-site health and social programs. In the territories – as a reserve system was not established and the territorial governments in the mid 1900s did not have the capacity to develop and administer health services to the population – the federal government assumed the role of service provider to the entire population. This set the stage for the present health system which is transparent to both Aboriginal and non-Aboriginal Peoples. When the territorial governments took over health service delivery, they did so for the entire population and the federal government transferred the health resources for the Inuit and First Nations populations. The only programs that were kept under federal jurisdiction were those that did not have a territorial counterpart, basically the NIHB Program. Since these transfers have taken place, new federal programming to First Nations and Inuit communities has remained under federal control.

The federal government does not acknowledge a fiduciary (trustee-like) responsibility or jurisdiction of Métis. Generally, the provincial governments’ positions have been that Métis can access health services on the same basis as the rest of the population, and therefore no Métis-specific provincial programming exists. Despite this, there are some limited examples of Métis-specific health programming, which will be covered later in this paper.

The issue of jurisdiction is slightly different in Newfoundland and Labrador. When the two domains were united in 1949, the Indian Act was not applied. A limited, ad hoc federal involvement in Aboriginal Peoples’ health began, such as the reimbursement of tuberculosis treatments for Aboriginal Peoples in Labrador. An attempt to clear up the ambiguity surrounding federal funding of Aboriginal health services was made with the negotiation of the Canada/Newfoundland/Native Peoples Health Agreement. This agreement resulted in federal dollars being provided to the Newfoundland government to fund public health nurses, operating costs of nursing stations and medical transportation.

Any other federal involvement in Newfoundland and Labrador has been on an individual basis with Aboriginal groups. Since the early 1980s, the Labrador Inuit Association has directly dealt with the federal government to secure health funding for its membership and created the Labrador Inuit Health Commission (LIHC). The province’s Innu and Mi’Kmaq communities receive some health programming funds from FNIHB, such as the NIHB Program (Mi’Kmaq) and community health services, medical transportation, and NNADAP prevention programming (Innu) and recent initiatives (e.g. ADI). The Labrador Métis (descendants of Inuit) do not receive any federal health programming other than what is available to all off-reserve and northern Aboriginal populations.

FIRST NATIONS COMMUNITY-CONTROLLED HEALTH SYSTEMS

Historically, the first federal approach to providing health services to Aboriginal communities was essentially public health driven. It dealt with and contained infectious diseases such as measles, smallpox and tuberculosis, which were sweeping through the communities. It also provided emergency health services to those who were at a distance from medical care in towns and villages.

As provincial health systems matured throughout the 20th century, then conformed to the requirements of the Medical Care Act 1966 and the Canada Health Act 1984, the federal approach to First Nations has remained consistent. Although evolving as required to complement or fill gaps in the provincial services, some of those services may not be accessible by these communities, such as health promotion programs,
### Table 2: Aboriginal Health Programs and Services by Jurisdiction

<table>
<thead>
<tr>
<th>First Nations living on-reserve in provinces</th>
<th>Federal&lt;sup&gt;ii&lt;/sup&gt;</th>
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<tbody>
<tr>
<td>Community health services: public health nursing, CHRs, NNADAP, HCC, ADI. Wellness programs: HIV/AIDS, FAS/FAE, CNCP, BF/BHC, AHS, dental health promotion, tuberculosis. NIHB Program. Some hospitals in northern locations. Emergency and non-urgent treatment services in remote and isolated communities in addition to the above.</td>
<td>Provincial/Territorial</td>
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<tr>
<td></td>
<td>Physician services and hospital services as covered under the Canada Health Act. First Nations People can generally access other provincial services in off-reserve locations.</td>
</tr>
<tr>
<td>First Nations People under the JBNQA</td>
<td>NNADAP, BF/BHC, Mental Health, HCC, CPNP, ADI, NIHB Program.</td>
</tr>
<tr>
<td>First Nations People in Yukon</td>
<td>Community health services: CHRs, ADI, HCC. Wellness Programs: HIV/AIDS, FAS/FAE, CNCP, BF/BHC, AHS, tuberculosis. NIHB Program</td>
</tr>
<tr>
<td>First Nations People living off-reserve in provinces</td>
<td>AHS, ADI (health promotion)</td>
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<tr>
<td></td>
<td>HIV/AIDS</td>
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<td></td>
<td>NIHB Program</td>
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<tr>
<td>Inuit living in Inuit communities</td>
<td>Labrador: same as First Nations People living on-reserve Northwest Territories, Nunavut and Quebec: BF/BHC, HCC, ADI, CPNP, NNADAP (training only in territories), FAS/FAE (territories only), mental health (Quebec only)</td>
</tr>
<tr>
<td>Inuit living outside of Inuit communities</td>
<td>Labrador: Physician services and hospital services. Some primary care services to Inuit communities through the Labrador Health Corporation. Northwest Territories and Nunavut: All universally available health services. The NWT and Nunavut territorial governments administer all federal programs (see previous column) through contribution agreements. Quebec: Oversees the JBNQA and provides same scope of health services as for the rest of the population.</td>
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<tr>
<td></td>
<td>AHS, HIV/AIDS, ADI (health promotion), NIHB Program</td>
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continued...
community-based substance abuse programs, and home care. Until the 1990s, First Nations community health services were designed around the positions of community health nurses, CHRs and NNADAP workers. With the establishment of programs in the last 10 to 15 years directed at early childhood development – Brighter Future/Building Healthy Communities (BF/BHC), AHS and the CPNP followed more recently with the Fetal Alcohol Syndrome/Fetal Alcohol Effects (FAS/FAE) Program – the breadth of community-based health programming has increased. Other community-based health promotion resources are directed to ADI, dental health, HIV/AIDS, and tuberculosis.

The fit of provincial services into the First Nations health environment has never been seamless. Visiting physicians, dentists and other primary care professionals are a fact in many, if not most, First Nations communities. This reality is the same for all small communities in northern and remote areas, regardless of whether they are federal or provincial jurisdiction. The Canada Health Act specifies a narrow portion of health services, namely physician and hospital care, which must be provided in order for provinces to obtain federal transfer payments. Therefore, jurisdiction can be a significant impediment to provision of many of the health services that are outside of the Canada Health Act. The grey area between provincial jurisdiction and federal policy can be enormous for First Nations, affecting a wide range of services from mental health programming and home-based palliative care to community long-term care institutions.

Initially, the federal government directly administered and delivered all health services in First Nations

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<table>
<thead>
<tr>
<th>Métis Settlements and communities</th>
<th>AHS</th>
<th>HIV/AIDS</th>
<th>ADI (health promotion)</th>
<th>All health services</th>
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<tbody>
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<td></td>
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<td>Note: In the Northwest Territories, a Métis Health Benefits Program is offered which is similar in coverage to the NIHB Program, except it is non-portable to other jurisdictions and covers 80 per cent of full costs.</td>
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</tbody>
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<table>
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<tr>
<th>Innu and Mi’Kmaq in Newfoundland and Labrador</th>
<th>NIHB (Mi’Kmaq)</th>
<th>community health services, medical transportation and NNADAP prevention (Innu)</th>
<th>All health services</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>AHS, HIV/AIDS, ADI (health promotion): all</td>
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<tr>
<th>Non-status Indians</th>
<th>AHS</th>
<th>HIV/AIDS</th>
<th>ADI (health promotion)</th>
<th>All health services</th>
</tr>
</thead>
</table>

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| ADI: | Aboriginal Diabetes Initiative |
| AHS: | Aboriginal Head Start |
| BF/BHC: | Brighter Futures/Building Healthy Communities |
| CHR: | Community Health Representative |
| CPNP: | Canada Prenatal Nutrition Program |
| FAS/FAE: | Fetal Alcohol Syndrome/Fetal Alcohol Effect |
| HCC: | Home and Community Care |
| NIHB: | Non-insured health benefits |
| NNADAP: | National Native Alcohol and Drug Abuse Program |

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xii For First Nations People and Inuit living outside of their communities and all Métis and non-Status Indians, the programs listed are those to which these groups are eligible for funding. The entries in the table do not denote actual funded programs.

xii All Aboriginal People in the territories and all Aboriginal People outside of First Nations and Inuit communities in the provinces are eligible to apply for funding offered by Population and Public Health Branch (PPHB) of Health Canada. These programs include Canada Action Plan for Children, Canada Prenatal Nutrition Program, Hepatitis C, Population Health, AIDS Community Action Program, and Community Animation Program. PPHB also administers the AHS to all off-reserve Aboriginal populations, including the territories.

xiii The programs and services described for Inuit communities in the Northwest Territories also apply to First Nations communities in the Northwest Territories.
communities. The change over to First Nations administration and control has been a phased-in process, first through contribution agreements, then since the late 1980s, through the Health Transfer process. The early focus in communities was to build the capacity and infrastructure to effectively manage and govern the health system. More recently, this focus has shifted to more fundamental changes within the system. In this respect, First Nations have had to deal with many of the same issues as provincial health reform: merging of program administrations and creation of more efficient management structures; effective governance models, recruitment and retention strategies; integration, mergers and other collaborative relationships with neighbouring First Nations; and primary care reform. In addition, provincial measures to reduce hospital admissions and length of stays and promote community-based services has meant First Nations systems have contended with increased pressures for home and long-term care services in their communities.

Case Study #1:

Eskasoni First Nation

Among the Health Transition Fund (HTF) projects that addressed primary care reform in Aboriginal communities, the Eskasoni Primary Care Project has provided valuable lessons on community integrated health services that are transportable to other First Nations. The project was created from a realization by Eskasoni leadership that a new approach was needed to deal with the high morbidity and mortality rates from substance abuse, diabetes, heart disease, and respiratory illness that gripped the community. Inadequacy of resources did not seem to be a primary issue. Eskasoni residents visited their physician at a rate four times the provincial average. Prescription abuse suggested widespread addictions were rampant, not lack of access to needed medications. Rather, a different model for delivering care was championed and culminated in an HTF pilot project on integrated primary care.²⁸

Although many of the right health resources were already in place, existing health programs had their own administrations and were highly competitive instead of collaborative. There was no integration of health information or health professionals, or even a clear health strategy. Primary care was fragmented with most community members simply visiting the local physician who also possessed the pharmacy license for the community. The Eskasoni Primary Care Project was designed to improve access and co-ordination of local health services, with particular emphasis in three areas: prenatal care, diabetes management and prescription drug abuse.

In the project, the Eskasoni First Nation collaborated with three other partners: the federal government, the provincial government and Dalhousie University Department of Family Medicine. The university partners provided the quantitative tools necessary to evaluate the impact of the project in changing the pattern of provincial hospital and physician service usage. Provincial funding of $500,000 per year was instrumental in achieving one of the most often recommended changes in primary care – the shift from fee-for-service to salaried physicians. HTF funding was directed to a nurse clinician, health educator, counsellor, project manager, and evaluation consultant. Existing federal funding provided for community health nurses, CHRs and part-time prenatal care co-ordinator and diabetes educator. A pharmacist is now located on site and is an integral part of the primary care team.

The achievement of a more integrated, accessible health system was not without challenges. Community and health provider acceptance and involvement of multiple jurisdictions cannot be adequately covered in a short profile. The project evaluation has provided the following evidence of improvements to the health system:

- The per capita number of physician visits decreased from 11 per year in 1997 to four per year in 2000. This decline has been attributed to a lack of incentives for physicians to maximize patient volumes and the presence of other health professionals such as primary care nurse, community health nurses, health educator/nutritionist, and pharmacist.
- The increase in family physician availability (regular office hours Monday to Friday) is credited with decreasing the medical transportation budget from $545,000 in 1997 to about $370,000 in 2000-2001. When the five-day, full-time physician availability was introduced, outpatient/emergency visits by Eskasoni residents to the local hospital decreased by 40 per cent.
- Physicians and community health nurses follow almost all pregnancies from prenatal care through delivery and post-natal care. Prior to the project, all deliveries were classified as high risk due to the absence of co-ordinated prenatal care.
- Referrals to the team nutritionist/health educator for diabetic management have increased by 850 per cent.
The successes of the project have also highlighted areas for system reform at a provincial policy level in order to maximize the integrated model of care. For example, the province will only provide primary care funding for physicians with a small amount of overhead included in physicians’ contracts that can be applied to nurse clinician or nurse practitioner positions. This has resulted in a ratio of three funded physician positions to one nurse clinician and a heavy medical bias to the Eskasoni model. Secondly, savings in the provincial hospital system (estimated to be $250,000 annually) from reduced outpatient and emergency room use have not been recoverable by the community and cannot be re-invested into extending the integration model to further areas such as substance abuse and mental health.

Eskasoni and its partners are now considering how to share this model of health services with other First Nations in Cape Breton. One of the challenges will be how to adapt the model to smaller population bases that will not have access to the same economies of scale on an individual basis and may need to collaborate on a multi-community approach.

Care Study #2:

Kahnawake First Nation

Kahnawake is one of three communities that make up the Mohawk Nation in Quebec. It is close to the second largest metropolitan area in Canada, being only 10 km southwest of Montreal on the south shore of the St. Lawrence River. In many respects, the community resembles small-town Canada, but with an Aboriginal focus. Kahnawake, with a population of about 8,000, has a thriving commercial sector with about 600 people employed within its territory. Five schools are also located in the territory, providing preschool, primary and secondary education to 800 students. An impressive range of community institutions are present including a museum, library, gymnasium, and arena.

The health system includes a community health unit offering public health services, a hospital with an extensive complement of health professionals for both inpatient and outpatient care, a medical centre offering specialty services, a dental clinic, and a nationally renowned diabetes education program. A community service centre provides a comprehensive range of mental health and social services including alcohol and drug abuse treatment.

Kahnawake has had extensive experience in managing its health system. As a result, it brings a mature perspective to a discussion on the issues faced by a community in developing an Aboriginal health system. One current challenge is the ongoing tension, brought on by change, that exists between health professionals and the community’s governance. It is similar to that seen in non-Aboriginal environments when programs are restructured to meet community needs. On the client side, Kahnawake must deal with apathy among its residents in taking charge of their own health and their unquestioning reliance on the health system to treat all ills.

Health service oversight is provided from the Kahnawake Health and Social Services Commission. It plans, co-ordinates and reviews all health and social programs. A number of initiatives have been undertaken under the auspices of this commission:

- Memorandums of understanding (MOUs) have been developed with collateral provincial agencies. These MOUs clearly define roles and responsibilities of all concerned and establish protocols for situations requiring joint service provision.
- A single entry point into the mental health and social services system provides triaging on a timely basis. The team meets every morning to go over the previous day’s cases.
- Program flexibility from Health Transfer and the budget process are fully exploited in order to reduce redundant or inefficient programming. As well, the directors of the various health and social programs meet regularly to participate in long-term global community planning, reduce duplication and share resources.
- The process of obtaining community input has been refined with a focus on reducing community resistance to change.

Managing change and successfully dealing with organized resistance in the community have proven to be pivotal areas in creating a Mohawk-controlled health system. Integral to their success to date has been a critical mass of visionary leadership who have been committed to stay the course. An early area of focus has been the development of Mohawk institutions where there is less reliance on external sources of financing. Currently, the community has constructed a 20-bed Elders lodge without assistance from government for capital costs.

Kahnawake’s vision of an Aboriginal health system is one where holistic practices supersede the medical model and prevention strategies provide the means for community members to be responsible for their own
health. This has meant that the community has had to clearly establish lines of authority over health professionals working in their jurisdiction to create a climate receptive to Aboriginal health practices and philosophy. In future plans, Mohawk law will support Mohawk policy and service delivery. As well, all institutions and health professionals working in the community will be internally regulated and licensed. This will ensure an acceptance of Mohawk standards and provide a direct line of accountability to the community. Health is seen as integrally connected to nation building and self-determination of the community and its people.

Case Study #3:

Nisga’a Valley Health Board

The Nisga’a Valley Health Board (NVHB) is located in the scenic Nass Valley of British Columbia, the home of the first modern-day treaty in B.C. involving First Nations and the federal and provincial governments. The health board, delegated under treaty from Nisga’a Lisims Government, provides treatment and preventative health services to a population of about 3,500 with a further 2,000 living in urban areas who are recipients of the Nisga’a administered NIHB Program. The Nisga’a Nation includes four communities, one of which is remote and serviced by air at the present time. There are four major hospitals within a 300 km radius, and one within 100 km.

From its origins in 1986 as a diagnostic and treatment (D & T) centre in one community, the NVHB has expanded to include four clinics (one per community), three doctors and a staff of 60. Its programs and services are organized around three themes: acute care, preventative care and the NIHB Program.

Funding is provided from both federal and provincial sources, the latter comprising 12 per cent of the health budget. Provincial funding has allowed the establishment of the D & T centre and the payment of physicians on a salaried basis. The NVHB provides health services to all residents within its territory, including the non-Aboriginal population. All village clinics are capable of first response treatment. Physician clinics are held in each community on a scheduled basis and 24/7 coverage is provided from the D & T centre and the nursing stations in the Valley.

The Nisga’a Nation is well known for its long treaty negotiation process, which came to a successful conclusion in 2000. The Nisga’a treaty did not change the funding levels for health services. Its real benefit has been in providing administrative flexibility through block funding and the means to change programs and be more responsive to community issues. Ingredients of an effective health system that are offered by the Nisga’a experience include:

- The flexible program base is respectful of culture and community needs and is subject to regular reviews. This review process may result in the closing of programs no longer deemed necessary for the Nation. In these cases, block funding provides the mechanism to address all supplemental issues that may result from health service changes.
- The governance structure is segregated from administration of health services. Accountability to communities is achieved through a community-elected board, dialogue between communities and the NVHB chief executive officer and annual community-based consultations.
- Fiscal responsibility provides accountability and professionalism in financial processes. Required data is accurate and timely.
- The strong budgetary system clearly defines the scope of the services funded and the value for money on a program-specific basis. Benchmarks and goals are set and regularly evaluated.
- The sizable population base allows a critical mass of health professionals, which can absorb fluctuations in staffing levels brought on by education leave, patients with high health needs or staff turnover.

A key area of focus for the NVHB is education, both to self-empower the client base and to improve the internal training of health staff. The balance between community autonomy and centralized service delivery is an ongoing developmental process. It requires considerations not only of economies of scale, but also of community-based capacity development and their need for a critical base of health funding.

Interestingly, the health and social systems are not integrated at an administrative level, but co-operate on an operational basis. The social services programs are delivered under the Nisga’a Lisims Government and Village Governments while health programs are through an independent, delegated health authority (NVHB). Overall program oversight and integrated health and social planning occur within the Nisga’a Nation’s governance.
The Métis homeland encompasses parts of present-day Ontario, Manitoba, Saskatchewan, Alberta, British Columbia, and the Northwest Territories. As of 1991, only one per cent of Métis resided on lands designated for Métis, including the eight Métis Settlements in Alberta, several parcels of land in Saskatchewan designated as Métis farms, and reserve land allocated to the Métis population of Rainy River, Ont., who were treated as Registered Indians under the Indian Act.

Métis are acknowledged as one of the Aboriginal Peoples in Canada under Section 35 of the Constitution Act, 1982 where the term Aboriginal is defined to include Métis along with Inuit and Indian Peoples. Although existing Aboriginal rights are recognized and affirmed in the Constitution Act, the federal government has not fully accepted fiduciary responsibility for the Métis. Métis are expected to access the same health services available to the general population. There is no comprehensive government policy to address Métis health issues. Métis are not eligible for most of the health care, education and social programs offered by the federal government to First Nations and Inuit.

Notwithstanding the above, federal involvement in Métis health programming has occurred recently, prompted by several developments over the past decade. These developments have included the recognition of the inherent right of Aboriginal Peoples to self-government; the release of the RCAP report and the federal government’s response “Gathering Strength;” and court rulings clarifying existing Aboriginal rights, the fiduciary responsibility of the federal government, and consultation requirements with Aboriginal Peoples on programs and services that affect the Aboriginal population. Even so, there is only scattered federal health programming directed to the Métis. It usually involves a health promotion focus, such the ADI, AHS and HIV/AIDS.

Métis voice similar needs as other Aboriginal groups in culturally appropriate, accessible, and community-controlled health programming. Métis health systems are at an early stage of evolution compared to First Nations and Inuit systems. There is little in the way of Métis infrastructure for health and social programs and scarce research on health statistics that would provide evidence to successfully lobby for health resources. What data does exist, primarily through the 1991 Aboriginal Peoples Survey, points to similar health concerns as other Aboriginal Peoples.

Métis-specific health initiatives are seen in some provinces and territories, for example, Saskatchewan, Ontario, Alberta, and the Northwest Territories. In Saskatchewan, the Métis Addictions Council of Saskatchewan Inc. (MACSI) has been provincially funded for more than 30 years to provide alcohol and drug recovery, reintegration and healing programs to all residents of Saskatchewan with a focus on Métis and off-reserve First Nations. MACSI provides a 28-day inpatient program in three treatment centres, outpatient programs, outreach, youth services, and a detoxification program. In addition, an extension program in collaboration with Corrections Canada provides 24-hour services to federal offenders on parole. MACSI is governed by a board of directors appointed by the Métis Nation of Saskatchewan and its regional councils.

The Métis Nation of Ontario administers health promotion programs through funding from the provincial and federal governments. These include long-term care, diabetes and gambling. It receives Ontario Aboriginal Healing and Wellness Strategy (AHWS) funds for Métis community-based programming such as prenatal care, disability outreach and liaison, diabetes education, stress and suicide prevention, healing circles, child safety education, and nutrition and fitness health promotion. As well, Ontario Métis are partners with other Aboriginal groups in the province’s health centres funded by the AHWS and the Métis Nation of Ontario sits on the AHWS Board.

The Northwest Territories offers a Métis Health Benefits Program which provides eligible Métis recipients 80 per cent coverage of full benefits similar to what First Nations and Inuit receive under the federal NIHB Program. The Métis Health Benefits Plan is a payer of last resort and assists eligible recipients who require health services beyond the N.W.T. Health Care Plan.

Case Study #4:

Métis Settlement Health Project

The Métis Settlement Health Project was a collaborative project between the Lakeland Regional Health Authority and the four eastern Métis Settlements in Alberta. The intent of the project, and a preceding one funded by the Health Transition Fund, was to address some of the inequities in health service delivery and health status that had been previously identified in the Settlements. These projects fo-
cused on the addition of an on-site Settlement nurse for public health and home care services. Previously, all health services were provided to the Settlements on a visiting basis from the health authority. The Métis Settlement Health Project was deemed to be a great success and has resulted in the permanent funding of on-site Settlement nurses by the province. The project evaluation reported that up to 83 per cent of respondents felt that the on-site service was very important. A majority judged the Settlement nurse to have helped a great deal or somewhat in improving personal or family health.33 Immunization rates of children doubled after the first project was completed.34

The success of the project depended on the contributions of many parties. The Lakeland Regional Health Authority provided services with its mandate, including the supervision of Settlement nurses. The community allocated municipal affairs funding to provide homemakers. Individual residents took the initiative to obtain suicide prevention training. Community health counsellors gained understanding in where and how to access additional funding in order to supplement the existing health services.35

This project makes a number of points regarding primary health services and an Aboriginal community:

• Community involvement in establishing the community health service is critical to its success. The four Settlements formed a provincially-recognized community health council which worked in partnership with both the Settlements and the health authority in addressing common health issues and goals.

• A trust relationship between Aboriginal communities and provincial health authorities will often take time to occur and will require an understanding of both Aboriginal and health authority cultures and ways of doing things. Only then can the resulting partnership be directed to other collaborative endeavours.

• Once the Settlement nurses were accepted in the communities, access to primary care services increased significantly, as did linkages to other health authority services such as mental health. Acceptance was made easier because Métis community representatives were active participants in the hiring process and the project was communicated through various activities. However, the most important factor was the nurses’ ability to relate to the community, be non-judgmental and caring, and have good interpersonal skills.

• The Settlements increased their capacity to take charge of their own needs and find creative ways to meet those needs in partnership with a number of organizations. The most important of these partnerships was the local health authority.36

Case Study #5:

Métis Nation of Ontario Health Services Branch

The Métis Nation of Ontario (MNO) Health Services Branch delivers provincially-funded long-term care services, AHWS programs and the Aboriginal Healthy Babies, Healthy Children Program, as well as diabetes and anti-gambling programming to 9,000 Métis in Ontario. This is an impressive list for an organization that only formally created a health branch four years ago in response to a call for proposal from the Ontario Ministry of Health for Aboriginal Long Term Care. The organization credits this rapid rise into the health care field as a combination of both soft and hard factors. Key soft factors include public relations activities, networking, timing, and innovative funders and programs. Key hard factors include well thought-out proposals (in the case of the long-term care application, the organization undertook a community health needs assessment), proven experience and political expertise.

The Branch operates 13 MNO health service sites throughout Ontario and employs 30 health service workers and a small, efficient administrative unit.

In addition to service delivery, the work of the Branch includes policy development, advocacy and evaluation. The MNO cites collaboration with MNO councils, citizens and stakeholders as essential for the success of its programs. The Branch also supports independent work of communities in seeking community health program funding through advocacy and support for proposal development.

INUIT HEALTH SYSTEMS

Inuit communities are located in Labrador, Northwest Territories, Nunavut, and Quebec. Each of these jurisdictions has unique circumstances which have influenced the development of its health system.

Labrador

The Labrador Inuit Health Commission (LIHC) is funded by the federal government and has a similar scope of services to that found in health systems in
First Nations communities. These are essentially public health, health promotion and targeted initiatives such as diabetes and home care. These are supplemented by provincial health services, including primary care nurses, through the Health Labrador Corporation (HLC). Other than the largest community, Happy Valley/Goose Bay, Inuit communities receive physician services every four to six weeks. The LIHC was the first Aboriginal organization to administer the NIHB program.

Northwest Territories

The Government of the Northwest Territories has a policy of universality in its health service delivery. All services are provided to all residents on an equal footing, unlike that seen in many provinces with respect to First Nations communities. This has a historical basis, stemming from the initial federal involvement as administrator of health services prior to these services being transferred to the territorial government.

Currently, a regional system of health and social service boards exists. The boards provide primary care, school health, community health, social services, addictions services, and visiting physicians and specialists. In this territory, Inuit (Inuvialuit) are primarily located in the Inuvik Region. The Inuvik Regional Health and Services Board has representation from Inuvialuit, Gwich’in, Sahtu, and non-Aboriginal residents. Many services are provided on a visiting basis to the 13 communities in the region and are populated by all Aboriginal groups: Inuit, First Nations and Métis. Federal health programs to First Nations and Inuit, which were established after transfer, are administered by the territorial government through contribution agreements. These include the NIHB Program, BF/BHC, HCC, CPNP, NNADAP (training), and ADI.

The Inuvialuit and Gwich’in are in the process of negotiating a self-government agreement for the Beaufort-Delta Region. The agreement will include a broad range of programs and services, including those related to health.

Nunavut

Soon after Nunavut was established, the previous Northwest Territories system of regional health and social service boards were disbanded in favour of a centralized administration. Local health committees exist in its 24 communities and advise the territorial government on local health priorities and goals. The vast majority of the territory’s population is Inuit and is reflected in its elected leadership, making the health system in essence Inuit controlled. As with the Northwest Territories, the Nunavut government administers federal Inuit health program funding through a contribution agreement.

Quebec

The James Bay and Northern Quebec Agreement (JBNQA) provides for an Inuit-controlled regional health and social services board in Nunavik. It is under the auspices of the provincial health and social services ministry. The federal government originally delivered health services to Inuit in Nunavik through nursing stations and health clinics. With the implementation of the JBNQA, the province assumed control of the stations and clinics on an interim basis, before transferring these institutions to the Inuit regional health and social services board. Federal funding included in the JBNQA is funnelled through the provincial government. The NIHB Program was also transferred to the Quebec government. It administers this program in collaboration with the regional board.

Federal programs created following this 1976 land claim agreement are provided directly to the regional board via contribution agreements.

Common Inuit Issues

An evaluation of models of health care delivery in Inuit jurisdictions found a number of recurring issues. Suicide is the most pressing health issue facing Inuit society today. It points to a need to improve or implement mental health services including suicide prevention, addictions, crisis intervention, and holistic programming that encompasses prevention to after-care. The most significant concern in primary health services is the chronic shortages of nurses and doctors in the north. Staff shortages strain the health care system and are found in the entire range of health workers, from community health workers to social workers to doctors. Difficulty in recruiting people in the community is related to the absence of training opportunities. As well, Inuit are seriously under represented in health professions.

Case Study #6:

Midwifery Practice in Nunavik

The Nunavik model of midwifery practice and education is an example of community-based, culturally-appropriate care where co-operation between health
care professionals and community-trained midwives serves the needs and interests of the community at large. Midwifery is an established component in the traditional health practices of the Inuit and Nunavik culture. However, it was suppressed beginning in the early 1970s when an evacuation policy was imposed on all pregnant women in Nunavik and they were transferred to southern institutions to give birth. The removal of this normal, but exceedingly important, life event from the community fabric had many negative effects on pregnant women and the families left behind. As well, community expertise in birthing was being lost.

In response, the communities led by women, advocated for the return of midwifery and found support in the Nunavik Regional Board of Health and Social Services. Community-based midwifery education was begun. It was initially a blend of expertise from Quebec midwives and the communities’ traditional knowledge. Today’s education program is entirely delivered as an apprenticeship in the communities and is reflective of northern needs, context and culture.

The Inuulitsivik Health Centre Maternity program in Puvirnituq began in 1986 as an integration of Inuit culture with western health care. It has been recognized by the World Health Organization, the Institute of Circumpolar Health and the Society of Obstetricians and Gynecologists in Canada as an excellent model of northern health care. Success has been measured in both qualitative and quantitative terms, through epidemiological and organizational studies. Perinatal statistics, once far below the Quebec average, are now equal to or, for some parameters, better than those of southern regions.

There are six Inuit communities in Nunavik that are part of the midwifery program. The Inuulitsivik Health Centre employs five Inuit and two non-Inuit midwives. As well as providing a birthing place, the centre co-ordinates prenatal and post-natal programs. In 2000-2001, 99 deliveries occurred at Inuulitsivik, with a further 35 births at the community health centre in Inukjuak. The University of Quebec at Trois-Rivières has indicated an interest in Inuulitsivik as a teaching site for Quebec midwives.

Nunavik communities are remote. As midwifery is a primary care service, it includes all women, not merely those judged as low risk or those who choose midwifery for at least part of their pregnancies. In practical terms, this means that northern midwives have a larger scope of practice than those in southern regions. Even so, Nunavik midwifery corresponds to the International Definition of the Midwife, with one exception being the recognition of its education program. This program has been tailored to the unique practice and specific living and learning needs of the people of Nunavik.

This midwifery initiative has had to deal with professional and legislative barriers. The scepticism on the part of the mainstream health system to this traditionally-based care have largely been overcome with physicians and nurses working collaboratively with midwives in the communities to deliver a unique blend of cultural and modern knowledge and skills. The legislative barriers still exist and have become more critical since 1999 when the Quebec government passed legislation related to the practice of midwifery. This legislation makes no mention of either the educational or practical component of midwifery as delivered in Nunavik. It has implied that Inuit women can no longer maintain responsibility for maternity care services and their administration, and must step aside to accommodate forced trusteeship from southern professionals. The Nunavik Regional Board of Health and Social Services is advocating for changes to this legislation to make it inclusive of the northern situation.

Other jurisdictions, both nationally and internationally, are now considering the Inuulitsivik perinatal program, including the Government of Nunavut that is in the process of designing a perinatal care system modeled after Nunavik.

**Case Study #7:**

**Nunavik Regional Health and Social Services Board**

In 1976, the Governments of Canada and Quebec, and the James Bay Inuit and Cree signed the James Bay and Northern Quebec Agreement. This land claim agreement contains a provision for the establishment of Inuit and Cree health boards to be locally operated with the support of the Quebec health and social services ministry. Today, the Nunavik Regional Health and Social Services Board is one of the province’s regional boards. It serves all of the 9,000 primarily Inuit residents of Nunavik. This board has 100 per cent Inuit representation from the 14 communities and two regional health establishments (hospitals/health centres) which deliver the region’s health and social services.

The regional board oversees an impressive list of programs and services. This is remarkable given the
remote geography of the communities. The two health centres provide beds for acute (short-term) care, long-term care, diagnostic services, and general and specialized medical care. These centres and the 12 other communities receive primary care (preventative and curative), physical rehabilitation and social reintegration services from local community health centres. The board is moving away from a physician-centred primary care model to one that includes nurses in expanded roles. This has been in response to the significant shortage of physicians to service the communities. Two child and youth protection centres are located in Nunavik. They include rehabilitation services and group homes for youth.

The board administers five federal programs: Brighter Futures, mental health, CPNP, family violence, and home and community care. This funding has resulted in 50 projects among the communities.

The health and social services system is not totally integrated at an administrative level as additional community-based programs are administered directly by the Quebec Ministry of Health and Social Services. This includes services targeted at women, men or youth at risk or in difficulty; home care services; and alcohol and drug rehabilitation services. The province administers benefits equivalent to the NIHB Program under the terms of the JBNQA.

The board is involved in improving and enhancing many sectors of its mandate, which are too numerous to mention in this short case study. The development of professional resources is a current area of focus. It is directed to supplementing basic training and providing community-based continuing education. The board has been successful in instituting management and professional training for Inuit managers in the health and social services network. Through a collaboration with the Kativik School Board and McGill University, these managers will receive a professional certification after they complete the three-year program. Another training initiative involves a 16-module, 990-hour program leading to an Occupational Studies Diploma. The program has been offered to home support workers and will be broadened to other staff as resources permit. For the past 10 years, McGill and Kativik School Board have offered a Social Work Certificate Program. As well, the McGill approach to training all professions working in home care in team service delivery has been adapted to the Nunavik situation. Community-based specialized training in rehabilitation services is under development.

The goal of the regional board is to serve as a resource and support for the health centres, communities and municipalities. The challenges are extreme. For example, transportation expenditures take up 24 per cent of the board’s budget and more than 50 per cent of total salary costs go to remoteness-related benefits deemed by the collective agreement of the union. Even so, the turnover of human resources is high. There are few Inuit health professionals. This is compounded by the requirement under Quebec legislation that all employees speak French. In a population which is Inuktitut-English bilingual and requires these languages to effectively provide care, the need for trilingual staff is considered burdensome and a barrier to Inuit employment.

The board sees the development of health technologies, such as telemedicine, as crucial in lowering expenditures and increasing the availability of health and medical specialists in communities. The direct representation of all communities on the regional board ensures that a strong grassroots voice can facilitate the development of culturally-appropriate health services. Community-based solutions to significant health issues include the Tapiriilirniq Committee. It is visiting all communities to develop local strategies to reduce the high rate of youth suicide and nurture better relations between Elders and youth.

The Board attributes its successes and progress in delivering culturally-appropriate and effective health services to the 100 per cent Inuit participation in the board, including all board member appointments from the municipal governments, the executive director and the two health centre executive directors. All of the 14 communities are represented by an elected Inuk on the health centre boards (seven to the Hudson establishment and seven to the Ungava establishment).

Case Study # 8:

Labrador Inuit Health Commission

Less than 20 years ago, the Labrador Inuit Health Commission (LIHC) did not exist. Indeed, there was no Inuit-specific health programming provided to the seven Inuit communities of Labrador. Since 1985, when the Labrador Inuit Association formed the LIHC to address Inuit health issues, the LIHC has grown from one program, seven employees and $150,000 in funding to seven programs, 120 employees and $13 million in funding.

The creation of the present-day LIHC was a gradual process. It initially assumed the administration of
the NIHB Program in 1989, negotiated Health Transfer with FNIBH in 1996 and assumed responsibility for community and public health services from the Government of Newfoundland and Labrador in 1997. The province continues to provide hospital, physician and primary care nursing to all residents in Labrador. This is expected to change somewhat when the Labrador Inuit land claim agreement-in-principle is successfully concluded. This agreement will include a provision for self-government. This will facilitate the transfer of responsibility of treatment clinics and nurses to the LIHC.

One of the key ingredients in LIHC’s health strategy is the development of partnerships both internally within the Inuit community and externally with the provincial system and academic organizations. A close relationship involving regular meetings and protocols in defined areas exists with the province’s HLC. The HLC provides community treatment clinics staffed by regional nurses and personal care workers who complement the LIHC’s community health nurses, community health aids, community service workers, and childcare workers.

The LIHC has developed a program in partnership with Torngasok. The Inuit cultural centre has the mandate for language and revival of cultural practices. The Language Nest Program provides cultural and social activities targeted to families with infants in Hopevale.

Through a partnership with the College of the North Atlantic, LIHC staff developed Inuit-specific training for home support workers. This 12-week program was offered in an Inuit community and was open to home support workers in all seven communities. As well, a training program for community health workers was developed with the college, again with the purpose of meeting Inuit-specific needs.

Inuit-specific training is included as a component of new programs as they are implemented, such as the community crisis response teams, which are comprised of both staff and community volunteers.

Recruiting Inuit into health careers continues to be a challenge. Through a partnership with the post-secondary education department of the Labrador Inuit Association, the LIHC is focussing on increasing the number of Inuit pursuing nursing. This evolving strategy is targeting students as they enter high school. Other issues related to service delivery involve jurisdiction barriers and eligibility for services, the lack of Inuit-specific data and research, and ensuring equity and access to health services on a comparable basis to other residents.

URBAN HEALTH SYSTEMS FOR ABORIGINAL PEOPLES

The APS was the first national survey that looked at all Aboriginal groups in Canada. It provided evidence to confirm what many people had intuitively known for many years, that the health status of Aboriginal Peoples, regardless of residence on-reserve or in other locations, was generally the same. Urban cities are home to a culturally diverse Aboriginal population. Not withstanding the many healthy urban Aboriginal Peoples, the inner cores of Canadian cities contain a component of marginalized, transient Aboriginal Peoples who are disconnected from community or family supports and who experience poverty, unemployment and lack of education. Providing health services to this population of First Nations, Métis and Inuit has many hurdles including cultural barriers to health services, which may be even more profound than that seen in rural and remote Aboriginal communities. Transportation is an ever present consideration in urban environments as even bus and taxi costs are out of reach to the homeless or unemployed. Health clinics find it more difficult to maintain a continuity of health services to this population as many lack a permanent home or even a contact address.

Aboriginal Peoples are disproportionately represented among the urban homeless. Anishnawbe Health Toronto (AHT) has provided street outreach services to the homeless in Toronto since 1989. Although Aboriginal Peoples make up two per cent of the urban population, they accounted for 21 per cent of all encounters with AHT’s street outreach patrols in 1999-2000 and 2000-01. From 1992-93 to 2000-01, the usage of these patrols increased by almost 200 per cent. During this time, Aboriginal Peoples represented an average of 24.3 per cent of encounters. It is estimated that they accounted for 41 per cent of all deaths among the homeless.

Health services in cities are the jurisdiction of the provinces, except for the federal NIHB program, which is provided to First Nations and Inuit regardless of residence. Although the core funding for urban Aboriginal health services is provincial, some program-specific federal funds may be provided. Provincially-funded health clinics controlled and administered by Aboriginal Peoples exist in four locations in British Columbia, 11 in Ontario and one in Manitoba. These all provide culturally-appropriate primary care services in a multi-disciplinary team approach with salaried or contract physicians, nurses
or nurse practitioners and other health professionals offering a range of services such as health promotion and diabetes education, traditional healers and Elders, prenatal care, nutrition programs, community outreach, FAS/FAE programs, mental health, and health referrals. The Ontario Aboriginal health centres include both urban and rural models as some serve a primarily rural population including First Nations communities.

There are differences among the three provinces that have funded Aboriginal urban health centres – such as the degree of emphasis on traditional medicine, the method of remuneration of physicians (salaried or fee-for-service contracts), and the use of nurse practitioners. Despite these differences, all centres share a common philosophy where care is directed at improving and/or balancing the physical, mental, spiritual, and emotional well-being of an individual. Traditional healers may be part of the health team, depending on the needs expressed by the Aboriginal community served by the clinic. The centres provide a focal point for Aboriginal Peoples and contribute to community development and empowerment. These centres are Aboriginal first and foremost, from staffing and governance to visible expressions of Aboriginal culture and hosting community events. They have been successful in breaking down the barriers so often seen with mainstream health services and Aboriginal Peoples. A case study follows based on the experiences of the 10 health centres in Ontario.

Case Study #9:

Health Centres, Aboriginal Healing and Wellness Strategy, Ontario

The AHWS is a collaboration of four Ontario government ministries: Health and Long Term Care, Ontario Native Affairs Secretariat, Ontario Women’s Directorate, and Community and Social Services. It funds four main streams of programs including community workers and health outreach; shelters, healing lodges and treatment centres; health centres, maternal and child centre and medical hostels; and clearing house, translator and advocate services.

The health centres use a model of primary care. It has similarities with community health centres, but has incorporated Aboriginal culture and beliefs into the healing process. They have been designed to reflect the needs of the entire Aboriginal community in a geographic area and include approaches that are solely urban or a mixture of rural and urban. Most centres are located off-reserve, however, many serve on-reserve populations, sometimes through satellite clinics. Commonalties among the centres include salaried physicians and the use of different levels of nursing expertise. The latter are generally nurse practitioners who may be supplemented by registered nurses and/or licensed practical nurses. These are complemented by a mix of other primary health professionals such as a nutritionist, psychologist, traditional co-ordinator, diabetes educator, or exercise therapist. The centres do not operate on a nine-to-five philosophy. After clinic hours, the space is often used for community events.

The first phase of a six-year longitudinal evaluation of the health centres has been completed. It involved four centres which had been in operation for one to three years. A main result of this first evaluation was the description of the health centre model. Four components were identified which form the core of the centres’ effective, distinct service delivery:

- a supportive environment, providing a sense of safety and trust, inclusivity and accessibility, where staff are role models, mentors and friends;
- cultural teachings and spiritual development combined with seeking a balance in the physical, mental, spiritual, and emotional aspects of a person;
- integrated interventions involving both traditional and western approaches to care, which respect the ethic of choice, non-interference and self-responsibility;
- community development and empowerment through the use of centres as community resources.

The health centres have been described as communities within communities. Incorporating community into service delivery has been an effective approach for health promotion to both adults and youth. One example is through videos or plays produced and performed by community members depicting personal experiences with HIV/AIDS or cultural teachings used to frame healthy lifestyle choices.

Key features of the centres are the use of a multidisciplinary team, a single point of entry and the ability to access health professionals such as dieticians without a referral. Outreach services and street clinics provide an effective alternative to emergency room visits in many cases. The centres may partner with other agencies, including non-Aboriginal, to meet the needs of all street people.

One of the goals of the health centres is to increase accessibility to health services. In the Phase 1 evaluation, 87 per cent of the urban respondents and
64 per cent of the respondents reported that their centre had improved personal access to health care a lot or a great deal. A high level of satisfaction with the full range of services received was reported, including emotional and mental health services, health promotion activities, and spiritual guidance. This has been attributed, in part, to the way the services are provided, the non-judgmental attitude of staff and their respect for cultural and spiritual beliefs.40

SUMMARY

This paper provides a summary of the primary strengths and challenges of Aboriginal-controlled health care systems in Canada. It also provides several detailed illustrations of what works in Aboriginal health systems in different regions of the country. Clearly, Aboriginal health systems in Canada must accommodate vast differences in cultural expectations, jurisdictional complexity and geographic diversity.

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Vision Statement

The National Aboriginal Health Organization, an Aboriginal-designed and -controlled body, will influence and advance the health and well-being of Aboriginal Peoples through carrying out knowledge-based strategies.

NAHO and its First Nations, Ajunnginiq and Métis Centres are unique in that we:

- Are founded on and are committed to unity while respecting diversity
- Gather, create, interpret, disseminate, and use knowledge on Aboriginal traditional and western contemporary healing and wellness approaches
- View community as the primary focus and view research methodologies as tools for supporting Aboriginal communities in managing health
- Reflect the values and principles contained in traditional knowledge and practices

Find out more about NAHO and its Centres by visiting:

www.naho.ca
Further Reading

**THE COMING OF THE SPIRIT OF PESTILENCE**

Introduced Infectious Diseases and Population Decline Among Northwest Coast Indians, 1774-1874

By Robert Boyd
University of British Columbia Press, 2000
ISBN 0774807555
448 pages

In the late 1700s, when Euro-Americans began to visit the Northwest Coast, they reported the presence of vigorous, diverse cultures – among them the Tlingit, Haida, Kwakwaka’wakw (Kwakiutl), Nuu-Chah-nulth, Coast Salish, and Chinookans. The population was conservatively estimated at more than 180,000. A century later, only about 35,000 were left. The change was brought about by the introduction of diseases that had originated in the Eastern Hemisphere, such as smallpox, malaria, measles, and influenza.

*The Coming of the Spirit of Pestilence* examines the introduction of infectious diseases among the Indians of the Northwest Coast culture area (present-day western Oregon, Washington and British Columbia and southeastern Alaska) in the first century of contact. The book also looks at the effects of these new diseases on Native American population size, structure, interactions, and viability. The emphasis is on epidemic diseases and specific epidemic episodes.

In most parts of the Americas, disease transfer and depopulation occurred early and are poorly documented. Because of the lateness of Euro-American contact in the Pacific Northwest, however, records are relatively complete. Therefore, it is possible to reconstruct, in some detail, the processes of disease transfer and the progress of specific epidemics, compute their demographic impact, and discern connections between these processes and culture change.

Author Robert Boyd provides a thorough compilation, analysis and comparison of information gleaned from many published and archival sources – both Euro-American (trading-companies, missions, and doctors’ records; ships’ logs; diaries; and Hudson’s Bay Company and government censuses) and Native American (oral traditions and informant testimony). The many quotations from contemporary sources underscore the magnitude of the human suffering. The Coming of the Spirit of Pestilence is the definitive study of introduced diseases in the Pacific Northwest.
DOING THINGS THE RIGHT WAY:

Dene Traditional Justice in Lac La Martre, N.W.T

By Joan Ryan
University of Calgary Press, May 1995
ISBN 1895176-62X
150 pages

Author Joan Ryan and the research team have carefully documented Dogrib traditional justice as it has been practised over the past century. Relying upon information received from the Elders of Lac La Martre, Northwest Territories, they have unearthed a sophisticated body of Dogrib law. Understanding Dogrib law has important implications for contemporary ways in which the Dogrib People and the Department of Justice can deal with social control.

The material is organized and presented in a way that makes it accessible to both Dene and non-Dene readers alike. The methodology of Doing Things the Right Way is one of participatory action research, in which the community itself owned and directed the research, training and outcomes.

By exposing the very different values and legal systems of the Dene and non-Dene, this book sets the framework for the possibility of a Dene-controlled and culturally-appropriate justice system. Doing Things the Right Way will be of value to those interested in Native self-government, constitutional rights and Aboriginal law, as well as to all those involved with First Nations Peoples.
Clearing the Path for Community Health Empowerment: 
*Integrating Health Care Services at an Aboriginal Health Access Centre in Rural North Central Ontario*

Marion Maar - B.Sc., M.A., Ph.D. Candidate  
Research and Evaluation Co-ordinator Noojmowin Teg Health Centre  
and Department of Anthropology, McMaster University

**Abstract**

The article provides a critical examination of the rewards and challenges faced by community-based Aboriginal health organizations to integrate the rapidly evolving provincially- and federally-funded Aboriginal health program streams within an existing mainstream rural and federal First Nations health care system in Ontario. The shift to self-governance in health care means Aboriginal health organizations are dealing with rapid organizational changes. In addition, community health program planners at the First Nations level are faced with the challenge of developing local Aboriginal models of care and integrating these within the often-conflicting backdrop of the existing mainstream model of community health. While political leadership and health organization typically both have mandates to work towards the health and well-being in their communities, the two sectors may not always have the same expectations on how to realize these goals. While autonomy in the development of services is essential to self-determination in health, there is also a need for Aboriginal health agencies to collaborate regionally in order to improve health at the community level in the most effective and timeliest manner. Using the example of the mental health and traditional Aboriginal health services, this article provides an analysis of the role of an Aboriginal health access centre in regional community health empowerment.

**Key Words**

Aboriginal health care services, community based health care, health empowerment, integrated health services, Aboriginal health, Aboriginal healing and wellness strategy, self-governance, health transfer, mental health, traditional Aboriginal medicine

**INTRODUCTION**

The comparatively high rates of health and mental health problems experienced by Aboriginal communities in Canada have been documented extensively in the health literature. Although the health profile of Aboriginal communities changed rapidly during the later half of the 20th century and infectious diseases declined dramatically, they were by no means eradicated. 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. The health problems commonly found in Aboriginal communities in Canada are similar to those experienced by other Indigenous Peoples worldwide, particularly those who share a history of colonization and encroachment of industrial forces on traditional lifestyles. Yet, in contrast to many other countries, where health services are inadequately funded in rural areas, primary health care in Canada is relatively advanced in terms of services and resources, despite the inherent difficulty in providing health services to remote northern Aboriginal communities.

Over the past decades, it has become evident that increasing the access to mainstream Canadian primary
health care services without addressing the broader political, cultural and environmental determinants of Aboriginal health will not have a significant impact on improving Aboriginal health and mental health status. For example, Young noted that although the Canadian model of health care delivery to remote 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.”2 The impact of cultural relevance, community control and self-determination on the effectiveness of primary health care did not receive much attention with health policy makers until the late 1980s when the broader socio-political aspects of Aboriginal self-determination and self-government surfaced to the Canadian public consciousness.

It could be argued that the federal government began to respond to the pressures of Aboriginal groups for self-determination with the release of the Indian Health Policy in 1979.3 However, the document failed to propose a mechanism to realize its goals of community development and intersectoral collaboration in Aboriginal health care. In 1986, the Department of Health and Welfare advanced the release of the Indian Health Transfer Policy as an option to begin serious negotiations concerning the transfer of Aboriginal control over health care to the local level.4 The long term goal of the health transfer policy is 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. Without a doubt, the health transfer policy does provide greater community involvement in health care. However Aboriginal groups have time and again asserted that they seek control over, not involvement in, health care.5

During the past decade, Ontario has taken an innovative and unique approach to the governance and provision of health care services for Aboriginal People. It has the potential to serve as a model for other provinces and territories. In 1993, Ontario began to reshape the province’s approach to Aboriginal health care services by adopting an Aboriginal health policy developed after extensive community consultation.6 A year later, the Aboriginal Healing and Wellness Strategy (AHWS) was created based on this policy and a provincial Aboriginal family violence prevention strategy. The unique intersectoral governance of AHWS employs a consensus model for decision-making, involving 10 ministries and eight Aboriginal organizations representing all Aboriginal People, including non-status Indians, Inuit and Métis.7 The AHWS 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; and general improvements to access to western and traditional Aboriginal medicines. As such, the province has made great strides in sharing control over health services with Aboriginal stakeholder organizations and is becoming a leader in this aspect, not only in Canada, but also in the world.

To accomplish its goals, AHWS funds various types of Aboriginal community-based health initiatives in Ontario, including 10 Aboriginal health access centres (AHAC). While these community health centres offer programs that are as diverse as the Aboriginal communities they serve, their primary focus is to improve access to culturally-based primary health care services while responding to gaps in services at the community level. This article discusses the rewards and challenges of working towards the integration of Aboriginal health access centre programs within existing rural health care services and the evolving federal First Nations health care system at one AHAC in North Central Ontario. This analysis is based on the author’s experience as a research and evaluation co-ordinator working in a supportive role to facilitate the development of integrated Aboriginal health services at the Noojmowin Teg Health Centre on Manitoulin Island, a provincially-funded AHAC.

INTEGRATED HEALTH SERVICES AT NOOJMOWIN TEG HEALTH CENTRE:

Rewards and Challenges

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. The Manitoulin District is home to about 11,000 residents. The population is made up of about 4,500 Aboriginal People and 5,500 non-Aboriginal people. Figure 1 shows the location and population size of the seven local
First Nations communities. 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.

Pre-Existing Health Services

Complex and at times disjointed layers of Aboriginal health services already existed in the Manitoulin District when the Noojmowin Teg Health Centre began operation in 1997. Three years earlier the seven First Nation communities in the Manitoulin District transferred the delivery of community health services under the federal health transfer initiative under three separate agreements. It was not only feasible, but also financially advantageous for the two larger communities to transfer individually. The five smaller communities transferred under one agreement, resulting in the creation of three local health authorities. This arrangement enabled the smaller First Nations 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 and Inuit Health Branch (formerly known as Medical Services Branch). In 1996, the three transferred health authorities jointly developed a proposal for a provincially funded AHAC to provide specialised 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.

The program priorities for this AHAC were largely based on community consultations undertaken during the pre-health transfer needs assessment. Today, 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. Programs are designed to bridge community-identified

Figure 1: Map of Manitoulin Island with Location of First Nations Communities

First Nations in the Manitoulin District with estimated Aboriginal on-reserve population size as of 1998 in parentheses: Aundek Omni Kaning (320), M’Chigeeng First Nation (800), Sheguiandah First Nation (120), Sheshegwaning First Nation (100), Wikwemikong Unceded Indian Reserve (2,600), Whitefish River First Nation (340), Zhiibaahaasing First Nation (35)
gaps in services. These are in turn provided through partnerships with eight community-based First Nations health agencies including community clinics, health authorities, and a semi-regional tribal health organization. The centre emphasizes a holistic Aboriginal approach to health, which acknowledges and promotes physical, mental, emotional, and spiritual health and well-being. In addition, the programs are developing innovative approaches to community health, specifically addressing the health and mental health consequences of multigenerational traumas such as residential schools; loss of language and cultural identity; and erosion of traditional lifestyles. In short, over the past five years, the Noojmowin Teg Health Centre has provided services through an integrated culturally-based model of service provision in collaboration with the existing First Nations health services and networking with mainstream health services agencies.

One of the primary goals during the first years of operation was to work towards the integration of Noojmowin Teg health services within the complex organizational structure of the existing federally-funded First Nations health services. The Noojmowin Teg health board intended to achieve meaningful collaboration between all local Aboriginal health services providers and put a strong emphasis on partnership development. In order to establish program objectives and activities, the organization developed mechanisms for extensive collaboration among the four regional Aboriginal health boards, health directors, and community health workers in the seven First Nations. Making integrated services feasible took initiative, dedication, desire, and a commitment on the part of boards, staff and partner agencies to collaborate through a process of consensus to make things work for everyone involved.

For program planning purposes, consensus among the AHAC, individual First Nations health care agencies, tribal health care agencies, and the political leadership in First Nation communities needed to be reached on an ongoing basis. This is still true today, after maintaining a successful partnership for five years. Noojmowin Teg staff still participate in Noojmowin Teg planning activities as well as planning activities sponsored by partner agencies. Accountability issues are carefully negotiated on an ongoing basis to ensure equitable service provision to all First Nations. This is a difficult task due to the differences in size and location of communities. During the start-up phase of the AHAC, several days per month were taken up by collaborative planning activities. This regional approach to planning was time consuming and taxing for many frontline work-
ers who felt their time could be more effectively spent on client contact. However, the process provided the basis for the beginning of integrated health care services. It allowed health professionals and paraprofessionals to learn about their co-workers’ scope of practice within the developing multidisciplinary team. This was particularly important since all staff were new to the experience of working on a team with the diverse skills sets and work experiences held by First Nations community program staff and the specialized health services staff. All staff had to adapt to deliver services based on an evolving model of care, in collaboration with a new multi-disciplinary and multi-cultural team. While the vast majority of the community program staff were members of the local Aboriginal community, only half of the 10 original staff members at the AHAC were Aboriginal and only two health care providers had local community ties. The non-Aboriginal staff members ranged in their background in working with Aboriginal communities. While some had extensive experience working in Aboriginal communities, others were completely new to it. Participation in planning activities provided an informal opportunity for the AHAC staff to learn more about the specific health priorities, organizational culture, and program expectations of each First Nations community. While this was a valuable exercise in the early phases of the AHAC program development, more efficient ways of identifying gaps in services and maintaining co-ordination of care will have to be developed in the future.

**CONSTANT FLUX:**

**The Rapid Evolution of the Aboriginal Health Care System**

Many First Nations in Canada are actively taking control over health services through transfer agreements with Health Canada. Communities are designing and implementing community-based, culturally-appropriate services. In the Manitoulin District, the diversity of available programs and the administration of these services have changed rapidly over the past 10 years as local First Nations have engaged in the health transfer process. In addition to the services originally provided under the federal health transfer initiative, the management of other services such as the Canadian Prenatal Nutrition Program,8 the Aboriginal Head Start Program On-Reserve,9 and the First Nations and Inuit Home and Community Care Program have also transferred to the First Nations or tribal council level during the past decade.

While these health programs are urgently needed within Aboriginal communities, the transfer of health programs, coupled with the rapid growth in other community-oriented programs causes health services to be in a constant state of flux. This provides special management challenges. 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.11 More negatively, communities are expected to design and deliver programs that operate within the often rigid parameters of governmental 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.

Funders’ expectations can be rigid in their reporting requirements or desired program outcomes. They can vary tremendously between funding streams and may even change mid-stream. The pressure on different programs to generate a variety of predetermined health outcomes provides a particular challenge to the provision of integrated services. Often, there is an expectation to connect specific health outcomes to a particular funding stream without taking into account the bigger picture such as the existence or absence of complementary programs and support systems at the community level. In addition, a funding stream may target improvements in health for a particular age group. At the community level however, it does not make sense to restrict clients from a program based on age. In particular, families affected with multigenerational issues require a continuum of care with services geared to all members of the family in order to be effective. In order to prevent overlap in services, service provision must be constantly negotiated with all Aboriginal health agencies as programs started under short-term funding are discontinued or new program streams become available. As a result, program priorities are frequently adjusted and staff and partner agency roles renegotiated.

Continuous changes in health systems do not allow for an adequate maturation and evaluation phase for newly developed community-based health services. This circumstance poses further challenges to the development of integrated health services. Short-term funding for community programs is problematic since programs can run out of funding just as momentum and community trust is created. This leaves clients discouraged and the impact of the program undeter-
employees. Only four staff members have held their positions continuously over the five years the centre has been operating. Some positions, including dietitians, nurse practitioners, and administrators have turned over three or four times during this five-year period. The positions with both high and low turnover rates were held by both Aboriginal and non-Aboriginal staff members. Some had family ties in the Mani-toulin District. Some did not.

This does not take away from the fact that more Aboriginal health professionals are urgently needed. As new community-based health care positions are created, the need for Aboriginal health care professionals such as physicians, psychologists, dietitians, therapists, nurses, and administrators increases dramatically. Male Aboriginal health care providers are particularly scarce. They are especially needed to improve the generally low use of health care services by men in the community. At Noojmowin Teg, male service providers have consisted exclusively of traditional healers. This may be a factor in explaining the effectiveness of the traditional health services program in reaching male clients. Today, there are many experienced Aboriginal health professionals working at the community level. However, the demand for their services still heavily outweighs their availability. For example, dietitians are urgently needed in community nutrition programs to address the high rates of chronic illnesses, particularly the clinical management and prevention of obesity, diabetes, and heart disease. Yet, according to statistics from the Aboriginal Nutrition Network of Canada, there are currently only 12 Aboriginal dietitians in Canada. Only eight of these professionals are actually working in the field of nutrition. While the number of Aboriginal dietitians is expected to double over the next several years, the high levels of chronic illnesses in Aboriginal communities point to the fact that many more are needed to provide culturally-based services.

Due to the relative scarcity of Aboriginal health professionals, many Aboriginal health organizations are faced with difficult hiring choices. Should the health centre make it a priority to hire staff who have the necessary knowledge of Aboriginal communities and culture even if it means some staff are less experienced on a professional level? Should they hire staff who lack some of the expertise and will require on-the-job training? Appropriate training may require university-based education. This is costly, time-consuming, and often unavailable in northern areas.

Unemployment rates are high in most Aboriginal communities. According to government statistics, the
1996 unemployment rate among First Nations People living on-reserve was 29 per cent. However, actual rates, particularly in northern communities, are often much higher. From a community governance perspective, it is empowering that community statistics indicate an improvement in employment rates and that community agencies employ a high percentage of Aboriginal workers.

In addition, this hiring approach can assure an agency that its new co-worker will not struggle with cross-cultural service provision. However, it can also lead to tremendous pressure and job burnout for Aboriginal health care workers. For example, recent graduates generally benefit from the mentoring and clinical supervision by experienced professionals in their discipline. However, Aboriginal staff members may be expected to perform their job in a leadership position right from the start. Similarly, workers who require a lot of on-the-job training may be left feeling frustrated and overwhelmed by the responsibility associated with providing care to many high needs clients.

In order to provide an empowering work environment for staff, it is important to have a clear understanding of the workers’ skill level and educational background and to match this to their position. Otherwise, Aboriginal staff may be subjected to unrealistically high community expectations.

A formal approach to capacity building is therefore of key importance to community health empowerment. Staff need to be able to identify areas of necessary skill development candidly and keep track of and assess their progress. For example, capacity building support for mental health staff may consist of counselling skill development, clinical supervision, and mentoring by experienced health professionals, as well as individuals with traditional knowledge.

An alternative is to hire a proportion of non-Aboriginal staff, with the awareness that some may work very well in Aboriginal communities while others may lack knowledge or appreciation of Aboriginal culture and communities or have a low aptitude for cross-cultural patient encounters. Both situations contribute considerable stress to the health care delivery system. Frequently, non-Aboriginal professionals are hired as interim measure to fill vacant specialized positions. Sometimes there are even advantages to services provision in small communities. Since non-Aboriginal providers are typically much less entrenched in the community they work in, some clients perceive them as providing more confidential services. However, cross-cultural service provision is at times seen as a challenge from the point of view of non-Aboriginal providers and Aboriginal clients. This is especially true when providing services to Elders and clients who speak English as a second language.

It is important to understand that the comfort level with the provision of community health services by non-Aboriginal providers varies considerably with each provider and each client. The key is to provide ongoing cultural sensitivity training to all staff who are not from the local community.

**DEVELOPMENT OF TRADITIONAL ABORIGINAL HEALTH SERVICES**

Contrary to many countries in Europe, Africa and Asia, medical pluralism has not been part of the development of Canada’s health services. Therefore, alternative and traditional Indigenous healing systems have not been government supported in the past. Over the past decade, however, governmental funding sources are increasingly acknowledging the importance of culturally-appropriate services in contributing to improvements in community health and the right of Aboriginal People to access traditional Aboriginal health services. One of the goals of the traditional health services program at the Noojmowin Teg Health Centre is to provide clients with culturally-appropriate care and to integrate traditional Aboriginal medicine within the health centre setting. While this sounds simple, providing traditional healing services in the new cultural setting of a health centre requires much groundwork, because traditional healing practices have evolved based on Aboriginal cultural frameworks, not western primary care models.

Traditional Aboriginal healing has always been a vibrant and complex health care system. Practiced in all Aboriginal communities in the past, this knowledge has been eroded in many communities due to the consequences of colonization. Most Aboriginal communities are currently experiencing a resurgence of traditional Aboriginal knowledge and beliefs. As Aboriginal health centres plan to incorporate traditional Aboriginal medicine services in their program, it is important to understand that each community and each individual is unique with respect to their expectations, familiarity and level of comfort with traditional Aboriginal medicine.

Providing Aboriginal healing services in a clinical setting provides a unique challenge for health centres. For example, mainstream health professionals are regulated by various agencies. Adherence to their policies ensures that professional standards are main-
tained and protects the rights of clients and providers. However, determining the expertise of traditional healers is less clear-cut from an agency perspective. The Canadian government has acknowledged that the determination of qualifications of traditional healers or medicine people and self-regulation will have to be addressed by Aboriginal Elders and the larger Aboriginal community. It is a sentiment that is clearly shared by the Aboriginal community. In the past, when virtually all community members had some first-hand knowledge of traditional medicine, the legitimacy of medicine people was determined at the community level. The regulation of medicine people was informal and based on the different oral traditions of each community. Therefore, it is expected that there will not be just one way to determine the legitimacy and the qualifications of traditional healers. The identification of legitimate healers may be based on local Indigenous knowledge and include processes not readily understood by people who are not immersed in an Indigenous worldview. Discussions around policy development for traditional healing practices in a health centre setting will need to take place at the community level. Sufficient time and resources are required to address community concerns about the protection of Aboriginal medicine, as well as the rights of healers, clients and health organizations. In the interim, as legal responsibilities of health centres and traditional healing for clients are yet to be determined on a national level, it leaves uncertainties in risk management for health centres and traditional health services providers alike.

While traditional Aboriginal healing has been practiced for thousands of years in Aboriginal communities, the integrating of traditional Aboriginal health services with western clinical health services is groundbreaking. Professionals responsible for developing these new forms of services have the task of identifying areas where Aboriginal and western health systems can interface and provide an opportunity for collaboration between practitioners. Program co-ordinators work on overcoming many barriers to integrate traditional Aboriginal medicine. Health care practitioners trained in western approaches are typically in need of extensive cultural sensitivity training in order to appreciate the benefits of Aboriginal medicine. Clear guidelines are still needed from professional licensing bodies to assure mainstream health professionals that collaborating with traditional Aboriginal health care providers will not put their license at risk.

At the community level, there are complex and at times conflicting expectations for traditional healing services. At the Noojmowin Teg Health Centre, many demands are placed on the Traditional Healing Services Co-ordinator who manages the traditional healing services. Traditional co-ordinators carry a large proportion of the responsibility of developing health centre protocols or guidelines for providing traditional Aboriginal medicine in a health centre setting. The protocols must ensure protection for traditional healers, clients and the health care organization while protecting the integrity of Aboriginal healing methods. The development of such guidelines must be based on local Aboriginal beliefs and customs, negotiated and agreed upon by the appropriate community stakeholders, reviewed by legal counsel, and endorsed by the appropriate health boards. Similar to all writings based on Aboriginal traditions and knowledge, it is important to recognize that the information is owned locally. Transplanting locally developed guidelines to other regions or unrestricted sharing of the details of the guidelines may not be respectful of local customs and should only occur with the expressed agreement of the people who developed them. Communities interested in developing guidelines may find it easier to seek out a community or agency willing to share their experience, such as the community processes necessary to develop such guidelines. At the Noojmowin Teg Health Centre, a community-based research process was used to provide the basis for traditional healing services protocols. It includes consultations with community Elders and individuals with traditional knowledge and historic research. Agencies that decide to engage in the process of developing guidelines need sufficient time and adequate support, including human and financial resources, to succeed. At this point, the traditional healing services at Noojmowin Teg and the western health care providers usually work in a co-operative, multidisciplinary fashion, mainly interacting through referrals back and forth. A full interdisciplinary integration model for traditional and western healing services, with ongoing case-by-case collaboration between practitioners, blending both healing systems has not been implemented at this point.

INTEGRATED MENTAL HEALTH SERVICES

The First Nations clinics on Manitoulin Island employ community-based mental health workers who are funded under diverse funding streams including federal programs such as the National Native Alcohol and Drug Abuse Program, the Building Healthy Communities Program, the First Nations and Inuit Home and Community Care Program, and the provincial Aboriginal Healing and Wellness Strategy. Most of
these funding sources have not been specifically designated for community mental health. However, these funding streams are flexible enough to allow communities to address mental health, which is generally under-funded. As a result, the community mental health workers’ roles vary tremendously within communities. Depending on their expertise, they provide direct client services such as mental health intake and assessment, short-term and crisis support, mental health and additions counselling, and referrals to specialist services. Some community mental health workers are not responsible for direct client contact, but rather for designing and implementing community mental health promotion programs.

Recently, several new mental health-oriented programs have been added to the existing services in many Aboriginal communities based on short-term funding from the Aboriginal Healing Foundation (AHF). The AHF was established to disburse a $350-million Healing Fund set up by the Government of Canada over a five-year period (1998 to 2003). The fund is intended to address the multigenerational impact of the residential schools system on Aboriginal Peoples including the legacy of physical and sexual abuse. The AHF has focused on funding community-based healing initiatives. Projects are normally funded for a period of one year. Some multi-year projects with proven track records have been renewed under this initiative for several years. However, there are no provisions for an extension of this healing initiative beyond the five-year time frame.18 AHF programs are administered by various organizations including health, social services, and cultural agencies. While agencies are aware of the time-limited nature of AHF projects, it is difficult to find alternative funding sources for initiatives such as programs for youth at risk or the development of services to deal with sexual abuse at the community level. This leaves agencies with the difficult choice of either not addressing many aspects of the residential school legacy or running the risk of being forced to shut down a successful program one or two years after initiating it. This leaves clients unsupported and vulnerable. The reality is that many agencies will develop proposals based on short-term funding streams hoping that more stable funding may be available in the future, particularly for programs that can demonstrate success.

In the area of mental health in the Manitoulin District, clinical counselling is provided at the community level by several layers of services. As a semi-regional health services provider, Mnaamodzawin Health Services provides the services of a mental health case manager on an outreach basis in five small communities under the health transfer budget. Similar to the community mental health services, the resources for this semi-regional mental health program are not designated for mental health services by the First Nations and Inuit Health Branch. The two larger First Nations communities on Manitoulin Island provide clinical counselling at the community level. The Noojmowin Teg Health Centre provides psychology services on an outreach basis at health centres in all local First Nation communities and to Aboriginal People living off-reserve. In the outreach model, mental health team members travel to local First Nations to offer services to clients either at their local health clinic or at the client’s home. This model varies substantially from the mainstream model where clients are required to travel outside of their First Nations community to meet the counsellor in a mental health office. In the Manitoulin area, professional services such as psychology were not readily accessible before the development of the Noojmowin Teg health services. However, it has become clear that there is a high demand for these services at the community level. Due to high rates of usage and the resulting waiting periods, Noojmowin Teg has expanded services from a single psychologist position to 1.5 positions with additional contract services whenever funds permit. The contract services are mainly used to support traditional healing services for clients affected by residential school experiences and multigenerational violence.

The North Eastern Mental Health Corporation (NEMHC) provides another layer of mental health services. NEMHC provides psychiatric services and a consulting therapist on a limited contract basis, normally a few days per month. NEMHC is a provincially-funded organization providing services for seriously mental ill clients for much of Northern Ontario. In First Nations health clinics, the community mental health clinic is managed locally. However, workers normally operate within NEMHC policies and procedures. Although a Native advisory committee has a representative voice on the board of directors of NEMHC, there is no formal mechanism to represent a First Nations community perspective in the planning or provision of these services.

With mental health workers who are socially entrenched in the community they serve, clients of the mental health program often perceive confidentiality as an issue. In First Nations communities, family relationships are an important aspect of community life. Most individuals have well-established relationships...
in their community, which are shaped by complex extended family networks. Clients and community health care workers often share one another’s history. For some people, this can lead to a particularly therapeutic environment. However, for others, these close community and kinship ties become a barrier to accessing services, particularly mental health services. As a result, a significant number of clients in the Manitoulin area welcome referrals to the integrated regional services providers of Mnaamodzawin Health and Noojmowin Teg. Clients are given the additional choice of meeting professionals in their home community clinic, the client’s home, or another health centre. This significantly improves clients’ access to mental health services compared with other, more common service provision models.

**REWARDS OF INTEGRATED SERVICE PROVISION**

Many barriers need to be overcome to establish integrated services at health centres in Aboriginal communities. Nevertheless, the experience at the Noojmowin Teg Health Centre shows there are definite benefits for clients, communities and health centre staff. For health centre clients, health services are becoming increasingly seamless, holistic, and community-based. Specialized care such as the services of psychologists, traditional Aboriginal healers, nurse practitioners, and dietitians are now provided through an outreach model at the community level. Follow-up services can often be shared with community clinic staff. This allows for the beginning of wrap-around services. Many staff members experience this team approach as the foundation for integrated services at Noojmowin Teg. The team process has the potential to contribute towards building community capacity and can help improve the client-practitioner relationship.

A model for true collaboration between western and traditional Aboriginal health practitioners is still in the developmental stage. Nevertheless, community health empowerment is clearly strengthened. Clients are now able to choose between western and traditional Aboriginal health services, or a combination of both, without being subjected to negative reactions by health care providers. The health centre staff work towards tailoring services to the identified needs of each community. They contribute to community health empowerment by collaborating with community staff and health boards in the planning of services and by enhancing the existing strengths and resources in each community. Traditional as well as the specialized health services provided on an outreach basis are much in demand in local communities. Waiting lists are growing for many of these services.

**CONCLUSION**

Similar to regional Aboriginal health care networks elsewhere in Canada, integration of health services in First Nations communities in the Manitoulin District is required at many different levels in order to improve service. There is a need for integration of federal and provincial Aboriginal health services; integration of mainstream rural and urban health services with First Nations-based health services; integration at the First Nations level among community health service and community sectors such as social services, housing and education; and, further integration between western community health services and traditional Aboriginal health care.

Integration of health services is by no means complete and some fragmentation of services remains to be resolved. However, the implementation of an Aboriginal health centre program in the Manitoulin area has contributed to an improved continuum of care and access to much sought-after specialized health care services. The partnership between the Noojmowin Teg Health Centre and the local federally-funded health authorities is contributing to local health empowerment in many ways. Due to the larger catchment area, Noojmowin Teg programs often act as catalysts for regional approaches to health care and improved inter-agency collaboration among Aboriginal organizations with long histories of working independently. For example, in the area of health research, Noojmowin Teg assumed a co-ordinating function to support the development of a regional research committee with representation covering all of the local communities. This committee has developed Aboriginal research ethics and research protocols based on local values. The committee plans to develop a research agenda in the coming year. For traditional Aboriginal health services, Noojmowin Teg has provided a forum for regional collaboration on the development of policy guidelines for the provision of Aboriginal medicine in a clinical setting. Newly implemented regional mental health networking meetings allow professional and paraprofessional mental health staff to address common issues including professional development, regional service planning, and the development of health information technology for mental health. Providing services to a greater number of people allows Noojmowin Teg to provide specialized health care as
a community-based service. This enables Aboriginal organizations to share control over these services with the communities they service.

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ENDNOTES


2. Young, Health Care and Cultural Change, p. 135.


8. The Canadian Prenatal Nutrition Program (CPNP) is a national program to address the health of high-risk pregnant women, improve birth outcomes and to promote breastfeeding. Program components include nutrition counselling and nutrition supplementation. A First Nations and Inuit committee was established to support the development of the Aboriginal component. The First Nations and Inuit Health Branch (FNHIHB) of Health Canada is responsible for the portion of the program intended for Aboriginal communities.

9. The Aboriginal Head Start Program was established in 1995 to enhance child development and school readiness of Aboriginal children living in urban centres and large northern communities. In 1998, the program was expanded to include “on-reserve” Aboriginal communities.

10. The First Nations and Inuit Home and Community Care Program provides basic home and community care services delivered primarily by trained and certified personal care/home health aide workers at the community level and supported by registered nurses. The program is developed at the local level to integrate with existing programs and services. The program is funded through the First Nations and Inuit Health Branch (FNHIHB).


13. See for example, First Nations and Inuit Regional Health Survey 1998.


NAHO’s Information Centre on Aboriginal Health

The Information Centre on Aboriginal Health (ICAH) will be a national database of Aboriginal health information and resources.

The National Aboriginal Health Organization is creating the Information Centre on Aboriginal Health to help direct both individuals and health care professionals to resources they can use to promote and improve health for themselves, their families and in Aboriginal communities.

The Information Centre on Aboriginal Health is an innovative way to ensure First Nations, Inuit and Métis people have easy access to relevant resources on health and well-being.

ICAH will allow you to search an English-French-Inuktitut Web site and virtual library for information on Aboriginal health, careers and training in the health field, Indigenous knowledge, programs and services for Aboriginal Peoples, and much more.

www.icahe.ca
UNFINISHED DREAMS:

Community Healing and the Reality of Aboriginal Self-Government

By Wayne Warry
University of Toronto Press, 2000
ISBN 0802009549
323 pages

Most writing on Aboriginal self-determination focuses on the Constitutional or structural aspects of self-government or related philosophical issues. In Unfinished Dreams: Community Healing and the Reality of Aboriginal Self-Government, author Wayne Warry argues that self-government can be realized only when individuals are secure in their cultural identity and can contribute to the transformation of their communities.

Warry draws on his research among Nishnawbe communities as well as on the reports and recommendations of the Royal Commission on Aboriginal Peoples. Case studies are used to illustrate the processes of community development and cultural revitalization that are essential precursors to self-government. Warry’s notion of community healing involves efforts to rebuild the human foundations for self-governing Aboriginal societies.

The book analyses key areas such as health care and the judicial and political systems where Aboriginal Peoples are engaged in practical everyday struggles to improve their communities. Central to these Aboriginal approaches to change is the need for holistic solutions to complex social problems. The search for these solutions is set against the broader political environment, which includes Euro-Canadian assumptions, government, policy, and post-colonial practices. The book also addresses the nature of applied social scientific research in Aboriginal communities and the need for collaborative, culturally-appropriate research methods.

Warry is an associate professor in the Department of Anthropology at McMaster University.
SHIFTING BOUNDARIES:
Aboriginal Identity, Pluralist Theory, and the Politics of Self-Government

By Tim Schouls
UBC Press, 2003
Cloth: ISBN 0774810467
240 pages

Canada is often called a pluralist state, but few commentators view Aboriginal self-government from the perspective of political pluralism. Instead, Aboriginal identity is framed in terms of cultural and national traits, while self-government is taken to represent an Aboriginal desire to protect those traits. Shifting Boundaries challenges this view, arguing that it fosters a woefully incomplete understanding of the politics of self-government.

Using relational pluralism as a theoretical lens, author Tim Schouls takes a fresh look at the complex issue of Aboriginal self-government. Taking the position that a relational theory of pluralism offers a more accurate interpretation, Schouls contends that self-government is better understood when an identification perspective on Aboriginal identity is adopted instead of a cultural or national one. He shows that self-government is not about preserving cultural and national differences as goods in and of themselves, but rather is about equalizing current imbalances in power to allow Aboriginal Peoples to construct their own identities.

In focusing on relational pluralism, Shifting Boundaries adds an important perspective to existing theoretical approaches to Aboriginal self-government. It will appeal to academics, students and policy analysts interested in Aboriginal governance, cultural studies, political theory, nationalism studies, and constitutional theory.

Schouls divides his time between the University of British Columbia and Capilano College, teaching and doing research in Canadian politics, Aboriginal governance issues and political theory.
The Politics of Trust and Participation:  
A Case Study in Developing First Nations and University Capacity to Build Health Information Systems in a First Nations Context

Brenda Elias, MA, University of Manitoba, Centre for Aboriginal Health Research  
John O’Neil, PhD, University of Manitoba, Centre for Aboriginal Health Research  
and Doreen Sanderson, Assembly of Manitoba Chiefs

Abstract

Recent success of First Nations involvement in health information management is establishing the social and cultural structures necessary to build trust and participation, produce counter knowledges that decolonize the health of First Nations Peoples, develop new forms of health information systems directed at First Nations wellness, and create new institutional research partnerships that could further enhance health information development and educational opportunities. This success is illustrated through a number of initiatives jointly developed and managed by Manitoba First Nations Centre for Aboriginal Health Research and the Assembly of Manitoba Chiefs Health Information and Research Committee. Alternative discourses are possible. Resistance in the form of counter discourses can produce new knowledge, speak new truths and constitute new powers such as First Nations ownership, control, access and possession of health information. In this new environment, non-Aboriginal researchers and governments will have to recognize that any work involving Aboriginal Peoples will occur in the context of resistance to colonization. However, that such resistance creates the possibilities for collaboration. For collaboration to be possible and successful, however, researchers will have to reflect on the positions represented by others, attempt to understand these positions within the context they occur, recognize that trust and participation is conditional, and accept that any sharing and production of health information will occur at the boundaries between systems of knowledge.

Key Words

First Nations, Aboriginal, research, health information, power/knowledge, decolonization, collaboration, trust, participation

INTRODUCTION

In Manitoba, the recent success of First Nations involvement in health information management helped establish the social and cultural structures necessary to build trust and participation, produce counter knowledges that could decolonize the health of First Nations Peoples, launch new forms of health information systems directed at First Nations wellness, and create new institutional research partnerships that could further enhance health information development and educational opportunities. This success is illustrated through a number of initiatives jointly developed and managed by Manitoba First Nations Centre for Aboriginal Health Research and the Assembly of Manitoba Chiefs Health Information and Research Committee.

The First Nations and Inuit Regional Longitudinal Health Survey established the social and cultural structures necessary to develop First Nations’ and universities’ capacity to work collaboratively in the area of First Nations population health research. Out of this initiative, the Manitoba First Nations Population Health Research Training Institute emerged. It involved various forms of cultural resources that could demystify health information and build on the skills of First Nations health managers and providers so they could critically apply health information to First Nations health policy and service areas. The trust and
participation developed through these initiatives created further connections and opportunities to resist the new epidemic discourses (i.e., authoritative ways of describing a population) that currently dominate First Nations health and made possible new institutional research partnerships based on principles of mutual respect, trust and participation. This respect, trust and participation occurred within the context of decolonization and at the margins between various knowledge domains and forms of sovereignty.

**ISSUES OF CONTROL OVER HEALTH INFORMATION**

If researchers accept the idea that power does not exclusively operate through brute force or political repression, but also acts through systems of knowledge about how societies work, researchers should then consider scientific discourses (studies, research projects, etc.) as a medium through which power operates and that power/knowledge characterizes the way scientific knowledge acts to control members of a society by defining what is normal and expected. What is normal and expected for one group, however, may not be the same for others.

If researchers also consider that epidemiological research studies operate as part of a broader surveillance system that regulates populations according to the values of the dominant society and that scientific discourse is rooted in the dominant value systems of ruling interests in a society, then science and state interests are interdependent. This interdependency is inevitable because government is only possible when the strength of the state is known. Researchers should also consider that alternative discourses are possible and resistance in the form of counter discourses will produce new knowledge, speak new truths and constitute new powers. In other words, although discourses can constrain the production of knowledge or restrict dissent and difference, they can produce new knowledges and difference(s) that can oppose the knowledges (counter-knowledges) produced by the status quo.

In the context of First Nations health research, these ideas are highly applicable, particularly when applied to understanding First Nations sovereignty, resistance, capacity, and health knowledge systems.

It is not uncommon to hear First Nations Peoples say that they have been “researched to death.” For many First Nations Peoples active in community wellness development, research is viewed, at best, as irrelevant to the needs of communities, or, at worst, as a serious encroachment on the integrity and autonomy of First Nations communities. Many First Nations communities are reluctant to participate in research projects, especially if they have no control over what information is gathered or how it is used. In many ways, these acts of resistance illustrate that First Nations Peoples are critically reflecting on the technologies, methodologies, communication strategies, etc.: through which science operates. At the same time, First Nations health authorities require health information and educational opportunities that further decolonize a long history of pathologizing discourses in First Nations health research. First Nations health planners and service providers require trustworthy health information to develop appropriate health programs and target services that can meet rapidly changing needs within a limited resource environment. They also need health information to inform negotiations with federal and provincial governments to secure adequate funding for health programs, services and training. First Nations Peoples have responded to this need and are developing a self-governance strategy to make health information available to First Nations communities and to ensure that First Nations health planners and service providers receive health research training.

Consistent with their Constitutional right to self-government, First Nations governing bodies have established the OCAP principles of ownership, control, access, and possession of health information. The main objective of these principles is to extend First Nations’ sovereignty over health information and to decolonize research relationships between First Nations organizations, universities and provincial and federal governments.

A major initiative that helped forge the OCAP principles was the First Nations and Inuit Regional Longitudinal Health Survey (FNIRLHS), which was launched in 1996-7. At the feasibility stage of this national survey, Aboriginal organizations (First Nations, Métis, and Inuit) throughout Canada were highly sceptical as to whether they should invest their time and energy in a project that would offer little in terms of direct benefit. These organizations were not alone in their scepticism. Resistance against research conducted by non-Aboriginal organizations and peoples is widely shared by Indigenous Peoples throughout the Americas, Australia and New Zealand. Such research is regarded as a repressive process under the control of others.

To make research more equal participation, researchers adopted participatory action research (PAR)
approaches that can empower participants to define their own world according to their own interests. Indigenous Peoples, however, have argued that PAR still does not prevent researchers and governments from exercising intellectual arrogance or employing evangelical and paternalistic practices.\(^8\)

The battle for sovereignty over the Regional Health Survey is proof of the way First Nations Peoples resisted PAR as a means to preserve a colonial relationship at the expense of First Nations sovereignty. At the initial planning stage of this survey, the FNIRLHS National Steering Committee, comprised of First Nations and Inuit representatives from nine regions across Canada, resisted the top down, paternalistic approach taken by the federal government. Medical Services Branch\(^9\) employees were opting for a PAR process that maintained their administrative control of the survey. However, several members of the FNIRLHS National Steering Committee, including the representative from the Assembly of Manitoba Chiefs (Audrey Leader), resisted this act by threatening to leave the process if they did not get full control over the survey.\(^10\) The federal Medical Services Branch eventually accepted this demand and transferred complete control over the survey to the FNIRLHS National Steering Committee. This victory was a major turning point. The outcome was higher levels of trust and participation at the regional level, particularly in Manitoba. This solidarity provided the base to formally establish and sanctify the OCAP principles over health information as a model for other Indigenous groups to follow.

In a code of research ethics, the FNIRLHS National Steering Committee entrenched the principles of OCAP to strengthen First Nations and Inuit self-determination over the survey process.\(^11\) The committee also established a number of obligations for researchers to guarantee that Inuit and First Nations Peoples are actively involved in the research process; promote the knowledge that this process is Inuit and First Nations owned; ensure the study design, data collection and dissemination of research results is culturally relevant and in compliance with standards of competent research; undertake research that contributes to Inuit and First Nations Peoples nationally and regionally; assist in advocating and addressing health and social issues as they emerge as a result of the research; and build Inuit and First Nations research capacity in survey development, data collection, computer use, analysis, and health planning.\(^12\) Today, this code of ethics stands out among other research agreements\(^13\) as a model that can nationally and regionally frame partnership models and that can build research capacity based on the principles of OCAP.

Entrenching the obligation to build health research capacity and information dissemination practices (e.g., meeting with communities or advisory boards, presenting at conferences, writing papers, etc.) into a research agreement was a significant departure from traditional PAR approaches. In health services research, the focus is generally on evidence-based decision-making or problem solving to address problems associated with changing the practice behaviours of health professionals.\(^14\) In health promotion, most work tends to examine barriers to disseminating information, primarily designed to change health behaviours in the public domain.\(^15\) However, neither of these approaches has been particularly relevant to rethinking how policy-oriented research is disseminated to health planners and program developers in a complex social, cultural and political environment. Research by N. Milio and by M. O’Neill and A.P. Pederson has revealed that effective dissemination of research results is dependent on the complexities of the relationships that must develop between the research and policy communities.\(^16\) As well, decision-making is influenced by the quality of the evidence, distribution strategies and the complex environment where the decision-making and the incorporation of the evidence is actively taking place.\(^17\) As well, evidence-based decision-making cannot occur if health information is not available. Its availability is often contingent on co-operation and partnerships between different research and governing bodies.\(^18\)

In Canada, the need for innovative research dissemination strategies is quite widespread. There certainly are far more questions than answers as to how to achieve this objective.\(^19\) The code of research ethics developed by the FNIRLHS National Steering Committee was one attempt to lay the groundwork on how to achieve this objective. The obligation to build First Nations and Inuit research capacity in survey development, data collection, analysis, and health planning established the standards to achieve this objective. This obligation opened the door for First Nations organizations and researchers to collaboratively develop new social and cultural structures and create new social connections and opportunities to build capacity among researchers and First Nations Peoples to engage evidence-based decision-making at the program, policy and funding levels.
Extending as far back as the 1950s, faculty members of what is now the Department of Community Health Sciences have worked with northern communities. At the request of Aboriginal Peoples in Manitoba and the Arctic and through the efforts of these faculty members, the Northern Medical Unit (now called the J.A. Hildes Northern Medical Unit) formed in 1969 to deliver medical services to northern communities. This Unit also provided a vehicle for various northern research and education efforts. These early activities in northern health research continued to grow, thus demonstrating the need to pool efforts and resources to develop a research unit.

External resources were found, and the Northern Health Research Unit (now known as the Manitoba First Nations Centre for Aboriginal Health Research) was established in 1987. Core funding from several foundations complemented internal University of Manitoba resources. The mission and objectives of this Unit were as follows:

- to initiate and conduct research projects northern communities determined to be relevant;
- to ensure research projects sponsored by the Unit were sensitive and responsive to community needs and were supported by the communities;
- to encourage research training of northern persons;
- to provide consultation, co-ordination and assistance to the university community engaged in northern research, including researchers both in Canada and abroad;
- to disseminate northern health research information; and
- to expose northern communities to university research methods and results, increasing their awareness and assisting them in setting their own research priorities.

This mandate made it possible for Northern Health Research Unit researchers to develop new partnerships with First Nations Peoples in Manitoba. For this partnership to be successful, however, the Unit staff needed to develop a deeper understanding and respect for First Nations self-governance over health and health information. The Regional Health Survey process helped broaden and enrich the Unit researchers’ understanding of self-government and decolonization. With the development of a Manitoba First Nations health information governance structure and a partnership between the Unit and the Assembly of Manitoba Chiefs, the Unit helped develop the Manitoba First Nations’ capacity to assume greater control for research conducted for and by First Nations Peoples.

In Manitoba, the primary health authority of Manitoba First Nations communities – the Chiefs Health Committee of the Assembly of Manitoba Chiefs – determined the First Nations governing structure that would oversee the Regional Health Survey. In a resolution passed in 1996, the Chiefs Health Committee created the Manitoba First Nations Regional Health Survey (MFNRHS) Steering Committee. It consisted of health directors from each of the tribal councils in Manitoba plus health advisors from the Assembly of Manitoba Chiefs and the Manitoba Keewatinowi Okimakanak (MKO), which is a political and administrative branch of the Assembly of Manitoba Chiefs for the northern half of the province. Membership also included two health directors from two independent communities that represent the northern and southern independent First Nations communities in Manitoba.

Throughout the Regional Health Survey process, the MFNRHS Steering Committee met regularly with Northern Health Research Unit staff by teleconference and in workshops. This included training and decision-making on all aspects of research methodologies. These meetings helped forge a strong and trusting relationship between the Unit staff and the MFNRHS committee members and helped build capacity among the MFNRHS committee members to assume additional responsibilities over health information. In 1998, the Assembly of Manitoba Chiefs formally recognized the MFNRHS Steering Committee’s contribution to developing a First Nations health infrastructure and granted it more decision-making power through a resolution. The resolution mandated this committee as the Assembly of Manitoba Chiefs’ Health Information and Research Committee (AMC-HIRC) to exercise greater control over research conducted for and by First Nations Peoples. This control included:

- overseeing the long-term development and implementation of the Regional Health Survey;
- reviewing research proposals that involved First Nations health and make recommendations to improve the focus of such proposals;
- establishing a health information system for the use and benefit of First Nations; and
- ensuring health research and information development is accountable to First Nations needs and priorities.

The high level of respect, trust and participation that developed between the Manitoba First Nations and the University of Manitoba throughout the survey...
A partnership between the Northern Health Research Unit and the University of Manitoba’s Continuing Education and Department of Native Studies was also established to provide academic credit for participants and facilitate student registrations for the course. The Unit and AMC-HIRC decided to offer the course over a one-week period, which would represent, in terms of time, the equivalent of a half-term course. Students not interested in using this course towards a degree had the option to take it as a non-degree offering. Consistent with university practice, organizers developed a course evaluation form to evaluate instructors and course content.

A curriculum-working group – which included faculty, tutors and the AMC-HIRC co-ordinator – established the curriculum objectives. Each faculty member contributed course materials that were organized into a student course manual. The curriculum involved a series of lectures and tutorial sessions designed to accommodate the broad range of educational backgrounds of the students. Introductory lectures were prepared to teach students the fundamentals of epidemiology, need assessments and ethical issues in Aboriginal epidemiology. The remaining lectures covered quantitative techniques used to appraise the health of populations. Lectures covered survey, health service utilization, and mortality databases. Tutorial sessions followed each lecture to provide students with hands-on experience using health information from these data sources. By and large, the lectures and tutorial sessions exposed students to health information techniques used to shape health programs and policy.

Overall, 46 Aboriginal health technicians registered for the course in the three years it was offered. Minor changes in the curriculum were made in this period, but in general terms, the program was structured as described here. Ten faculty and four graduate students from the Department of Community Health Sciences participated in the program.

Students worked in pre-assigned topic areas, representing one of the following domains: women, Elders and children. Their assignment involved abstracting survey, health service utilization, and mortality data to justify a program to deal with health inequalities in their respective areas. Each group worked as a team. On the last day of the course, they jointly presented a project proposal to the Institute instructors who posed as a Chiefs’ Committee on Health.

The evaluation of the course was highly positive. A sharing circle provided everyone with the opportunity to share in the extensive partnership work that made
the Institute a possibility. Students left the Institute with an introduction to evidence-based decision-making. The intense working group environment helped build a research network they could draw upon later.

In the second year, organizers took the Institute on the road and built research capacity in communities that participated in the first wave of the Regional Health Survey. As part of the survey dissemination plan, preliminary reports for each community were prepared. These reports provided the base for a workshop to give communities hands-on experience using data to assess health status, target resources and justify new funding. Two workshops were held—one in the north and one in the south. More than 20 First Nations community health planners attended the workshops. A few former Institute students also attended. They helped instil interest in evidence-based decision-making among the First Nations health planners who initially expressed little experience in applying health information to community health plans.

In the third year, organizers held a second Institute open to First Nations community health planners and service providers from across Canada. Another 22 Aboriginal health technicians attended and 10 faculty/tutors participated. The second Institute was similar to the first, with a few exceptions.

The college used in the first year was not available, so an alternative site was selected. The only site available was St. Andrews College, which is a Ukrainian Christian Orthodox College located on the University of Manitoba’s main campus. This shift in venue triggered concern among some the Northern Health Research Unit staff and associates. This site was adorned with Christian icons. Given the tragic history of the residential school system, staff and associates were worried that such a setting could create mistrust and limit participation among participants who attended a residential school. Staff brought their concerns to the HIRC and then to the students. Neither group perceived the presence of Christian symbols as a problem that could foster distrust or limit participation. Overall, they were comfortable with the venue and appreciated staff’s concern over the potential harm such a venue could create for some attendees.

Another departure from the first Institute involved the tutorial projects. Rather than pre-assign students to groups targeting vulnerable populations, organizers assigned them to the strategic policy areas of diabetes and community healing, which recently received new federal funding. Although the curriculum remained much the same, organizers added an advanced course in survey methods. Only one student was interested in taking this course so it was offered only as a pilot course.

The Institute generally went well. Participants positively evaluated all lectures and tutorial sessions. The exception was a presentation made by a Medical Services Branch representative regarding the roll out of the community-based First Nation Health Information System (HIS) to all First Nations across Canada. In a question-answer period that followed, several participants commented that the HIS initiative would not provide accessible data or adequate training and that its development and administration did not follow the principles of OCAP. The debate became quite heated. At the end of the presentation, several First Nations participants felt the only solution to effectively develop research capacity was through a First Nations health info-structure based on the principles of OCAP. A few weeks after the Institute, MSB sent a letter to the Department Head of the academic unit accusing organizers of creating a hostile environment at this Institute. Although the intent was not to create such an environment, organizers did accept the responsibility of playing a significant role in developing First Nations capacity to critically apply population health techniques to secure First Nations self-governance over health information. One lesson from this incident is that any advancement of the OCAP principles could potentially reveal a deep historic distrust and a lack of participation between parties. The other is that the Institute did serve its purpose. It created a new group of First Nations health planners and service providers to use population health techniques to produce counter-knowledges that can resist colonial encroachments on First Nations health.

COUNTER-KNOWLEDGES AND NEW PARTNERSHIPS

Overall, the trust and participation built through these initiatives went beyond the Institute. They helped create new social connections and opportunities to build evidence-based decision-making in the form of counter-knowledges that could decolonize the health of First Nations Peoples, develop new institutional research partnerships that could further enhance health information development and educational opportunities, and facilitate new forms of health information systems directed at First Nations wellness.

Since then, the Northern Health Research Unit has been actively involved in building research capacity in other Assembly of Manitoba Chiefs’ health working groups. We have worked with the Manitoba First
The MFN-CAHR supports meetings with the Assembly of Manitoba Chiefs (AMC) to build capacity in reviewing research that targets the determinants of diabetes, and community-based evaluations that assess the effectiveness of diabetes intervention programs. Since then, a major diabetes study has been launched to address surveillance and health services issues in Manitoba.

The Unit has also worked in full partnership with the Assembly of Manitoba Chiefs disability committee in a pilot study to identify First Nations Peoples with a disability, document their social economic conditions and job training needs, and discover other factors and barriers (health, housing and transportation) related to their disability. The final report produced through this partnership was presented at a special Assembly of Manitoba Chiefs meeting on health. A resolution created a mandate to undertake a process that would comprehensively review and evaluate the current service delivery system as it relates to First Nations Peoples with a disability and their families. This information will be used to develop a strategy for constructive program and policy change.

In terms of new institutional partnerships, further discussions between the Assembly of Manitoba Chiefs and the Northern Health Research Unit resulted in the idea of developing a Manitoba First Nations Centre for Aboriginal Health Research (MFN-CAHR). The development of MFN-CAHR became a reality in 1999 with a generous contribution from the Assembly of Manitoba Chiefs for capital construction; the awarding of an infrastructure grant from the Canada Foundation for Innovation; and partnership funding from the Health Sciences Centre Research Foundation, the University of Manitoba, and the Province of Manitoba. The new research centre opened in the spring of 2001 in 225 square metres (2500 square feet) of new research space in the Buhler Research Centre on the Health Sciences Campus of the University of Manitoba. The MFN-CAHR continues to be a unit of the Department of Community Health Sciences in the Faculty of Medicine at the University of Manitoba.

The mission of the MFN-CAHR is to initiate, coordinate and support research activities designed to assist Aboriginal communities and organizations in their efforts to promote healing, wellness and improved health services in their communities. The research program also integrates scientific and Aboriginal approaches to health as illustrated in the following objectives:

- To conduct studies on the determinants of health in Aboriginal communities;
- To support culturally-appropriate studies of Aboriginal healing ways in Aboriginal communities;
- To support and co-ordinate basic medical research into disease processes currently prevalent in Aboriginal communities;
- To conduct community-based studies into innovative culture-based approaches to healing and wellness in Aboriginal communities;
- To conduct studies into factors that influence the development of health service systems that meet the needs of Aboriginal communities;
- To provide community- and university-based education and training in health research to Aboriginal communities and students;
- To facilitate capacity building in Aboriginal communities and organizations in the use of health information for policy and program development;
- To assist with the development of a quality health information system that can describe changing health conditions in Aboriginal communities;
- To advise Aboriginal governments and organizations on health policy issues based on the best available research evidence; and
- To facilitate communication and knowledge sharing concerning Aboriginal health development nationally and internationally.

An advisory board provides general policy direction for the Centre for Aboriginal Health Research. Membership on the board includes the University of Manitoba, Manitoba Aboriginal communities and other stakeholders in Aboriginal health. The AMC-HIRC, as well as an Aboriginal Health Research Group (AHRG) consisting of faculty involved in Aboriginal health research in the Faculty of Medicine, provides direction to the advisory board.

The MFN-CAHR supports meetings with the AMC-HIRC to build capacity in reviewing research
proposals and assessing the ethics of a research project. The MFN-CAHR sponsors bimonthly AMC-HIRC meetings and workshops and assists in creating new partnerships between university investigators and the HIRC. In 1999, for instance, the MFN-CAHR had co-ordinated a partnership between the HIRC and the Manitoba Centre for Health Policy (MCHP). Several workshops and meetings between the two groups had involved building capacity in the AMC-HIRC to design a project using Manitoba Health service utilization data that can identify and assess health status indicators of Manitoba First Nations Tribal Council areas.

The MFN-CAHR currently holds a number of significant operating grants in partnership with Manitoba First Nations that build Manitoba First Nations capacity in developing and managing health info-structures. The Aboriginal Capacity and Developmental Research Environment (ACADRE) Training Program funded by the Institute of Aboriginal Peoples’ Health will expand the pool of Aboriginal researchers who can compete for national grants in the field of Aboriginal health research. This program has the following objectives:

- To train a new cadre of Aboriginal professionals in the field of health research;
- To further the development of a research environment based on collaboration and partnership between the University of Manitoba and Aboriginal communities and organizations;
- To develop a research environment that fosters participation for scientists from all disciplines to engage in collaborative research with Aboriginal communities and organizations; and
- To ensure that research training is available for students and faculty that emphasizes the importance of appropriate communication and dissemination activities that are consistent with Aboriginal values and goals for healthy, self-governing communities.

The research program will concentrate in four areas where the University of Manitoba has already established excellence: population health, health services research, child development and health, and ethics. In addition, the ACADRE program will encourage new research initiatives and partnerships in new and emerging areas of research collaboration in the Canadian Institutes of Health Research themes of basic and clinical sciences.

The primary purpose of the program is to attract Aboriginal students into health research careers. The training initiative will be directed toward Aboriginal health researchers at the graduate and junior faculty levels. However, in order to attract the most qualified candidates into health research, the organizers will provide opportunities for Aboriginal undergraduate and high school students to discover the opportunities that health research offers. The program will also expand the opportunity for increasing health research capacity in Aboriginal communities and organizations. Faculty and students associated with the ACADRE initiative will participate in the design and implementation of a Community Training Institute (CTI) that will be held once every two years. Participants will be drawn from the Aboriginal communities and organizations both regionally and nationally. Participants will have the opportunity to interact with academic health researchers in different fields and disciplines with the intention of nurturing new research ideas.

The Aboriginal Health Survey Support Program (AHSSP), funded by the Institute of Aboriginal Peoples’ Health, will contribute to the improvement of health survey activity in First Nations, Métis, and Inuit communities. The AHSSP will facilitate university and Aboriginal governments and communities to undertake complex surveys as well as build capacity of those with limited survey research and statistical knowledge. The purpose of the program is to heighten the profile of and interest in survey research and to respond to current and potential data needs to inform health policy, health and social programs, and health service delivery. The AHSSP is committed to working in partnership with First Nations, Métis and Inuit organizations on a number of projects related to the area of survey research. It is also committed to working, in partnership with the ACADRE Training Centres to develop a research environment based on collaboration and partnerships between universities and Aboriginal communities and organizations across Canada.

The AHSSP will support the development of national expert working groups to work on existing surveys and to develop new surveys that address emerging health issues. The intent of supporting these initiatives is to strengthen a national network of faculty, practitioners, students, and Aboriginal organizations committed to research, education and services in the advancement of the health and well-being of First Nations, Inuit, and Métis Peoples. The AHSSP potentially will undertake survey research in a variety of areas, subject to agreement with the appropriate decision-making structures. The AHSSP has interest in supporting off-cycle surveys, new sur-
veys, ethical/data management protocols, and data
linkage.

The AHSSP will also undertake several initiatives to facilitate statistical capacity among Aboriginal communities and universities. The AHSSP will work closely with the ACADRE training centres to ensure research training is accessible to students and junior faculty. The AHSSP program will also build on the MFN-CAHR Applied Aboriginal Population Health Research Institute and will design and implement a Summer Institute in Survey Research (SISR). As part of this activity, the AHSSP will facilitate a working group of instructors and Aboriginal organizations to develop survey research instructional materials that bridge western science and Aboriginal ways of collecting and interpreting data.

The 2002-2003 First Nations and Inuit Regional Longitudinal Health Survey has been launched by the First Nation Centre at the National Aboriginal Health Organization (FNC at NAHO) under the direction of the First Nations Information Governance Committee. The MFN-CAHR is working in full partnership with the Assembly of Manitoba Chiefs in launching this regional survey in Manitoba, developing the survey and training the regional co-ordinators. For the Manitoba regional survey, the MFN-CAHR is providing technical support and training in sampling, ethical protocols, interviewing, data quality assurance, database management, and dissemination of research results. Data from this survey will also be shaped into a tutorial database to use in the MFN-CAHR Applied Aboriginal Population Health Research Institute.

Linked to this project is the “Why are Some Communities Healthy and Others Not?” project funded by the Social Sciences and Humanities Research Council. This project helped develop and test new measures of social determinants, health and well-being to integrate into longitudinal health surveys in Aboriginal communities.

The MFN-CAHR is also working with the AMC-HIRC and communities throughout Manitoba to better understand how factors such as social cohesion, traditionality, resilience, poverty, and the social environment predict variations in the health and well-being of First Nations Peoples. An extension of this project is the Social Capital (e.g., trust and participation at the community level) as a Determinant of Health in First Nations Communities, which is funded by Canadian Institute of Health Information/Canadian Population Health Initiative. This project developed a conceptual framework for social capital as a determinant of health in First Nations communities and a social capital measurement scale. The project involved qualitative and quantitative methodologies to identify dimensions of social capital, develop culturally-appropriate items to measure social capital, conduct pilot testing of the developed instrument, and analyze the instrument and revise accordingly.

Another project under consideration is the Manitoba First Nation Health Information Data Repository System. The First Nation Health Information System (FNHIS) contains detailed health information about Status and non-Status First Nations residents of all provinces who access health services on-reserve. Information includes name, address, gender, birth date, residency, and status. It may include Band registration number, provincial health card number, and immunization status as well as data pertaining to reportable and chronic diseases, mortality, medication, medication allergy and adverse reaction, test and exams, public education, abuse, maternal/child health, and psychosocial health. The MFN-CAHR has agreed that, at some future date and at the request of the Assembly of Manitoba Chiefs, it would house the Manitoba FNHIS database in the form of a research data repository consistent with First Nations principles of OCAP.

The MFN-CAHR is also discussing with the AMC-HIRC about the development of a memorandum of understanding suitable to all partners including Manitoba First Nations, Manitoba Health, Indian and Northern Affairs Canada, and the First Nations and Inuit Health Branch (Health Canada) that would provide for the creation of a Master First Nations Health Registry. This data repository would be developed from the Indian Registry System maintained by the Department of Indian Affairs and Northern Development. It contains the name, treaty number, on- or off-reserve status, birth date, and sex of every First Nations Person in Manitoba. This file is also maintained by the First Nations and Inuit Health Branch and is known as the Status Verification System (SVS). These federal departments use these files to determine recipients of various benefits provided by both departments. Linking the SVS file/Indian Registry to the Manitoba Health database would produce a research database, updated annually, describing the health conditions and health service patterns of First Nations Peoples in Manitoba. This Registry would be maintained by Manitoba Health under lock and key and would not be available to any party for any purpose without the written agreement of the signatories to the memorandum of understanding.

Altogether, these initiatives illustrate that many forms of partnerships and research can develop when
there is a high level of trust and participation. They also show that scientific discourse, when there is trust and participation, can take root in the First Nations self-government value system and coexist with First Nations self-government to ensure that the strength of First Nations Peoples are known.

CONCLUSION

Alternative discourses are possible. Resistance in the form of counter discourses can produce new knowledge, speak new truths and constitute new powers such as First Nations’ ownership, control, access and possession of health information. Several initiatives helped produce the social and cultural structures necessary to produce counter knowledges in the area of First Nations health. Research agreements helped create a First Nations research network and partnership structure that could build and maintain trust and reciprocity. In return, they could generate a system of expectations and obligations. The membership attained through various partnerships and involvement in the Manitoba research network conferred both obligations and benefits to academic researchers and to First Nations health planners and service providers. What’s more, these agreements helped secure the necessary resources that First Nations Peoples can access through these partnerships or through their membership with research working groups or policy teams. As well, OCAP, as a social control mechanism, can protect the interests of First Nations communities.

These developments also demonstrated that capacity building is not just more computer training and greater exposure to quantitative methods and databases, but also the full engagement of First Nations self-determination and governance in health services and information systems. In Manitoba, capacity building extended across knowledge systems with the intent to build the necessary social connections, opportunities and agreements for internal and external agencies, organizations, institutions, departments, and ministries. The initiatives currently underway at the MFN-CAHR clearly demonstrate that distinct knowledge domains exist and can overlap to form partnerships where information can be exchanged between various forms of sovereignty (First Nations, university, federal and provincial governments). Building First Nations capacity in applied population health, however, has resulted in new restrictions on the freedom of academics and governments to conduct or present research on First Nations Peoples, and for good reason. The literature on First Nations health is dominated by pathologizing discourses. The social control function of OCAP will help undo this negative view of First Nations Peoples by uncovering the strength and resiliency of First Nations Peoples. The question for non-Aboriginal academics and governments to ponder is – are they open to agreements that respect First Nations determination, that build First Nation research capacity and that oblige them to enter the politics of trust and participation?

In this new environment, non-Aboriginal researchers and governments will have to recognize that any work involving Aboriginal Peoples will occur in the context of resistance to colonization. Such resistance, however, creates the possibilities for collaboration. The previously described experiences illustrate collaboration is possible, but much work will occur on the margins between various knowledge domains and forms of sovereignty. For collaboration to be possible and successful, researchers will have to reflect on the positions represented by others, make every attempt to understand these positions within the context they occur, recognize that trust and participation is conditional, and accept that any sharing and production of health information will occur at the boundaries between systems of knowledge.

ACKNOWLEDGMENTS

The accomplishments reported in this paper would not have been possible without the strong will and determination of Audrey Leader who passed away in April 2002 after a lengthy illness. During her tenure as Health Director for the Assembly of Manitoba Chief, she rallied Manitoba First Nations communities and governing organizations to embrace health information as a means to advance self-determination over health service delivery and to improve the health of Manitoba First Nations Peoples through the determinants of health. Indeed, her great spirit, sense of humour, self-determination, and willingness to forge new partnerships made the Manitoba First Nations Centre for Aboriginal Health Research a reality. The authors would like to also acknowledge members of the Assembly of Manitoba Chiefs Health Information and Research Committee who were equally as important to the development of a Manitoba First Nations Health Information System and who are continuing to lead the way in advancing the principles of OCAP. The authors would further like to thank the staff of the Centre for Aboriginal Health Research, particularly Dawn Stewart, for their dedication and commitment to making all this possible. Financial support was also critical to our success. Support for the Summer Insti-
tute Program was received from the former National Health Research and Development Program of Health Canada. Funding from the Institutes of Aboriginal Peoples’ Health, Canadian Institutes of Health Research and other research granting agencies is making possible the diverse and strong research and training program offered at the Centre for Aboriginal Health Research.

ENDNOTES

2. Foucault, Discipline and Punish.
3. The term discourse refers to any authoritative way of describing. Discourses are propagated by individuals and institutions and are used to divide the world in specific ways. For instance, discourses can constrain the production of knowledge, restrict dissent and difference and at times produce new knowledge and difference(s) that can oppose (or counter) the knowledge produced by the status quo. B. Elias and J. O’Neil, A Study into the Social, Cultural, and Disciplinary Understanding of Risk Perception and Risk Acceptability of the Contaminants in the Canadian Arctic (Arctic Environmental Strategy – Contaminants Program, Indian and Northern Affairs Canada, 1995). J.D. O’Neil, J.R. Reading and A. Leader, “Changing Relations of Surveillance: The development of a discourse of resistance in Aboriginal epidemiology,” Human Organization, Vol. 57(2) (1998), p. 230-237.
11. FNIRHS National Steering Committee, National Report.
12. NIRHS National Steering Committee, National Report.
20. Northern Health Research Unit, A Report on the Activities of the Northern Health Research Unit, 1988-1990 (Northern Health Research Unit, Department of Community Health Sciences, Faculty of Medicine, University of Manitoba, 1991).
ABORIGINAL CONDITIONS

Research as a Foundation for Public Policy

Edited by Jerry P. White, Paul S. Maxim and Dan Beavon
University of British Columbia Press, 2003
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What role does social science research play in public policy decisions on Aboriginal issues? How can policy makers, Aboriginal organizations and social scientists collaborate to best serve Aboriginal communities and the policy making processes that affect them? Aboriginal Conditions considers such questions with an aim to promote policy making that is firmly based on social scientific evidence.

Aimed at three main constituencies – Aboriginal and non-Aboriginal social scientists, government and Aboriginal policy makers, and Aboriginal communities – this book has multiple purposes. First, it presents findings from recent research with the goal of advancing a research agenda and stimulating positive social development. Second, it encourages greater links between the social scientific and external research communities and demonstrates the kind of research needed as a foundation for public policy. Finally, it acts as a guide to research methods for Aboriginal communities and organizations and promotes co-operation between researchers and Aboriginal Peoples in an effort to ensure that research decisions serve both groups equally.
Ownership, Control, Access, and Possession (OCAP) or Self-Determination Applied to Research

A Critical Analysis of Contemporary First Nations Research and Some Options for First Nations Communities

By Brian Schnarch
First Nations Centre
National Aboriginal Health Organization

Abstract

The principles of ownership, control, access and possession (OCAP) crystallize themes long advocated by First Nations in Canada. Coined by the Steering Committee of the First Nations Regional Longitudinal Health Survey, the principles are discussed as an expression of self-determination in research. The key notions outlined in this paper relate to the collective ownership of group information; First Nations control over research and information; First Nations’ management of access to their data and physical possession of the data.

Following a critical review of colonial research practices and recent institutional efforts to improve ethics in Aboriginal research, this paper highlights policies and strategies adopted by First Nations organizations – approaches which offer a way out of the muddle of contemporary Aboriginal research and the ethical dilemmas that characterize it. The benefits of OCAP are described including the rebuilding of trust, improved research quality and relevance, decreased bias, meaningful capacity development, and community empowerment to make change.

Key Words
Aboriginal, First Nations, Indigenous communities, research ethics, self-determination, collective rights, participatory research, research methods, ethics review

INTRODUCTION

Ownership, control, access, and possession, or OCAP, is self-determination applied to research. It is a political response to tenacious colonial approaches to research and information management. OCAP has become a rallying cry to many First Nations and should be a wake up call for researchers. It offers a way out of the muddle of contemporary Aboriginal research and the ethical dilemmas that characterize it.

The principles of OCAP apply to research, monitoring and surveillance, surveys, statistics, cultural knowledge and so on. OCAP is broadly concerned with all aspects of information, including its creation and management.

Originally coined as OCA – a more resonant acronym with its nod to the 1990 Oka Crisis – OCAP is changing the way research is done. OCA originated during a 1998 brainstorming session of the National Steering Committee of the First Nations Regional
Longitudinal Health Survey (RHS). The original acronym has been attributed to Cathryn George, a member of the committee representing the Association of Iroquois and Allied Indians.

Although OCAP originates from a First Nations context, many of the insights and propositions outlined are relevant and applicable to Inuit, Métis and other Indigenous Peoples internationally. Likewise, although many of the examples provided here are related to health information, the OCAP principles have broader application.

The notions inherent in OCAP are not new. The term’s salience lies in the fact that it crystallizes themes advocated by First Nations for years. Although there may be a good degree of consensus, the meanings and implications of OCAP continue to take shape and to be debated. OCAP is not a doctrine or a prescription. It is a set of principles in evolution. This paper seeks to contribute to the discussion by offering some context and critical analysis and by outlining strategies for putting the principles into practice. The following definitions are offered to help bring some focus to the subject:

**Ownership**

Ownership refers to the relationship of a First Nations community to its cultural knowledge/data/information. The 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 or care taking of data or information by an institution that is accountable to the group is a mechanism through which ownership may be asserted.1

**Control**

The aspirations and rights of First Nations Peoples 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 First Nations Peoples, their communities and representative bodies are within their rights in seeking to control all aspects of research and information management processes which impact them. First Nations control of research can include all stages of a particular research project – from conception to completion. The principle extends to the control of resources and review processes, the formulation of conceptual frameworks, data management and so on.

**Access**

First Nations Peoples 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 First Nations communities and organizations to manage and make decisions regarding access to their collective information. This may be achieved, in practice, through standardized, formal protocols.

**Possession**

While ownership identifies the relationship between a 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 is in the possession of another, there is a risk of breach or misuse. This is particularly important when trust is lacking between the owner and possessor.

Most importantly, OCAP is forward-looking and pro-active. It opens up new avenues for the expression of self-determination and self-governance in the areas of research and information and provides a measure of hope for positive change. Before looking at the way forward, a review of the challenges posed by past practices in First Nations as well as Inuit and Métis research is in order.

**WHERE RESEARCH HAS GONE WRONG**

OCAP has been described as “a political response to colonialism and the role of knowledge production in reproducing colonial relations.”3 Much of the impetus for OCAP can be linked to the sorry history of research relations with Aboriginal Peoples in Canada. According to the report of the Royal Commission on Aboriginal Peoples:

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,

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**AUTHOR’S NOTE**

The First Nations Regional Longitudinal Health Survey was previously known as the First Nations and Inuit Regional Health Survey. The name was updated for the current survey to reflect the project’s longitudinal nature and the decision of Inuit groups to pursue Inuit-specific processes.
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.4

“We’ve been researched to death.” It has been said many times. To understand what it means, consider some of the recurring grievances about research and researchers over the years. These complaints provide the backdrop out of which OCAP emerges.5

• First Nations have been subject to too much research.6
• The majority of research projects are initiated, paid for and carried out by non-Aboriginal people from universities, government and industry.
• Researchers have selected subjects of personal or academic interest or of interest to the larger society, but have not been interested in First Nations priorities.
• Researchers have essentially pre-empted meaningful community involvement by presenting completed research designs, often already funded, for community approval rather than collaborating from the start.
• Governments gather administrative and other data on First Nations without their knowledge or consent.
• Governments and researchers analyze, interpret and report First Nations data without consent, approval, review or input by First Nations representatives.
• Research funding is largely controlled by a few external agents and is generally not accessible to community groups and First Nations organizations.
• Researchers have profited professionally and economically from First Nations research without employing local people or compensating research subjects.
• Researchers have treated First Nations as merely a source of data.
• Researchers have pressured community authorities and individuals to support or consent to a project, because it is “good for the community” rather than asking community members what kinds of projects might serve their needs.
• Individuals have felt pressured to participate in a study or other data gathering process because community authorities have consented or are involved.
• Individuals have been persuaded to participate in research without fully understanding risks to health and safety or the potential application or misapplication of research outcomes.
• First Nations have been led to believe that participation in a research project is necessary in order to maintain their right to health services.
• Researchers have not explained their studies in a language or manner adequate to ensure fully informed consent.
• Researchers have treated First Nations researchers as informants rather than colleagues and have appropriated or failed to acknowledge some of their work.
• Although community Elders consider certain researchers unworthy to speak the community’s truths, researchers rely primarily on peers and funding agencies to confer their speaking rights.
• After building good rapport, members of a research team have been replaced with people who are not known or trusted by the community members.
• Researchers have not respected individual or community confidentiality to the same degree that they would for non-First Nations people.
• Research has disrespected basic human dignity of participants or their religious, spiritual or cultural beliefs.
• Researchers have collected First Nations genetic material for purposes that are demeaning to the dignity of First Nations communities and individuals.
• Researchers have gathered information on dissident Indigenous groups, which has later been used against them by repressive regimes (e.g. in South America).
• Researchers have disregarded cultural taboos and secrecy by publicizing (and sometimes profiting from) sensitive cultural information. They have also presented cultural information out of context and drawn inaccurate conclusions.
• Human remains and cultural property have been taken for storage, display in museums, or sale.
• Information made available by researchers has been distorted, appropriated and treated as a commodity. For example, First Nations legends and stories have been used for movies, books, toys etc. Spiritual practices and ceremonies have been adapted and often marketed to practitioners of New Age spirituality.
• Researchers, particularly from governments and industry, have collected information about traditional remedies, sometimes under false pretences, in a search for medicines to be patented and commercial gain.
• Researchers have used leftover portions of blood samples for secondary research without consent.
Researchers have recklessly sensationalized problems among First Nations, without regard for impact on communities or their social and political interests.

Research focuses on problems without looking at the positive and has often portrayed First Nations as poor, sick, dependent, violent, and child-like.

Research results are not returned to the community or they are returned in a form or language that is inaccessible.

Benefits to First Nations individuals and communities are often unclear.

Many, if not most, First Nations Peoples and communities can relate to at least some of these grievances. Although research in other contexts can fall prey to similar pitfalls, there are a number of reasons why they occur more frequently and are most acutely felt in First Nations communities. Key among these are the small size of First Nations communities and their relative lack of power.

Mainstream society is large enough to more effectively dilute the impacts of research. In First Nations research, the researcher-to-subject ratio is generally higher and communities are usually more tightly knit. Thus, a larger proportion of the population is researched and any negative influences or impacts may well reverberate through the whole community. More significant, though, is the difference in power between First Nations Peoples and communities and the mainstream researchers, government and industry representatives who come to study them.

Researchers, government officials and corporations (including those that are Aboriginal) may or may not understand, support or even be aware of the aspirations of First Nations. They may not prioritize and may even be at odds with community interests. Nonetheless, researchers are generally seen by both Aboriginal and non-Aboriginal people as unbiased experts, endorsed by others with power, and able to speak with authority about First Nations realities. When the results of a study about First Nations, Inuit or Métis health are presented in a scientific journal, at a conference, or at a government policy planning session, academics and government people typically do the talking. In key venues where truth and facts are established about them, First Nations Peoples, themselves, have to shout to be heard, assuming they are present at all. In the research game, the playing field is anything but level.

To put it more succinctly, the problems with research stem from who is in control – and thus what gets done and how it is done – and who knows about it. The question of whose interests are served is central. And of course, there is an unambiguous relationship between control and benefit. Ceal Tournier, former co-chairperson of the First Nations Information Governance Committee (FNIGC), put it this way: “He who controls the data, controls the gold.”

**HOW RESEARCH HAS TRIED TO RIGHT ITSELF**

Ethical guidelines and their enforcers – research ethics boards – are designed to rein in the researchers and encourage/ensure appropriate research practices. They aim to lessen the power differential between researchers and subjects and between researchers and Aboriginal communities or groups. According to a paper prepared for the Inuit Tapirisat of Canada: “Where power, knowledge and authority are clearly unequal, ethical guidelines seek to place limits on the exercise of power by the powerful – chiefly by moral suasion.”

In Canada, the Tri-Council Policy Statement (TCPS): Ethical Conduct for Research Involving Humans, adopted by the three major funding agencies, is the established norm for the ethical review of research. Following a series of revisions, the TCPS included a section on research involving Aboriginal Peoples. Unlike the rest of the document, this section restricted itself to discussion and a listing of best practices. The section is prefaced as follows:

During the drafting of this Policy Statement, suggestions were made to create a Section dealing with research involving aboriginal peoples. The Councils, however, have not held sufficient discussions with representatives of the affected peoples or groups, or with the various organizations or researchers involved. The Councils have therefore decided that it is not yet appropriate to establish policies in this area. The text of Section 6, which builds on the extensive literature on research involving aboriginal peoples, is intended to serve as a starting point for such discussions.

Several years later, the consultations have yet to occur. Nonetheless, the ideas outlined in the TCPS, however tentative, are based on an international literature review – primarily Australian, Canadian and American – and reflect the current shift in thinking about Indigenous research.
The concepts of participatory research and community involvement, the incorporation of traditional knowledge, culturally-appropriate, and community-based research methods have gained momentum in recent years within First Nations and Inuit settings. Important exchanges have been held on the issues and there is a growing body of literature about research ethics in Aboriginal communities. In many cases, researchers have adopted fresh approaches and strategies.

These changes are in no small part a direct response to increasing opposition from First Nations Peoples fed up with the research status quo. Researchers, to some extent, have had to adapt and innovate in order to stay in the game.

Doing respectful research in Aboriginal communities takes more time, more money and, arguably, moral fibre. Imagine having to get permission from Chief and Council, attend joint advisory committee meetings and solicit input from the Elders, in addition to your regular supervisor in order to do your job. The tendency to fall back on the simpler tried-and-true approaches will be strong. There are significant pressures on researchers to complete their projects in a timely manner, publish extensively and for students to complete their theses and get their degrees before debt overshadows them. These considerations are at cross-purposes with the requirements of ethical research.

A more respectful and ethical approach to research in Aboriginal communities has gained momentum in recent years, but it is not a given. The implications of this new approach were crystallized during a 1995 conference on ethics in Aboriginal and Northern research. Referring to this emerging understanding, some participants commented that certain researchers and government officials simply didn’t “get it.” On the other hand, a lot of people did “get it” – some for the first time.

The importance of “getting it” underlined the need for the education or re-education of researchers. It also raised important questions about individual suitability. Some individuals may simply not have the necessary sensitivity or interpersonal or research skills to work in a First Nations, Inuit or Métis setting.

New Ethical Guidelines

For those who do or want to “get it,” there are a number of important ideas described in recent documents. Generally, the documents deal with practices, standards, principles, and guidelines. They discourage the long list of bad practices described in the previous section and promote the following:

• All of the usual ethical requirements for research, such as individual informed consent and confidentiality, apply in addition to others specific to the Aboriginal context.
• Researchers should provide ongoing explanations of all aspects of the research project, including its purpose, sponsorship, anticipated benefits and risks, methods, community and individual involvement, and reporting plans.
• Community involvement, participation and consultation are required. Some documents go further by identifying community consent as a requirement (the TCPS does not), also noting that research should be suspended if deemed unacceptable by the community.
• The research relationship must be negotiated, ideally resulting in a written agreement or contract.
• Local and traditional knowledge should be incorporated.
• Research must respect the privacy, protocols, dignity, and individual and collective rights of Aboriginal Peoples. It must also derive from Aboriginal culture and validation methods.
• Meaningful capacity development for Aboriginal Peoples should be incorporated into the project.
• Reports and summaries should be returned to communities in an appropriate language and format.
• Aboriginal Peoples should have access to the research data, not just the reports.
• Community protocols should be respected.
• Community interests should be supported, benefits maximized and harm reduced or avoided.

Before turning to the merits and limitations of these principles, it is important to note that, from the perspective of an Aboriginal community, the guidelines are a form of government/academic self-regulation. Government and the academic research communities have their own set of rules and expectations for how members should behave. The rules may or may not be in the best interests of Aboriginal communities.

The existing research ethics guidelines and the research ethics boards (REBs) that apply them can provide a (sometimes false) sense of security. Unfortunately, the guidelines and REBs are not necessarily able to adequately address First Nations, Inuit or Métis research issues and generally do not have Aboriginal participation or mandates. While self-regulation is entirely understandable and well intentioned, it can have the ironic impact of precluding direct First Nations’ regulation of research.

Returning to the principles clearly stated by the new ethical guidelines, perhaps the most important
and progressive element is the move beyond mainstream concern with individuals to a focus on issues related to communities or groups of people. Although many of the principles apply to other groups with common interests or conditions (e.g. Montrealers of Haitian origin, men with prostate cancer), the case of Aboriginal communities is afforded additional consideration, in part because of the unique Constitutional rights and distinct legal status of Aboriginal Peoples in Canada. According to the TCPS ethics policy statement, Aboriginal Peoples “have distinctive perspectives and understandings embodied in their cultures [...and...] have a unique interest in ensuring accurate and informed research concerning their heritage, customs and community.”

ABORIGINAL RIGHTS AND JURISDICTION

The recognition of alternative, culture-based perspectives and understandings, although an important step forward, is a pale reflection of the broader legal assertions of First Nations. Recognition of the unique status of First Nations as nations and of their inherent, Constitutional and treaty rights has important implications for research and data. Jurisdiction over research, not simply unique interests, are recognized in the following statements from the Kahnawake Research Ethics Code, Martha Flaherty of Pauktuutit and United States Indian Health Service:

The sovereignty of the Kanien’ke ha ka (the people) of Kahnawake to make decisions about research in Kahnawake is recognized and respected.17

We, Inuit, have more than a “valid concern” over the conduct of ... research, we have RIGHTS... It is time for Inuit to set our own terms [which researchers] who want to come to our land... must abide by.18

All research involving American Indian/Alaska Native tribes [must] be approved by the tribal governments with jurisdiction.19

First Nations governance and self-government imply jurisdiction and control over a full range of institutions and processes, including research and information. Developing a research project or agenda, setting up a research or statistical office, or implementing an information system are all parts of good governance.

In a thoughtful analysis prepared for the Royal Commission on Aboriginal Peoples, Russel L. Barsh outlines the interaction between the three minimum requirements for effective government: power, resources and legitimacy.20 OCAP touches on all three.

Power, according to Barsh, is the authority to act, whether derived from a constitution, laws or custom. Most importantly, the actions of a government need to be recognized and respected by other governments and institutions. OCAP asserts First Nations’ authority to control their own research and information.

Resources include natural, financial and human resources as well as information, knowledge and technology. In recent years, information and information technology have emerged as critical to both the economy and to governments. Information can produce prosperity and can serve as the bedrock for policy and planning. OCAP is about enhancing First Nations’ resources. It is about nation building.

Legitimacy refers to support and public confidence in a government. Information serves to help governments make better decisions and stay in step with their constituents. Governments use information to inform, educate and remain accountable. When outsiders control information, two things can happen: legitimacy of First Nations governments is undermined and the information is suspect in First Nations’ eyes. OCAP is about legitimacy and accountability for First Nations’ authorities and institutions.

DEFINING THE RESEARCHER

OCAP draws the questions of who into focus. While emerging ethical guidelines encourage better representation in the research process, the principles of OCAP suggest that First Nations communities and groups can also lead or control it. More fundamentally, OCAP raises questions about the rules of the game – what constitutes proper research – and the ability and biases of existing gatekeepers (e.g. academic peer review committees, funding agencies) who evaluate Aboriginal research.

Conventional understandings of who the players are and how the game is supposed to be played are deep rooted. Assumptions can be implied or clearly defined in a variety of ways. Funding program criteria and ethical research guidelines present windows onto how the rules are determined.

First, consider this declaration from the introduction to a set of Australian Indigenous research guidelines:21 “At every stage, research with and about In-
Indigenous peoples must be founded on a process of meaningful engagement and reciprocity between the researcher and the Indigenous people.”

This generally constructive statement betrays something important. Notice that there are two parties: researchers and Indigenous Peoples. Notice also that the relationship is between a single researcher from the outside and the Indigenous Peoples – an image reminiscent of classic anthropological methods as well as a large number of movies in which a single white hero helps or saves a tribe of nameless Native Peoples.

It is, by definition, the researcher – whether doctor, scientist, expert, student or government agent – who does the research. Communities are consulted, involved or are supportive. They consent. They may be partners. Generally speaking, they are not researchers.

Restrictive definitions of research and researchers are spelled out in project and program funding criteria. Generally speaking, Aboriginal communities and organizations have limited access to research funds, unless they partner with a proper researcher. The researcher must have the appropriate track record and credentials – conferred by peers – and must be affiliated with a recognized institution, usually a major Canadian university. The researcher, not the Aboriginal partner, receives the funding and is responsible for completion of the project.

**Model from the United States**

More OCAP-friendly alternatives are emerging. Perhaps the most significant example is an initiative from the United States. The American Indian Health Service announced funding for Native American Research Centers for Health (NARCH). The multi-million-dollar strategy debuted in 2001 and has been affirmed and expanded for four additional years since then. Some key elements of the program that depart from the normal way of doing business are shown in Table 1.

The Indian Health Service program unambiguously defines American Indian organizations as research organizations and their staff as researchers. At the same time, the 70 per cent rule helps ensure AI/AN organizations will benefit by making it impossible for university-based researchers to use AI/AN organizations as fronts to flow funding.

**Model from Northern Quebec**

Another example of innovation in funding criteria, from the author’s own experience in Northern Quebec, provides some insight. In the early 1990s, the Health Board for the Inuit region of Nunavik restricted its research-funding program to local and regional organizations. This was a departure from years of funding projects designed and implemented by outsiders from the south. The new policy resulted in two distinct shifts: a gradual increase in the number of true

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<th>Table 1: American Indian Health Service’s Native American Research Centers for Health</th>
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<td><strong>Purpose of Program</strong></td>
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<td><strong>Recipient of Funds</strong></td>
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<td><strong>Principal Investigator</strong></td>
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community-led projects and a renegotiation of relationships between several university-based researchers and regional/community groups.

Most of the projects under the new criteria involved a Northern promoter partnering with or contracting a university-based researcher(s). In some cases, southern-based researchers essentially used regional organizations to administer and flow funds with little or no input into the project. (There was no equivalent to the IHS’ 70 per cent rule.) This generally involved a friend of the project or of the researcher based at the Northern organization. In other cases, there was a close partnership based around a southern-designed project. In a few cases, projects were initiated by Northern organizations and carried out by external researcher(s) or students on contract. In those cases, the researchers were generally also able to use the work to advance their academic careers.

Most interesting were the true community-based projects. At first, many of the applications did not fit program criteria. Differences in perspective were revealed. Community leaders and workers generally want to take action on problems, not study them. They wanted intervention, not research, dollars. Also, generally speaking, community members saw research as something done by experts from the south.

Promotion of a broader definition of research, which spoke to community experience, helped to refocus the issue. For example, making the connection between data gathering and analysis and the skilled and organized methods required to make decisions about a hunt or camp move helped demystify the research process. From that perspective, Inuit have always conducted their own research. This refocusing of research and a relatively broad definition of eligible projects encouraged applications from organizations that had never previously led research projects. Other factors that increased accessibility include active promotion of the program; a short, plain-language, tri-lingual application form and guide; and the availability of ongoing assistance for proposal writing, methodology and all aspects of project implementation.

Among those projects that were led and carried out by communities themselves, the level of scientific rigour was uneven. But in terms of project relevance, developing and drawing out community capacity and ultimately in terms of community impact, these homegrown projects were clearly superior.

CAPACITY AND QUALITY

Capacity development and OCAP are interwoven. They are the warp and the weave that support successful First Nations-controlled research initiatives. On the one hand, the capacity to access resources, manage and carry out research, and promote and disseminate results makes it possible and desirable to have control. On the other hand, having control implies a sense of ownership and responsibility that motivates – even requires – accelerated capacity development.

But what kind of capacity development is most useful? The first and most obvious answer is that all kinds of capacity development – in all aspects of research – are needed. The next answer is that, while capacity development should benefit individuals, it must also support and build Aboriginal communities and organizations. Capacity building is fundamental to nation building, not just career building. The implications are important.

Increasing the number of First Nations, Inuit and Métis Peoples with PhDs related to research, while laudable, does not by itself necessarily result in any benefit to the community. In fact, the individuals are often lost to their communities as they pursue careers in the mainstream. Government and university departments and industry are the actual beneficiaries.

The potential for Aboriginal communities to benefit from their people working within the system is unclear at best. Meanwhile, opportunities to work directly for the community in a research capacity are rare. There is also concern about the effect of assimilative education processes on First Nations students in mainstream universities. Holding on to First Nations perspectives, values and interests while learning and working in academia, industry or government is a monumental challenge. First Nations students in academia may have to work twice as hard to meet and bridge academic and community expectations. They are sometimes forced to make difficult choices between their values and advancing their careers as they walk a two-culture tightrope.

The way out of this apparent catch-22 is to implement strategies that provide individual opportunities that also produce benefits for the collective. Putting research dollars into First Nations communities and organizations23 and other strategies that increase First Nations control tend to serve both purposes.

The issue of research capacity quickly leads to questions about quality (i.e. scientific excellence, rigour). Critics of OCAP are quick to raise concerns
about the potential consequences if appropriate expertise is not present. Some may say:

• We believe 100 per cent in community control, but we need to ensure that the community-based capacity is there.
• These things require a high level of expertise.
• But a partnership will ensure strong, reliable results and I’m sure the community would want that.

These kinds of suggestions may appear supportive and helpful at first glance. On closer inspection however, paternalistic assumptions are revealed. They imply communities cannot go it alone and cannot grasp the mysteries of serious research. The upshot is that it would be best for everyone if the researchers, in the conventional sense, stay in control. The paternalism, distrust and generally low expectations of First Nations research capacity mirror attitudes towards self-governance, described below in the American context:

Studies of intergovernmental relations on Indian reservations in the past 20 years, for example, show that in the unhealthy and unproductive stages of these relationships, state and local government tend to object to the very idea of tribal government itself, the notion often being that Indian people should not have the right to and lack the capacity for self-government in any circumstances.24

Undeniably, building capacity is important. It is a central principle of countless Aboriginal initiatives undertaken in the last decade in just about every field. There is, therefore, something perverse about using lack of capacity as an argument to quash or take control of Aboriginal initiatives. Discouraging messages about Aboriginal non-capacity are deeply ingrained and can be heard from both Aboriginal and non-Aboriginal people. Fortunately, the growing number of Aboriginal success stories – in research and in other areas – is helping to overcome the false stereotype that Aboriginal Peoples can’t do it.

As former First Nations Centre Director at the National Aboriginal Health Organization Gail McDonald has often noted, “research is not rocket science.” At least not all research has to be. While specialized, education-intensive research is undeniably important in many disciplines. It is not the only, nor necessarily the most worthwhile type of research. This is particularly true when looking at population health or social phenomena. Complex methodology, sophisticated academic frameworks and scientific jargon are not – or should not be – the only game in town.

Decisions about whether to fund a research project or allow publication of the results are normally made on the basis of culturally circumscribed notions of quality. Typically, scientific excellence, rigour or some variant is the primary yardstick. From inside academia, the measures may seem obvious and uncontroversial. For many Aboriginal communities and organizations, scientific excellence is a self-serving barrier that keeps control and resources where they are.

In addition to excluding those lacking the formal credentials, conventional thinking about what constitutes good research effectively puts blinders on the research endeavour, restricting it to a western, scientific model – an approach that is particularly ineffective in Aboriginal and other non-western societies.

According to Dr. W. Freeman, research that relies on Aboriginal knowledge and ways of knowing is, in all likelihood, methodologically stronger as it diminishes outsider biases.25 Although OCAP does not guarantee the development of Indigenous research frameworks, it does provide fertile ground for their development.

What other means of assessing the value of a research project or report could be adopted? Consider the following anecdote:

An Aboriginal community of about 1,000 people wanted to assess the extent of the solvent abuse in their community and find solutions that could be applied by their locally-controlled treatment facility. They wanted to know which kids were sniffing and how to help them.

An outside researcher conceived a careful, ethically-sensitive and scientifically-rigorous approach involving one-on-one confidential interviews with school children. If implemented, the results were expected to help identify risk groups and risk behaviours. The proposed study would provide only a rough idea of numbers and, certainly, no names. The results would be available in about two years, if all went well.

The community did not want to wait so long for so little return. An alternate research strategy was quickly put into place. A small delegation of respected adults went from classroom to classroom and asked the students “Who sniffs?” Generally after a pause, the
children turned and pointed fingers to the sniffers. The data collection, which confirmed suspicions, was complete in an afternoon. Discussion with sniffers and their families ensued and the students and families received offers of support, counselling and treatment.

It is rather unlikely that this project would have passed a conventional academic review process. It would likely have been declared unethical and the scientific merit would have probably received a score close to zero. In fact, it is doubtful that the project description would have ended up on a 40-page application in the first place.

Was the community’s initiative a bad idea? Should it have gone ahead? Could it even be qualified as research? These questions aside, the story suggests that a simple, home-grown research strategy can be quicker, cheaper, more relevant, and more useful than a painstaking and complex methodology. Further, because the approach was conceived and implemented by the community to meet community goals, the commitment to follow-up and deal with potential fallout was strong.

The most elegant study design in the world is only as valuable as the impact that it makes in people’s lives. By the same token, a methodologically inferior study can have tremendous impact and benefit. The answer to the question of how to evaluate research now suggests itself. Rather than focus on scientific excellence, an assessment of potential and anticipated community benefits, however these are measured, could be emphasized.

This is, by no means, an argument against high quality research. All else being equal, a higher quality project is more likely to produce positive results. The point here is that, particularly in an Aboriginal context, community relevance and community usefulness may be the most telling measures of the worth of a study. The question of quality is subordinate. The next point is that a community-driven, community-controlled project is more likely, although not guaranteed, to score highly on those measures.

Aboriginal communities have gone along with externally-driven research – both excellent and not-so-excellent projects – for generations with relatively few examples of clear benefit. Is it now time to support communities’ own research initiatives – whether they are excellent or not? The potential benefit is tremendous.

**OCAP IN PRACTICE**

OCAP hinders bad research practices and fosters good ones. The real challenge now is how to do research in ways that respect OCAP. The challenge is taken up and worked through in a variety of ways.

In trying to put the principles into action, it is important to recall that at the heart of OCAP is self-determination, including recognition of First Nations jurisdiction over research in their communities. It is also important to remember that OCAP represents a threat to existing authority. It is a threat that is guaranteed to be taken up on many fronts.

**Resistance**

One of the first responses to this perceived attack is that it has been taken too far. Those who have something to lose from a redistribution of power might complain. Some may say:
- You need to compromise.
- If you are too inflexible in applying your principles, you’ll end up with nothing.
- Your principles are getting in the way of essential research that is needed to develop policy or interventions to improve Aboriginal health.

They may also cite concerns about capacity (described in the previous section) or the threat to their academic freedom and the pursuit of the objective truth.

While not outright rejections of OCAP, these positions are important challenges. On the part of the researcher, they imply unwillingness to compromise and a resistance to adopting new approaches. The attribution of blame for perpetuating poor health conditions is particularly insidious. A community might reply that it is the researchers who need to rethink their principles and that it is their inability to adapt that is continuing to put health at risk.

Ultimately, some researchers might look elsewhere, where there are fewer hurdles. Before mourning such a loss, a community might do well to ask itself what it is really losing here. Undoubtedly, the answer will sometimes be not much. At other times, when the community perceives great value in a given project, they may seek to carry it out themselves, with or without the involvement of another, more amenable researcher.

However communities choose to interpret and apply OCAP principles, the road ahead is bound to be rocky at times. Until OCAP is better understood, more firmly entrenched, and researchers and Aboriginal groups find new ways of relating, some research will undoubtedly be held hostage.
Strategies

The parties involved will have to judge: how to respect OCAP and get research done; what compromise is acceptable; whether to proceed with a project; and under what terms.

Consider the following strategies. They have been employed by First Nations organizations.

- Be clear about what you want and don’t want to get from research. Determine priorities.
- Become more informed and share information about research initiatives that impact your community or constituency. Influence them. Talk to their proponents. Seek to improve First Nations representation in key decision-making venues (e.g. university and government committees).
- Transfer or take over First Nations initiatives run by non-First Nations entities (when appropriate and properly resourced).
- Refuse to participate in processes that do not respect OCAP or First Nations protocols.
- Seek advice and support from Elders and leadership. Educate leadership. Raise the profile of health research/data issues.
- Self-fund autonomous research projects run by and for your community or constituency with little or no outside involvement.
- Develop culture-based frameworks, methods, tools, training, review, and reporting strategies. Don’t let anyone tell you: “That’s not the way you do research.”
- Model good research practices by following stringent ethical guidelines and community and cultural protocols.
- Build research skills among people in your community or organization. Focus on those who have a strong commitment to the community.
- Access research funding sources with criteria and processes that are community/Aboriginal friendly.
- Identify respectful researchers and cultivate long-term relationships with them. An excellent discussion and template to help communities negotiate research relationships was prepared in 1993 for Dene and Métis in the Northwest Territories.26
- Collaborate with other like-minded Aboriginal groups/communities.
- Build on successful First Nations initiatives and processes.
- Negotiate written agreements or memoranda of understanding that spell out the research relationship between your community or organization and your research partner(s).
- Require review prior to publication of research involving your community or constituency.
- Alternatively, agree to a right to dissent - an elegant solution to the conflict between academic freedom and OCAP, whereby each party can include their own interpretation in any publication. The need to actually resort to this sort of he-said, she-said scenario is extremely rare as partners are motivated to work out their differences.
- Contract, rather than partner with, researchers (if you can afford it). The contract involves the purchase of services and makes clear the lines of accountability.
- Spread it around. By involving numerous parties in various capacities at various stages, you can avoid having one of them overwhelm and control. Be wary, though, of situations where the community or First Nations organization is outnumbered or outgunned by experts.
- Develop a code of research ethics, guidelines, policies, by-laws or legislation where applicable. Once in place, ensure they are disseminated, understood and respected.
- Set up a research review board.
- Develop data sharing strategies and agreements that maximize the distribution of information while protecting sensitive information.

Other strategies have undoubtedly been identified elsewhere as well. Because available capacity and resources vary, and because First Nations perspectives on OCAP do too, there can be no blanket prescriptions. Although larger communities and organizations may have more latitude in applying the principles, the potential for smaller groups to make change remains significant.

A more in-depth discussion of two of the key strategies is provided below:

**First Nations Research Policy**

Research guidelines and codes of ethics developed by First Nations quickly distinguish themselves from the self-regulating codes developed by funding agencies and universities. The policy statement excerpts from two recent codes – First Nations Regional Longitudinal Health Survey (RHS) and Kwanlin Dün Health Centre – are examples:

It is acknowledged and respected that the right of self determination of the First Nation and Inuit peoples includes the jurisdiction to
make decisions about research in their communities. The benefits to the communities, to each region and to the national effort should be strengthened by research. Research should facilitate the First Nation and Inuit communities in learning more about the health and well-being of their peoples, taking control and management of their health information and to assist in the promotion of healthy lifestyles, practices and effective program planning.27

And

It is acknowledged and respected that the right of self-determination of the Kwanlin Dün First Nation includes the jurisdiction to make decisions about research in the community. The Kwanlin Dün First Nation has designed this Code as a tool to assist in the protection and safety and well-being of the community in research activities and to facilitate cultural self-determination and preservation.

The Kwanlin Dün recognizes the importance of research to its community, Aboriginal people and society in general.

Research should benefit the community by providing information on the health and well-being of its people which will assist community leaders, health professionals and individuals to make decisions on health and health services which are based on evidence.

Research should empower the community to support community goals of health and wellness, capacity development, increased knowledge of health practices and benefits and provision of effective health services to its population.

When determining whether or not approval should be given to a proposed research project, greater consideration should be placed on the risks to the physical, psychological, human, proprietary and cultural values than to the potential contribution of the research to knowledge.28

Principles of the Mi’kmaq Ethics Watch address similar themes, emphasizing the role of the collective and of traditional protocols:

Mi’kmaq knowledge is collectively owned, discovered, used, and taught and so also must be collectively guarded by appropriate delegated or appointed collective(s) who will oversee these guidelines and process research proposals.

Each community shall have knowledge and control over their own community knowledge and shall negotiate locally respecting levels of authority.

Mi’kmaq knowledge may have traditional owners involving individuals, families, clans, association and society which must be determined in accordance with these peoples own customs, laws and procedures.29

Research policy documents prepared by First Nations include the following common themes and objectives:

• Research should provide clear benefits to First Nations Peoples and communities
• Research should help develop capacity in meaningful ways
• Research should increase First Nations control of information and research processes
• Research should respect sovereignty/jurisdiction/rights of First Nations
• Research should support self-determination
• Research should support cultural preservation and development

A growing number of communities and organizations have developed research and ethical guidelines,30 ethical review processes,31 privacy codes,32 and other key framework documents that can serve as models.

Data Ownership and Data Sharing

OCAP has gained the attention of some departments of the Canadian government in connection with negotiations around the sharing (or not) of survey databases.33 Because it is a fundamental resource in the research industry, the exchange and sharing of data has significant implications. In the information age, data is a form of currency.

Many researchers and others have argued that data cannot and should not be owned, that it should be freely available to all who wish to derive meaning from it. This seemingly progressive notion – essentially an adjunct of the search for truth – is a fallacy based on unexamined assumptions of power.
There is a mistaken assumption here that data is value neutral, ready to be gathered or collected and interpreted by anyone on an equal basis. In fact, data is not gathered, but created by those with the resources and opportunity to do so. Data is constructed through the choice of research framework, methods and instruments. Delsys Research Group describes the issue in connection with Statistics Canada’s activities:

Data are not out there existing absolutely. Instead, we (every single one of us) are situated in a social experience. What emerges as problematic from one experience may not be problematic to another experience. What emerges as an important area of study for Statistics Canada or government policymakers may not be an important area of study for First Nations. Who emerges as a legitimate knower in the problematic is a pre-research choice. What categories emerge as related to the problematic will differ based on social location and/or culture. Although analysis of the data is undertaken by Statistics Canada and also by outside institutions, the ability to control the epistemology and the creation of the data is central to defining the universe available for analysis or interpretation.

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.

A considerable amount of First Nations data is in the hands of entities that are not accountable to them. Returning that information to First Nations Peoples is similar to the protection of cultural medicinal knowledge, regaining sacred material from museums, or getting back land.

As First Nations become increasingly involved in research and in possession of research data, the question of whether to share that data and how becomes more important.

Sharing data provides opportunities to do more with it. By making their information available to others, First Nations groups can help maximize its dissemination and its potential impact. But this is a two-edged sword. Once data is out there, the way it gets used may or may not coincide with the community’s aspirations.

While certain types of information might seem to be fair game to a researcher, the community might consider them private or confidential. Sensitive cultural information, including knowledge and teachings about traditional medicines, may need to be kept within the community of origin. In many cases, community or group privacy may also be a cultural value. The desire to avoid the identification of specific groups has been heightened by unfortunate experiences involving stigmatizing depictions of specific communities and populations.

The First Nations Regional Longitudinal Health Survey (RHS) has developed a simple protocol to address collective ownership. Community level data or statistics are not released without the explicit permission of community authorities. The same applies to regional-level statistics. Nationally, a Chiefs-appointed steering committee, the First Nations Information Governance Committee, makes decisions about the release of nationally aggregated information.

Another consideration in decisions about data sharing relates to the uneven playing field for Aboriginal participants in research activities. Control of data can help counterbalance the relative lack of capacity and lack of voice at those privileged venues where the interpretation of data is heard and validated. The following protection mechanisms have been used both individually and in combination to help offset the imbalance:

- Releasing or sharing data only after there has been adequate time for the First Nations/Aboriginal group to complete and disseminate its own interpretation.
- Releasing/sharing data for specific and agreed upon purposes only.
- Releasing only tabular or statistical data for quantifiable information, not record-level information.
- Reviewing and approving prior to release of publications developed using the data or, alternatively, invoking a right to dissent.

Sharing statistics diminishes the potential for unforeseen and potentially incorrect or inappropriate analyses and interpretations. On the other hand, a large record-level database opens a wide and unpredictable range of outputs. It may be quite difficult to track the uses.

There are potentially substantial benefits to First Nations that decide not to share record-level data – benefits in the form of increased resources and capacit...
ity. If those interested in the data cannot perform the desired analyses for themselves, they may become clients of the First Nations data holder. The organization can offer data products and various reports, on a cost-recovery basis perhaps, while the staff and organization build skills in statistical analysis, report writing, etc. The release of statistics can also be linked to a review process that addresses data release and/or publication approvals.

Some researchers may balk at the idea of a First Nations review/approval process, construing it as political interference contrary to academic freedom. They do, however, readily accept the constraints of peer review for funding proposals, journal articles, and so on. As with academic review, a First Nations review process is generally intended to ensure quality of the work, its relevance, and the appropriateness of interpretation. The review should be viewed as an opportunity rather than a threat. The definition of peer needs to be broadened.

The RHS Code of Research Ethics outlines a procedure for First Nations review of analysis and interpretation “to ensure accuracy and avoid misunderstanding.”38 In the East, the Mi’kmaw Ethics Watch was formed to review research proposals according to Mi’kmaw Principles and Guidelines that “seek to ensure that the right of ownership of Mi’kmaw knowledge and heritage rests with the appropriate Mi’kmaw communities.”

Institutional review prior to publication is also a common requirement in both corporate and governmental contexts. Here is an excerpt from Statistics Canada’s policy:

All information products, and especially interpretative, analytical and methodological products, for which Statistics Canada is wholly or partially responsible, are subject to review prior to release outside the Agency. The review should ensure that their content is compatible with the Agency’s mandate as a government statistical agency, and that they adhere to the generally accepted norms of good professional practice.

These reviews consist of institutional review for all information products, and peer (professional) review for interpretative, analytical and methodological products…

Institutional review is intended to ensure that information products disseminated to the public are free of material which would compromise the Agency’s reputation for non-partisanship, objectivity and neutrality. Institutional review is a line management responsibility and is carried out as part of normal line management processes.39

The key challenge in data sharing is how to maximize benefits while protecting First Nations information. There are no right answers, only options to explore and practical decisions to be made considering the nature of the information and the interests of the parties. Over time, it is anticipated that proponents of OCAP will innovate various data sharing/data access protocols and some best practice options will emerge.

**THE BENEFITS OF OCAP**

The previous sections outlined how non-First Nations institutions have had a lock on research and information management through legislative authority, the control of funding, peer and ethical review processes, definitions of research and researchers, formulation of theoretical frameworks, methods and instruments, possession of databases, and so forth. OCAP underlines this situation as intolerable and calls for change.

The application of OCAP principles promises to deliver significant benefits to governments, researchers, First Nations Peoples, and their communities. Research and information management practices also stand to benefit. OCAP:

- Helps rebuild, and may be a prerequisite, for community trust. It allows research to happen where it might otherwise be impossible.
- Improves quality and accuracy because First Nations communities will invest more effort in data collection when the information is perceived as valuable.
- Results in more democratic (participatory) research methods.
- Translates into increased participation rates.
- Encourages a more holistic (First Nations) approach to health.
- Promotes coherent First Nations analyses and perspectives and minimizes the biases and misinterpretations stemming from other cultural frameworks.
- Contributes to community empowerment, self-determination, and healing activities.
- Produces more relevant and useful results, which lead to change.
- Encourages meaningful capacity development.40
Research is a tool for promoting changes that can transform people’s lives. Putting OCAP into practice enhances that potential. OCAP is part of the broader self-determination aspirations of Aboriginal Peoples. By regaining control of institutions and processes that impact them, communities build hope for a healthy future.

ACKNOWLEDGMENTS

The First Nations Information Governance Committee continues to shape the OCAP principles. Without their direction and vision, this paper would not have been possible. I wish to express my gratitude and appreciation to Gail McDonald of the Akwesasne Mohawk Territory. For more than 10 years, no one has worked harder for First Nations control and capacity in health and research.

ENDNOTES

2. The ‘P’ (Possession) was added to ‘OCA’ following a legal review by Krista Yao (Nahwegahbow, Nadjiwan, Corbiere) highlighting how statistical information in the government’s possession is readily accessible through Access to Information requests regardless of ownership or written agreements. Another example of how possession is nine-tenths of the law.
3. Espey, Stewardship and OCAP.
5. Several items paraphrased from: American Indian Law Center, Model Tribal Research Code: With Materials for Tribal Regulation for Research and Checklist for Indian Health Boards, 3rd edition (September 1999).
6. The same cannot be said for the Métis, among whom very little, some say not enough, research has been done.
7. Previously the National Steering Committee for the RHS, the FNIGC’s role was broadened to more globally address issues related to First Nations data, research and information issues. The group was mandated by and reports to the Assembly of First Nations’ Chiefs Committee on Health. It is composed of representatives from 10 regional First Nations organizations.
11. The funding agencies include the Canadian Institutes of Health Research (previously the Medical Research Council), the Social Science and Humanities Research Council, and the Natural Sciences and Engineering Research Council.
23. Indian Health Service, “IHS and NIH continue partnership in 2002 by expanding funds available for American Indian and Alaska Native Research Centers.”
25. Indian Health Service Research Program Director Dr. W. Freeman, Personal communication, Feb. 13, 2002.


31. The Mi’kmaw Ethics Watch, which reviews research proposals, is co-ordinated by the Mi’kmaw College Institute, University College of Cape Breton.


33. Most notably were negotiations related to the First Nations and Inuit Regional Health Survey.

34. Espey, *Stewardship and OCAP*.

35. The 1997 and 2002 FNIRLHS samples permit relatively little in terms of community level statistical aggregation.


37. Example include scientific journals, conferences, government meetings, and key government policy and briefing/background documents.


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**Call for Papers**

The *Journal of Aboriginal Health* will share success stories in Aboriginal health, discuss issues and opportunities, and provide the latest information and research of interest to First Nation, Inuit and Métis Peoples. It will publish in-depth analysis of health research and issues with full citation of sources; facilitate informed discussions on new research, recent publications and projects; and explore health determinants from an Aboriginal viewpoint.

This Journal is a tool for community members including traditional healers, Aboriginal health and social service care practitioners and organizations; tribal, treaty, regional, and national political organizations; Aboriginal and other Canadian health scholars and researchers; people who influence and determine Aboriginal health research and policy including Canada’s federal/territorial/provincial and Aboriginal politicians, public servants, consultants, think tanks, and foundations; and finally, anyone with an interest in Aboriginal health in Canada. Readers can use the Journal to share their work, experience and knowledge. They can also use it to refine and/or expand their thinking around Aboriginal health and Aboriginal Peoples.

While each issue will focus on a theme and solicit appropriate papers from a variety of perspectives under the direction of a Guest Editor, general research papers with an Aboriginal health focus will also be accepted.

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Communications Editor Virginia St-Denis
130 Albert St., Suite 1500
Ottawa, ON K1P 5G4
Phone: (613) 233-1543 ext. 512
Fax: (613) 233-1853, or
e-mail: vst-denis@naho.ca.
COLONIZING BODIES:
Aboriginal Health and Healing in British Columbia, 1900-50

By Mary-Ellen Kelm
University of British Columbia Press, 1999
ISBN 0774806788
272 pages

Recent debates about the health of First Nations Peoples have drawn a flurry of public attention and controversy, and have placed the relationship between Aboriginal well-being and reserve locations and allotments in the spotlight. Aboriginal access to medical care and the transfer of funds and responsibility for health from the federal government to individual bands and tribal councils are also bones of contention. However, comprehensive discussion of such issues has often been hampered by a lack of historical analysis.

Promising to remedy this is Mary-Ellen Kelm’s Colonizing Bodies. This book examines the impact of colonization on Aboriginal health in British Columbia during the first half of the 20th century. Using post-modern and post-colonial conceptions of the body and the power relations of colonization, Kelm shows how a pluralistic medical system evolved. The author begins by exploring the ways in which Aboriginal bodies were materially affected by Canadian Indian policy, which placed restrictions on fishing and hunting, allocated inadequate reserves, forced children into unhealthy residential schools, and criminalized Indigenous healing. She goes on to consider how humanitarianism and colonial medicine were used to pathologize Aboriginal bodies and institute a regime of doctors, hospitals and field matrons, all working to encourage assimilation. Finally, Kelm reveals how Aboriginal People were able to resist and alter these forces in order to preserve their own cultural understanding of their bodies, disease and medicine.

This detailed, but highly readable, ethno-history draws on archival sources, archaeological findings, fieldwork, and oral history interviews with First Nations Elders from across British Columbia. Kelm’s cross-disciplinary approach results in an important and accessible book that will be of interest, not only to academic historians and medical anthropologists, but also to those concerned with Aboriginal health and healing today.

Colonizing Bodies won the 1999 Sir John A. Macdonald Prize and the Clio Award for British Columbia and was selected as a Choice Outstanding Title.
AKAK’STIMAN:

A Blackfoot Framework for Decision Making and Mediation Processes

By Reg Crowshoe and Sybille Manneschmidt
University of Calgary Press, March 2002
ISBN 1552380440
104 pages

Today, two health structures exist on the Peigan Reserve. One is based on Blackfoot culture and the other on western European theories of health and healing. Although both methods are used on the reserve, the government only acknowledges the western approach. This book describes in detail Blackfoot healing traditions, their spiritual foundations and their historical development. Akak’stiman shows how Blackfoot healing methods can be integrated with western approaches on the Peigan Reserve. Oral evidence from interviews with Elders and historical documents bring varying approaches to this timely topic.

Reg Crowshoe is a well-known Blackfoot ceremonialist who lives on the Peigan Reserve in southern Alberta. He is the director of the Oldman River Cultural Centre and has pioneered and initiated cross-cultural programs for many organizations and institutions across Western Canada. Crowshoe is the son of the revered Native spiritual leader Joe Crowshoe and recently earned an honourary doctorate in law from the University of Calgary.

Sybille Manneschmidt is a psychologist, international health consultant, author, and rancher. She earned her doctorate from the University of Alberta and has worked with the Peigan First Nation for 15 years. She makes her home in southern Alberta where she is a sessional teacher at the University of Lethbridge.
INTRODUCTION

In September 1992, the Royal Commission on Aboriginal Peoples (RCAP) brought together about 80 Aboriginal Peoples who were involved in research as academics, lawyers, graduate students, project staff and consultants, community leaders, and Elders. We met at a workshop at Nakoda Lodge in Alberta to shape the emerging research agenda of RCAP. As Co-Director of Research, I was the chairperson of the initial session in which numerous participants voiced harsh criticism of past research and serious scepticism that RCAP research would serve them any better. “We’ve been researched to death!” they protested. The workshop was not off to a promising start, until an Elder who had opened the meeting spoke quietly from a corner of the room. “If we have been researched to death,” he said, “maybe it’s time we started researching ourselves back to life.”

That piece of wisdom has been repeated often in the past 10 years. It was prophetic of the change that would gather remarkable momentum in just a decade. Aboriginal knowledge has always been informed by research, the purposeful gathering of information and the thoughtful distillation of meaning. Research acquired a bad name among Aboriginal Peoples because the purposes and meanings associated with its practice by academics and government agents were usually alien to the people themselves and the outcomes were, as often as not, misguided and harmful. Aboriginal Peoples in organizations and communities, as well as universities and colleges and some government offices, are now engaged in transforming Aboriginal research into an instrument for creating and disseminating knowledge that once again authentically represents ourselves and our understanding of the world.

Researching ourselves may mean self-initiated action or it may mean entering into effective partnerships. In either case, the ground rules that should guide new practices are not immediately evident. Where Aboriginal expectations diverge from past practice, resistance from the academic research establishment is to be expected.

This paper proposes a set of principles to assist in developing ethical codes for the conduct of research internal to the Aboriginal community or with external partners. The context and rationale for the principles presented, the paper outlines features of the current public dialogue on research ethics, how ethics are framed in Aboriginal cultures, and how Aboriginal perceptions of reality and right behaviour clash with norms prevailing in western research. Current initiatives of Aboriginal communities and nations, research granting councils and institutions to establish ethical guidelines for Aboriginal research are highlighted as evidence that the development of workable ethical regimes is already well begun.
In this paper:

**Research** means activity intended to investigate, document, bring to light, analyse, or interpret matters in any domain, to create knowledge for the benefit of society or of particular groups.

**Aboriginal** refers to First Nations, Inuit and Métis Peoples as referenced in the *Canadian Constitution*. Indigenous is used interchangeably with Aboriginal, usually in international contexts. Where sources refer to specific groups, such as First Nations, the terminology of the source is retained.

**Aboriginal research** means research that touches the life and well-being of Aboriginal Peoples. It may involve Aboriginal Peoples and their communities directly. It may assemble data that describes or claims to describe Aboriginal Peoples and their heritage. Or, it may affect the human and natural environment in which Aboriginal Peoples live.

**Ethics** refers to rules of conduct that express and reinforce important social and cultural values of a society. The rules may be formal and written, spoken, or simply understood by groups who subscribe to them.

The language, images and perspectives in this paper are those of a Mohawk woman and academic of a certain generation. I suggest that the principles I articulate are relevant more broadly to Aboriginal research, though readers from other cultures, particularly Métis and Inuit colleagues, will undoubtedly need to do some translation to connect my words with their own world views and experiences.

**AN ACTIVE DISCOURSE ON RESEARCH ETHICS**

International concern about research ethics arose from revelations in the Nuremberg trials of atrocities committed in experimentation on humans by the Nazis during the Second World War. To prevent future violations of human rights in the name of science, western nations developed the Nuremberg Code representing broad international agreement on ethical standards in medical research. The Nuremberg Code was replaced by the Helsinki Declaration, which was adopted in 1964 and subsequently updated. Ethical codes place emphasis on informed consent and are intended to strike a balance between the risk incurred by participants and the potential benefit of the research to society.

In Canada, research ethics in universities and publicly-funded research institutes are guided by the Tri-Council Policy Statement, adopted jointly by the major research granting councils: the Natural Sciences and Engineering Research Council (NSERC), Social Sciences and Humanities Research Council (SSHRC), and Canadian Institutes of Health Research (CIHR), formerly the Medical Research Council. The three councils receive funding from the federal government for distribution to research bodies across Canada.

Current ethical guidelines and the governance structures through which they are administered are being reviewed because a number of shortcomings have been identified:

- Ethical guidelines are administered on a voluntary basis through a patchwork of procedures and institutions. Universities and research institutes administering research grants from the granting councils are expected to adopt procedures consistent with the Tri-Council guidelines as a condition of funding. There is some follow-up to ensure that this occurs. Academic and professional associations, anthropologists and psychologists for example, also develop guidelines which their members are expected to follow. Governments’ contracts are generally silent on the subject of ethical compliance, relying on researchers to abide by the ethics of their profession or institution.
- Universities have ethics committees. They are responsible for administering the institution’s guidelines for research on human subjects. The committees review research proposals for compliance with ethical guidelines as a condition for approving the flow of funds through the university to the principal investigator(s). Once the proposal is approved, there is no provision for monitoring how the research is actually conducted.
- Ethics committees are perceived to focus on the procedure proposed for obtaining informed consent from human subjects involved in research. The ethical character of the research project itself is generally not examined.
- There are no sanctions available to discipline researchers who violate existing ethical guidelines, beyond complaints to universities or professional associations with which they are affiliated.
- Research that is funded by individuals or corporations independent of a university or research institute is not subject to publicly approved ethical guidelines. Corporations funding research in collaboration with public institutions may have commercial interests that conflict with institutional ethics and may exert pressure to override ethical concerns that arise.
Advances in medical research, for example reproductive technology and genetic research, have raised public concern about research ethics that are not adequately dealt with by fragmented and voluntary guidelines. The federal government is a major funding source, directly and indirectly, of research involving human subjects. It relies on other agencies to ensure that an ethical balance between benefit and risk is maintained in much of the research that it funds. This leaves open questions about the adequacy of safeguards of the public interest.

Aboriginal Peoples interested in research share the concerns cited above and welcome the current review of principles and processes for governing research involving human subjects. However, even if ethical oversight of research sponsored by public institutions is made more consistent, up-to-date and enforceable, there is a danger that concerns particular to Aboriginal Peoples will be neglected or made subject to inappropriate regulation.

It is essential that Aboriginal Peoples and their organizations put forward, not only concerns, but also solutions to the ethical problems that too often have made research affecting them inaccurate and irrelevant. Reframing ethical codes and practice is necessary to ensure the social benefit that motivates research also extends to the Aboriginal Peoples whose universe is being studied.

AN ABORIGINAL PERSPECTIVE ON ETHICS

Descriptions of Aboriginal societies seldom speak of the ethics that support order, cohesion and personal responsibility in those societies. Anthropological studies document customs that sometimes have the character of law. Dr. Clare Brant, a Mohawk physician who became the first Aboriginal psychiatrist in Canada, wrote an influential paper entitled Native Ethics and Rules of Behaviour. In it, he used the language of ethics to illuminate some powerful, unspoken assumptions that guide behaviour he observed in his Iroquoian, Cree and Ojibway patients. Brant’s elaboration of the ethic of non-interference, which inhibits argument and advice-giving as normal means of communication, is particularly relevant for researchers and professionals offering services to Aboriginal Peoples. While non-interfering behaviour may be perceived as passive and irresponsible, Brant points out that it is consistent with teaching based on non-intrusive modelling rather than direct instruction that attempts to shape the behaviour of the learner.

Traditional teachings are conveyed through example, through stories and songs, in ceremonies and, most importantly, through engagement with the natural world which is governed by laws of life just as human beings are. A recent initiative in Saskatchewan documented the language used by Elders sharing their knowledge of culture, history and treaty making in their various nations. Elder Peter Waskahat spoke of the foundations of knowledge and the connections between land, family, spirituality, values, and everyday living:

We had our own teachings, our own education system – teaching children that way of life was taught by the 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.

When Aboriginal Peoples speak about maintaining and revitalizing their cultures, they are not proposing to go back to igloos and teepees and a hunter-gatherer lifestyle. They are talking about restoring order to daily living in conformity with ancient and enduring values that affirm life. The relationships between individual behaviour, customs and community protocols, ethics, values, and world view are represented in Figure 1 using the symbol of a tree.

The leaves represent individual behaviours. Protocols and community customs are small branches while ethics, the rules governing relationships, are the large branches. Values, deeply-held beliefs about good and evil, form the trunk of the tree. The world view or perception of reality underpinning life as it is lived, like the roots of the tree, is not ordinarily visible. The whole of the tree is rooted in the earth which supports us. In this symbolic representation, I suggest that the earth is like the unseen world of spirit – vast, mysterious and friendly if we learn how to respect the laws that govern it.

Some nations have codified their ethical systems. The Iroquois Great Law of Peace teaches the importance and the requirements of cultivating a “good mind” in order to live well and harmoniously in the
world. The potlaching ceremonies of West Coast nations were public means of validating genealogies, family responsibilities, inheritance rights, and land tenure. Many other nations transmitted their ethical codes orally and non-verbally through family and community relationships. Public ceremonies reinforce the community’s world view and provide instruction for living. Skills for decoding complex messages from the social and natural environment are embedded in traditional languages.

The persons who are most knowledgeable about physical and spiritual reality, the teaching and practice of ceremonies, and the nuances of meaning in Aboriginal languages, are Elders. Elders typically have been educated in the oral tradition, apart from the colonizing influence of the school system. They carry credentials that are recognizable within Aboriginal society, but invisible to those who assess expertise on the basis of formal education. They enjoy respect as sources of wisdom because their way of life expresses the deepest values of their respective cultures. In many cases, they have exceptional skills in transmitting these values to those who seek their counsel.

The mutually reinforcing means of transmitting Aboriginal world views, guided by the wisdom of Elders, are represented in Figure 2. Language, which carries the code for interpreting reality, is learned within the family and reinforced by the practices and values endorsed by the community. Public ceremonies and private rituals give shared expression to teachings. In turn, these become incorporated in the language of family and community relations.

The misguided policies that sought to undermine the role of language and the influence of family, community and ceremony in shaping individual and community life have been thoroughly documented and critiqued in recent years.7 RCAP, mapping the choices necessary to navigate a turning point in Aboriginal/Canadian relations, wrote:
Another fundamental issue is the need for Canadians to recognize that Aboriginal cultures were vibrant and distinctive not only in the beginning but remain so today. Though bruised and distorted as a result of the colonial experience, inevitably changed by time and new circumstances, even in danger of extinction in some important dimensions such as language, nevertheless a fundamentally different world view continues to exist and struggles for expression whenever Aboriginal Peoples come together.\(^8\)

Within Aboriginal communities, the struggle has gone beyond survival as small enclaves set apart from non-Aboriginal Canada. The struggle now extends to applying cultural ways in the management of lands and economic activity; the structures of governance; the provision of health, education, justice and other human services; and relations with the larger Canadian society and the world community. The struggle is to live and thrive as peoples and nations maintaining and expressing distinctive world views and contributing uniquely to the Canadian federation. In the language of the United Nations Working Group on Indigenous Populations, this is the pursuit of self-determination.

Indigenous peoples have the right of self-determination. By virtue of that right they freely determine their political status and freely pursue their economic, social and cultural development.\(^9\)

Fundamental to the exercise of self-determination is the right of peoples to construct knowledge in accordance with self-determined definitions of what is real and what is valuable. Just as colonial policies have denied Aboriginal Peoples access to their traditional lands, so also colonial definitions of truth and value have denied Aboriginal Peoples the tools to assert and implement their knowledge. Research under the control of outsiders to the Aboriginal community has been instrumental in rationalizing colonialist per-
ceptions of Aboriginal incapacity and the need for paternalistic control.

Aboriginal scholars who have been educated in western universities and who are conversant with Aboriginal ways of knowledge-seeking are challenging western assumptions and methodologies of research. In the study of Elders’ language referred to earlier, the authors explain:

The Elders’ comments allude to formal and long-established ways, procedures, and processes that First Nations persons are required to follow when seeking particular kinds of knowledge that are rooted in spiritual traditions and laws. The rules that are applied to this way of learning are strict, and the seekers of knowledge are required to follow meticulous procedures and processes as they prepare for and enter the “quest for knowledge journey.”

In the world of Aboriginal knowledge, a discussion of ethics cannot be limited to devising a set of rules to guide researcher behaviour in a defined task. Ethics, the rules of right behaviour, are intimately related to who you are, the deep values you subscribe to, and your understanding of your place in the spiritual order of reality. Ethics are integral to the way of life of a people. The fullest expression of a people’s ethics is represented in the lives of the most knowledgeable and honourable members of the community. Imposition of rules derived from other ways of life in other communities will inevitably cause problems, although common understandings and shared interests can be negotiated. This is the ground on which Aboriginal Peoples stand as they engage in devising ethical regimes that are appropriate for Aboriginal research.

Should ethics be restricted to research on human subjects?

In Aboriginal knowledge systems, the boundary between material and spiritual realms is easily crossed. Similarly, the boundaries between humans, animals, plants, and natural elements are also permeable. This is represented in traditional stories of communication between humans and other beings, and transformation of persons into animals and sea creatures, or vice versa.

The inter-dependent relationship between humans and natural elements was described by Simon Lucas, a B.C. Elder speaking at an RCAP hearing:

The sea and its resources is the heart and soul of our people. Sea resources have sustained our people since time began for us. The health of the ocean means a healthy emotion. It has a direct impact on our mental state. A healthy ocean means a healthy state of mind for us. The health of the ocean means that my body is going to stay healthy. That is important for people to understand. My spirituality, the spirituality of our forefathers, was tied directly to the ocean. The health of the ocean means that my spiritual well-being is going to stay intact.

Scientific research conflicts with Aboriginal sensibilities when it sets ethical guidelines for research involving human subjects, but assumes that the earth and the waters are inanimate or lifeless, and that mice, monkeys or fish can be treated as objects of research rather than co-inhabitants with humans of a living

“JAGGED WORLDVIEWS COLLIDING”

Leroy Little Bear coined the phrase “jagged worldviews colliding” to describe the encounter of Aboriginal philosophies and positivist scientific thought. Aboriginal world views assume that human action, to achieve social good, must be located in an ethical, spiritual context as well as its physical and social situation. Scientific research is dominated by positivist thinking that assumes only observable phenomena matter. Little Bear points out that much externally-sponsored research has documented customs, but missed the deeper significance of those customs:

[Anthropologists] have done a fairly decent job of describing the customs themselves, but they have failed miserably in finding and interpreting the meanings behind the customs. The function of Aboriginal values and customs is to maintain the relationships that hold creation together.

Research was defined earlier in this paper as knowledge creation for social benefit. If researchers and those researched have vastly different notions of what constitutes social benefit and how it is achieved, the research is unlikely to satisfy the needs and expectations of participants on both sides of the divide. This section outlines some of the issues that arise in devising ethical regimes that are appropriate for Aboriginal research.
biosphere. Because many Aboriginal societies maintain primary dependence on a healthy natural environment to meet their needs, industrial development that sacrifices environmental values directly infringes on their well-being and human rights. Ethical regimes for Aboriginal research must therefore extend beyond current definitions of research involving human subjects to include research that affects Aboriginal well-being. This includes environmental research that will impact their physical environment or archival research that may perpetuate negative or inaccurate representations of Aboriginal Peoples.

Maintaining a balance between reductionist analysis and holistic vision

The prevailing model of scientific inquiry reduces the scope of analysis to smaller bits of reality that can then be analysed with greater specialization. This is referred to as a reductionist approach. Research that takes measures to exclude variables or influences from the environment that might contaminate cause-effect sequences is applauded as more reliable than data about complex and unexplainable lived experience. Social sciences exploring human experience have adopted scientific method as the hallmark of their credibility even though human behaviour is subject to many variables that interrupt linear cause-effect sequences. The science of ecology has emerged as an approach to understanding the interdependence of elements and processes in the natural world, to some extent countering the dominance of reductionist research. However, the role of intuitive insight or vision in scientific breakthroughs is regularly downplayed in western disciplines and institutions.

In contrast, the heart of Aboriginal science acknowledges the spirit of the plant, animal or the land and the importance of relationships in supporting life. Gregory Cahete, a Tewa educator, writes:

Native peoples through long experience and participation with their landscapes have come to know the language of their places. In learning this language of the subtle signs, qualities, cycles and patterns of their immediate environments and communicating with their landscapes Native people also come to know intimately the “nature” of the places which they inhabit. Learning the language of place and the “dialects” of its plants, animals, and natural phenomena in the context of a “homeland” is an underlying foundation of Native science.14

Aboriginal science does not ignore analysis of the particular. In fact, the perception of patterns is synthesized from multiple keen observations. The teaching device of the medicine wheel applied in Figure 2 fosters awareness that any particular event or phenomenon functions as part of a larger whole.

Holistic awareness and highly focussed analysis are complementary, not contradictory. There are examples of effective partnership between communities and scientists. The Sandy Lake Health and Diabetes Project in northwestern Ontario has brought together clinical treatment, community-based prevention strategies, and participation in genetic studies.15 The Akwesasne Mohawk community enlisted scientists from Cornell University to assist in verifying the nature and degree of pollution that was destroying the health of their crops and animals. Too often, however, perceptions and concerns at the community level are dismissed as anecdotal while priority setting for research proceeds on a different track.

“A living, dialogical relationship with the world”

This phrase is drawn from Marie Battiste and James (Sa’ke’j) Youngblood Henderson’s work on Protecting Indigenous Knowledge and Heritage.16 It encapsulates the Aboriginal ethic that all aspects of the world we know have life and spirit and that humans have an obligation to learn the rules of relating to the world with respect. We enter into mutual dialogue with the many people and other beings with whom we share the world. When you harvest salmon, you are engaging in a reciprocal relationship in which the spirit of the fish gives sustenance to human beings and humans in turn observe the protocols that demonstrate right relationship. When you seek knowledge from an Elder, you offer tobacco or other appropriate gifts to symbolize that you are accepting the ethical obligations that go with received knowledge. In each case, the exchange confirms a relationship that continues beyond the time and place of the exchange. Knowledge is not a commodity that can be purchased and exploited at will.

Because knowledge carries with it power to do good or ill to the knower and the community, many Elders decline to have their knowledge recorded in writing or electronic media. They want to be assured that the seeker is properly instructed and compliant with the ethical obligations that will be assumed.

Information can be gathered by individuals to shape personal perceptions. Aboriginal societies tradi-
tionally were respectful of the unique vision of individuals. However, individual perceptions had to be validated by community dialogue and reflection before they became collective knowledge, the basis of collective action. This was the function of the many councils responsible for family, clan, village, or nation affairs.

Research that seeks objectivity by maintaining distance between the investigator and informants violates Aboriginal ethics of reciprocal relationship and collective validation. If the researcher assumes control of knowledge production, harvesting information in brief encounters, the dialogical relationship with human and non-human sources is disrupted and the transformation of observations or information into contextualized knowledge is aborted. Attempts to gain an understanding of Aboriginal life and concerns from an objective, short-term, outsider vantage point have produced much research that Aboriginal Peoples reject as distortions of their reality.

Where Aboriginal Peoples control access to research sites, for example research on First Nations territories, organizations and local governments are increasingly insisting on community control. This may mean assuming full responsibility for conducting the research or it may mean collaborative research in which the respective responsibilities of community and outside researchers are set out in a contract. Some initiatives to achieve balanced, mutually-respectful partnerships between Aboriginal communities and researchers are described in a later section of this paper.

Who are the owners of Aboriginal knowledge?

The three national granting councils grappled with questions of collective rights and consent in the formation of their joint policy statement in 1998. In the end, the policy avoids taking a definitive position. The preface to Section 6 of the Tri-Council Policy Statement (TCPS) on Aboriginal research states that the best practices cited are guidelines only and that final standards should be developed in consultation with Aboriginal Peoples. Section 6 of the TCPS, Research Involving Aboriginal Peoples, recommends:

When research involves aboriginal individuals, researchers and REBs [research ethics boards] should consider the interests of the aboriginal group, when any of the following considerations applies:

a. Property or private information belonging to the group as a whole is studied or used.

b. Leaders of the group are involved in the identification of potential participants.

c. The research is designed to analyze or describe characteristics of the group.

d. Individuals are selected to speak on behalf of, or otherwise represent, the group.

The TCPS leaves open for discussion the question of when individuals may be interviewed as individuals without regard to the group as a whole and without seeking permission from any group authority or spokesperson.

Darrell A. Posey and Graham Dutfield, in a major study published by the International Development Research Centre, explore numerous violations around the world of Indigenous Peoples’ rights to maintain the integrity and derive equitable benefit from their traditional knowledge. They underline the vulnerability of Indigenous Peoples to exploitation and the inadequacy of intellectual property laws to protect knowledge that falls outside the definition of property that prevails in western culture. In particular, state laws provide protection of intellectual property for a limited time if it is attributable to individuals and if it is expressed in a fixed form such as a manuscript, recording or art object. These laws are in direct conflict with Aboriginal norms of collective ownership of traditions handed down from time immemorial and recorded in the memories of Elders. Illegitimate use of Aboriginal knowledge for pharmaceutical and other commercial usage is characterized by Posey and Dutfield and other observers as cultural and bio-piracy. Collecting knowledge from persons who are not authorized to transfer a community’s heritage is regarded by Aboriginal Peoples as akin to illegitimate land transfers historically or purchase of sacred artefacts in violation of community ethics on access. Such transactions also violate international norms on consent, which provide that persons giving consent should be competent, that is, aware of the implications of consent and having the authority to give consent where others’ interests are involved.

Voluntary consent

In many cases, research in Aboriginal communities and on Aboriginal matters is initiated by agencies from whom Aboriginal Peoples receive essential services. The research is often funded by governments that control resources on which the community depends. Rightly or wrongly, many Aboriginal Peoples fear that refusing to consent to research may result in loss of funding for essential needs. They are at a disadvantage in negotiating conditions that would alter
the imbalance in power between researchers and the community and give adequate recognition to community priorities and approaches to knowledge creation.

Privacy of health data collected routinely in the delivery of services has become a major concern in health research, especially with the possibility of sharing masses of data electronically across borders. Once information is transferred, it becomes difficult to monitor the secondary or tertiary purposes for which it is used.

The Organization for Economic Co-operation and Development (OECD) outlined an influential set of principles for data protection in 1980. The standards put forward mean that only relevant and accurate data should be collected for precise and limited purposes and that disclosure and use should be restricted to those original purposes unless consented to by the data subject or authorized by law.\(^{19}\)

Aboriginal Peoples express concern that use of Census and population health data, once records are stripped of personal identifiers, is not restricted under ethical rules or privacy legislation. Thus, they have no control over assembled information that may be used for unauthorized surveillance or that may reinforce negative stereotypes of them as communities and peoples.

**Methodology and validation**

Culturally different approaches to knowledge creation imply the need for different methods of gathering and validating information. Participatory research has received a positive reception in Aboriginal communities and has gained acceptance in some quarters of the research community. The study of Elders’ language cited earlier provides a detailed description of how the method is applied.

The treaty commissioner for Saskatchewan commissioned documentary research on treaty making from the Crown’s perspective. He also commissioned research with Elders on Aboriginal perspectives. Forums were convened with the assistance of the Federation of Saskatchewan Indian Nations, with Elder helpers available to assist with ceremonies and translation of contributions in First Nations languages. Audio and video recordings of meetings were made. Successive translations and interpretations of Elders’ words were checked with the Elders themselves to confirm consent and verify accuracy. These reviews resulted in reworking the translations to incorporate both editorial and substantive changes. The final text of *Treaty Elders of Saskatchewan* was published with confidence that it embodies a beginning theoretical framework grounded in the knowledge of Cree, Saul-teaux, Dene, and Assiniboine participants.\(^{20}\)

If validating intercultural research and communication seems labour-intensive, time-consuming and expensive, it is because the integrity of knowledge transfer has received too little attention in the past. Aboriginal communities, political organizations and scholars are insisting that the integrity and validity of research cannot be assured by western methodologies alone. They must be tempered by methodologies that are compatible with Aboriginal methods of investigation and validation.\(^{21}\)

**The challenges of bicultural research in Aboriginal communities**

Aboriginal Peoples have always conducted research within their communities to update and adapt knowledge. This is the way a people survives in a changing environment.\(^{22}\) Legal and political struggles to assert rights over their lands in the latter decades of the 20th century brought new methods of research into play. Participating in the discourse of courts and governments required expertise in English and French and mobilization of documentary evidence. Preparation of land claims relied heavily on outside consultants to conduct research and prepare arguments, although traditional and experiential knowledge of Aboriginal Peoples provided the foundations and shaped the form of the claims put forward.

Aboriginal lawyers and researchers are assuming increasing prominence in litigation and negotiation of land questions. Both Aboriginal and non-Aboriginal scholars in many domains and disciplines are now working to formulate and express Aboriginal knowledge and ethics that are implied in traditional and more recent bicultural research.

It is difficult to secure resources with the Aboriginal community for research addressing issues that are priorities to insiders. Consequently, much of what is formally called research is addressed to both insider and outsider constituencies. Research under Aboriginal community control, even when it is undertaken with an ethical commitment to respect cultural perspectives, presents a number of challenges.

- Traditional ethics and practices may be fragmented and their applicability to contemporary circumstances unclear, requiring meticulous research and testing to plan effective action. The Harvard Project on American Indian Economic Development has made an important contribution in mapping the role of traditional ethics in the success of economic projects.\(^{23}\)
As masses of information are collected and stored, Aboriginal citizens have become concerned about privacy, secure storage and management of information, and access to information by outside agencies. There is a vacuum in ethical codes at the community level to address these concerns.

Aboriginal Peoples are intent on preserving the distinctive character and autonomy of their local communities. Still, they recognize the need to assemble data across communities to address common needs. The mechanisms to achieve these goals in a complementary manner are at early stages of definition.

Research and information management activities compete with other urgent priorities of direct service in housing, health, education, etc. Long-term planning is overridden by ad hoc responses to crises, perpetuating the conditions that create the crisis.

Aboriginal citizens, communities and nations are ill-informed about their rights and the options available to protect and preserve their intellectual heritage from misappropriation and misrepresentation, whether research is mounted by insiders or outsiders to their communities.

**Encouraging ethical research**

If the conflicts generated by “jagged worldviews colliding” remain unresolved, there is a danger that Aboriginal research will undergo a chill. Efforts of Aboriginal communities and organizations to negotiate ethical conditions for research are characterized as attempts to assert control. Despite post-modern critiques that research is captive already to the unacknowledged assumptions of researchers and their cultures, control of research by interest groups is perceived as compromising the integrity of the research enterprise.

There are many research needs identified by Aboriginal communities – environmental degradation, epidemic health threats, culturally-appropriate economic development to name a few. Although Aboriginal participation in higher education is rising and bicultural scholars are emerging, the numbers of science specialists is still small. The relatively small size of the Aboriginal population, located within a larger society and interacting with it on many fronts, dictates a continuing need for intercultural knowledge exchanges. It is essential that the criteria for ethical intercultural research be developed and distributed.

**INITIATIVES TO DEVELOP CODES OF ETHICS FOR ABORIGINAL RESEARCH**

Ethical guidelines for Aboriginal research developed by various agencies over the past 15 years provide substantial guidance for principles and practices which have wide support among Aboriginal Peoples as well as in the broader research community.

The most comprehensive set of Aboriginal-specific guidelines is found in the report of a seminar convened in 2000 by resolution of the United Nations Commission on Human Rights. The Report of the Seminar on the Draft Principles and Guidelines for the Protection of the Heritage of Indigenous People treats research ethics as one aspect of protecting Indigenous heritage. It assumes that such protection “should be based broadly on the principle of self-determination, which includes the right of indigenous peoples to maintain and develop their own cultures and knowledge systems, and forms of social organization.”

Also in the international sphere, the Inuit Circumpolar Conference (ICC) has produced research guidelines.25

In Canada, RCAP published Ethical Guidelines for Research.26 The guidelines applied in the Commission’s extensive research program and have been widely referred to in subsequent years. The current Tri-Council Policy Statement refers researchers to the guidelines published by RCAP, ICC and the Association of Canadian Universities for Northern Studies.27 In 2002, the Strategic Grants Directorate of the Social Sciences and Humanities Research Council distributed an open invitation to those interested in Aboriginal research to participate in a dialogue on establishing priorities and guidelines for a targeted funding program. The three granting councils have established a Panel on Research Ethics (PRE) to work on updating the TCPS. The PRE recognized that there are significant issues relating to ethics of Aboriginal research and actively sought nominees with Aboriginal research expertise to fill a position on the panel as of the summer of 2003.28

Other initiatives have been taken at local and regional levels. The Kahnawake Schools Diabetes Prevention Project adopted the KSDPP Code of Research Ethics29 to guide collaboration between the Mohawk community of Kahnawake, community-based researchers and academic institutions. In 1999, the Grand Council of the Mi’kmaq ratified a Mi’kmaw Ethics Watch. It sets out Principles and Guidelines for Researchers Conducting Research With and/or Among Mi’kmaq People.30 The University of Victoria...
has established an ethics review process to accommodate First Nations ethical standards.31

Concern about balancing the risks and benefits of research affecting communities and individuals is not confined to research among Aboriginal Peoples, but the best-developed and best-thought-out guidelines relate to Aboriginal communities. Charles Weijer, a bio-ethicist at Dalhousie University examined 16 of these documents written by and for Aboriginal Peoples internationally, including Canada, Australia and United States. Weijer identified five major themes running through the documents.

1. Consultation with the community when developing research protocols and keeping them informed during implementation.

2. Informed consent from community leaders prior to approaching individuals, although the community right of withdrawal was generally not addressed in the documents.

3. Community involvement in conducting the research and transfer of skills and expertise to the community.

4. Access to data and samples is contentious and not always mentioned in guidelines. Community consent to additional use of samples beyond the original project and agreement on storage and subsequent destruction of samples should be required.

5. Advance drafts of research reports should be distributed to the community to identify community views. Community rights to modify the report vary.32

Canadian-specific guidelines emphasize participation of Aboriginal groups and communities as full partners in the research enterprise.33 Where the community is a geographical entity with local governance structures, the authority to give community consent may logically reside with the local government. The Kahnawake Schools Diabetes Prevention Project set up a structure for approval that involves agencies mandated by the Mohawk Council of Kahnawake, a community advisory committee, and local health and education systems working in collaboration with university-based researchers. Project implementation and distribution of results requires approval of all the project partners. Reports cannot be vetoed by any one partner, but the dissenter must have the option of presenting alternative positions in oral or written communications.34

University of Victoria guidelines apply to research undertaken in Indigenous Governance Programs and are complementary to the university’s policy on Human Ethics in Research. They are to be applied in any research that “has effects on or could potentially affect Indigenous people.” Where there are no identifiable persons or groups to give informed consent, then an Indigenous mentor/consultation group will be established for areas where Indigenous public information/knowledge is cited.35

The Mi’kmaw protocol takes yet a different approach to involving community. The Mi’kmaw Ethics Watch was adopted by the Grand Council of Mi’kmaw to assert the responsibility and authority of Mi’kmaw People as guardians and interpreters of their culture and knowledge system. The protocol applies to “any research/study or inquiry into collective Mi’kmaw knowledge, culture, arts, or spirituality.” It establishes a centralized location and format for reviewing applications to conduct research, but assigns primary responsibility for monitoring research within each community. There is a strong element of informing communities of their rights and supporting them in exercising their responsibilities.36

The First Nations and Inuit Regional Longitudinal Health Survey (RHS), an initiative funded by Health Canada to gather national data on First Nations and Inuit health, is another site of negotiation for Aboriginal participation as partners in research. Survey data on the Aboriginal population comparable to data collected on the general Canadian population has varied from incomplete to non-existent. General surveys such as the National Longitudinal Survey of Children and Youth have not included on-reserve samples. Significant numbers of First Nations reserve communities declined to participate in the 1991 and 2001 national Census and related Aboriginal Peoples Surveys that sought more detailed information on Aboriginal Peoples. Health Canada data on medical services on-reserve provide disease and treatment statistics, but not the basis for planning to promote health of the population.

To develop a more complete picture of population health, Health Canada entered into negotiations with representative First Nations and Inuit organizations to partner in data collection in a Canada-wide sample survey on health in 1997. Regional organizations endorsed the survey, with conditions attached to their participation. There were many positive results. Regional organizations took responsibility for administering the survey instruments. They were able to add questions relevant to their own communities in the process of instrument construction. Response at the community and individual level was very high. Appropriate expertise in survey design and analysis was engaged in the regions.
Tensions between government and First Nations partners developed, however, over control of the data. The RHS National Steering Committee, reporting to the Assembly of First Nations Chiefs Committee on Health, adopted protocols to recognize collective ownership of data generated by the RHS. Community level data, including individual records, are not released without explicit permission of community authorities. Community data that is brought together at the regional level is released only with permission of the regional authority. The First Nations Information Governance Committee, mandated by Assembly of First Nations chiefs, makes decisions about the release of analysis and reports produced nationally. Publications developed using the data are similarly subject to review and pre-release approval.

Decisions on control of RHS data are seen as setting benchmarks for partnerships in research. They have generated public discussion that is elaborated on in papers prepared for the National Aboriginal Health Organization (NAHO)\(^37\) and the First Nations Statistical Institute.\(^38\) The latter is an emerging organization slated to receive its mandate as one part of a legislative package brought forward in 2003 by the Minister of Indian Affairs.\(^39\) The suite of legislation establishing fiscal and management institutions serving Indian bands has yet to complete passage through Parliament.

Of particular interest for this discussion of research ethics are the principles of ownership, control, access, and possession (OCAP) clearly set out by the RHS Steering Committee to guide decisions on the use of RHS data. The principles assert: collective ownership by First Nations communities of information about themselves and their members; authority to designate who controls or makes decisions about research affecting them; criteria for access to information about themselves held outside the community and management of access to information held by communities or their agents; and possession of actual records by themselves or their designated agents.\(^40\)

Government agencies have been less than satisfied with the limitations on access imposed by the RHS National Steering Committee under the OCAP formula. They argue that maximum social benefit of publicly-funded research requires open access to data with the usual provisions for protecting the privacy of individual respondents. There are visible benefits from First Nations endorsement of the RHS in terms of response, efficiency and quality of results. Despite the differences in position between First Nations and government parties, a second survey was undertaken in partnership in 2002 as part of a longitudinal research agenda.

**FROM GUIDELINES TO GOVERNANCE**

The discussion on ethics of Aboriginal research over the past decade has clearly demonstrated that more appropriate and enforceable protection of Aboriginal Peoples’ interests in research activities is required. Aboriginal Peoples are wary, however, of regulations that seek to include them as an addendum to protocols based on western assumptions about the construction and distribution of knowledge. This section proposes some principles flowing from the previous discussion which could guide the development of appropriate ethical regimes.

**Creating Knowledge – An Aboriginal Right**

Aboriginal Peoples in Canada enjoy Constitutional protection of rights to maintain their identity and participate as collectives in Canadian society. Creating and sharing knowledge that authentically represents who you are and how you understand the world is integral to the survival of a people’s identity. The Royal Commission on Aboriginal Peoples, in its analysis of the foundations and exercise of self-government, proposed that “all matters that are of vital concern to the life and welfare of a particular Aboriginal people, its culture and identity” fall within the core of Aboriginal jurisdiction.\(^41\) The Government of Canada has acknowledged the inherent right of self-government, although the substance of the right has not been defined. This leads to the first principle in devising an ethics regime for Aboriginal research.

**Principle 1:**

*Aboriginal Peoples have an inherent right to participate as principals or partners in research that generates knowledge affecting their culture, identity and well-being. This right is protected by the Canadian Constitution and extends beyond the interests that other groups affected by research might have.*

**Fiduciary Obligations**

The restricted capacity of Aboriginal nations and communities to protect their interests and rights in
face of more powerful governments and institutions has led to case law defining fiduciary obligations of Canadian governments. A duty to consult, which could affect how research is conducted, has been recognized in decisions of the British Columbia Court of Appeal. NAHO is currently preparing a paper exploring related issues in Federal Government Fiduciary Obligations to Aboriginal Peoples and Health.42

Principle 2:
The Government of Canada has a fiduciary obligation to guard against infringement of Aboriginal rights in research activities, particularly in institutions and activities for which it is responsible. The appropriateness of particular safeguards must be endorsed by Aboriginal Peoples through their representative organizations.

Diversity of Aboriginal Cultures

In the speech from the throne Sept. 30, 2002, Governor General Adrienne Clarkson announced the Government of Canada’s intent to “work with provinces to implement a national system for the governance of research involving humans, including national research ethics and standards.” Interdepartmental discussions on governance of research involving human subjects are already underway, led by Health Canada.43 Review of research ethics by the three research granting councils will take on new urgency to influence the direction of national legislation and accompanying regulations. Ethical codes developed by Aboriginal Peoples recognize the diversity of Aboriginal communities and the primacy of community authority in deciding what matters are appropriate for research, the protocols to be respected, and how resulting knowledge should be distributed.44

The situation of the Métis deserves specific attention. Although they are recognized in the Constitution as one of the Aboriginal Peoples of Canada, they are excluded from federal and most provincial legislation protecting their Aboriginal rights and access to culturally-specific services. They generally lack resources to develop organizational and governance infrastructure and to conduct or partner in research undertakings. A search for examples of community-based research protocols did not turn up examples of Métis-specific documents.

Principle 3:
Action by the Government of Canada to establish ethical standards of research should strike a balance between regulations that restrict infringement of Aboriginal rights and those that respect the primacy of ethical codes originating in affected communities, including Métis communities.

The Scope of Ethics Regimes

Earlier in this paper, I argued that ethics that govern research only on human subjects is too restricted to provide the protections sought by Aboriginal Peoples. The report to the Commission on Human Rights from the seminar on draft principles and guidelines for the protection of the heritage of Indigenous People provides a useful model for defining the scope of ethical regulation. The report proposes that heritage broadly defined should be the object of protective measures.

Principle 4:
Ethical regulation of research affecting Aboriginal Peoples should include protection for “all knowledge, languages, territories, material objects, literary or artistic creations pertaining to a particular Aboriginal Peoples, including objects and forms of expression which may be created or rediscovered in the future based upon their traditions” as cited in emerging international norms.

Harmonization of Ethical Protection and Intellectual Property Law

A study of intellectual property and Aboriginal Peoples sponsored by Indian and Northern Affairs Canada underlines the inadequacy and inappropriateness of existing intellectual property regimes in protecting traditional Aboriginal knowledge. National and international rules governing copyright, trademarks, patents, and licensing procedures consistently conflict with Aboriginal culture norms or are practically inaccessible.45 Canadian rules are designed to conform to international standards.

Authority to enact legislation to protect heritage, including intellectual property, should logically be assumed by Aboriginal governments as they emerge. However, it appears that new governments established under the Nunavut Act46 and the Nisga’a Final Agreement sidestep a number of issues. The Nunavut government has authority to legislate in the areas of prop-
property, language, and matters of a local or private nature. It is unclear whether the intangible dimensions of property would fall under its jurisdiction. In the Nisga’a Final Agreement, authority over intellectual property is specifically addressed:

42. Except as provided for by federal or provincial law, Nisga’a Lisims Government jurisdiction under paragraph 41 to make laws in respect of Nisga’a culture and Nisga’a language does not include jurisdiction to make laws in respect of intellectual property, the official languages of Canada or the prohibition of activities outside of Nisga’a Lands.47

The RCAP Report provides a more extensive analysis of issues relating to the protection of Aboriginal heritage and intellectual property.48 The principle proposed here echoes RCAP recommendation 3.6.7.

Principle 5:
“The federal government, in collaboration with Aboriginal peoples, [should] review its legislation on the protection of intellectual property to ensure that Aboriginal interests and perspectives, in particular collective interests, are adequately protected.”49

Administrative infrastructure

Implementation of an ethics regime in Aboriginal research requires more than the clear statement of principles. Legislation at best sets out boundaries for protection of heritage rights. As noted earlier, the administration of existing guidelines is in the hands of research ethics boards (REBs) located in universities and research institutes from which Aboriginal communities are generally distant socially and culturally. The Indian Act, which sets parameters for program funding for registered Indians, makes no provision to support research administration or ethics enforcement in its administrative regimes.

The Mi’kmaw of Nova Scotia and the Mohawks of Kahnawake have created their own administrative structures to implement community codes of ethics. There are undoubtedly other Aboriginal communities that have devised creative responses to the challenges described in this paper. Equitable benefit from legislation and regulations will require investment in administrative structures to monitor compliance with ethical processes. Exploration of the American experience with research reviews could prove useful in this regard. The U.S. Department of Health and Human Services’ Indian Health Service (IHS) has a national Institutional Review Board (IRB) plus 13 regional-level IRBs. University-based projects are reviewed by their own institutional review boards. Then, they go to the IHS regional body for approval of area-specific protocols. In some regions and projects, tribal approval at the local level is required before the regional or national level IRB gives approval.50

In its submission to Health Canada on Governance of Research Involving Human Subjects, NAHO recommended the creation of a system of Aboriginal research ethics boards (AREBs) to address local, regional and national Aboriginal concerns. The brief further recommended that a national committee be formed consisting of Aboriginal experts who would develop ethical standards that could provide a reference point for AREBs and minimum standards for institutional REBs.51

Principle 6:
Development and implementation of ethical standards for Aboriginal research should be in the hands of Aboriginal Peoples, as experts in devising minimum standards for general application and as majority members on Aboriginal-specific research ethics boards serving local, regional and national communities.

Costs of implementing an ethical regime

Briefs submitted in response to SSHRC’s invitation in 2002 noted that establishing the relationships and ground rules for research in Aboriginal communities required time and effort prior to finalizing a research proposal.52 Granting councils generally do not fund up-front costs of developing a research plan, thereby placing serious limitations on respectful, that is, ethical research practice in or with Aboriginal communities.

Aboriginal involvement in research to support evidence-based decision-making in service planning is generally not recognized in the administration budgets of Aboriginal communities and organizations. The First Nations and Inuit Regional Longitudinal Health Survey (RHS) is an exception. When given the opportunity to shape the 1997 RHS in accord with their self-defined priorities, Aboriginal communities engaged in the research enterprise with a high degree of efficiency and effectiveness.
Principle 7:
The costs of community consultation, development of research plans, negotiation and implementation of ethical protocols, and skills transfer should be recognized in budget formulas for research grants and project planning whether conducted by researchers internal or external to Aboriginal communities.

Education for Ethical Practice

Ethics of consent, safety and social benefit in research have evolved over decades. Ethical practice is advanced through a combination of institutional regulation, peer monitoring and communication in the venues where researchers meet and confer with one another. Establishing research practices that respect Aboriginal world views, priorities and authority will also be an evolving process.

Aboriginal communities that have taken up the challenge of conducting and monitoring research have promoted a broad base of local involvement in field research, management committees and board governance. By their actions, they have demonstrated that research is too important to be left to a small group of academics, even if the experts are Aboriginal. Aboriginal community researchers, in concert with their peers in graduate schools and universities, are now talking about reinstating Aboriginal research methodologies to explore processes that have been neglected or poorly represented in past research. The terminology used for this process is community control, borrowing the language that has driven parallel moves to assert Aboriginal authority over government institutions, education, health, and social services.

Aboriginal initiative is essential to reform research practice and bring it into conformity with Aboriginal notions of ethical behaviour. Aboriginal assertiveness is already evident in the surge of activity devising community research codes and the demands for effective partnership in major research undertakings. Research granting councils have a complementary role to play in developing and promoting policy guidelines. A few professional associations have begun to formally recognize the legitimacy of Aboriginal-specific protocols. Some universities have adapted their review processes to promote ethical relationships with Aboriginal communities, including communities of interest.

Principle 8:
Responsibility for education of communities and researchers in ethics of Aboriginal research rests with Aboriginal communities and organizations, government funders, granting agencies, professional associations, research institutions, and individual researchers working collaboratively.

CONCLUSION

This paper places the discussion of ethics governing Aboriginal research in the context of cultural world view and the struggle for self-determination as peoples and nations.

Self-determination has been seen as a political goal expressed most notably in self-government that recognizes a degree of autonomy in relation to Canadian state institutions.

The language of self-government has obscured the reality that Aboriginal Peoples are engaged in a struggle to re-establish ethical order in their communities and nations. This order re-affirms fundamental values that are rooted in their traditional construction of reality, sometimes called a world view. Efforts to regain control of education, health, justice, etc. are only in part about the power to govern. They are fundamentally about restoring order to daily living in conformity with ancient and enduring principles that support life.

Aboriginal Peoples are digging deep into their traditional teachings, reviving their ceremonies, and working to conserve their languages. As they take control of community services and institutions, they are proving that traditional teachings offer a sturdy ethical framework for restoring vitality to community life. Aboriginal academics, professionals, service providers, and political leaders are rediscovering and updating traditional values in the practice of education, the arts, health services, justice, and government. They are also challenging the assumptions of research rooted in a scientific world view that clashes with their concepts of reality and right relationships.

It would be wrong to suggest that all Aboriginal Peoples hold traditional world views with the same degree of tenacity. However, applied research, going on spontaneously and autonomously in Aboriginal communities and organizations, is demonstrating that when learning, healing or rehabilitating is aligned with traditional ethics and values, it takes on astounding energy. The leaves of a tree, connected to their vital source, display health and vigour.
The active discussion of research ethics now going on in government and in granting councils opens up an opportunity for Aboriginal Peoples to engage in dialogue on how research can be adapted to achieve social benefit as they define it. The principles proposed in this paper start with an affirmation of the right of Aboriginal Peoples to generate and disseminate knowledge for and about themselves. This is not to say that all dialogue should halt until complex questions about rights and responsibilities are definitively resolved. Starting with such an affirmation simply underlines that governance of research touches on fundamental issues of Aboriginal culture, identity and well-being.

Establishing and enforcing ethical practice in Aboriginal research will require a continuing commitment to implementing protective legislation, administrative infrastructure and education of the many participants in research.\(^2\) It is my hope that the articulation of issues and principles in this paper will advance the dialogue that is already underway.

ACKNOWLEDGMENT

I wish to thank the National Aboriginal Health Organization (NAHO) for providing the stimulus and the forum for exploring these important matters.

ENDNOTES

1. This paper was commissioned in 2002 by the National Aboriginal Health Organization to assist in developing an organizational position on research ethics. Documentary research and conceptual development were substantially advanced by conversations with NAHO staff, particularly Richard Jock, Yvonne Boyer and Gail McDonald. Analysis and interpretation, errors and omissions are entirely the responsibility of the author.


4. The summary draws in part on the research and expanded discussion in a draft “Issues Identification Paper” developed within Health Canada in 2002.


28. The author of the present paper was appointed to the Interagency Advisory Panel on Research Ethics effective June 2003 for a standard two-year term.
36. Mi’kmaw Ethics Watch, *Principles and Guidelines for Researchers*.
42. Yvonne Boyer, *Aboriginal Health – A Constitutional Rights Analysis*.
50. NCEHR, *Research Involving Aboriginal Individuals and Communities*.
52. Social Sciences and Humanities Research Council (SSHRC), A Discussion Paper for the Roundtable Consultation Nov. 29, 2002 (Ottawa: SSHRC, 2002).
Further Reading

BEYOND INTELLECTUAL PROPERTY:

Toward Traditional Resource Rights for Indigenous Peoples and Local Communities

By Darrell A. Posey and Graham Dutfield
International Development Research Centre, 1996
250 pages

If a stranger entered your community and started asking questions about its people, its resources, and its history, what would you do?

In today’s global marketplace, no stone goes unturned. Where there is commercial value, there are profits to be made. However, as entrepreneurs scour the world in search of new commodities, a voice of dissent is growing and demanding to be heard. That voice belongs to the world’s Indigenous Peoples.

In Beyond Intellectual Property, authors Darrell A. Posey and Graham Dutfield listen and respond to this voice. They offer sound and reasonable advice on how Indigenous Peoples and local communities worldwide should approach and deal with the wide variety of issues surrounding intellectual property and traditional resource rights.

For Indigenous Peoples’ groups, intellectual property activists and policymakers, and all those concerned with the preservation of our planet’s biological and cultural diversity, Beyond Intellectual Property provides an invaluable and eye-opening look into one of the most provocative and explosive issues of the 20th and 21st centuries: the patenting of life.

Posey is Titled Researcher for the Brazilian National Council for Science and Technology at the Goeldi Museum in Belém, Brazil. He is Director of the Programme for Traditional Resource Rights of the Oxford Centre for the Environment, Ethics and Society and a Fellow of Linacre College, University of Oxford. Posey was Founding President of the International Society for Ethnobiology. He is also President of the Global Coalition for Bio-Cultural Diversity, under whose auspices he founded and co-ordinates the Working Group on Traditional Resource Rights. He was the recipient of the Sierra Club’s first Chico Mendes Award for Outstanding Bravery in Defense of the Environment and is one of the recipients of the United Nations Global 500 award.

Dutfield is Research Co-ordinator for the Working Group on Traditional Resource Rights. He holds degrees in Latin American Studies from Portsmouth University and Environment and Development from Cambridge University. Dutfield has addressed international conferences in India, the Netherlands and the United Kingdom on the resource rights of Indigenous Peoples and local communities. His work has been published by the International Union for the Conservation of Nature and the journal Biodiversity and Conservation.
PROTECTING INDIGENOUS KNOWLEDGE AND HERITAGE:

A Global Challenge

By Marie Battiste and James (Sa’ke’j) Youngblood Henderson
Purich Publishing Ltd., Spring 2000
336 pages

Whether the 500 million Indigenous Peoples of the world live in Canada, the United States, Australia, India, Peru, or Russia, they have faced a similar fate at the hands of colonizing powers. That fate has included assaults on their language and culture, commercialization of their art, and use of their plant knowledge in the development of medicine—all without consent, acknowledgment or benefit to them.

Authors Marie Battiste and James (Sa’ke’j) Youngblood Henderson paint a passionate picture of the devastation this assault has wrought on Indigenous Peoples. They illustrate why current legal regimes are inadequate to protect Indigenous knowledge and put forward ideas for reform. Protecting Indigenous Knowledge and Heritage: A Global Challenge looks at the issues from an international perspective and explores developments in various countries including Canada, the United States, Australia, and New Zealand as well as the work of the United Nations and relevant international agreements.

“Indigenous peoples have the right to practice and revitalize their cultural traditions and customs... as well... as the restitution of cultural, intellectual, religious and spiritual property taken without their free and informed consent or in violation of their laws, traditions and customs.” Declaration on the Rights of Indigenous Peoples, UN Working Group on Indigenous Populations.

Protecting Indigenous Knowledge and Heritage includes: what constitutes Indigenous knowledge; Eurocentric views on what constitutes cultural and intellectual property; the importance of preserving Indigenous languages; the importance of international agreements in advancing Indigenous rights to language, culture and knowledge; foreign, national and provincial legislation and the protection of Indigenous culture and knowledge; why current intellectual property laws are inadequate to protect Indigenous rights; and proposals for creating a legal regime that will help revive and protect Indigenous knowledge and require consent for its use.

Battiste is a Mi’kmaw from Unama’kik (Cape Breton, N.S.), and a graduate of Harvard and Stanford. She is a professor in the Indian and Northern Education Program at the University of Saskatchewan and a United Nations technical expert on the guidelines for protecting Indigenous heritage. She is the editor of several books including First Nations Education in Canada and Reclaiming Indigenous Voice and Vision.

Youngblood Henderson is Chickasaw, born to the Bear Clan of the Chickasaw Nation and Cheyenne Tribe in Oklahoma. He was one of the first American Indians to graduate in law from Harvard University. He is a member of the University of Saskatchewan’s College of Law and is research director of its Native Law Centre. He is the author and editor of many books including Mi’kmaw Concordat; The Road: Indian Tribes and Political Liberty; Aboriginal Tenure in the Constitution of Canada; and Continuing Poundmaker and Riel’s Quest. He is a leading advocate of the rights of Indigenous Peoples in Canada and the international forum.
Guidelines for Writing and Publishing Articles in the National Aboriginal Health Organization’s Journal of Aboriginal Health

SCOPE

The following guidelines apply to authors writing articles for the National Aboriginal Health Organization’s Journal of Aboriginal Health. If there are any questions or concerns, contact the NAHO Communications Editor Virginia St-Denis at 56 Sparks St. Suite 400, Ottawa, ON K1P 5A9, (613) 233-1543 ext. 512, fax (613) 233-1853, or e-mail vst-denis@naho.ca.

GENERAL OVERVIEW OF SUBMISSION OF ARTICLES

Authors should send all proposed manuscripts and associated files to the NAHO Communications Editor as listed above. As well as an electronic version sent as an e-mail attachment or mailed on diskette, a hard copy faxed or mailed should also be included to confirm the file transferred properly. The initial correspondence should include a statement that the proposal’s content is unpublished material that has not been submitted for publication elsewhere.

The Communications Editor will send the files to the Guest Editor who will determine the appropriate anonymous peer reviewers. At least two subject experts representing both scientific and community perspectives will review each paper being considered for print.

The peer reviewers will annotate the file with comments and requests for additions, deletions and modifications before returning it to the Guest Editor who will then return it to the corresponding author for editing prior to publication.

Upon receipt of the final manuscript, the Guest Editor will transmit the electronic files to the Communications Editor for the preparation of the publication.

LENGTH

There is no restriction on the length of full-length articles. However, succinct writing is encouraged and undue length may be a cause for rejection. Write clearly and concisely using accessible language for people with a secondary school reading level.

Text should be in 12 point Times New Roman on 8.5 by 11 inch pages with one inch margins on all sides. Double space text and print on one side of the page only. Pages should be numbered in the bottom right corner starting with the front page.

Do not tab or space the beginning of each paragraph. Do not have more than one space following end punctuation.

ELECTRONIC FILES

The author should send all proposed manuscripts as word processor files (preferably Microsoft Word) with separate files for tables, captions, images, etc. Hard copies are required to ensure conversion in word processing programs.

Images should not be embedded into the word processor file, but saved as separate 300 dpi jpg files in cymk colour if applicable.

Electronic files can be e-mailed to vst-denis@naho.ca or mailed on a diskette to Virginia St-Denis, National Aboriginal Health Organization Communications Editor, 56 Sparks St. Suite 400, Ottawa, ON K1P 5A9.
ORDER OF PAGES

Articles should be organized as follows:

Title Page

The title page should include title of the article, the author(s) full name and title with highest academic degree(s), affiliation(s) and name of department and institution to which the work should be attributed, and the complete address of the corresponding author including address, telephone number, fax number, and e-mail address.

This page will not be sent to peer reviewers.

Second Page

A one-paragraph abstract of 150-250 words should state the purpose of the study, basic procedures, major findings, and main conclusion emphasizing new and important aspects of observations. No abbreviations or reference citations should be included in this section.

List three to 10 key words for indexing purposes.

While writing should be accessible with acronyms spelled out in their first reference followed by the acronym in parenthesis afterwards and technical terms and symbols explained on first reference, a glossary of terms may also be needed. If so, it should be included on the second page as a nomenclature. If nomenclature is extensive, this section can be carried over onto a third page.

Subsequent Pages

While the paper should be organized according to appropriate subheadings as indicated below, modifications to these are acceptable if they are consistent with the style and content of the paper.

INTRODUCTION should state the purpose of the article and rationale for the study, but not the data or any conclusions.

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10. Canada, Department of the Environment, Trademarks on Base-Metal Software (Ottawa: Canada Communications Group, 1991).

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