

# **First Nations Public Health:**

A Framework for Improving the Health of Our People and Our Communities

November 2006

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# **Foreword**

"We believe that our health is connected to the health of Mother Earth. Today she is suffering, and we are suffering, too, with diseases that were unheard of in the past." Quebec Elder William Commanda

First Nations people suffer a disproportionately higher rate of morbidity across many diseases and mortality compared with the rest of Canadians. This disparity is a reflection of systemic, societal and individual factors that influence the health of our people. The majority of these factors do not necessarily lend themselves to simple intervention as they generally are beyond the control of individual First Nations. These influences are considered the broader determinants of health. We would consider them influences of our own circle of life. This tacit belief system goes beyond the physical and emotional dimensions of life and includes the spiritual aspect of who we are as peoples of this land. This system is rooted in a harmonious and sustainable relationship with the world around us. We do not necessarily separate ourselves from our world, but see ourselves integral to it.

If you were to measure wealth with regards to material and social matters, it has generally been shown through research that you will be healthy. As your wealth decreases you become less healthy and, unfortunately, many First Nations people live in poverty. In addition, for First Nations, when we consider a framework for improving our health, it is necessary to include a spiritual component. If we begin to add other influences that act as barriers to participation in Canadian society, such as racism, lack of opportunity and interaction with a health care system that is unable to meet our cultural needs, it is no wonder that our health, when compared to mainstream Canadians, is worse. Further, if we begin to critically analyze the influence of historical factors, such as assimilation policies, and how they have left many First Nations people without an awareness of their cultural knowledge and the resulting dependency on government and outside experts, instead of drawing upon existing strengths within their own community, we begin to see how we have arrived at the present time. In short, there are several factors that impact the health of First Nations people.

To improve the health of our people, we must begin to look past the mainstream interventions, recognizing there may be some validity to some of the suggestions, but begin to look at First Nation specific approaches. Approaches must reflect and respect First Nations autonomy, values and practices.

This document is a step towards First Nations people's autonomy and First Nations health reform, advocating for a true partnership with the rest of Canadians and outlining a path towards improving public health for First Nations people. The content of this document is derived from a First Nations perspective and discusses numerous public health issues at various levels – community, regional, national, organizations, university and government.

Finally, we would like to thank the Assembly of First Nations for undertaking this necessary initiative and to the Advisory Committee for all their hard work and commitment.

In Health in all its forms,

Dennis Wardman, MD, FRCPC, MCM Member of the Key First Nation

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# **Executive Summary**

There has been a recent shift by the Canadian government to refocus efforts in the areas of preventative medicine. These efforts are driven almost exclusively by the alarming fiscal reality that a treatment-focused approach to health in Canada is not sustainable. The arrival of SARS also raised the awareness of the need to not only promote good health, but also the need to protect it.

One of the most important responsibilities any nation has is to ensure that the health of its most vulnerable group is included in any health promotion, disease prevention and health protection activities. The health of the First Nations population remains indisputably poorer than others in Canada. The area of First Nations public health requires the most urgent attention if the gap between First Nations health and the rest of Canada is to close.

Over four centuries, colonization took its toll on the physical, mental, emotional and spiritual health of First Nations communities. The present day determinants of health reflect these injustices. The high rates of unemployment, lower education opportunities, poor housing, overcrowding and lack of basic amenities such as running water and indoor toilets are but a few social issues that contribute to the poor health of First Nations.

First Nations believe that true community healing and well-being will only be achieved through the path of self-government and self-determination. As a form of collective action, First Nations governments have a critical role in providing the formal public health system infrastructure that First Nations communities require. This relies on the full recognition of First Nations jurisdictions and the development of an effective governance structure that allows communities to address their unique public health needs and improve public health accountability. This includes the need to address the challenges faced in the Yukon and the Northwest Territories where functioning First Nations governments with health responsibilities are not currently able to access health program enhancements available in the south.

A wholistic approach to medicine has always been the preferred way of achieving good health by First Nations. This approach is much more relevant, especially in the area of public health where healthy communities, rather than individual health, is the focus. To achieve a state of wellness, it is essential that a community have access to information about itself. Public health data is not available to communities in many circumstances largely due to the dysfunctional surveillance system for First Nations in Canada. This document recommends information collection solutions to address the needs of First Nations and that they exercise the principles of self-determination that come through data ownership, control, access and possession (OCAP).

A key requirement to improve the infrastructure of First Nations public health is that of enhanced capacity. This capacity is needed in terms of funding and also in the areas of health human resources, enabling legislation, and a truly collaborative framework and ethos among all levels of provincial, territorial, federal and First Nations governments.

Finally, the task of improving the health of First Nations is not solely one for health professionals and health ministries. There is an urgent need to address the broader determinants of health that prevent any public health program from achieving all that it could. As long as these remain unaddressed, all efforts in the areas of health promotion, health protection, and disease prevention are destined to fail.

The recommendations proposed in this Public Health Framework take into consideration the distinct communities that First Nations represent across Canada. There will never be one solution that will make sense to all First Nations and, as such, the recommendations are based on a recurring theme of creating options that respect the principles of self-governance and allow individual community flexibility in the provision of public health services to First Nations. Finally, to ensure health protection and disease prevention, a long overdue mechanism of accountability and assurance is also proposed in the form of a *Public Health Act for First Nations*.



# **Portraying Public Health**

# **Chapter 1: Introduction**

"Prevention goes hand in hand with a traditional healthy lifestyle. Good health is achieved when we live in a balanced relationship with the earth and the natural world. Everything we need is provided by our common mother, earth: whole foods, pure water and air, medicines and the laws and teaching which show us how to use things wisely. Combined with an active lifestyle, a positive attitude, and peaceful and harmonious relations with people and their spiritual world good health will be ours." Malloch, 1989

The ultimate desire for communities to have healthy populations is a goal iterated by many First Nations leaders from across Canada. Relying on current health care planners and providers to do this in a manner consistent with First Nations beliefs and desires is not realistic. First Nations themselves must be the creators of a population health strategy. The Assembly of First Nations (AFN) Public Health Advisory Committee was mandated by the Chief's Committee on Health to provide a third party assessment of current public health efforts for First Nations and to provide a framework for ongoing and future public health directions for First Nations both on and off reserve. Committee members represented a multitude of disciplines and perspectives from across Canada. They reviewed source documents, conducted interviews, and engaged First Nations community members in focus groups for feedback on their recommendations.

A great many systemic deficiencies within public health services to First Nations were identified as the committee went about its task. Among these were: obstructive jurisdictional layout; lack of essential resources and services; lack of surge capacity in the clinical and public health systems; absence of protocols for data or information sharing among levels of government; uncertainties about data ownership; the role of personal identifiers; inadequate capacity for epidemiologic investigation of an outbreak; lack of coordinated business processes across institutions and jurisdictions for outbreak management and emergency response; inadequacies in chronic disease programming and infectious disease surveillance; the unique situation of communities in the Yukon and Northwest Territories; and weak links between public health and the personal health services system, including the recognition of the important role of traditional medicine, traditional healers, elders and other First Nations leaders in health.

The public health system, unlike the clinical or personal health services system, tends to operate in the background, little known to most Canadians unless there is an unexpected outbreak of disease.<sup>2</sup> However, the public health system has many essential roles. These include health protection, disease and injury prevention, and health promotion, along with time-honored fundamentals such as access to safe foods, safe drinking water, and proper sanitation systems. An effective public health system is essential to preserve and enhance the wellness of First Nations, to reduce the amount of disease, premature death, and pain and suffering in the population.<sup>3</sup>

## Background

## **History of Canadian Public Health**

Public health can be described as the science and art of promoting health, preventing disease, prolonging life and improving quality of life through the organized efforts of society.<sup>2</sup> As such, public health combines sciences, skills, and beliefs directed to the maintenance and improvement of the health of all people through collective action. The programs, services, and institutions involved tend to emphasize two things: the prevention of disease and the health needs of the population as a whole. This population-focus distinguishes public health from the clinical enterprise that is governed by the Hippocratic imperative with its focus on the individual patient.

In 1974, then Health Minister Marc Lalonde published an influential volume entitled *A New Perspective on the Health of Canadians*. Lalonde argued that health status was influenced not only by health services and genetics or biology, but also by environmental and lifestyle factors. While this "New Perspective" drew positive national and international responses, its legacy was clouded on two scores. First, by highlighting the limits to health care based on broad population health trends and aggregate mortality statistics, the volume understated the value of clinical services for relevant outcomes such as disease-specific mortality, function, and quality of life. In part, it reopened the unhelpful divide between advocates of more clinical spending and champions of public and population health. Second, the term 'lifestyle,' with its emphasis on personal choices, was characterized by some critics as 'victim blaming' because it downplayed the social roots of unhealthy behaviours at the individual level. The "New Perspective" did lend momentum to health promotion efforts, pre-staged the need for intersectoral collaboration in public health, and foreshadowed the population health paradigm that now holds sway. However, it appears to have had little lasting effect on federal or provincial spending in public health.<sup>2</sup>

Throughout the latter half of the 1980s, when economic recession was coupled with escalating health care costs, most provinces and territories published reviews of health and health care. Nearly all of these reports shared two recommendations: improved control over resources (through processes such as integration of services, alignment of incentives, regionalization, and utilization management) and an increased emphasis on prevention and health promotion. In every province, recommendations related to control of resources were operationalized. Those related to prevention and health promotion received much less attention.

The scope and importance of the HIV pandemic became increasingly evident during the 1980s, sparking worldwide concern about infectious diseases. An expert panel in the US Institute of Medicine conducted an 18-month study, culminating in 1992 in a major report, *Emerging Infections: Microbial Threat to Health in the U.S.* Health Canada's Laboratory Centre for Disease Control (later restructured inside the Population and Public Health Branch of Health Canada) also recognized an Expert Working Group on Emerging Infectious Diseases Issues. A multidisciplinary group of 40 researchers and practitioners met at Lac Tremblant from December 7-9, 1993, producing a declaration whose opening sentences were prophetic:

The HIV pandemic has demonstrated that the world is rapidly becoming a global community. Global interdependence, massive internal and external population movements, rapid transportation, increasing trade and changing social and cultural patterns expose large populations to new and different pathogens and pose new threats to their health and well-being. National boundaries no longer offer isolation or protection from infectious diseases, toxic chemicals and hazardous products. <sup>4</sup>

In its long list of recommendations, the group called for "a national strategy for surveillance and control of emerging and resurgent infections," support and enhancement of "the public health infrastructure necessary for surveillance, rapid laboratory diagnosis and timely interventions for emerging and resurgent infections," coordination and collaboration in "setting a national research agenda for emerging and resurgent infections, "a national vaccine strategy," "a centralized electronic laboratory reporting system to monitor human and nonhuman infections," and strengthening "the capacity and flexibility to investigate outbreaks of potential emerging and resurgent infection in Canada."

Little action was taken apart from some organizational changes, and most of the working group's recommendations from 1993 remain entirely valid over a decade later. Indeed, this report essentially recapitulates many of these recommendations, highlighting the disparity between First Nations health and the health of the rest of Canadians.

Mr. Justice Horace Krever provided a more general call to action in his report of the *Commission of Injury on the Blood System in Canada* (1997)<sup>5</sup> Krever wrote: "Public health departments in many parts of Canada do not have sufficient resources to carry out their duties...Continued chronic under-funding of public health departments is a disservice to the Canadian public...It is recommended that the provincial and territorial ministers of health provide sufficient resources

Changing social and cultural patterns exposes large populations to new and different pathogens and pose new threats to their health and wellbeing. National boundaries no longer offer isolation or protection from infectious diseases, toxic chemicals and hazardous products.

for public health services." Krever made specific reference to the need for better surveillance for infectious diseases, not least those that had contaminated the blood supply on which he was originally reporting. No specific reference to First Nations by Krever was made.

On September 11, 2000, the provincial premiers and federal government reached an agreement on new funding for health care. This agreement provided \$23.4 billion in additional funds over a six-year period (from 2000/01-2005/06). There was no earmarked funding for public health infrastructure, although funds from the Canada Health and Social Transfer (CHST) could, of course, be directed to public health by provinces.<sup>2</sup>

At the provincial level, recent reports have begun to highlight the need for specific investments in public health. For example, in June 2000, the Quebec government created the *Commission d'étude sur les services de sante et les services sociaux*. The Quebec report defines the health system broadly, encompassing services to individuals, public programs aimed at prevention, and social policies aimed at improving health and welfare.<sup>6</sup> The first of the 36 recommendations is: "That prevention be the central element of a Quebec health and welfare policy." The report explicitly integrates recommendations about public health and preventive services with those focused on personal health and social services. *Healthier Together: A Strategic Health Plan for Newfoundland and Labrador* was released in September 2002 and focuses extensively on a population approach to health.<sup>6</sup> The report outlines only three broad goals. The first is a wellness strategy, and the third is "to improve the quality, accessibility, and sustainability of health and community services." Throughout the report, there are many references to health promotion, health protection, illness and injury prevention, child and youth initiatives, and the non-medical determinants of health.<sup>6</sup>

From a national perspective, in 2001, the Commission on the Future of Health Care in Canada, under the direction of the Honorable Roy Romanow was asked to "recommend policies" that would strike "an appropriate balance between investments in prevention and health maintenance and those directed to care and treatment." The Romanow report devotes one chapter to primary care and prevention. His definition of primary care ("services...provided not only to individuals but also to communities as a whole, including public health programs that deal with epidemics, improve water or air quality, or health promotion programs designed to reduce risk related to tobacco, alcohol and substance abuse") conflates general practice with traditional public health activities.<sup>7</sup>

Three of Romanow's recommendations deal specifically with public health issues. He recommends a national immunization strategy, a physical activity strategy, and strengthening health promotion and prevention programs,

focusing initially on obesity and tobacco use. Funding for these initiatives would come from a primary health care transfer. He proposes a Health Council of Canada to monitor these activities, establish common indicators, and set benchmarks. Romanow also recommends that the federal government take a more active role in international health, focusing on public health initiatives and the training of health care providers in developing countries. Romanow dedicated a chapter to Aboriginal health. In this chapter, he calls for a new approach which will tackle the root causes of health problems for Aboriginal Peoples. "Combined with pervasive poverty, persistent racism and a legacy of colonialism, Aboriginal Peoples have been caught in a cycle that has been perpetuated across generations."

In Learning from SARS: Renewal of Public Health in Canada released in October 2003, the National Advisory Committee on Severe Acute Respiratory Syndrome (SARS) and Public Health confirmed that "the health status indicators for Canada's First Nations and Inuit people are dramatically worse than those for the majority populations. These health status disparities are a national disgrace." The Committee goes on to note the critical importance of adopting a "wide-angle approach to health determinants and community development that must clearly be integrally supported and guided by the affected Aboriginal communities." The report recognizes that First Nations are not simply "stakeholders" but have aspirations of self-determination that factor into the effectiveness of public health intervention.

...(A)lmost without exception, those characteristics, which are identified as necessary or vital to a well functioning health system, are under-funded, under-resourced or, at times, non-existent in (First Nations) communities. Hence, the Committee appeared to recognize that any public health system is only as strong as its weakest link. That is, in the area of public health, the greatest need is in First Nations populations or communities. This is evidenced by the fact that, almost without exception, those characteristics, which are identified as necessary or vital to a well functioning health system, are under-funded, under-resourced or, at times, non-existent in these communities. For example, basic public health measures that have been recognized since the 19th century as fundamental to health, i.e., water treatment, sewers and sanitation, and food security are still issues that many First Nations have to deal with in the 21st century.<sup>3,6</sup> There are also issues related to the potential outbreak of infectious

diseases such as SARS in remote and isolated communities, where communities are only accessible by air and do not have resident physicians, diagnostic equipment and other key resources.<sup>6</sup>

The magnitude of the public health challenges facing First Nations communities and the difficulties in providing adequate services (e.g., relatively small population sizes over large geographical areas; transferring the responsibility for delivery of health services; need for strong interface between primary care and public health, etc.), demand a separate specific assessment and analysis of public health system infrastructure for First Nations.

The Assembly of First Nations' contribution to the Blueprint on Aboriginal Health, termed "Agenda for Restoring and Improving First Nations Health", is a ten year transformative plan for making significant progress in closing the gap in health outcomes between the general population and First Nations. It was supported by all First Ministers and the National Chief of the Assembly of First Nations in 2005. However, the financial resources required to implement its recommendations have not yet been committed. It contains specific recommendations related to First Nations public health.

#### A Framework for First Nations Public Health

It is premature for the Assembly of First Nation's Public Health Advisory Committee to recommend precisely which activities and programs should be included at this point, beyond indicating our support for a strong and harmonized organization. A more effective approach to continuing challenges in First Nations population health must be considered as part of any scoping process, that is, any proposed framework must evolve and adapt to a changing environment in a comprehensive First Nations' Framework for Public Health.

The Advisory Committee also recommends that, as an early priority, the Chiefs Committee on Health continue the collaborative development of a First Nations public health strategy. The strategy should include specific health targets, benchmarks for progress towards them, and collaborative mechanisms to maximize the pace of progress. In developing a First Nations strategy, First Nations must not only work with provincial/territorial jurisdictions and other federal departments and agencies, but consult widely with stakeholders in the broader health community such as non-governmental agencies and private organizations.

#### The Challenge

A continuing challenge in mounting appropriate responses is a recurring tension between the rights and aspirations of First Nations peoples to greater self-determination within the Canadian federation. This challenge is most felt when mapping out the path that will ensure independent First Nations self-governance and self-determination together with a more harmonized approach to delivering and obtaining health. Hence, a distinct but interdependent First Nations public health strategy must be established.

## The Healing of Our First Nations Communities

Nwachuku and Ivey (1991)<sup>8</sup> propose that the healing process in Aboriginal communities must begin with the exploration of people's natural healing styles. In McCormick's study (1995/1996)<sup>9</sup>, First Nations people utilized several healing modalities to heal their communities and themselves. These included: exercise and the expression of emotion to restore balance; establishing social

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connections to create inter-connectedness; and addressing spirits to achieve transcendence. All of these modalities had one thing in common: they were intended to place an individual in the context of the community and were evolved around this concept:

Throughout the history of First Nations people, the definition of health evolved around the whole being of each person-the physical, emotional, mental and spiritual aspects of a person being in balance and harmony with each other as well with the environment and other beings. This has clashed with the western medical model which, until very recently, has perpetuated the concept of health as being "the absence of disease" (Favel-King, 1993:125).<sup>10</sup>

As Waldram, Herring, and Kue Young state in their study on Aboriginal health in Canada:

Epidemics were not simply medical events but had far-reaching consequences for Aboriginal societies. In some cases, whole communities were decimated... epidemics spurred on community break-up and migration...among the survivors, the loss of a significant number of community members altered leadership roles and disrupted the existing social structures...Still, relatively little is known about the health and disease histories of particular communities or reserves, so that the picture of health and disease up to the Second World War can be drawn in only the broadest of strokes.<sup>11</sup>

"It is proposed that early periods of colonization, during which Indigenous culture experienced significant death and destruction and during which the images of death became, in a sense, imprinted upon Indigenous people's collective (non-)remembering consciousness, constitute the nucleus traumatic memory." <sup>12</sup>

Woven in with social and economic determinants of health is also the impact of nation identity. Disparities among nations suggest that there are other, pervasive characteristics of our society that cause poor health among First Nations. These characteristics are thought to include institutional racism and the ongoing effects of the history of colonization and land confiscations. Racism affects health partly because Indigenous and minority populations tend to experience less favorable social and economic circumstances and access to health care and partly because of the more direct psychosocial stress that racism engenders.<sup>12</sup>

Although this Advisory Committee was not charged with the goal of studying in-depth the process of healing in First Nations communities, it is suggested that a key to unlocking some of the barriers to healing is through community self-empowerment, self-pride and hope for the health of First Nations people.

#### **Rationale**

Although the need for attention to First Nations' public health needs should come as no surprise to any Canadian, the need for a specific framework that is not included as part of a pan Canadian strategy and that is unique to First Nations may. However, First Nations are not simply 'stakeholders' in the area of public health. First Nations have inherent Aboriginal and treaty rights, including the inherent right of self-government and as such, First Nations comprise independent jurisdictions with unique rights and interests as the original peoples of Canada and North America. Despite this, a general lack of recognition of First Nations jurisdiction, authority, and control over public health and health data has impeded First Nations policy and legislative development in this area. <sup>13</sup>

Furthermore, there is an absence of an appropriate and sustained level of resources for First Nations to develop, implement, and maintain policies and legislation on public health, health services, information governance and health protection overall.<sup>6</sup>

Consequently, gaps exist in public health capacity and the protection of First Nations individual and collective health data. Furthermore, there is an absence of an appropriate and sustained level of resources for First Nations to develop, implement, and maintain policies and legislation on public health, health services, information governance, and health protection overall.

While limited to date, First Nations engagement in public health-related policy and legislative development has raised unique issues to be considered in this document. Broadly speaking these can be divided into three pillars that require strengthening:

- 1. Collective approach to decision making;
- 2. Intersectoral Partnerships; and,
- 3. Defining the scope of public health essential functions.

## 1. Collective Approach

Only weak mechanisms exist in public health for collaborative decision-making with regards to systematic data sharing across governments. Furthermore, governments have not adequately sorted out their roles and responsibilities during a national health crisis. Each level of government, from local (including First Nations) to federal must collaborate if First Nations are to achieve a seamless, interdependent approach to public health and to managing a health crisis.

This collective approach means that, as even the brief history above has illustrated, public health has long included a regulatory function. Regulation is an effective means of protecting the public from a variety of hazards, including carriers of infectious diseases, food, drugs, consumer products, pesticides, improper waste disposal, impure drinking water, recreational water, dangerous motor vehicles, unsafe work places, second-hand smoke and many others. In Canada, all levels of governments – federal, First Nations, provincial/territorial, and municipal – are involved in the regulatory function of public health.<sup>4</sup>

#### 2. Intersectoral Partnerships

Public health practice relies heavily on intersectoral partnership. Public health professionals must be able to work with a range of disciplines, and form collations to advocate for the mitigation of health risks or for the implementation of health-enhancing changes to the various environments. The voluntary sector is a key partner in public health today. This includes non-governmental agencies (such as health charities and professional associations), local associations of all kinds, community development groups, recreational associations, business groups, organized labor and other workplace programs. Joint activities include health promotion initiatives, the provision of services, advocacy, and community development. These participatory approaches are particularly important for First Nations populations.

#### 3. Defining the Scope

Over the past decade, many countries have tried to define the essentials functions of their public health systems. In Canada, no single accepted list exists, although a report of the national Advisory Committee on Population Health (ACPH) recently recommended the following list of essential functions:<sup>4</sup>

#### (a) Health Protection

This is a long-standing core function for all public health systems. The assurance of safe food and water, the regulatory framework for control of infectious diseases, and protection from environmental threats are essentials to the Public Health mandate and form much of the body of current public health legislation worldwide. Included in this function is the provision of expert advice to national regulators of foods and drug safety.<sup>4</sup>

#### (b) Health Surveillance

Surveillance allows for early recognition of outbreaks, disease trends, health factors, and cases of illness, which in turn allows for earlier intervention and lessened impact. Surveillance also assists in our understanding of the impacts of efforts to improve health and reduce the impact of disease. For example, a new strain of Salmonella occurring in many parts of the country over a short period of time may indicate contamination of a widely distributed food product.<sup>4</sup>

#### (c) Disease and Injury Prevention

More than a decade ago, the Centers for Disease Control and Prevention in the USA identified as much as twothirds of premature mortality as preventable through the application of available knowledge. Many illnesses can

either be prevented or delayed and many injuries can be prevented (e.g., bicycle helmet use). This category of activity also includes investigation, contact tracing and preventive measures targeted at reducing risks of outbreak of infectious disease. It overlaps with health promotion, especially with regards to educational programs that promote safer and healthier lifestyles.<sup>4</sup>

## (d) Population Health Assessment

This involves the ability to understand the health of populations, the factors that underlie good health, and those factors that create health risk. These assessments lead to better services and policies.<sup>4</sup>

Last, public health also plays a key role in Disaster Response. Many natural disasters not only place immediate demands on the health care system, but may involve secondary threats to population health through contamination of

may involve secondary threats to population health through contamination of food or water supplies or through communicable disease outbreaks.<sup>4</sup>

"By far the greatest share of health problems is attributable to broad social conditions. Yet health policies have been dominated by disease-focused solutions that largely ignore the social environments. As a result, health problems persist, inequalities have widened, and health interventions have obtained less than optimal results."<sup>14</sup>

Inequalities in the distribution of and access to material resources – income, education, employment and housing – are the primary cause of health inequalities. Differential access to health care services and differences in care for those receiving services also has a considerable impact on health status and mortality. Everyone is affected there are no neat cut-off points. Each socioeconomic group experiences worse health than the group that is a little better off. This gradient applies to most causes of death – from cancer, cardiovascular disease and Alzheimer's dementia, to injuries. Individual behaviors, such as smoking, only partly explain this relationship, and such behaviors themselves are strongly related to social and economic factors.<sup>23</sup>

One of the barriers to the broader vision is its difficulty in addressing issues that fall outside of the health sector, such as the environment, housing, and income disparity. Positive economic outcomes result from policies that

By far the greatest share of health problems is attributable to broad social conditions. Yet health policies have been dominated by disease-focused solutions that largely ignore the social environments. As a result, health problems persist, inequalities have widened, and health interventions have obtained less than optimal results.

facilitate a high rate of employment, safe working conditions, and investments in social and human capital, and that also encourage low disparities in income and wealth. Positive social outcomes result from policies that ensure all social groups are encouraged and able to participate fully in society.<sup>23</sup>

Poor health, like poor education, holds back many people. Moreover, the cycle of poor health, unemployment and poverty compounds over a person's life. If we can work towards creating a society that incorporates the positive features outlined above, we will be able to harness the skills and potential of the whole First Nations population, rather than only some individuals within it. More importantly, people will be able to live healthier and longer lives and, in turn, a healthier population will increase the country's prosperity.

It is undeniable that public health has advanced over the centuries as society's response to threats to the collective health of its citizens. However, it has had its greatest impact on population health status when well organized, supported and funded. Where have we failed in responding to the public health needs of First Nations and how can we ensure that opportunities for health promotion, protection, and disease prevention are guaranteed?

#### **Outline**

This framework consists of nine chapters. At the end of each chapter there is a list of recommendations made by the Advisory Committee. Chapter Two reminds the reader of the important role that addressing the broader determinants of health has when tackling community health. Chapter Three summarizes the way in which public health is currently delivered through a review of governance and jurisdiction. Chapter Four reviews surveillance of health data and the emerging role of electronic technology in this domain. Chapter Five proposes a comprehensive scope of public health programs required for healthy First Nations. Chapter Six describes the essential capacity and funding needed to support First Nations community health programs. Chapter Seven repeats the call for a health human resource strategy. Chapter Eight reviews best practices from certain international models of Indigenous peoples' public health programs. Chapter Nine includes a summary of all of the recommendations and a proposal for next steps.

# **Chapter 2: Health Determinants**

"Most of the healing work we have done has incorporated the genius of our ancestors. This makes sense, for if we have become sick from dispassion, then the only way we are going to get better is to reclaim the cultural, intellectual and spiritual ways that were taken from us. In order to have good health and a good life as [First Nations] people, we have to become secure again with our [First Nations] cultures and selves. If we are alienated from who we are and where we have come from, we experience an intellectual, emotional and spiritual rupture that can make us sick." Kim Anderson, 2005

The announcement of a 2005 First Ministers Meeting (FMM) on Aboriginal Issues clearly established the need for a broader discussion on living conditions experienced by First Nations. While a key product presented at the 2005 FMM was a ten-year Blueprint for First Nations Health, the priorities of Relationships, Education and Housing have also been underlined in collaborative discussion. The AFN took a lead role in formulating national policy positions for First Nations presented at that meeting, including positions that address other key health determinants such as economic development and environmental stewardship.

The concept of transformative change, initially announced by the former Prime Minister during the April 19, 2004, Canada-Aboriginal Peoples Roundtable, set the stage for the National Chief's challenge of *Closing the Gap in Ten Years*. Such an ambitious goal must be guided by a firm understanding of the root causes and fundamental building blocks for addressing disparities in health status and non-medical determinants of health.

Time and time, again social, economic, cultural and political inequities have resulted in a disproportionate burden of ill health and social suffering on First Nations of Canada.

Many of the factors influencing health lie in the complex social, economic and physical environments in which people live, and therefore, when embarking on a health reform mission, a more wholistic view of health is required. While healing and wellness programs have their place in the short term, it is economic and social reform that will bring lasting change. Societies that enable all citizens to play a full and useful role in the social, economic and cultural life of their society will be healthier than those where people face insecurity, exclusion and deprivation.

As a nation state, Canada is wealthy due to its natural resources and an economy based on related industries such as its mining, forestry and farming. This wealth has, for the most part, been denied to First Nations both in terms of economic profits to communities, as well as knowledge transfer for ongoing sustainability of First Nations communities. The gap between the poverty faced by First Nations communities today and the wealth that Canada boasts with respect to its Gross National Product is a disgrace recognized by the United Nations (UN). The UN has noted that Canada's index ranking could be markedly improved if the sharing of resources was more equitable. UN special investigator Rodolfo Stavenhagen noted that Canada would rate 48th out of 174 countries (rather than its current standing of 8th) if judged solely on the economic and social wellbeing of its First Nations peoples. The ranking index revolves around the estimation of three sub-indices of life expectancy, educational attainment and Gross Domestic Product (GDP) per capita.

Poor social and economic circumstances affect health throughout life. People further down the social ladder usually run at least twice the risk of serious illness and premature death compared to those near the top. The most fundamental approach to reducing inequalities in health is to tackle their root cause; that is, to address the social, cultural, economic and historical inequalities themselves. This requires policies directly concerned with education, occupation, income and the economy. For example, it involves investment in education and the social security system, and the development of labor market policies that strengthen the position of those most at risk of unemployment. If policy fails to address these facts, it not only ignores the most powerful determinants of health standards in modern societies, it also ignores one of the most important social justice issues facing Canadian society.

#### **Public Health and Determinants of Health**

Many determinants affecting people's health have been influenced or controlled through public health interventions. Research into causes of injury and illness has identified a range of social, environmental, and behavioural factors that affect health. These factors include poor diet, physical inactivity, smoking, consumption of alcohol, exposure to ultraviolet radiation, workplace safety, discrimination and road safety.

Most public health issues are notable for their complexity. For example, the National Public Health Partnership (NPHP) states that "the propensity of an individual to smoke, and therefore the prevalence of smoking-related disease in the community, is determined by a range of contributory factors including age, gender, social class, price, advertising, peer pressure, outlet density and smoking opportunities. These factors combine with even broader influences, such as demographically targeted advertising, the political influence of multinational cigarette companies on government legislation, and the historical reliance of governments on tobacco sales tax for general revenue." <sup>16</sup>

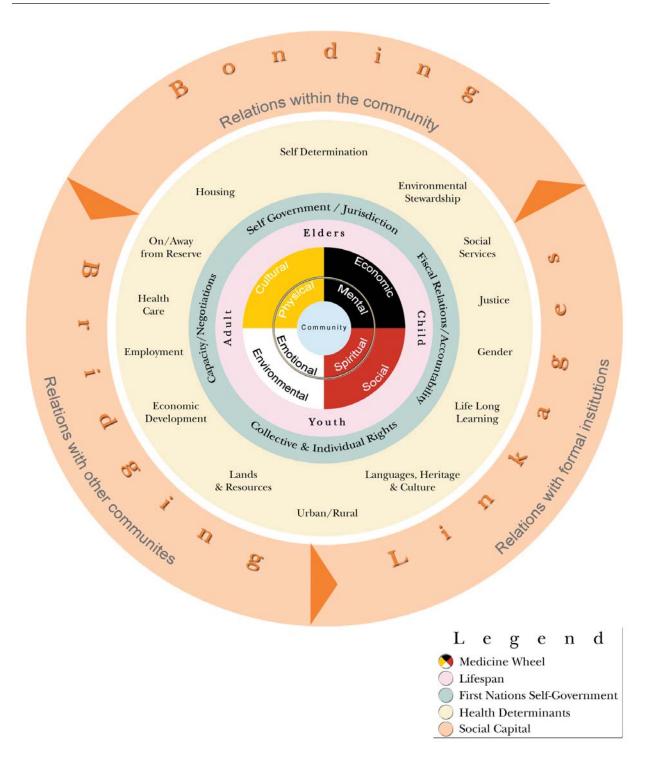
Identifying individual determinants of a health problem is useful for public health planning, but is not sufficient explanation. To avoid simplistic models of causation that lead to simplistic solutions, the interaction of determinants and how they operate in context must also be considered.

## Model Adopted by the Assembly of First Nations

The Assembly of First Nations has long recognized the need to include the broad determinants of health when tackling any health related issue. It has most recently developed a model that represents the determinants of health relevant to First Nations and to be used widely within the organization and its policies and advocacy work.<sup>17</sup> This model is illustrated here and the determinants explored further. National Chief Phil Fontaine challenged the commitment to transformative change from the former Prime Minister and Premiers by setting a target of "closing the gap in ten years" during the First Ministers Meeting on Aboriginal Issues in November 2005. Such an ambitious goal must be guided by a firm understanding of the health determinants perspective, informed by the AFN's proposed model, and foremost, of how it can be translated into relevant policy.

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# 1. PROPOSED FIRST NATIONS WHOLISTIC POLICY AND PLANNING MODEL



Chapter 2: Health Determinants

While 14 Health Determinants are identified as key in the AFN planning model, broadly speaking, health determinants can be categorized into those that are environmental, economical, cultural and social.

#### **Environmental Determinants**

A social model of health implies that we must intervene to change those aspects of the environment that are promoting ill health. We cannot continue to simply deal with illness after it appears, or keep exhorting individuals to change their attitudes and lifestyles, when the environment in which they live and work give them little or no choice or support.

At the same time, we know that health is determined by the complex interaction of a number of factors and that the choices we make as individuals are made easier or more difficult by the physical, social and economic conditions in which we live. Providing supports for healthy personal choices also means building strong and supportive social environments that enable and encourage healthy, independent living for all people. Thus, the healthy choices must also be made the easy choices. This can be accomplished through diverse approaches operating in different ways – from behaviour change programs to changes in legislation and public policy.<sup>14</sup>

A rapid transition from living on the land in harmony with all that the environment provided, to a life in First Nations communities with poor housing, restrictions on land use, and subsequent dependency on government policies, has resulted in the creation of a hostile environment conducive only to the maintenance of poor health.

Increased levels of contaminants in the environment pose potential human health risks, especially to those practicing traditional lifestyles. The impact of the environment on health is recognized in the *Canadian Environmental Protection Act*. The potential presence of contaminants in traditional foods (wildlife, vegetation, and fish) has brought about a move away from traditional lifestyles (hunting and gathering) and an increase in the consumption of store bought foods, which can be linked to increased rates of diabetes, obesity, and heart disease.

First Nations must be recognized as legitimate stewards of lands and resources in their regions\* to promote environmentally friendly use and development that is sustainable, renewable and includes profit sharing to eliminate poverty, create wealth, and protect the future of the land.

#### **Economic Determinants**

Having financial security is one of the factors that make it easier to feel secure psychologically. Affirmation of identity – whether cultural identity or sexual orientation – is also closely related to health. Those who are financially secure, psychologically confident, and socially supported are also more likely to look forward to the future and to want to adopt and maintain health related behaviors that yield long term health benefits. Those who are not financially or psychologically secure, or who live in deprived neighborhoods, are more likely to undertake self-destructive behaviors that threaten their health, such as smoking, eating high-fat diets and being less physically active.

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<sup>\*</sup> In this document, whenever First Nations regions are mentioned, it is to be understood that this also includes specific Treaty and Nation approaches, as appropriate. For instance, the Alberta region includes Treaty 6, 7 and 8.

Relative poverty means being much poorer than most people in society and is often defined as living on less than 60% of the national median income. It denies people access to decent housing, education, transport and other factors vital to full participation in life. Being excluded from the life of society and treated as less than equal leads to worse health and greater risks of premature death. Social exclusion also results from racism, discrimination, stigmatization, hostility and unemployment. These processes prevent people from participating in education or training, and gaining access to services and citizenship activities.

As well as direct effects of poverty, health can also be compromised indirectly by living in neighborhoods blighted by concentrations of deprivation, high unemployment, poor quality housing, limited access to services and a poor quality environment. The greater the length of time that people live in disadvantaged circumstances, the more likely they are to suffer from a range of health problems, particularly cardiovascular disease. Poverty and social exclusion increase the risks of divorce and separation, disability, illness, addiction and social isolation.

Among First Nations people, there is an across the board lag in the completion rate of all levels of education when compared to other Canadians. However, even with higher levels of post secondary education, First Nations men and women continue to face barriers to employment.<sup>18</sup>

Infometrica Inc. were recently commissioned by the First Nations and Inuit Health Branch (FNIHB) of Health Canada to conduct a study of First Nations economies.<sup>19</sup> The paper reveals a model economy for a small community based on a review of the literature on regional and Aboriginal economic development. The model is a framework for analysis of local economic development based on five factors:

- 1. connection to cities;
- 2. the economic base of rural and remote communities;
- 3. local capacity;
- 4. housing; and,
- 5. recent growth.

In spite of similarity in size and location, the economics of First Nations communities have only just over one-half the level of economic development of the mainstream communities.

In spite of similarity in size and location, the economies of First Nation communities have only just over one-half the level of economic development of mainstream communities when measured by average earning from employment. Mainstream communities have an economic rationale for their existence that gives them a certain level of employment, and recent growth according to whether the economic base is sharing or expanding. This is not the case in First Nations communities where a lack of jobs, low education, isolation, and high birth rate are the characteristics of most communities, and growth is not clearly connected to the economic base.<sup>19</sup>

Unemployment rates are 28.7% among reserve-dwelling First Nations members compared to a Canadian national average of 9.8%. Overall, First Nations household incomes are substantially lower than their non-First Nations counterparts. Registered First Nations household incomes for those living in First Nations communities are almost half that of the non-First Nation house in Canada. Personal incomes for First Nations people both living in First Nations communities and living away from First Nations communities are less than half of the Canadian average.<sup>17</sup>

Chapter 2: Health Determinants

One important example of the effects that economic conditions have on social gradients and health status is that of diet. The main dietary difference between social classes is the source of nutrients. In many First Nations communities, the poor tend to substitute cheaper processed foods for fresh food. High fat intakes often occur with people living on low incomes (such as young families, elderly people and the unemployed) who are least able to eat well. The integration of public health perspectives into the food system to provide accessible, affordable and nutritious fresh food for all, especially those with least access, needs to be ensured.

#### **Social and Cultural Determinants**

Social and psychological circumstances can cause long-term stress. Continuing anxiety, insecurity, low self-esteem, social isolation and lack of control over work and home life, have powerful effects on health. Such psychosocial risks accumulate during life and increase the chances of poor mental health and premature death. For brief periods, this does not matter, but if people feel tense too often or the tension goes on for too long, they become more vulnerable to a wide range of conditions including infections, diabetes, high blood pressure, depression and aggression.<sup>20</sup>

First Nations housing and infrastructure is in crisis. Apart from the severe shortage and, in many cases, deplorable housing structure and air quality, there are significant demographic factors placing even more pressure on the existing housing stock. The First Nations population is young and rapidly growing and which is increasing demands on existing family housing units and for future housing. In addition, the reinstatement through Bill C-31 of the registered Indian status of many First Nations citizens, including a large percentage of women and their children, has impacted supply and demand. This increase in demand, coupled with the poor conditions of existing units, provide incentive for the migration of First Nations citizens to urban areas.

The most recent First Nations Regional Longitudinal Health Survey has shown that First Nations were 25 times more likely to live in over-crowded homes than other Canadians. Other measured indicators in the survey showed that First Nations homes were more likely to be in need of major repair, to have no piped water supply, no bathroom facilities and no flush toilet compared to other Canadians.<sup>21</sup>

A history of colonialism, including the creation of the reserve system; forced relocation of communities to new and unfamiliar lands; the forced removal and subsequent placement of children into institutions often located far away from their families and communities; inadequate services to those living in First Nations communities; inherently racist attitudes towards First Nations; and a continued lack of vision in terms of the effects of these tortured relations – all of these factors underlie so many of the health conditions faced by First Nations

While we may talk about First Nations populations in general terms, we must appreciate the individual effects of the collective burden of a history of discriminatory practice, unjust laws and economic or political disadvantage. There are, in other words, far too many First Nations people who suffer as a result of a shared history of inequality with non-First Nations Canadians.

people today. Only now is the federal government acknowledging the profound effects that residential schools have had on individuals and their families.

Social inequities exact a high personal toll in the form of disease, disability, violence and premature death. While we may talk about First Nations populations in general terms, we must appreciate the individual effects of the collective burden of a history of discriminatory practice, unjust laws and economic or political disadvantage. Thus, while some may continue to argue that there is a genetic basis for the disproportional increase, for example, in

chronic diseases such as Type 2 Diabetes, we must equally examine the role of changing diets, changing or limited work options, poverty, access to resources, societal stressors, and the cultural valuations of food as part of the more complex picture of disease in the contemporary context.<sup>1</sup>

There are many practices that do not readily translate across linguistic, cultural, social or economic divides between western style medicine and First Nations. Cultural differences in how we come to understand what health means, economic conditions, living and social conditions, and one's level of formal education are all elements that must be addressed in concert with public health priorities and initiative if we are to understand and effectively take on the formidable task of reducing health disparities and promoting equity in First Nations populations.<sup>1</sup>

Thus, despite the current move towards administrative health services transfer and improvements in health services, there are numerous issues that may confound even the best efforts to negotiate the control and delivery of health care to First Nations communities. Health researchers Kirmayer and colleagues suggest that there is a "need to rethink the applicability of different models of intervention from the perspective of local community values and aspirations."<sup>22</sup>

A 2002 financial modeling report from England found that a scenario that fully engaged preventive interventions

Kirmayer and colleagues suggest that there is a "need to rethink the applicability of different models of intervention from the perspective of local community values and aspirations." would ultimately cost less. The purpose of prevention though is to spare people from avoidable misery and death, not always to save money on the health care system. Derek Wanless is a Commissioner with the Statistics Commission and had been a financial services executive for over 30 years. He was asked by the British Chancellor of the Treasury to provide the first ever evidence-based assessment of the long-term resource requirements for the National Health System. The report modeled health costs over the next 20 years under 3 scenarios: solid progress in people becoming more engaged in their health; slow uptake in level of public

engagement; and fully engaged. The fully engaged model spent similar amounts of money in the next 10 years but is able to spend less in subsequent years. The model shows that how the funds are distributed across health services is very important. A major assumption in scenario 3 is that a much healthier profile of health behaviours is achieved and that the greatest gains are in those at greatest risk. The report explicitly acknowledges that the major killers are linked to socio-economic inequality.<sup>2</sup>

By 1998, Health Canada too had recognized that factors outside the health care system significantly affect health. The National Forum on Health (that took place in 1997) voiced the limited nature of Canada's existing health care policies, pointing to the need for enhancing non-medical interventions. The Forum recommended a broader approach with five strategies for health promotion (reflecting the WHO's Ottawa Charter): Building Healthy Public Policy, Creating Healthy Environments, Strengthening Community Action, Building Personal Skills, and Reorienting Health Services. With respect to Aboriginal communities, the Forum acknowledged that the lack of a flexible, accepting and responsive external environment was a significant barrier to achieving a wholistic approach to Aboriginal well-being.

In 2004, the Canadian government appointed a Minister of State for Public Health and tasked the Public Health Agency of Canada to tour the country with a view of hearing from Canadians (and First Nations) what their visions were for the development of public health goals for Canada. It should be celebrated that many voiced the concerns

that public health was intricately linked with broader social determinants of health and that these needed to be included as part of the goal setting agenda. The next stage would be to develop indicators that reflect these goals so that Canadians can determine whether we have all successfully attained the stated goals. In 2006, the position of Minister of State for Public Health has been dismantled and the fate of the goals is uncertain.

#### Conclusion

In the first few years of life, we begin to acquire the personal skills and resources critical for healthy behaviours that we draw on throughout our lives. These skills help us become self-reliant, problem-solvers and enable us to make informed choices; deal with the challenges associated with life transitions; cope with injury, illness and other adversity; and generally exercise some control over our health and our environments. But these skills alone are not enough. In order to remain self reliant and resourceful, the surrounding environment must facilitate these choices to be obvious, easy, and in the individual's, family's and community's best interest. First Nations' collective history has included discrimination, colonization, and trauma that has had an impact on population health beyond individual behaviour. Finally, there is limited opportunity for First Nations to exercise healthy behaviour with limited access to food security, clean water, healthy housing and other essential components that the rest of Canada has come to expect and enjoy.

## Recommendations

Recommendations specific to health determinants need to be interwoven into each of the subsequent chapters in this framework. Recommendations specific to individual determinants will not address the public health issues that these non-medical, cultural and health determinants could have. Policy at all levels – in government, public and private institutions, workplaces and the community – must take proper account of evidence suggesting a wider responsibility for creating healthy First Nations societies. It is the goal of this framework to ensure that all of the subsequent chapter recommendations have inherent goals to meet the recommendations below:

**Recommendation #1:** Opportunities to develop and maintain personal life skills and a sense of life control and effectiveness, must be available to all First Nations including the critical importance of self-government.

**Recommendation #2:** Resources and supports in society must be implemented to enable and maintain healthy lifestyles through government policies on the fair distribution of income, the removal of barriers to health care and affordable housing, and the reduction of social stratification.

**Recommendation #3:** Opportunities for all people to live with dignity would see the elimination of poverty and its ramifications .

**Recommendation #4:** Reduction of preventable illness, injuries, disabilities and premature deaths must be a priority, particularly in a population with a large and growing youth cohort.

**Recommendation #5:** A new strategic approach to a First Nations health system administration that fosters a wholistic system and encourages multi-sectoral partnerships within communities (linkages with education, justice and other essential community services) are favored by First Nations, as demonstrated in the recommendation to create a First Nations Wholistic Health Strategy in the 2005 Blueprint on Aboriginal Health, as well as in the First Nations Wholistic Policy and Planning Model proposed by the Assembly of First Nations.

# **Chapter 3: Jurisdiction and Organization**

"The purpose of the treaties was to secure a positive future for their children and future generations. The treaty negotiators and the beneficiaries at the time of the treaty understood an enriched livelihood as a sufficient, sustainable, supplemental livelihood. The three purposes for entering into treaties or 'covenant' with the British sovereign were to ensure that future generations (1) would continue to govern themselves and their territories according to [First Nations] teachings and law; (2) would make a living, providing for both spiritual and material needs. and (3) would live harmoniously and respectfully with treaty settlers." J.Y. Henderson, 2002

The crisis in First Nations health is attributed to a variety of historical sources including Canada's legislation and policies of assimilation, the residential school system and imposed change from Indigenous lifestyles to those of Canada's industrialized society. The 1996 Report of the Royal Commission on Aboriginal Peoples (RCAP) documents how the policies of the federal government, designed to implement the treaty promises of settlement, diminished the treaty avocation of hunting, fishing, and trapping in the transferred lands and resulted in suffering, starvation, disease, and death. Residential schools had inadequate health facilities and contributed to the spread of the settlers' diseases in addition to their long lasting psychological impact. Traditional medicine, health ceremonies, and First Nations languages were discouraged and prohibited. 23

The RCAP report concluded that because of the false promises made by the colonialists, "it is indisputable...that existing treaties have been honoured by government more in the breach than in the observance."<sup>23</sup>

The delivery of public health to First Nations has not been spared from poor policy and program design, including negligence in the face of the *Canada Health Act* and the Canadian Constitution. It has been less than adequate in meeting the health needs of the First Nations population and communities. The organization, jurisdiction and governance structures of public health in Canada for First Nations have resulted in a confused patchwork of public health program delivery with little accountability. The essential responsibilities of the Canadian public health system have never been officially defined, even for the entire Canadian population, although a national working group has recommended the following list (as outlined in Chapter 1):

The 1996 Report of the Royal Commission on Aboriginal Peoples documents how the policies of the federal government, designed to implement the treaty promises of settlement, diminished the treaty avocation of hunting, fishing, and trapping in the transferred lands and resulted in suffering, starvation, disease, and death.

- population health assessment;
- health surveillance;
- health promotion;
- disease and injury prevention; and,
- health protection.

The public health "system" in Canada might be better described as a grouping of multiple systems with varying roles, strengths and linkages. Each province and territory has its own public health legislation although the age and content of these vary considerably. Most legislation focuses on the control of communicable diseases, although most preventable disability and death are now due to chronic diseases and injuries. Quebec has the most recently updated legislation and it provides a comprehensive approach to public health addressing all of its essential functions.

Federal legislation, although currently under review, is limited to the *Quarantine Act*, (which dates predominantly back to 1872), and a variety of health protection-related Acts. Overall, the existing legislation does not identify the federal government's mandate, roles, and responsibilities in public health, nor does it specifically spell out this role with respect to First Nations.

Attempts at addressing gaps in Federal public health legislation have begun. On April 24th, 2006, the House of Commons was introduced to Bill C-5 "an Act respecting the establishment of the Public Health Agency of Canada and amending certain Acts". There was no First Nations consultation for this Bill despite that fact that it may have impacts on First Nations and citizens including the recognition of First Nations collective privacy rights. A presentation by the Assembly of First Nations to the Senate Committee on this Bill describing concerns regarding the lack of consultation and the need for inclusion was largely ignored.

First Nations possess inherent Aboriginal and treaty rights, as stated in section 35 of the *Constitution Act*.<sup>12</sup> While the federal government does not recognize health as part an Aboriginal or treaty right, the federal government maintains a role in providing health care services to First Nations as a matter of policy. First Nations however, believe that the federal Crown has a responsibility under their fiduciary obligations to provide health care to First Nations regardless of residency. Irrespective of federal responsibility, public health services for First Nations are organized in such a way that promotes fragmented delivery, jurisdictional ambiguity and continued poor health. Below we describe the background to public health organization in Canada, the current jurisdictional issues and legislative governance of public health and finally, we propose recommendations to enhance a system under which the First Nations population can flourish.

#### The Vision

The ultimate outcome of these recommendations is to propose an organized approach to the delivery of public health services to First Nations that overcomes the current legislative and jurisdictional hurdles. The structure will respect the variations of First Nations communities across the country and will ensure that public health program delivery provides a standard of care that is up to at least the level of the province or territory within which the community resides and respects the flexibility and freedom for individual community design. The vision extends to First Nations living away from their communities by increasing access to current and additional provincial and territorial programs.

# Background

#### **Organization**

#### 1. Regional Responsibilities

A significant change to the delivery of health services in Canada occurred in the 1990s. Federal, provincial and territorial governments devolved greater responsibility for planning, allocation of resources and delivery of programs and services to regional/municipal health authorities (with the exception of Yukon, Nunavut and New Brunswick in the case of public health services). As such, primary responsibility for public health services is at the municipal or local level, through about 140 health units and departments that each serve populations ranging from 600 to 2.4 million people, with catchment areas from 4 to 8,000,000 square kilometers. The next level of organization is provincial or territorial. At the provincial/territorial (P/T) level, staff engage in planning, administer budgets, and advise on programs. They also provide technical assistance to local units as needed. The P/T-level capacity for coordination and technical support of local health agencies varies sharply from one province to the next.

More than 50% of First Nations reside away from First Nations communities and in Northern territories. In these areas, there has been concern that prevention and promotion programs in general, as well as First Nations health needs, are being overlooked in the competition for scarce resources. Furthermore, First Nations people are not well represented in the decision-making process of regional health authorities. At a minimum, there is general agreement that attention to First Nations health needs within regional structures has been uneven. Some provinces have allocated one or more Aboriginal positions on the boards, however, positions often have been difficult to fill. First Nations members feel isolated and overburdened, cultural differences pose barriers, and tensions can arise over allocation of resources and inter-jurisdictional conflict.

#### **Transferred Communities**

First Nations governments and organizations are slowly gaining greater control of programs and services. The federal government has been negotiating varying degrees of transfer of responsibility for existing health services with First Nations and Inuit community bodies. Funding for the delivery of health and wellness programs is also being provided to urban Aboriginal organizations with unclear accountabilities in some cases to First Nations leadership. Promotion/prevention programs able to be transferred to First Nations governments include community nursing, community health representatives, health education, nutrition, environment health services, alcohol and drug abuse prevention, and prenatal nutrition. Communicable disease control, environmental health, and Medical Officer of Health services are mandatory services that must be provided by communities under transfer agreements.<sup>24</sup>

The Health Transfer Policy was implemented in 1989 and had three original objectives:

- 1. To enable Indian Bands to design health programs, establish services and allocate funds according to community health priorities;
- 2. To strengthen and enhance the accountability of Indian Bands to Band Members; and
- 3. To ensure public health and safety is maintained through adherence to mandatory programs.

There are two basic models under which communities can gain greater control over various aspects of their existing health services: the transfer model and the integrated model.

Under the *transfer model*, communities can take on the administration of a range of community-based, zone and regional programs under a single, flexible, three to five year Contribution Agreement that allows communities to allocate funding based on local community priorities. Funding can be carried over from year to year, and allocated to local health priorities as identified by the community.

Under the *integrated model*, communities can take on a range of community-based services under a single Contribution Agreement that can be up to five years in length. Under the agreement, communities can allocate funding based on their community work plan and must seek permission from FNIHB to make changes. The carry over of resources is not allowed.

Transfer has the potential to allow communities to shift resources to a more preventative, wholistic, cultural-based approach. However, the rigid nature of funding agreements, funding levels, and the high level of acute care needs in communities are barriers to positive outcomes.

A reported benefit of transfer has been an improvement in employment opportunities for community members. This has the potential to improve continuity of care and community trust in service providers. Local control tends to raise the awareness of community health issues, health determinants and the services offered in the community. This can result in members living healthier lives that include a sense of empowerment and self-determination.<sup>24</sup>

A summary of each of the regions' models of public health is outlined below, including those for First Nations living away from their communities. Further in the chapter, the federal government's role in delivering care to those First Nations people living in First Nations communities is more fully described.

#### **British Columbia**

For residents of British Columbia, public health is delivered under a new health governance structure consisting of six governing health authorities (a Provincial Health Services Authority and five geographic health authorities). Within the five health authorities are 16 health service delivery areas. Appointed boards are responsible for the provision of health services, including public health services, within the defined Regional Health Authority geographical area. The governance for public health is thus combined with that for other health services.

Each of the Health Authorities has approximately two to four Medical Officers of Health. An Aboriginal Manager is also employed within each region to act as a voice for the needs of Aboriginal peoples living away from First Nations communities. This relationship is often via other existing services such as Friendship Centers. There are approximately 179,025 registered First Nations people in British Columbia. The First Nations population living away from First Nations communities is 66,000.

The British Columbia Centre for Disease Control (BC CDC) was established in 1997 to take responsibility for provincial-level management of infectious disease prevention and control, including laboratories. The division director and other key scientific and medical staff in the BC CDC hold appointments at the University of British Columbia, and have protected time to enable academic activities. A specific effort is made to ground practices in research evidence. The BC CDC's budget flows through the Provincial Health Services Authority.

Coordinated by the Aboriginal Health Division within the Ministry of Health, the province is developing a Provincial Aboriginal Health Services Strategy (PAHSS). Improving health for Aboriginal people was identified as one of six provincial health goals in 1997. There was recognition that program development and objectives must take place with the involvement of Aboriginal health stakeholders and political organizations. PAHSS was being developed over three years (2000/03) by a multi-stakeholder steering committee and involves capacity building and consultation with First Nations and Métis communities, development of resource materials, and information sharing. While its initial focus is on access to health services and a meaningful role for Aboriginal people in healthcare decision-making, the strategy intends to address prevention and promotion in the future.

At the time of writing this Framework, the division has hosted two provincial meetings for Aboriginal board members in regional health authorities to identify issues and make recommendations to strengthen the involvement of Aboriginal people in regional authorities and improve their abilities to address Aboriginal health. The recommendations were accepted by the Ministry of Health (MOH). There is now a requirement that health authorities have a minimum of two Aboriginal governors (board members) and develop Aboriginal health plans in collaboration with Aboriginal communities.

#### **First Nations Communities**

Twenty-seven Tribal Councils oversee more than 200 First Nations communities with a First Nations population of 66,000. Half of these tribal Bands have negotiated Health Transfer Agreements. Developing partnerships with local Regional Health Authorities has been key in promoting public health activities for First Nations communities. In addition to the Regional Health Authority Medical Officer of Health, there are three Regional Medical Officers of Health (RMOs) who report to the Regional Director of FNIHB. These RMOs do not have any authority as Medical Officers of Health under the provincial public health legislation, nor do they have any Environmental Health Officers or nursing staff reporting to them with the exception of one who has two communicable disease nurses reporting to him/her. Many First Nations communities connect directly with their local health authority medical officer which makes coordinated planning somewhat difficult from the perspective of FNIHB.

The First Nations Chiefs' Health Committee exists to develop political strategies and action plans that advocate and support the development of adequately resourced and responsible health programs and services for First Nations in British Columbia. The goal of the committee is to identify First Nations' health priorities and jointly develop a regional budget plan with First Nations and Inuit Health Branch of Health Canada. This Committee reports to the First Nations Summit.

#### Alberta

In 1995, the Alberta Ministry of Health and Wellness regionalized the delivery of health care to Albertans. Currently, nine regional health authorities exist, each with an Advisory Council on Aboriginal health issues. The Regional Health Authorities are governed by appointed boards and together employ 16 Medical Officers of Health. The province of Alberta is home to 156,220 First Nations people, half of whom live away from their reserves.

## **First Nations Communities**

Alberta is divided into three treaty areas: Treaty 8 (23 communities), Treaty 6 (18 communities) and Treaty 7 (7 communities). Only three communities in the province have currently negotiated health transfer agreements, although two more are considering this.

Alberta First Nations have a unique relationship with FNIHB through the Alberta Regional Health Co-Management Committee. This committee consists of First Nations Chiefs in Alberta from Treaties 8 and 7 and FNIHB personnel. The mandate of the group is to consider issues and make decisions on matters relating to program resources and service delivery as well as common health issues. In theory, such a relationship should translate into improved health delivery and cooperation between First Nations and the federal government. However, in practice it is often met with predictable challenges.

From the perspective of public health, First Nations in Alberta have been able to secure more of a role for their Regional Medical Officer of Health. One FNIHB employed Regional Medical Officer of Health is recognized under the public health legislation of the province. Article 16 of the *Public Health Act* allows the Minister, for the purposes of communicable disease and emergency management only, to have authority as a provincial Medical Officer of Health. Furthermore, this Medical Officer of Health has 11 Environmental Health Officers (EHOs) that report to him/her. Although his/her authority for environmental health issues is not recognized under Article 16, the work of these EHOs is carried out in a more efficient manner than if they were reporting to a non-public health professional who was not recognized under the Act as so much of the work is related to communicable disease control.

#### Saskatchewan

Saskatchewan has 13 Regional Health Authorities. Elected boards are responsible for overseeing the provision of health services, including public health, by these Regional Health Authorities within their defined geographical area. Saskatchewan is home to 130,990 First Nations.

The Athabasca Health Authority (AHA) in northern Saskatchewan is the only authority that manages health services for First Nations people living both in and away from First Nations communities. However, AHA relies on outside provincial agencies for Medical Health Officers (MHOs) and EHOs. The Mamawetan-Churchill River Health Authority provides an MHO and Public Health Inspectors for the area of AHA servicing First Nations people living outside of First Nations communities. The areas of AHA on First Nations communities receive MHO services from the Northern Inter-Tribal Health Authority (NITHA) Inc.

NITHA is made up of four Tribal Councils. Each of the four Chiefs from these Tribal Councils make up the Board of Directors of NITHA and provide overall direction and decision making for the organization. The Health Directors from the four Tribal Councils provide the recommendations and technical advisory support to the NITHA Chiefs. The CEO provides supervision and administration to all NITHA employees and oversees the daily operations of NITHA. The NITHA management team consists of the CEO, Director of Operations, Medical Health Officer, Finance Officer and the Executive Assistant/Acting Human Resources. Program Managers provide direct supervision of individual programs and staff.

#### **First Nations Communities**

There are approximately 99 First Nation communities in Saskatchewan. However, with Treaty Land Entitlement agreements, there are now over 450 reserves in Saskatchewan; most are small parcels of land with one or two houses on them. This rapid creation of new reserves scattered throughout the province is challenging existing public health services. Also, First Nations are purchasing land in urban areas and converting them to reserves, which has resulted in much confusion about who should be providing public health services on these urban reserves: FNIHB? First Nations? Or the local Regional Health Authority?

The Federation of Saskatchewan Indian Nations (FSIN) represents 74 First Nations in Saskatchewan. The Federation is very active in promoting, protecting and fostering the progress in the health of their membership.

#### Manitoba

Manitoba is home to 150,040 First Nations people. Public health is governed by two different authorities in the province.

A Chief Medical Officer of Health oversees new and emerging public health issues while the communicable disease and legislative side of public health is governed through a Director of Public Health. Both of these positions report to the Deputy Minister of Health. The Chief Medical Officer of Health does not have direct responsibility for any specific program but all of the provincial Medical Officers of Health report to the Chief Medical Officer of Health. A unique feature of this province is that it has created a specific provincial Ministry of Healthy Living. The future of public health governance in the province of Manitoba will soon change. There will be a change in legislation that will merge both offices to be run by a Chief Provincial Medical Officer of Health, and permit the appointment of medical officers of health by the Government of Manitoba.

Manitoba has 11 Regional Health Authorities with appointed boards. Under Manitoba Health, there is an Aboriginal Health Unit that is intended to function as a voice for Aboriginal peoples in Manitoba living away from First Nations communities. There are multiple health centres and clinics in urban centres, which are intended to have a strong First Nations service focus. All have varying funding arrangements. For example, the Aboriginal Health and Wellness Centre is a multi-service urban health centre in Winnipeg, Manitoba. The centre was launched in the summer of 1994 after a year of planning and the development of the first federally-funded program. Achieving core provincial health program funding required significant community and provincial health staff efforts between 1993 and 1997. Currently, the centre receives funding from Health Canada, Manitoba Health, Healthy Child Manitoba, the Aboriginal Healing Foundation, and the United Way of Winnipeg. Thirty of 32 staff members are of Aboriginal descent, including nurses, physicians, family support workers, counselors, and traditional healers.

Approximately 73,000 First Nations live in 62 Manitoba First Nations communities. Thirty-two of these communities have negotiated Health Transfer Agreements with the federal government. Six of these communities have the province of Manitoba delivering public health to them under the "64 Agreement." This Agreement was signed in 1964 between the federal and provincial government to arrange the delivery of services to six First Nations communities in extreme remote settings where non-First Nations communities were in close proximity and receiving duplicate services by the province. In return for the province providing services to these six communities, the federal government provides services to non-First Nations living in First Nations communities.

The Manitoba Chief's Health Committee works closely with Health Canada and recently established the Health Canada/Manitoba First Nations Health Council. One of the goals of this council is to facilitate partnerships with provincial governments, other federal departments and non-government organizations and improve existing partnership processes. For example, Manitoba First Nations have been very active in the development and governance of the Manitoba Centre of Aboriginal Health Research (CAHR) of the University of Manitoba.

#### **Ontario**

The Public Health Division of the Ministry of Health and Long Term Care oversees the funding and policy of programs delivered through 36 Public Health Units. Almost all Health Units have at least one First Nations community that falls within their provincial jurisdictional boundaries.

Local boards of health in Ontario are responsible for public health and some other community services. Boards serve either single or multiple municipalities as well as the province. In large cities, the public health board is usually a committee of city council. Ontario is home to 188,315 First Nations.

The Ontario Aboriginal Healing and Wellness Strategy is unique in Canada due to its breadth of programming and joint management with Aboriginal organizations. Implementation began in 1994/95 as a partnership between 15 First Nations and Aboriginal Organizations, the Ministry of Health, Ministry of Community and Social Services, Ontario Native Affairs Secretariat and the Ontario Woman's directorate. Funding in 2000/01 was \$33 million, directed toward health programming and family violence prevention and intervention for First Nations both living on and away from their communities. The strategy also funds the operation of ten community health access centers that offer culturally sensitive and appropriate primary health care and a wide range of prevention and promotion programs. Other allocations support 125 community prevention and health promotion workers in

105 communities, crisis intervention teams in 47 First Nations communities and 30 urban communities, and 14 health outreach workers in areas without an Aboriginal health center. As well, nine health liaisons positions in provincial Aboriginal organizations and five Aboriginal Health Planning Authorities are supported. In addition to these permanent allocations, a community support funding program contributes to specific programs and proposals that support healing and wellness and increase capacity.

While the program is not without problems in its ability to fairly allocate resources and address needs across the province and across nations, it is supporting culture-based health programming with a significant prevention/promotion component. First Nations leadership has expressed concern regarding the Pan-Aboriginal nature of the strategy and are seeking a bilateral relationship with the Province.

As part of the mandate of the Ministry of Health and Long Term Care, the Aboriginal Health Office was developed to oversee the health care of First Nations living away from First Nations communities in addition to other Aboriginal groups.

#### First Nations Communities

139 First Nations communities divided into five Treaty Councils and three independent councils represent a population of 100,000 First Nations.

Chiefs of Ontario is a coordinating body for 134 First Nations communities. The purpose of the Chiefs of Ontario office is to enable the political leadership to discuss regional, provincial and national priorities affecting First Nation people in Ontario and to provide a unified voice on these issues. Health, and public health in particular, is a priority item listed by the Chiefs of Ontario office.

#### Quebec

Quebec's Health and Social Services Network is three tiered with a central advisory organization under the Minister's Authority. Eighteen Regional Health Departments report to this organization. 95 Centers for Health and Social Services provide services under the Regional Health Departments.

Quebec established the National Public Health Institute in 1998 by transferring its staff from several regional public health departments and the Ministry. It oversees the main public health laboratories and centres of expertise. Unlike the BC CDC, it has a general mandate that covers prevention, community development and healthy living, workplace health, and chronic diseases as well as infectious diseases. The Institute includes the Quebec Toxicology Centre, the Screening Expertise Centre, and the Poison Control Centre.

#### First Nations Communities

Approximately 75% of the First Nations population lives in First Nations communities. There are 28 First Nations reserves in Quebec (of which 22 have negotiated Health Transfer Agreements). In 1994, the First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC), was created. With joint funding from FNIHB, Indian and Northern Affairs Canada (INAC), and the Quebec government, it assists First Nations communities to exercise their inherent rights in health and social services as well as in the achievement and the development of these services. Their major focus includes tobacco strategies, HIV/AIDS, Mental Health, Fetal Alcohol Syndrome, Diabetes and Prenatal Nutrition.

Land claim agreements have resulted in greater control of health programs for some First Nations in Quebec. The *James Bay and Northern Quebec Agreement* of 1975 (JBNQA/NEQA) was the first such agreement that led to the creation of the first official health board governed by First Nations. The agreements allowed the Quebec government to develop vast resources (hydroelectric) in exchange for monetary compensation and the recognition of several First Nations rights. The federal government now subsidizes the province and First Nations communities for many services it formerly provided. These are now administered by First Nations governments and the province. The Cree Regional Board of Health and Social Services of James Bay is responsible for the administration of the delivery of services to the Cree. Nine Cree communities and one Naskapi community fall under this agreement.

Any new programs which are developed since the signing of the JBNQA /NEQA are still available to communities, such as Home and Community Care, the Aboriginal Diabetes Initiative and so on. Non-Insured Health Benefits (NIHB) for members of these nine Cree communities and Naskapi community are provincially administered.

### **The Atlantic Provinces**

Throughout the Atlantic Region, there are approximately 35,000 First Nations people, 25,000 living in their communities. For the entire region, there is one Regional Medical Officer based in Nova Scotia. Several First Nations organizations participate in advocating for improved health services for their membership including the Confederation of Mainland Micmacs, the Union of New Brunswick Indians, the Mawiw Council, the Atlantic Policy Congress, and the PEI First Nations Organization.

### **Newfoundland and Labrador**

Newfoundland and Labrador have a total population of over 560,000 people. Five Health Boards are responsible for overseeing public health across this province. Currently, public health is being downsized with Medical Officers of Health being let go, as well as other public health staff. The Office of the Chief Medical Officer of Health is extremely small with only two other staff overseeing public health for the entire province.

There are three reserves in the province. The two reserves of Labrador have populations of 739 and 1,072. The reserve in Newfoundland has a population of 904. Only the community in Newfoundland has negotiated a health transfer agreement.

### **New Brunswick**

Public health services are delivered through the province's seven health regions under the management of Regional Directors. Six Regional Medical Officers of Health oversee public health issues of these seven regions. A Chief Medical Officer of Health and a Deputy Chief Medical Officer of Health oversee the development of policy and regulations, and provide medical operational support to the Regional Medical Officers of Health.

There is minimal focus on First Nations service delivery despite a sizeable population of First Nations. Throughout the province, there are 15 communities ranging from a population of 46 to 2,715. The total First Nations population living in First Nations communities is 9,265.

### **Prince Edward Island**

PEI has one Health Authority and, as such, service funding is entirely provincial. There are only two First Nations Bands in PEI. The smaller community, with 160 members, has negotiated a Health Transfer Agreement. The larger community has a population of 362 and has negotiated an integrated health agreement.

#### **Nova Scotia**

Nova Scotia has one of the more sophisticated public health models in the Atlantic Region. The province, not the Boards of Health, employs all of the Medical Officers of Health. The province is divided into 9 District Health Authorities. Cape Breton has five First Nations communities and has designated seats for First Nations on their District Health Boards.

A total of 8,587 First Nations live in First Nations communities in this province and represent 13 Bands. Six of these Bands have negotiated Health Transfer Agreements and four are integrated. The population of these communities varies from 62 members to 3,602. Five communities on Cape Breton provide an excellent example of community care. Their capacity to work well with the District Health Authority allows them to operate effectively and with good outcomes for the community members.

### **The Northwest Territories**

Among the provinces and territories, the Northwest Territories has the second largest proportion of Aboriginal people in its population, making up 50%, or 18,730 people. The territorial government provides health and social services to 26 First Nations communities – many in small, remote areas.

The current *Public Health Act* does not recognize the existence or role of the Regional Authorities. These Authorities are responsible for the provision of health and social services in the various regions of the Northwest Territories, including primary health care. Many public health functions are not currently governed by the *Public Health Act*, such as health promotion. Regional Authorities work administratively with the Medical Health Officers and Environmental Health Officers and employ Public Health Nurses. Regional Authorities have a manager or director who oversees public health services in the broad sense and these individuals have a role to play in the interdisciplinary nature of public health services.

The territorial government has adopted a broad population health approach with a stated emphasis on health promotion and prevention. In 1998, the report *Shaping Our Future: A Strategic Plan for Health and Wellness* indicated the importance of dealing with the root causes of health and social problems, and the promise in placing greater emphasis on health promotion, disease prevention and early intervention programs (Northwest Territories Health and Social Services, 1998). A health promotion strategy was created in 1999 to provide a more detailed framework for increased investment in promotion and prevention activities. Three priorities for action were established: active living, healthy pregnancies, and tobacco-harm reduction and necessitation (injury prevention was added in 2000). Knowledge of tradition and a wholistic approach are two of the five principles of the strategy (Northwest Territories Health and Social Services, 1999). However, like most other jurisdictions, the Northwest Territories government struggles to make prevention and promotion a priority in a fiscally constrained environment.

Inter-departmental cooperation is crucial as environmental protection (issues such as rabies control and environmental health risk assessment) is primarily the responsibility of the Department of Resources, Wildlife and Economic Development. Water treatment and waste disposal are under the responsibility of Public Works and Services.

Using a regionalized structure, the Department of Health and Social Services works with nine health and social services boards, including the Lutsi Ke Dene Band Council, Deh Cho Health and Social Services and the Dogrib Community Services Board. They offer programs and services in family support, child protection, public health, home care, independent living, community wellness, environmental health, and uninsured services. The regional and community boards plan and manage promotion and prevention services, which are delivered primarily by community health representatives, community health nurses, social workers, and increasingly, home support workers as a part of an integrated team. In some cases, partnerships are formed with Aboriginal organizations for the delivery of programs. Promotion and prevention programs draw heavily on federal-funding sources such as Aboriginal Head Start; Canada Pre-natal Nutrition Program; Better Beginnings, Brighter Futures; and the Population Health Fund.

### The Yukon

There are 14 First Nations in the Yukon Territory. All are comprised of less than 1000 people. Most are situated outside the urban centre of Whitehorse, including one accessible only by air.

Eleven of the Yukon First Nations are self-governing. These have recognized authority to legislate and provide programs and services in relation to the health of their citizens in the Territory. Most have assumed responsibility from Canada for the management and delivery of programs and services they previously administered as Indian Bands under integrated agreements. Only one established a health transfer agreement prior to assuming responsibility for matters as a government.

Unconditional federal financial transfers contribute to the cost of assumed responsibilities and enable the First Nations to direct their human and financial resources to the priorities, needs and preferred approaches of their communities. However, a significant portion of First Nation health programs overall still derive from federal programs and initiatives, with their attendant limits and administrative burdens. This is a source of continuing difficulty for First Nations wanting to advance their engagements and improve outcomes in the field.

Universal health services were transferred from Canada to the Yukon several years ago. Yukon legislation provides for the delivery of hospital services by way of a statute-mandated corporation. Health and social service boards can also be established at the district level as an element of public government. First Nations could participate in these arrangements but generally have chosen not to do so.

Instead, they have pursued arrangements which give effect to self-government and provide opportunities to build on the First Nation presence. The scope includes both innovations in First Nations program delivery as well as more effective co-operation among all governments in program delivery and the achievement of desired health outcomes at the community level.

Challenges have emerged: in the transition from serving as a local agent for federal programs to a functioning First Nation government with health responsibilities; in securing access to health program funding enhancements available in the south; in achieving recognition for northern self-governing First Nations, despite Canada's on-Reserve/off-Reserve paradigm; and, in sorting out on-going federal/First Nation, federal/territorial and First Nation/territorial responsibilities, given both self-government and the universal services transfer.

Environmental health is an important concern in every Yukon First Nation community. Public government engagements on these issues are uncertain and the regulatory environment is unclear. These weaknesses leave First Nations governments on the front line, needing to address community conditions while having comparatively little to work with to achieve effective results. This is a significant and growing issue.

### 2. Federal Responsibilities

### Northern Secretariat, Health Canada

Improvements in the administration of federal prevention/promotion programming for First Nations in the territories were expected as a result of the formation of the Northern Secretariat at Health Canada. The Secretariat was created in 1998 and given responsibility to manage Health Canada's community-based health promotion and illness prevention programs for First Nations and Inuit in the territories, as well as to integrate and streamline these programs.

### **Health Canada: Outside of First Nations Communities**

Federal activity in the area of public health was previously concentrated in the Population and Public Health Branch (PPHB) of Health Canada. In 2004, PPHB was moved to the new Public Health Agency of Canada. The restructuring of the Agency is ongoing and continues to impact the service intended to fall under its responsibility. Agency department names continue to change but, at the time of writing, the Agency includes Centers for Infectious Disease Prevention and Control, Chronic Disease Prevention and Control, Emergency Preparedness and Response, Surveillance Coordination, and Healthy Human Development. The Agency also oversees the National Microbiology Laboratory in Winnipeg and the Laboratory for Foodborne Zoonoses in Guelph. The Public Health Agency of Canada recognize First Nations living away from First Nations Communities as part of their policy related activities with Provinces and Territories but leave FNIHB to oversee public health activities for First Nations living in First Nations communities.

#### **Health Canada in First Nations communities**

FNIHB remains within Health Canada and houses the Office of Community Medicine which services First Nations people in First Nations communities through Regional Medical Officers of Health and other health professionals. Other federal government departments and agencies are involved with public health to a variable extent including Indian and Northern Affairs Canada, the Canada Mortgage and Housing Corporation (CMHC) and Environment Canada.

The FNIHB Office of Community Medicine currently employs two Community Medicine Specialists at Headquarters and provides support to Regional Medical Officers of Health in 10 regions servicing public health needs of First Nations. Reporting to Regional FNIHB Directors, the RMOs (other than Alberta and Saskatchewan) do not have any delegated legislative authority for carrying out public health activities in the provinces in which they work. In most regions, they do not have any staff that report directly to them. Instead, community nurses are employed by FNIHB and report to the Regional Director. This current set up prevents a more efficient and higher quality of care with respect to public health for those First Nations whose Medical Officers of Health have no authority and are not included in provincial program developments and resource sharing that would enhance services to First Nations communities.

### **Indian and Northern Affairs Canada (INAC)**

INAC provides funding for water treatment, sewage treatment, and the provision of housing. The lack of jurisdictional authority over their own housing has left First Nations people living in extreme poor housing conditions. Several factors contribute to this, including poor construction, lack of inspection compliance, inadequately trained personnel building the homes, and the less than ideal location of the homes. Another factor contributing to poor housing in First Nations communities is lack of ownership by the occupants, who often do not maintain the dwelling.

### **Health Jurisdiction and Relevant Legislation**

### **International**

Health is a basic human right. This is confirmed in a variety of United Nations instruments on conventions that comprise the United Nations Framework of Rights. The right to health includes the right to health care and encompasses the right to a culturally appropriate health care system. As with other human rights, the discourse surrounding the right to health has been particularly concerned with the people who are disadvantaged and the vulnerable, while confirming standards of equality and non-discrimination. Canada, as signatory to a number of international treaties and covenants, has acknowledged the importance of health to the well-being of First Nations. However, its international and domestic obligations under the treaties and covenants signed are not being fulfilled.<sup>13</sup>

**National** 

Three pieces of legislation are specifically relevant to review with respect to public health and First Nations:

The right to health includes the right to health care and encompasses the right to a culturally appropriate health care system. Canada, as signatory to a number of international treaties and covenants has acknowledged the importance of health to the well-being of First Nations. However, its international and domestic obligations are not being fulfilled.

- 1. Canada's Constitution Act;
- 2. Indian Act; and,
- 3. Canada Health Act.

Below is a review of relevant pieces of such laws as they pertain to First Nations and health, as well as a brief explanation of fiduciary law and its relevance.

### **The Canadian Constitution**

Since 1982, Aboriginal and treaty rights have been recognized and affirmed as constitutionally protected rights under section 35(1) of *Canada's Constitution Act*, 1982. The Supreme Court of Canada has determined that a treaty is an exchange of solemn promises between the Crown and Indian nations, the nature of which is sacred. The basis of treaty rights is the promises made to the Indian nations during negotiation rather than the written text of the treaties. Treaty 6 is the only treaty to have specifically included medical care in the written text of the treaty itself. The federal government has acknowledged that a similar clause was also promised during treaty negotiations of Treaties 7, 8, 10 and 11.

The Supreme Court of Canada has held that governmental powers or regulations must be consistent with Aboriginal and treaty rights to be valid; they cannot conflict with, contradict or impede these rights.

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The Constitution Act's few explicit references to health-related matters grant both provincial and federal levels of government jurisdiction to deliver health services. Sections 92(13) and 92(16) of the Constitution Act give provinces the responsibility, respectively, for property and civil rights and for matters of a local or private nature. Both are relevant to the primary authority that provincial governments claim in Canada to pass legislation concerning public health. The Constitution confers jurisdiction over "hospitals" and "asylums" to provinces, and jurisdiction over "quarantine" and "marine hospitals" to the federal government. Since the goal of the drafters of the Constitution Act was to create two levels of government with distinct areas of jurisdiction, these provisions have been interpreted as dividing jurisdiction over public health, with the provinces governing local public health matters, and the federal government attending to public health risks that arise at Canada's international borders and address issues of national concern (hence the references to quarantine and marine hospitals). Where jurisdictional issues between federal and provincial responsibilities intersect is in the direct service delivery to First Nation located on reserves. Section 91(24) of the Constitution Act states the federal government is responsible for Indians and lands reserved for Indians. Health is an area where it is unclear (from a constitutional perspective) who has jurisdictional obligations for health care delivery to First Nations on reserves.

Over time, court decisions have placed many aspects of health care regulation within provincial jurisdiction. The courts have held that provinces possess jurisdiction over public health, including legislation for the prevention of the spread of communicable disease, and sanitation. The provinces have exercised this jurisdiction to engage in health surveillance (including reporting and tracking), outbreak investigations, quarantine, isolation, and mandatory treatment. Moreover, the courts have granted provinces jurisdiction over a variety of related areas: drug addiction (including legislation for involuntary treatment), mental health (including legislation for involuntary committal), the medical profession (including the practice of medicine), workplace health and safety, the regulation of foods for health reasons, the safety and security of patients, and hospitals. The Supreme Court has stated that provinces have jurisdiction over "health care in the province generally, including matters of cost and efficiency, the nature of the health care delivery system, and privatization of the provision of medical services," as well as "hospital insurance and medicare programs."<sup>13</sup>

The uncertainty about federal powers specifically in public health is underscored by the state of disease surveillance. While the *Statistics Act* and the *Department of Health Act* provide the government of Canada with a mandate to collect information on public health risk of a pan-Canadian nature, Health Canada (and the Public Health Agency of Canada) does not currently have a clear legal power to require provinces/territories to share health surveillance data with each other and the federal government. As was evident in the Severe Acute Respiratory Syndrome (SARS) outbreak, these transfers occur voluntarily.

Environmental health further illustrates the jurisdictional ambiguities. The federal and provincial/territorial governments all have legislation bearing on environmental facilities and water testing. Municipal governments may pass by-laws, provide many environmental services, and be involved in enforcement.

Local public health agencies and/or provincial/territorial health ministries are responsible for advertising on human health impacts of environmental health problems, for undertaking inspections and enforcement, and for investigation of environmental health hazards and health events thought to be environmentally caused. Public health laboratories undertake some testing, as also do various federal, provincial, university or contract laboratories. Other government

departments such as Natural Resources, Transportation and Recreation are inevitably involved. Lastly, emergency preparedness and response authorities, including provincial/territorial ministries of public security, will be involved in responding to environmental disasters. However, no one admits responsibility for setting standards and enforcement for environmental health issues in First Nations communities, especially with respect to housing. This lack of accountability translates into poor living environments.

No one admits responsibility for setting standards and enforcement for environmental health issues in First Nations communities, especially with respect to housing. This lack of accountability translates into poor living environments.

The Assembly of First Nations has released an Environment Action Plan<sup>25</sup> that focuses on the development of an environmental stewardship that involves First

Nations exercising their inherent rights to lands and resources under their jurisdiction, coupled with provisions for working in cooperation with other jurisdictions. The goal is to address the systemic inequities of existing gap approaches to environmental stewardship.

### The Indian Act

Although little reference is made specifically to health under the *Indian Act*, Articles 73 (1) and 81 (1) are worth noting. Under these sections, the power to enact regulations that would improve the health of First Nations exists and failure to use this power effectively could be seen as an infringement on the federal fiduciary responsibility. Furthermore, the possibility of enacting a *First Nations Public Health Act* is enabled under these provisions without opening the *Indian Act* itself.

- 73. (1) The Governor in Council may make regulations
- (a) for the protection and preservation of fur-bearing animals, fish and other game on reserves;
- (b) for the destruction of noxious weeds and the prevention of the spreading or prevalence of insects, pests or diseases that may destroy or injure vegetation on Indian reserves;
- (c) for the control of the speed, operation and parking of vehicles on roads within reserves;
- (d) for the taxation, control and destruction of dogs and for the protection of sheep on reserves;
- (e) for the operation, supervision and control of pool rooms, dance halls and other places of amusement on reserves;
- (f) to prevent, mitigate and control the spread of diseases on reserves, whether or not the diseases are infectious or communicable;
- (g) to provide medical treatment and health services for Indians;
- (h) to provide compulsory hospitalization and treatment for infectious diseases among Indians;
- (i) to provide for the inspection of premises on reserves and the destruction, alteration or renovation thereof;

- (j) to prevent overcrowding of premises on reserves used as dwellings;
- (k) to provide for sanitary conditions in private premises on reserves as well as in public places on reserves;
- 81. (1) The council of a band may make by-laws not inconsistent with this act or with any regulation made by the Governor in Council or the Minister, for any or all of the following purposes, namely,
- (a) to provide for the health of residents on the reserve and to prevent the spreading of contagious and infectious diseases;
- (b) the regulation of traffic;
- (c) the observance of law and order;
- (d) the prevention of disorderly conduct and nuisances;
- (e) the protection against and prevention of trespass by cattle and other domestic animals, the establishment of pounds, the appointment of pound-keepers, the regulation of their duties and the provision for fees and charges for their services;
- (f) the construction and maintenance of watercourses, roads, bridges, ditches, fences and other local works;
- (g) the dividing of the reserve or a portion thereof into zones and the prohibition of the construction or maintenance of any class of buildings or the carrying on of any class of business, trade or calling in any zone;
- (h) the regulation of the construction, repair and use of buildings, whether owned by the band or by individual members of the Band:
- (i) the survey and allotment of reserve lands among the members of the Band and the establishment of a register of Certificates of Possession and Certificates of Occupation relating to allotments and the setting apart of reserve lands for common use, if authority therefore has been granted under section 60;
- (j) the destruction and control of noxious weeds;
- (k) the regulation of bee-keeping and poultry raising;
- (l) the construction and regulation of the use of public wells, cisterns, reservoirs and other water supplies.

The 2001 Survey of Public Health Capacity in Canada highlighted the issue of jurisdictional fragmentation:

At a national level, First Nations and Inuit public health addresses the five core public health functions, although services and programs are much more integrated into primary care and treatment in the field.<sup>26</sup> Jurisdiction has always been an issue in First Nations and Inuit Health. While the [First Nations and Inuit Health Branch of Health Canada] has the lead federal responsibility in this area, Indian and Northern Affairs Canada and Environment Canada also play important roles in health issues. First Nations and Inuit public health is subject primarily to provincial and territorial public health and health protection legislation.

The survey also revealed that, in most communities, administrative responsibilities for health services, including public health, have been transferred to First Nations. However, such transfer agreements do not translate to self-government or jurisdictional autonomy or control over public health. First Nations jurisdiction stems from Aboriginal and treaty rights, including the inherent right to self-government – not transactional agreements with Health Canada or other federal departments. To illustrate, Medical Officers of Health employed by First Nations Bands are subject to the legislative authority of provincial and territorial governments in which they operate and not First Nations law and policies.

### Canada Health Act

The federal government introduced proposals for the *Canada Health Act* in May 1982, and it was enacted in April 1984. The Act sets out program criteria and conditions of payment for the cash portion of the federal contributions made to the provinces for insured health services and payments made to the provinces for extended health-care services. The criteria include public administration, comprehensiveness, universality, and portability.

The Canada Health Act states that the Minister of Health is responsible for "the promotion of the physical, mental and social well-being of the people of Canada, the protection of the people of Canada against risk to health and the spreading of diseases, and the investigation and research into public health, including monitoring of diseases.<sup>13</sup>

The *Canada Health Act* sets out the conditions of funding for physician and hospital services, but does not cover public health. Indeed, only the *Department of Health Act* offers a broader public health mandate, and apart from the regulation of food, drugs, and pesticides, its wording is more permissive than prescriptive. It states that the Minister of Health is responsible for "the promotion of the physical, mental and social well-being of the people of Canada, the protection of the people of Canada against risk to health and the spreading of diseases, and the investigation and research into public health, including monitoring of diseases." Spending is not dictated as part of the funding transfer and provinces and territories are left to define their own health policies and allocate funding accordingly. As such, public health programs must compete with big budget hospitals and doctor fees and, because of this, fail to obtain the funding required for regions.

The SARS outbreak raised concerns about the legislative framework for health emergencies management in Canada. Since the fall of 2001, all jurisdictions have been reviewing and upgrading their emergency planning and preparedness frameworks. However, the federal/provincial/territorial legislative frameworks for health emergencies have not been analyzed for comparability and interoperability. Moreover, none attempt to specify the roles and responsibilities of emergencies that involve First Nations nor clarify the term of inter-jurisdictional cooperation.

The current federal legislative renewal process with regards to the development of the *Canada Health Protection Act* is another example of the development of laws that will impact on First Nations without First Nations consultation

during their development. Although one information session was provided to First Nations, this does not constitute a consultative process. The first example references "North American Aboriginal medicine" as a form of natural health product and the second mentions that Health Canada has a special role to play in public health and safety, particularly in areas which "impinge upon federal areas of responsibility, such as environmental health risks due to radiation, quarantine, post-market surveillance of regulated products, and Aboriginal health." However, the legislation proposal could have direct implications for First Nations traditional healers and their medicine, Aboriginal rights in respect of traditional healing and medicine, First Nations information governance and the privacy interests of First Nations individuals and collectivities. Similar decisions in the development of the National Collaborative Centre on Aboriginal Health by the new Public Health Agency of Canada were made without consultation but rather through information sessions. Despite the large role of the federal government in the provision of health services and data collection of First Nations, the only mention of First Nations peoples in the proposed legislation is in the context of two examples reflected within the proposal. There has been no further consultation with First Nations on Bill C-5 despite it being introduced in the House of Commons.

First Nations are caught between federal and provincial jurisdictional obscurities. Although the federal government remains responsible for health services for First Nations, its lack of legislative authority in many essential aspects of public health results in a dependence on provincial and territorial involvement in areas that include immunization programs, health emergencies and disease surveillance. First Nations living away from their communities are faced with a provincial/territorial system that remains confused with respect to jurisdictional authority for service delivery and program development. As a highly mobile population, First Nations often move into and away from First Nations communities freely. This contributes to the off-loading of health services responsibility witnessed between the provinces, territories and federal government. As Chief Justice Dickson of the Supreme Court of Canada commented, the Aboriginal perspective of their relationship with the Crown does not depend on the particular representative of the Crown, since "from the Aboriginal perspective, any division that the Crown has imposed on itself...are internal to itself." <sup>13</sup>

Hence, any right to health that First Nations have should be portable and not jeopardized by any arrangement made between provinces, territories and the federal government.

### **Fiduciary Law**

Fiduciary law describes the duty to act primarily for another's benefit. The duties include good faith, trust, special confidences and candor. This area of law governs relationships between 'fiduciaries' and 'beneficiaries'. In particular, it is concerned with the duties and obligations of the fiduciary and the benefits owing to the beneficiaries of that relationship.

All fiduciaries must act with utmost good faith toward their beneficiaries.

Fiduciary law is a particularly valuable tool for the control and regulation of socially valuable relationships. It shapes the boundaries of the beneficiaries' reliance on the fiduciary's discretions and has been described as "the law's blunt tool for the control of the fiduciary's discretion." <sup>13</sup>

All fiduciaries must act with utmost good faith toward their beneficiaries. If fiduciaries stray from the standard of good faith, they are in breach of their duties. The fiduciary doctrine is not interested with "why" or "how" the breach occurred, but only that the breach happened. Circumstances of the event causing a breach of fiduciary duties come into play only when determining remedies.

In law, a fiduciary is required to act within a prescribed set of principles in matters impacting – either directly or indirectly - upon its beneficiary. There are, for examples, certain positive duties that are imposed upon a fiduciary:13

### A fiduciary:

- must not act in a conflict of interest situation, must not benefit from their position, must provide full disclosure of their actions and may not compromise their beneficiary's interests;
- may delegate their authority, provided that absolute responsibility remains with the fiduciary; and
- is personally liable for the direct breach of their duties or the wrongful actions of its delegates that results in a breach.
- in a fiduciary relationship, the beneficiary acquires a number of benefits, including:
- the ability to commence legal action for any breach of fiduciary duty once the cause of action is exposed;
- alleging a breach is sufficient the onus of discharging the allegation of breach rests with fiduciary; and,
- the ability to seek remedial aid upon the finding of a breach.

Since the beginning of the British assertion of sovereignty, the guiding principles of fiduciary law have governed Crown/First Nations relationships. The entrenchment of inherent Aboriginal and treaty rights in the Constitution Act, 1982 has solidified the Crown's fiduciary obligations in the supreme law of Canada.<sup>13</sup> Notwithstanding there are very limited applications of fiduciary responsibility by the federal Crown and this has only been through a determination by the Courts. Recently, the federal government has acknowledged that there needs to be a process (outside of litigation) that defines the parameters of the

A Public Health Act for First Nations is now, more than ever, needed to oversee the governance and jurisdiction of population health issues that face First Nations communities.

federal government's obligations under its fiduciary duty. This process is partly outlined in the Political Accord that was signed by the National Chief and the former Minister of Indian and Northern Affairs, the Honourable Andy Scott on May 31, 2005. Within the Political Accord is a process to define fiduciary duties, and Aboriginal and treaty rights through a joint AFN and federal government Steering Committee on the recognition and implementation of First Nations governments.

## The Gaps

Several obvious gaps in the organization, jurisdiction, administration, and governance of public health for First Nations exist. Lack of clear federal legislation, the absence of multi-jurisdictional working arrangements, and the overall non-existent accountability for First Nations public health delivery have contributed to the current state of mismanaged and, in many cases, absent public health programming.

A Public Health Act for First Nations is now, more than ever, needed to oversee the governance and jurisdiction of population health issues that face First Nations. A new Public Health Act for With increasing transfer of services and more integration of services within First Nations would not require provincial health systems, some level of clear First Nations' expectations needs the opening of the Indian Act. to be legislated and not just agreed upon in a temporary memoranda of agreement.

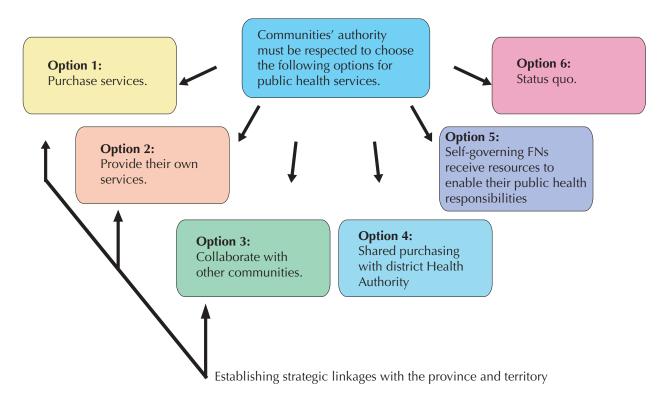
The need is particularly urgent when one becomes increasingly aware of electronic health systems and surveillance technology that are currently being developed and will include First Nations as users and beneficiaries. The age of technology places First Nations in a more vulnerable position for having their rights potentially jeopardized more frequently and more easily.

Environmental health is not often seen as a priority by any federal or provincial government and yet the environments in which First Nations live are currently contributing to their general poor health. Unless authorities address these impacts in First Nations specific legislation, it is likely that no change for the better will occur.

The complexities of roles and responsibilities of INAC, FNIHB, First Nations governments, territorial and provincial governments and other designated agencies with regards to First Nations public health require strict guidelines and clarification in an Act that will legislate these roles and responsibilities. The need for a First Nation community to have strong and clear links to a public health system exists. The question remains as to how First Nations can maintain their autonomy and yet participate in a public health system. One solution may be First Nations Regional/ Sub-Regional (Treaty) Public Health Secretariats who would link with other relevant governments and public health authorities.

# **Jurisdiction over Service Provision**

(using existing bylaw making authorities of First Nations)



While a national standard of excellence for public health must be ensured, the methods required for successful delivery, management, and accountability are unique to every community and are ever-changing. Six jurisdictional options are proposed to deliver public health to First Nations. One option is to utilize what, in many circumstances, are better services locally through purchasing services from local provincial Health Authorities or Public Health Units. The second option would only be feasible for communities with a population large enough to support hiring a Medical Officer of Health and other public health staff. Options three and four encourage First Nations governance

through First Nation Regional Health Authority's creation or shared purchasing agreements with local/provincial district health councils. The fifth option, especially relevant in the Yukon, is to have self-governing First Nations enable their public health responsibilities through resource enhancement. The final option is that of enhanced programs within FNIHB, or a separate national First Nations agency to deliver services to communities. Each of these options already exist across the country and each has inherent pros and cons. However, the largest gap is the coordination and leadership of these varying public health activities. Here lies the greatest potential role for the federal government, either through FNIHB, or the Public Health Agency, in assuring quality services are available either by facilitating service acquisition locally, or enhancing First Nations capacity to provide public health services to their communities. Assurance is required for each of these delivery options in the form of a prearranged or authority if any of these options are to be effective and accepted.

Programs should be directed to community priorities, growing capacity and changing awareness of needs. Different approaches can be geared to particular groups (e.g., youth, young mothers, isolated elders, etc.) and therefore be more effective at reaching these groups. This must be enabled in any future legislation.

The role of the Public Health Agency of Canada remains uncertain. It is clear that the National Collaborating Centre on Aboriginal Health can not fulfill the role of advocating effectively for First Nations within all policy and program responsibilities governed by the PHA, nor can it offer the leadership that will be required to maintain connections within the public health system for First Nations. One possible way of ensuring consistent First Nations priorities within the Agency's strategies is through the development of a specific national Secretariat. Alternatively, a separate but strategically interconnected First Nations Public Health Agency should be considered. This would likely operate at a Regional level and may function most effectively if a joint relationship was established with FNIHB and Regional First Nations Organizations operating as the central link to the system.

### Recommendations

The following recommendations address issues surrounding public health jurisdiction, authority and governance. The ultimate outcome of these recommendations is an organized approach to the delivery of public health services to First Nations that overcomes the current legislative and jurisdictional hurdles. The structure will need to respect the variations in First Nations communities across the country, and will ensure that public health delivery is not done in a piecemeal approach but rather with minimal basic program requirements for a First Nations public health system and maximum freedom for individual community design. It will also endeavour to connect First Nations communities, no matter which option they choose to obtain public health services, under one harmonized system.

**Recommendation #6:** FNIHB should assume the role of assurance and facilitator, and when decided upon by First Nations' plans, provider of public health to First Nations communities. Their facilitator role should consist of their participation in tripartite agreements with provinces and territories interested in providing public health services to First Nations communities. Their facilitator role should also consist of enhancing the capacity of communities interested in assuming governance of their own public health services, such as through First Nations Regional/Subregional Public Health Authorities. Their assurance role would ensure the fulfillment of the pre-agreed upon role of other provinces and territories.

**Recommendation #7:** Smaller First Nations communities of less than a critical mass number (as yet to be defined) should have access to flexible mechanisms of accessing services. Economies of scale and First Nations political structures will need to be considered when determining best ways of providing public health services. Collaboration between First Nations communities will likely be essential in ensuring the success of community health programming that is both feasible and sustainable.

**Recommendation #8:** Wellness Centers, Friendship Centers, and other First Nations organizations, agencies and community programs need to be included as key stakeholders in the delivery of public health programs. Many of these existing agencies and services have the knowledge and experience but lack the funding capacity to enhance their services and to reach more First Nations. Of critical importance, these service delivery centres must solidly connect to their First Nations government and not usurp First Nations government capacity to deliver public health programs to their membership living both on and away from their communities.

**Recommendation #9:** A more significant role of the Public Health Agency of Canada in program development and evaluation may be better achieved through the creation of a First Nations Public Health Secretariat within each of the provinces and territories, or by supporting a new national First Nations Public Health Agency.

**Recommendation #10:** The enactment of new federal legislation, entitled the First Nations Public Health Act, should be considered. This Act will include a description of the authority of the provincial and territorial Public Health Acts in addition to unique laws relevant to First Nations. This act would also describe a well-defined Public Health System with core basic programs. Included in the Act would be the option of extending the authority required to have public health programs governed by First Nations communities either through regional/ sub-regional First Nations Public Health Authorities or other proposed means. Communities that opt not to govern their own public health programs will have the option of having them provided by FNIHB. Such services will need to be protected from the realities that most public health professionals face with acute health care often calling them away from public health activities.

**Recommendation #11:** Regional/Sub-Regional First Nations Public Health Authorities described in Recommendation 10 should be governed by a Board of Directors that would consist of Chiefs from each community (or their designates). A CEO of the Health Authority would report to the Board, and Health Directors from the communities would act as an advisory body to the Board.

**Recommendation #12:** Clear descriptions of roles, responsibilities, funding and accountability protocols need to be annexed to any proposed *First Nations Public Health Act* to ensure effective, efficient, sustainable service delivery structures. This Act would also detail out the fiduciary role of FNIHB in facilitating tripartite agreements and assisting in the assurance and evaluation of services provided to First Nations communities.

**Recommendation #13:** The new proposed *First Nations Public Health Act* would endeavour not to complicate the delivery of public health in Canada. Rather, it would attempt to harmonize and formalize the way in which public health is most effectively regulated and delivered – that being at the local level. This would include a review of other relevant/conflicting legislation, such as that which governs the licensing of food premises.

**Recommendation #14:** Intergovernmental Agreements or Memoranda of Understanding should be struck between the federal government, First Nations governments, and the provinces and territories. These agreements should outline the unique relationship the federal government has with First Nations under a potential new *First Nations Public Health Act.* For example, where provincial Regional Health Authorities or Boards of Health fail to comply with service delivery of public health programming to First Nations, the MOU between federal, First Nations, and provincial governments will enable the provincial ministries to enforce their authorities that govern Regional Health Authorities and Boards of Health, and therefore ensure that services are provided with as little interruption as possible to First Nations living on or away from their communities.

**Recommendation #15:** With respect to surveillance, rules governing the following: case identification (e.g., uniform criteria for diagnosis and laboratory testing), data sharing (e.g., timelines and procedures for reporting new cases and norms governing the protection of privacy), and information dissemination (e.g., responsibility for communicating to national and international audiences and the content of such communications), need to be incorporated into both the intergovernmental agreements as well as any potential *Public Health Act*. These rules, first and foremost, must respect the principles of Ownership, Control, Access and Possession (OCAP) of First Nations to their collective and individual health data.

**Recommendation #16:** The federal government must continue to honour its fiduciary relationship with First Nations communities as part of the new public health programming arrangement. A clear statement to this effect must be made in any proposed *First Nations Public Health Act*. The federal government's role is especially important for communities who opt not to govern their own public health services.

**Recommendation #17:** A dialogue should begin between the Assembly of First Nations, First Nations regions, and the federal government to explore the federal government's relationship with provinces under the *Canada Health Act*. This dialogue should specifically explore the possibility of unique funding arrangements to provinces so that they can offer access to quality public health services unique to First Nations living away from First Nations communities but with some direct accountability to First Nations governments who also represent these individuals

**Recommendation #18:** The role of INAC in the delivery of public health relevant services, such as housing, water and sewage, should be detailed under the *First Nations Public Health Act*.

**Recommendation #19:** In order to achieve healthy housing for all First Nations, recognition of complete First Nations jurisdiction in the area of housing and infrastructure and the acceptance of First Nations as equal partners in government-to-government based decision-making processes related to housing and infrastructure must be guaranteed.

**Recommendation #20:** Provincial Regional Health Authorities and Public Health Units should have First Nations representation on their public health governing bodies, especially in urban communities with large First Nations populations.

**Recommendation #21:** New methods of creative accountability on the part of the federal government to First Nations should be developed, including the possibility of third party auditors that are non-government employees. Similar changes need to happen on the part of First Nations accountability to include assessment based on outcomes of population health versus outputs of programs i.e., reporting that enhances First Nations capacity to effectively plan and monitor public health services instead of impeding this capacity due to a high administrative burden.

**Recommendation #22:** Additional funding will need to be made available for the new programs, as defined under the proposed *First Nations Public Health Act*. This is particularly relevant for communities that have already negotiated Health Transfer Agreements or for those that fall under other funding arrangements with the federal government such as James Bay Cree, self-governing First Nations and the territories.

**Recommendation #23:** Medical Officers of Health (currently named Regional Medical Officers of Health) who service First Nations communities must be granted full authorities under the provincial legislation where they work. They should be allowed the same rights as all other provincial and territorial Medical Officers of Health, and invited to participate in all provincial and territorial meetings and consultations. The proposed new act would scope out their responsibilities including their relationship with FNIHB. These Medical Officers may be employed by FNIHB, or by First Nations or by the province.

**Recommendation #24:** An official consultation policy should be adopted by the federal government and used by all federal ministries and departments when any potential policy decision is being discussed that would impact First Nations and their public health. The aim of this recommendation would be to achieve the meaningful consultation that is expected under a fiduciary obligation.

**Recommendation #25:** Any changes to the current way in which public health is delivered to First Nations can not adopt a Pan-Aboriginal approach, nor can the funding envelope be a Pan-Aboriginal one. Instead, a specific First Nations approach and funding for public health need to be assured.



# **Providing Public Health**

# **Chapter 4: Surveillance**

"Pan-Canadian investments in Health Research, Electronic Health Records (EHR) and Telehealth have generally not reached First Nations, despite federal recognition of the need for an Aboriginal Health Infostructure. Concern over First Nations ownership over information is a key consideration for e-health, health research and health systems accountability. First Nations capacity to support health information management and research would prove effective in gaining better access to health data and evidence." Assembly of First Nations, 2004

Health surveillance includes collecting, interpreting and communicating health data so that it can be acted on. It assists in the early recognition of outbreaks, disease trends, causes of illness, and health factors. For example, surveillance can help identify and deal with immediate situations, such as contamination of public water supplies, and can also be used to track data over the longer term, such as smoking and cancer rates. Its importance in setting priorities for community health programs and in their impact evaluation is significant.

The particular needs and circumstances of First Nations in relation to public health surveillance are unique. Historical, geographic, cultural, epidemiological and socioeconomic factors together account for significant disparities between First Nations and the Canadian population in issues of public health generally, as well as considerable diversity within the First Nations population. Therefore, addressing the information needs in the public health domain among First Nations is a complex task.

The task is further complicated when factoring in the issue of scale. Many communities are small, over 30% are remote or isolated. Since each First Nation Since each First Nation has has its own unique public health situation, it will be important for public health its own unique public health information to be community-specific to the extent possible. Therefore, this situation, it will be important raises the need to achieve a balance in decision-making and the distribution of for public health information resources between national and regional/Treaty First Nations jurisdictions, and to be community-specific, to individual First Nations. These jurisdictional and scale issues will likely need the extent possible. ... Access to to be settled early in the progress, since the establishment of public health provincial health data on First surveillance systems should be preceded by the establishment of surveillance Nations health is essential. priorities and responsibilities.

This chapter will review the move by the federal government to encourage the development of a Pan Canadian approach to disease surveillance and the most recent decision by FNIHB to begin negotiations with Canada Health Infoway to include First Nations as part of this project. It is imperative that First Nations, with national coordination provided by the Assembly of First Nations, participate as equal partners to ensure that the best interests of First Nations are maintained and the full capacity of surveillance achieved for First Nations communities.

### The Vision

In this chapter, the Advisory Committee outlines two stages necessary to achieve the creation of a First Nations Public Health Infostructure. The first stage is the development of a First Nations Public Health Infostructure including regional autonomous networks and a central advisory body that feeds communities relevant, useful and non-identifiable information about the health of their communities. The second involves greater collaboration with current provincial and federal surveillance activities. While it may be argued that stage two should happen in advance of stage one, the Advisory Committee felt that stage two could not happen in an effective way without stage one having been completed.

# Background

### **Surveillance Systems**

Public health surveillance results from a series of connected activities. These include a system of data collection, a system of data organization and analysis, and a system of response (or information dissemination). Ideally, the planning of each of these systems should be done in a coordinated fashion.

The attributes of a good public health surveillance system for First Nations are:

- feasibility;
- acceptability;
- accuracy;
- flexibility;
- timeliness:
- cost-effectiveness;
- consistency over time;
- confidentiality through restricted access; and,
- OCAP compliant (see glossary for full OCAP definition).

To achieve these attributes, it is important that surveillance systems have clear and limited objectives.

For a specific public health issue, a surveillance system can have several uses. These include:

- providing quantitative estimates of the magnitude of a health problem. For example, this could include measures of mortality, morbidity or disability rates associated with the health problem;
- describing health outcomes for a disease such as the rate of renal failure or other complications in diabetes;
- detection of epidemics this could refer to both communicable and non-communicable disease and other health events (such as a suicide attempt);
- documentation of the distribution of health events/states (time, place, person);
- evaluation of prevention/control measures; and,
- monitoring changes in the frequency and distribution of a health event over time.

### Public Health Surveillance in Canada

The 2004 Federal Budget provided \$100 million to support public health surveillance in Canada, specifically the surveillance and management of infectious diseases. In March of 2004, an agreement between the government of Canada and Canada Health Infoway was concluded to manage this investment in conjunction with federal/provincial/territorial jurisdictions. The terms of the agreement indicate that the investment must be completed within three years and its success evaluated within five years. The investment is to focus on a pan-Canadian approach to health surveillance and, where appropriate, integrate it into the Electronic Health Record architecture and general infostructure investments.

### The Current Surveillance System

The system of public health surveillance in Canada has many components. The most well developed and widely distributed surveillance system is focused on communicable diseases. Many communicable (infectious) diseases are notifiable to local and provincial/territorial public health authorities under public health legislation at the provincial/territorial level. Decisions regarding which diseases are notifiable are taken at the provincial/territorial level, but these decisions are influenced to a large degree by national consensus through scientific bodies. There is substantial variability between provincial and territorial jurisdiction in the mechanisms for data collection, analysis and reporting. This will likely change in the foreseeable future with the current Pan-Canadian investment in a new tool for disease surveillance.

### First Nations and Inuit Health Information System (FNIHIS)

The First Nations and Inuit Health Information System (FNIHIS) was launched nationally in 1997 as one of the three Canadian Health Infostructure initiatives. In 2002, a Treasury Board Submission granted the FNIHIS funding (approximately \$17M) directly to FNIHB. Additional dollars were also made accessible to develop Home and Community Care and Diabetes Modules and a National Native Addictions Information System through the three-year Government On-Line First Nations and Inuit Electronic Health Record Project. Once FNIHIS funding was transferred to FNIHB's direct control, it became managed under a new First Nations and Inuit e-Health Solutions Unit (eHSU), which also looks after telehealth interests.

The FNIHIS experience has shown that developing a system functionality that does not align and integrate with provincial public health systems creates partial systems that are of limited value (e.g., part of an immunization record in provincial system and part in FNIHIS is of little value). When two systems do not speak to each other, the likelihood of one system housing incorrect information about a client is highly likely. FNIHIS is not used by any provincial health authority. As our recommendations later in this chapter propose a decentralized approach through a regional alignment with provincial public health information systems, FNIHIS will be unable to miss this critical requirement. Furthermore, FNIHIS technology has become obsolete and too costly to maintain. Much was learned by those involved with FNIHIS: training and skill maintenance was largely overlooked, introducing a non-Web based system in an era of modern technology was short-sighted, and developing tools for use by First Nations without involving them created multiple problems. Not widely used for planning purposes, this legacy system is being phased out by Health Canada and a loss of \$36M in funding will be experienced by First Nations starting in 2007. Below, we note how First Nations are currently being represented by FNIHB and the AFN (through enabling capacity to gather and communicate First Nations input) in the federal government's endeavour to ensure that funding is made available for a comprehensive disease surveillance system in keeping with national goals and objectives set by federal, provincial, First Nations and territorial governments.

### i-phis and New Initiatives

Recently, Health Canada has initiated an attempt to organize and promote various health surveillance initiatives. The concept is to establish a national surveillance network that would link initiatives, support the development of infrastructures, and disseminate innovations. To that end, a federal/provincial/territorial working group has been struck to develop a strategic plan for the surveillance network.

Canada Health Infoway has made available \$100 million for the development of a spin-off of the integrated-public health information system (i-phis) across the country. There is now consensus as to what the system will look like and which modules will be funded by Infoway and adopted by provinces and territories. British Columbia and Saskatchewan have been using i-phis and have agreed to sign on for the new (recently named "Panorama") system. Manitoba will likely join next year as it is already using i-phis in Winnipeg. Ontario is implementing i-phis across the province but is prepared to accept the new surveillance system. Although Quebec is unsure, the Atlantic provinces and territories will also be adopting the pan-Canadian solution. Alberta is the only remaining region with complications based on existing agreements that seven rural health authorities have signed with Meditech. This pan-Canadian application is being supported and promoted by Health Canada, and therefore, Health Canada will remain the custodian of the application.

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Despite its capacity to act as a communicable disease surveillance tool, the new system will only work with diseases that are reportable under provincial and territorial legislation and will therefore miss all other communicable diseases

(for example, in some provinces, HIV is not reportable, however AIDS is). The other major limitation is that it will not be a surveillance tool for chronic diseases, the illness that is responsible for far more deaths and disabilities in Canada and among First Nations. However, it is the goal of Health Canada, the provinces, territories and Infoway to ensure that additional modules can be developed and added to the solution, as well as to ensure that the computer health language used by the system will be interoperable with other provincial and territorial health data collection systems, such as those employed by hospitals.

FNIHB is currently in negotiations with Infoway to ensure all First Nations communities will have access to training and implementation dollars for this solution. This will be done through contributions by Infoway, the provinces and the federal government. There is also a possibility that client registry costs may be covered by Infoway.

It is the goal of Health Canada, the provinces, territories and Infoway to ensure that additional modules can be developed and added to the solution as well as to ensure that the computer health language use by the system will be interoperable with other provincial and territorial health data collection systems, such as those employed by hospitals.

Dr. Jeff Reading reviewed surveillance in First Nations communities and noted that surveillance posed logistical difficulties, which are compounded by jurisdictional uncertainties. He described how most notifiable disease systems are funded and maintained by provincial governments. Thus, notifiable diseases that occur in First Nations communities are generally documented and analyzed by provincial health authorities. However, responsibility for data collection and public health intervention has generally rested with the federal government and, more recently, First Nations. This situation can lead to a disconnect between surveillance and public health practice, and quality control in surveillance systems can be compromised. The transfer of health services to the control of First Nations could further complicate these relationships unless concerted efforts are made to promote collaboration between provincial public health agencies and First Nations. The success of i-phis and any other system will depend on clear reporting frameworks developed in advance of deployment.

Public health surveillance in Canada is not limited to data collected by i-phis. Dr. Reading noted that other systems include, but are not limited to:<sup>26</sup>

- The Canadian Integrated Public Health System (CIPHS) will link, in standard manner, data from health laboratories, public health units and other potentially valuable information sources to provide timely information to manage risks to health.
- The Global Public Health Intelligence Network (GPHIN) is an early warning, real-time, Internet-based system that continuously monitors international sources of information to detect outbreaks of infectious disease of international public health importance. Canadian federal institutions and the public health community use the information to monitor the potential risk of these outbreaks to the health of all Canadians.

Another important new theme in public health surveillance in Canada is a much greater emphasis on non-infectious diseases. Within the past decade, a number of new national surveillance initiatives have emerged, largely through the support of Health Canada. These include the Canadian Perinatal Surveillance System, the National Diabetes Surveillance System and an emerging system for surveillance of cardiovascular disease. Conducting surveillance on these health issues has motivated new mechanisms for collecting surveillance data. The model for national health surveillance for infectious diseases and cancer was based on individual or aggregate case reports from provincial or local jurisdictions. This model is impractical and inappropriate for non-communicable diseases. One reason is the sheer numbers of cases. For example, for a disease like diabetes, there are approximately 1.5 million persons with the disease and more than 100,000 persons diagnosed each year. Furthermore, since these are chronic conditions, maintaining and updating information on outcomes on these conditions would be a formidable task for a system that relied on case reporting. Therefore, for these non-infectious diseases, existing provincial health information systems are being used. The best-developed example of this approach is the National Diabetes Surveillance System (NDSS).

The NDSS is guided by a Steering Committee that is comprised of representatives from federal, provincial and territorial governments, academic institutions, NGOs and national Aboriginal organizations. For data collection and collation, the NDSS has funded provinces and territories directly to extract the data from their administrative health information systems in a standardized fashion, and to send aggregated data to a central repository for national analyses. The appeal of this approach was its proposed relative efficiency, since it relies primarily on existing databases. However, concern has been raised around the lack of engagement by First Nations to design the reporting format and the lack of OCAP compatibility. Although it had been the intention of the NDSS to establish a distinct Aboriginal component, this has not come to fruition and the Assembly of First Nations has currently halted its participation in the Steering Committee process.

### Integration and Management of Health Information across Jurisdictional Boundaries

Currently, federal First Nations health data are generally maintained by Health Canada (First Nations and Inuit Health Branch). At the provincial/territorial level, health data (based on physician claims for service provided) and health services utilization data (physician claims and hospitalization data) are maintained within the various provincial/territorial health ministries; often with no clear indication of the First Nations status of the user of services. When First Nations communities and organizations need to gather information and data relevant to their citizens or communities, they must rely on information and data that is made available from the federal and provincial/territorial departments and ministries who hold the information about their communities.

Since federal/provincial/territorial governments control much of the data, the analysis of both federal and provincial health data is conducted by non-Aboriginal organizations and agencies on behalf of the respective levels of government. 26 Increasingly, provincial governments and regional health authorities are interested in comparative or cost analysis of, for example, First Nations health utilization patterns. Sometimes these analyses are conducted by specialized units set up within provincial health departments. In other instances, university-based research units are contracted to examine First Nations health issues using provincial administrative data. Since most provincial governments have only recently begun to recognize the need to work collaboratively with First Nations

Since government controls much of the data, the analysis of both federal and provincial health data is conducted by non-Aboriginal organizations and agencies on behalf of the respective levels of government.

recently begun to recognize the need to work collaboratively with First Nations governments, this information is generally not available for First Nations organizations or communities to utilize in health planning.

Five provinces identify First Nations clients in their databases through unique health card numbers or First Nations health premium lists (New Brunswick, British Columbia, Alberta, Saskatchewan and Manitoba). No province claims to have an exhaustive coverage of all First Nations. In Manitoba for example, the Health Department estimates that their data undercounts First Nations persons by as much as 30%, since First Nations persons and their descendents registered under Bill C-31 are not identified as First Nations on their health cards.

In Ontario, a residence code analysis has been done by provincial government to extract hospital utilization information for First Nations clients living in First Nations communities. In this case, identification is through postal code correspondence to reserve location, not health card numbers.<sup>26</sup>

The western regions also have relationships with provincial vital statistics departments, either directly (Pacific, Alberta, Saskatchewan) or, in Manitoba, indirectly through the Department of Indian and Northern Affairs Canada (INAC) in order to obtain birth information for registered Indians. Both First Nations populations living in and away from First Nations communities are included. Other users of INAC are noted below.<sup>26</sup>

- Pacific is the only region where the Status Verification System (SVS) file is shared with the provincial vital statistics department under a Tripartite Memorandum of Understanding (MOU), allowing all verification of status births to be done by the province.
- In both Saskatchewan and Alberta, the FNIHB regional office conducts a manual record matching exercise on provincial births using the SVS file to extract First Nations births. Saskatchewan goes one step further by determining residency in or away from First Nations communities.
- In Manitoba, the birth database is sent to the INAC regional office, which verifies status entitlement and forwards this information to Manitoba FNIHB Region.

In the eastern part of Canada, no formal linkages exist with provincial vital statistics registries and birth information is obtained only for the First Nations population living in First Nations communities. FNIHB birth information is obtained directly from the communities, most often through reports provided by the Community Health Nurses (CHNs) to the regional office. Ontario Region is unable to provide an estimate of their coverage of birth information as the mechanism of data capture is the First Nations Health Information System (FNHIS), which is not being used by most First Nations.<sup>26</sup>

In summary then there are three main methods used to identify First Nations persons in provincial health databases:

- 1. Identification of those health card numbers that belong to First Nations. From that, a search can be made of all health records belonging to the First Nations health card numbers. Most provinces do not have ethnic identifiers on health card numbers. This includes Nova Scotia, Newfoundland, Prince Edward Island, British Columbia, Alberta, Ontario and Quebec. Although New Brunswick and Manitoba discontinued the use of ethnic identifiers some years ago, existing numbers were not changed, meaning that there can be a partial identification of the First Nations population in these provincial health card numbers databases. In Alberta and British Columbia, the health insurance premium database for First Nations people has been linked to health card numbers. This has allowed First Nations utilization and expenditure analysis to occur in these provinces.
- 2. Utilization of a geographic indicator, such as postal or residency codes that belong to First Nations communities. In this case, all records of residency in the selected areas will be extracted, not just First Nations. Also, the postal code may extend past the reserve boundaries and include other provincial residents. Currently, Ontario uses a version of a geographic identifier to provide information on First Nations. Pacific Region, in association with the vital statistics department, is currently developing a methodology based on postal codes to separate those living in and away from First Nations communities in their already identified First Nations population.
- 3. Sharing the FNIHB Status Verification System database with provincial health departments. This database contains the names, sex, birth dates, and Band membership information of all registered First Nations persons living in or away from First Nations communities who are eligible for federal benefits through INAC or FNIHB. Sharing of SVS information with provincial departments or agencies should require the permission of the First Nations in the province, generally through regional First Nations bodies. In recent projects that have investigated provincial health care utilization and expenditure rates of First Nations, FNIHB has established a policy that sharing of SVS data with the province would require First Nations approval and participation. However, at the time of writing, INAC is currently reviewing its policy related to the release of SVS information, including to FNIHB and provincial health authorities. As such, any disease surveillance activities reliant on SVS have been paused for the last year with no current proposed release date for a new INAC policy.

None of these methods for identifying the First Nations population in provincial health databases are perfect, however. In addition to the problems in coverage identified above, identification of First Nations persons through realistic linkage methodology (identifying persons based on matches across two databases on variables such as names, age and sex) is inherently problematic for obvious reasons related to similarity of names in many First Nations communities.<sup>26</sup>

Analysis using the health premium database may predispose the First Nations population to a slightly poorer socio-economic profile than would be the case if the SVS were used to identify First Nations. This is because some employers provide premium coverage as a benefit, therefore some working First Nations people would be excluded from the premium list shared with the province. There are also concerns in Alberta that, as health card numbers encompass dependents, some dependents may not actually be identified as status First Nations under the *Indian Act* (i.e., Bill C-31 inheritance rules). When subsequent analyses are undertaken, they may reach conclusions that are not accurate representations of the entire First Nations population.<sup>26</sup>

Of the five provinces with a capacity to identify First Nations in the provincial health databases, three (Manitoba, Saskatchewan and British Columbia) currently share hospital separation data on a regular basis with FNIHB regional offices, whereas Alberta and Ontario do not.<sup>26</sup>

# **Implications of Transfer**

Transfer of responsibility for a health service has important implications for public health surveillance. In the pre-transfer environment, FNIHB (or MSB) maintained responsibility for the regional and national monitoring of health conditions in communities. In the context of transfer, these responsibilities (and to some extent the resources required to meet them) have been allocated to either individual communities or regional First Nations organizations. In the process of dividing resources for public health surveillance activities, the capacity to produce a comprehensive analysis of changing health conditions has been weakened. Efforts to renew this capacity under First Nations control and with the addition of new surveillance technologies are currently underway.

In his review of public health surveillance capacity, Dr. Jeff Reading noted that many individual First Nations may not have the technical capacity within their communities to analyze, interpret and report data from surveillance systems. Dr. Reading noted that it will be important for First Nations to establish some more centralized capacity to perform this function. To do this, a determination will have to be made as to where those responsibilities lie, and how those technical capacities will be developed. One approach would be to create a fairly centralized national analytic resource that would provide this service for more local jurisdictions. Another alternative would be to create a series of regional analytic resources centers. Each could provide broad technical support to communities within their region, while functioning as a national centre of excellence for one or more specific health information areas. Dr.

The advantage of establishing regional analytic resource centers is that they could provide services that extend beyond surveillance per se and might include more general expertise and infrastructures in population health research.

Reading concluded that the advantage of establishing regional analytic resource centers is that they could provide services that extend beyond surveillance per se and might include more general expertise and infrastructures in population health research.

Optimally, these regional analytic resource centers should be under control of First Nations authorities and should be staffed by First Nations technicians. In reality, few regions have the capacity to realize this goal, even in the long term. Indeed, most provincial health departments and regional FNIHB offices struggle to find competent people to fulfill these functions. Developing, managing and utilizing complex health databases is a demanding task which requires highly

qualified individuals who are in high demand from both the public and private sector. University Units involved in health information system development also struggle to retain competent staff and are constantly looking for resources to expand training programs. This issue is further addressed in Chapter 7, Health Human Resources.

Just as First Nations authorities are reluctant to relinquish possession of health information that has been collected under their jurisdiction, so are provincial and federal departments reluctant to relinquish databases that have been aggregated through their service activities. In addition to the sense of "ownership" that data stewardship implies, provincial and federal agencies must be concerned about their legal responsibilities related to both the legislation through which data has been collected, and to the privacy and ethical requirements that are increasingly applied to the use and potential abuse of confidential information about individuals.

In the short term at least, First Nations regional analytic centers for health information and public health surveillance will likely involve collaborations and partnerships among First Nations authorities, federal and provincial agencies, and relevant research centers. These collaborations are necessary in order to maximize existing human resources, to resolve many of the technical problems related to linking and developing databases, and particularly in order to build trust among the various partners that the principles of OCAP can be respected and implemented.

In the short term at least, First Nations regional analytic centers for health information and public health surveillance will likely involve collaborations and partnerships among First Nations authorities, federal and provincial agencies, and relevant university centres.

The data in these systems will come, for the most part, from communities and provincial service and data collection activities. Data collection at the First

Nations community level will always be difficult if the service providers who generate the data are not properly trained and resourced, and do not see the value in ensuring that data collection is consistently of high quality. Current efforts within the Canada Health Infoway negotiations to promote training and First Nations management of the process are extremely important and must continue to be supported. Data quality will be a more easily achieved goal if the results of data analysis are relevant to community needs and can be easily disseminated and utilized in community health planning. Regional centers are more likely to be able to provide the logistic support for training and data utilization.

The ultimate governance structure of the regional analytic centres data collection should look very similar to the current structure of the First Nations Information Governance Committee. This model is one that has successfully incorporated the regional structure of First Nations governance and has had substantial experience in the consideration of health data, disease surveillance and all relevant considerations.<sup>27</sup>

One example of successful data collection and analysis that fully respects the principles of OCAP while maintaining a very high degree of respect among researchers, epidemiologists and relevant stakeholders is the First Nations Regional Longitudinal Health Survey (RHS). In the most recent survey, data was collected between August 2002 and November 2003 in 238 First Nations communities across Canada. A total of 22,602 surveys were administered. Interviews were coordinated by First Nations regional organizations and administered by First Nations interviewers using laptop computers. Data were encrypted and 'uploaded' directly from the communities to secure servers. The success of such a product clearly indicates the capacity and willingness among First Nations to participate in surveys that promise to respect the principles of OCAP in addition to offering meaningful feedback to participating regions.

As described in Chapter 3, the large body of federal, provincial and territorial legislation that governs public health does not spell out the terms of inter-jurisdictional cooperation. Non-legal documents such as policy statements, intergovernmental agreements and memoranda of understanding are used inconsistently to formalize the terms of intergovernmental collaboration. Health Canada depends on the voluntary cooperation of provincial and territorial authorities, both regarding health surveillance (including case reporting) and responses to outbreaks. Although there are disease specific arrangements (e.g., AIDS), there is not a comprehensive federal/provincial/territorial document that assigns specific roles and responsibilities to federal, provincial and territorial government actors. The lack of formal terms of cooperation impedes rapid responses to emergency situations. Formal documents are clearly necessary to deal with issues such as data sharing, data ownership, privacy, permitted distribution of data, and the consequences of governmental non-compliance with these terms.

### **Broadband Connectivity**

Despite recommendations of the Advisory Council on Health Infostructure, the National Broadband Task Force and the Romanow Commission, the federal government has yet to completely fulfill its commitments to address, as a matter of priority, the broadband infrastructure needs of First Nations communities. In April 2003, Health Canada invested \$2.3M for high-speed satellite Internet service to 148 sites including hospitals, nursing stations, clinics and treatment centers. With phasing out of Health Canada's funding for the First Nations Health Information System starting in 2007, the future sustainability of these sites is in question.<sup>27</sup>

# **Health Emergencies**

Even when Canada has in place a fully functioning disease surveillance network, it will still be necessary to have additional capacity to deal with emergency situations requiring surveillance. Moreover, it is extremely important that the necessary protocols are in place in order to ensure coordination between different jurisdictions in case of an emergency, and that the appropriate level of government assumes a leadership role as required.

The federal government created the Centre for Emergency Preparedness and Response (CEPR) in July 2000 to act as a national coordinating point for public health security within Health Canada and across various levels of government in the country. This addressed the need for a more consistent, sustainable and integrated approach to preparing for, and responding to, all types of public health emergencies in Canada. The Centre brought together most of Health Canada's emergency preparedness and response programs and created a 'critical mass' of resources to allow for a more cohesive and synergistic response to emergency situations from both a departmental and interdepartmental perspective.

The CEPR mandate focuses on public health issues arising from various threats to the safety and health security of Canadians, including:

- natural events and disasters such as floods, earthquakes, fires and highly dangerous infectious diseases; and,
- human-caused disasters such as accidents of criminal and terrorist acts involving explosives, chemicals, radioactive substances or biological threats.

In sum, in the face of pandemic influenza and the most recent water disaster in the community of Kashechewan, it is clear that little progress has been made at the level of P/F/T/First Nations communication and clarifying roles and responsibility among those responsible for health services, social services, public security, and public health. If progress is to be made in collaboration across and within jurisdictions, First Nations governments need to invest urgently in formal mechanisms to exchange information, share best practices, undertake conjoint training, integrate and test contingency plans, and examine the interoperability of processes, protocols and equipment to respond to health emergencies. The role of INAC in these activities must not be ignored.

### **Health Research**

Finally, we devote a section of this chapter to the importance that health research has in the advancement of health for First Nations, specifically in the promotion of health and prevention of disease.

The Royal Commission on Aboriginal Peoples (RCAP) recognized the critical link between self-determination and control over information.<sup>26</sup> A critical component of the RCAP Report was the development of Ethical Guidelines for Research. These guidelines served to increase awareness about the unique research needs of Aboriginal people and

were one of the first standards for Research Ethics Guidelines specific to Aboriginal people. The RCAP Research Ethics Guidelines ensured that "appropriate respect [be] given to the cultures, languages, knowledge and values of Aboriginal peoples, and to the standards used by Aboriginal peoples to legitimate knowledge." The RCAP guidelines have played an integral role in various documents on this subject – such as the Tri-Council Policy Statement's Guidelines for Research Involving Aboriginal Peoples. Since RCAP, First Nations have made tremendous gains in the area of First Nations driven research, and have developed guidelines for ethical research for First Nations at the community, regional and national level. The RHS profiled earlier in this chapter is a demonstration of success in First Nations driven research and OCAP – compliant research ethics.

The Aboriginal Capacity and Developmental Research Environments (ACADRE) Centres which were established by the Institute of Aboriginal Peoples' Health of the Canadian Institutes for Health Research in 2001 aimed to create a nationally coordinated regional network of researchers working in the biomedical, clinical, health systems and services, social, cultural and environmental factors affecting the health of populations in partnership with Aboriginal communities. Each ACADRE centre receives \$500,000 per year over a period of three years totaling \$1.5 million. This funding is received by the centres to be awarded for research grants, student fellowships and administration. While the ACADRE Centres have had some success in helping to fund research by scholars in the area of Aboriginal Health Research, the involvement of First Nations communities in community-based research continues to improve incrementally. Consequently, the health information institutes described herein would be an appropriate network for linking First Nations involved in community-based research and promoting the benefits of this type of research for communities and other researchers alike.

# **Current Gaps if we are to Achieve the Vision**

The current lack of data, the indiscriminant ways in which First Nations health information is governed and accessed, and the lack of funding to initiate a comprehensive and sustainable disease surveillance system have contributed to the current vulnerable state of First Nations health and of the overall ability to anticipate, prevent, identify, respond to, monitor, and control disease and injuries among First Nations. The current gaps compromise the ability of First Nations to design, deliver and evaluate public health activities.

### **Achieving the Vision**

### Phase 1

The first phase would be the building of First Nations Health Information Institutions (FNHII) and the development of required First Nations client registries. As depicted above, a FNHII would integrate health information activities under the control of regionally based analytic resource centers. Individually, the centers would fill the needs for training to build health information capacities at the regional level while together they would form a virtual network linking regional capacities in a collegial national network. Such a model is consistent with regional autonomy while promoting national level collaboration on health issues of common concern. Nationally, these centers could participate through cross appointments to a national advisory body on First Nations health information activities and First Nations health research, potentially emulating the existing First Nations Information Governance Committee.

Discussions with Health Canada have suggested that even if Panorama is the technology of choice that is rolled out before First Nations institutions are able to function as autonomous data warehouses and analyzers, First Nations data can be collected by the pan-Canadian system. Data will be directed to these First Nations institutions and shared back to the provinces/territories and federal government based on data sharing agreements that follow First Nations principles of OCAP.

A key assumption in this work is the ability to identify clients in the system. Just as populations and communities are made up of many individuals, in the same way, health data that identifies trends and outbreaks in populations are made up of health data about many individuals. However, when information about individuals is used for surveillance, the name of the individual is removed, since this is not needed. Information about the health of an individual is obtained every time a client accesses a health care provider, hospital or health program etc. Many of the providers of such health care are part of the provincial system, but the information they gather about the individual is a small but vital part of the population health data that is needed for surveillance to be effective on behalf of the community. The linking of this data with other health information, such as Vital Statistics or survey data (e.g. RHS), that is currently collected is vital.

A Client Registry can be developed by a jurisdiction and held by that jurisdiction. A surveillance system would access client files from the client domain registry established by that jurisdiction. In the context of First Nations client registries, these would be established most likely at Regional/Sub-regional levels and held by FNHII mandated by First Nations leadership, but also meeting the requirements of federal, provincial and territorial legislation in the area of protection of health information. The latter enables the FNHII to hold FPT data on First Nations, extracted from links between the First Nation client registry and the FPT databases in accordance with data sharing agreements. Currently, for instance, in the case of the National Diabetes Surveillance System, a memorandum of understanding is signed between the Public Health Agency of Canada, a specific First Nation(s) (e.g. Treaty or Tribal Council), and the respective province/territory. The province/territory receives financial compensation from the federal agency to link the Status Verification System held by the First Nations and Inuit Health Branch of Health Canada via a Memorandum of Understanding with Indian and Northern Affairs Canada (i.e. the Indian Registry), and the provincial/territorial diabetes surveillance system. While data resulting from the link is shared with the concerned First Nation(s), the First Nation(s) does not receive any funding from conducting further analysis, interpretation or dissemination of the data. This is not an equitable distribution of resources and capacity, nor does it favor the creation of economies of scale for First Nations public health surveillance, nor does it fully meet the First Nation principles of OCAP.

Hence, the development of an interoperable First Nation client registry architecture that could be adopted and implemented by all First Nations in Canada and held by multiple, appropriately mandated FNHII, offers a more sustainable and empowering option for First Nations public health surveillance. It would facilitate access and extraction of data across the majority of public health surveillance systems, electronic health records, pharmanets, labnets, telehealth client rosters, health professional databases etc., within Canada and potentially even abroad. A conceptual outline of the proposed process is provided below.

# Band **INAC SVS** Rosters Data First Nations Pseudony-Client Registry mi ed In each P/T. but FN owned Report Report **EMPI Trusted Services** P/T and FN in bilateral agreement to external data warehouse Provincial Dataset<sub>1</sub> Provincial Dataset<sub>2</sub> Disease Registry Note: EMPI stands for Electronic Management Patient Index.

# Conceptual Process for Disease Surveillance Using FN Client Registry

First Nations need data to assist in sectoral health services discussions with a number of agencies including regional health authorities and provincial ministries of health, social service agencies and other health related service entities. A majority of First Nations are directly involved in the transfer of the authority for community-based health programs and services to First Nations control and efforts are underway to further explore and expand national Non-Insured Health Benefits (NIHB) and other program co-management opportunities. In an environment where evidence-based program planning is a critical success factor to cost-effectiveness and quality assurance, First Nations need to ensure that the necessary information tools and analysis expertise are available for appropriate and timely response.

### Phase 2

Governance in an information age means negotiating agreements with information gatekeepers and health data stewards who submit data for analysis and who assemble and interpret health data for policy. This phase should involve collaboration between federal/provincial/territorial/First Nations governments in the development of tripartite agreements that would allow for data collected to be aggregated and shared between First Nations communities, the province/territory and the federal government. Communities would receive data in a way that would facilitate program development and evaluation, health advocacy and financing, in a more effective and appropriate manner than what currently exists.

The capacity to effectively achieve Phase 2 in a manner that best serves the interests of First Nations relies on the success of Phase 1. Without Phase 1, it is unlikely that tripartite agreements will be more than a form of lip service to First Nations. A tripartite agreement that is truly equitable for all three participant groups will require resources and capacity that do not currently exist.

## Recommendations

Recommendation #26: First Nations Health Information Institutions (FNHII) should be developed immediately. They should be driven by the needs, priorities and interests of First Nations people, under the complete ownership of First Nations and not under the ownership of federal, provincial, territorial or other governments. A national coordination office will act as the facilitator and supporter of Regional/Sub-regional FNHII in each of 10 or more participating regions/sub-regions. In turn, community resources will be determined by a needs assessment completed by the community itself, with the assistance of regional coordinators. To ensure that the FNHII keeps pace with other Canadian health infostructures, adequate community infrastructure (including physical space such as facility modifications, information and communications technology, security) will be required as will a periodic increase in resource levels to evaluate the infostructure and accommodate technological changes and advancements.

Region (such as a treaty area), the provincial or territorial government, and the federal government to build a coordinated national health surveillance system (in keeping with Phase 2 described above). It is highly likely that a great deal of regional variance will exist as each region decides on its surveillance needs. The only pre-requisite should be that the system design ensures national interoperability and health language applications. Such a system would include improved co-ordination between public laboratories and other public health surveillance bodies as well as a requirement to share data that is currently collected by federal/provincial/territorial governments that should include, but is not limited to, hospital stays, emergency room visits, reportable disease lists, patient billing lists and other patient registries where current First Nations identifiers exist. These lists should be of aggregate data only and prevent the identification of individuals, but should be of sufficient breakdown that the information is meaningful to communities whose population health is being evaluated. It is vitally important that health data be shared across all jurisdictions to create a national picture of health risks and health outcomes.

**Recommendation #28:** New federal funding for public health should be explicitly tied to these surveillance strategies and plans, with process and outcome reporting. These new federal funds should not displace existing health commitments.

**Recommendation #29:** Pan-Canadian investments in Health Research, Electronic Health Records and Telehealth need to include First Nations as equal partners in the development of strategies and program design.

**Recommendation #30:** First Nations leaders should consider supporting the current efforts behind the development and implementation of the Pan-Canadian i-phis replacement across the nation to ensure their inclusion in a national system, recognizing the flexibility of data ownership that such a system could provide.

**Recommendation #31:** First Nations leaders should consider supporting the current efforts behind the development and implementation of the pan-Canadian i-phis replacement "Panorama" across the nation to ensure their inclusion in a national system, recognizing that First Nations data ownership can be provided by such a system.

**Recommendation #32:** FNHII must be designed to improve public health surveillance capacity in First Nations communities under First Nations control. Health Canada must support and negotiate with First Nations national, regional, and sub-regional institutions, a concerted approach to public health information gathering, use and dissemination contrary to the current fragmented approach of building disease/domain-specific registries with minimal First Nations engagement.

**Recommendation #33:** Agreements will be made with other government jurisdictions, agencies, research institutions and others for the opportunity to share and have access to First Nations data collected by the institutions described in Recommendation #26.

**Recommendation #34:** Health Canada and Canada Health Infoway must work with First Nations in developing federal, provincial and territorial client registries to establish linkages with federal/provincial/territorial electronic health records that are flexible and appropriate to the needs of each First Nations community. First Nations communities must determine independently the information exchange and access protocols that are acceptable and valuable to them. Personal identifiers should be developed for the purposes of health care delivery, including electronic health records, but these identifiers should be drawn and approved by First Nations governments and held by the FNHII to protect individual privacy.

**Recommendation #35:** Band membership lists or lists of members under self-government agreements need to include those First Nations living away from First Nations communities to be included in the surveillance system and given personal identifiers.

**Recommendation #36:** The Government of Canada must fulfill recommendations of the Advisory Council on Health Infostructure, the National Broadband Task Force, the Romanow Commission and subsequent federal commitments to address, as a matter of priority, the broadband infrastructure needs of First Nations communities, especially as these needs relate to high-speed health communications/applications.

**Recommendation #37:** FNHII must be regularly evaluated in terms of their contribution to measurable improvements in First Nations health and well-being. These recommendations must also be understood to be evolving based on First Nations priorities and experiences.

**Recommendation #38:** First Nations institutions should be encouraged to establish a network of community-based health service/program expertise and urban community centers such as the Wellness Centers that could be connected to the FNHII for the purposes of First Nations living away from First Nations communities' disease surveillance capture.

**Recommendation #39:** The development of FNHII and the development of public health surveillance systems must be given higher priority. Resources must be made available on an equitable and sustainable basis. Not only are health surveillance activities a fundamental component of self-government, but the erosion of a coordinated health surveillance capacity in the context of health transfer is both dangerous from a public health perspective and seriously undermines the health planning process at a time when resources are inadequate to meet health needs.

**Recommendation #40:** A review of the capacity and protocols needed by public health laboratories to respond effectively to routine and emergency infectious disease investigations on behalf of First Nations needs to be evaluated and the potential for a direct link with FNHII explored.

**Recommendation #41:** A scan of the current acceptability by First Nations of First Nations personal identifiers under the control of First Nations infostructures needs to be determined, with follow-up education on the pros and cons of such identifiers applied to personal health information.

**Recommendation #42:** Health care professionals need to be included as stakeholders in the development of a surveillance tool to ensure early buy-in and acceptability.

**Recommendation #43:** Any system to be developed for health data collection needs to be flexible and compatible with a range of health systems and health system languages so that additional modules may be added with minimal disruption and costs.

**Recommendation #44:** Any data sharing agreement with provincial/territorial or federal governments needs to clearly outline the responsibilities that each has with respect to responding to any alerts generated by the data in both the urgent and non-urgent setting. Clear communication protocols should also be detailed at the same time.

**Recommendation #45:** Any proposed infostructure needs to include funding resources for community based computers, training and software as well as ongoing maintenance and evergreening costs.

**Recommendation #46:** Any future potential *Public Health Act* will need to explicitly address First Nations personal health information identification.

**Recommendation #47:** Determinants of health should be addressed as variables to be surveyed, collected and analyzed as part of the surveillance system.

**Recommendation #48:** There is an urgent need for First Nations Leaders and Health Planners to work with their communities, INAC, Regional Medical Officers of Health, and provincial counterparts to create integrated protocols for outbreak management followed by training exercises to test the protocols and assure a high degree of preparedness to manage outbreaks. Protocols must include:

- agreement on roles and responsibilities;
- agreement on data ownership, custody, sharing with the aim of facilitating greater sharing of data;
- security and privacy mechanisms;
- prior agreement on the use of data for publication and authorship; and,
- clear identification of persons responsible for: (a) management of the outbreak; (b) data management; and, (c) communications.

# **Chapter 5: Health Promotion, Protection and Disease Prevention**

"[H]e was a medicine man, and I remember that he had to hide in the hills to heal people. There was a great TB epidemic that was rampant everywhere on the reserves. Our traditional people saw this coming in their dreams. But even knowing was not enough. Some of the medicine people, like my grandfather, knew that they could help and did. But they had to hide in the hills to cure people because they weren't allowed to practice what they knew." 12 as cited in Johnson and Budnick

Despite Canada's generally high standard of living and despite a system that promises universal access to high quality care, disparities in health remain a pressing national concern. These disparities are not randomly distributed. Specifically, First Nations populations suffer a burden of illness and distress greater than other Canadians. It is ironic, then, that the emphasis on public health for First Nations by federal health care policy and program designers, up until very recently, has been minimal and that existing programs have been supported with minimal funding. This chapter will provide a way of approaching the prevention of disease and maintenance of good health within First Nations communities.

With a shift towards an emphasis on illness prevention, health promotion and protection of good health, there is a strong need to describe, in considerable detail, the scope of public health programs needed for First Nations both living in and away from First Nations communities. Their implementation and maintenance will require collaboration with First Nations, provincial/territorial and federal stakeholders who will assist in the delivery of these programs, as well as their funding. At the present time, the majority of promotion/prevention programs and services are based on Western approaches that have been adopted with few modifications. An unknown (and likely increasing) number of First Nations people are accessing mainstream services as they concentrate in urban centers. There is greater awareness, among First Nations and other service providers, of the need for more cultural approaches in programs.

The content in a defined scope of public health programs for First Nations must have the following characteristics:

- values First Nations traditions and cultures;
- recognizes the importance of ritual and ceremony;
- values the wisdom and role of Elders;
- includes Traditional Healers and their medicines;
- emphasizes connectedness;
- works to restore balance;
- supports nurturing and mutually respectful relationships; and,
- honors the central place of women.

# The Vision

First Nations governments, together with their federal and provincial counterparts, will work together to understand and improve the health of the First Nations population. This will include the strengthening of skills of individuals to encourage healthy behaviours and the building of healthy social and physical environments to support these behaviours. Central to success of these healthy public policies is that they translate into public health programs that strengthen communities and facilitate the growth of supportive environments.

The vision also includes a public health system that is flexible in two respects. On the one hand, the system must be flexible in its delivery method and, on the other hand, the system must be flexible in the mechanism through which it can be accessed by First Nations. Flexibility means that options must be available for communities to obtain public health services, either through FNIHB, provincial/territorial services or First Nations Health Authorities and that accessibility be assured whether in or away from a First Nations community.

# **Background**

A number of emerging health issues have reached crisis proportions within the First Nations population. The focus of this chapter is to address the approach to prevent the growth of disease patterns rather than to offer treatment programs for those currently afflicted. Treatment is not within the scope of this document, nor the role of the domain of public health. These emerging health issues include:

- New cancers. Continuing increases in lung cancer are expected as a result of smoking and exposure to second-hand smoke. Reproductive cancers likely will increase as a result of high levels of sexually transmitted diseases.<sup>29</sup>
- *Nutritional status* among First Nations people may continue to deteriorate as a result of overall unhealthy lifestyles, poverty and Western diets. Poor nutrition is resulting in cardiovascular diseases, diabetes, vitamin and mineral deficiencies, and overall lack of wellness. While pre-natal and infant nutrition are being addressed to some extent, adult nutrition has not been a focus of current programming.<sup>30</sup>
- With migration to cities, more sedentary lifestyles and an aging population, *a growing level of physical inactivity* will contribute to more health problems.
- If diabetes, accidents/injuries and violence continue unchecked, levels of *disability* will climb.
- Comprehensive approaches to sexual health (encompassing sexuality education, healthy sex roles and relationships, acceptance of sexual diversity and disease prevention) have yet to be developed in First Nations communities.
- There is need for renewed, integrated and wholistic approaches to *substance abuse*.
- Many Northern residents have been exposed to chemicals used in mining. Forestry occupations
  may involve exposure to pesticides. *Outdoor occupations* in general involve increased exposure to
  environmental contaminants.
- *Community violence* (child and youth bullying, sexual assault, intimidation, retaliation, etc.) needs to be included with the same frequency as attention paid to family violence.
- **Problem gambling** is identified as an addiction affecting some First Nations people. Compulsive young gamblers are a particular concern.<sup>29</sup>
- *Environmental issues* including clean water, healthy housing and safe foods remain priorities for many communities living in Third World conditions.

The specific demographics of the First Nations population have an impact on promotion and prevention issues. It is a population that is:

- **young** requiring both greater efforts to promote health and prevent disease among children and youth and to ensure the conditions for health are established early:
  - 38% of the population is under the age of 15, compared with 21% of the general Canadian population; and
  - 18% are aged 15 to 24, compared to 13% in the general population;<sup>30</sup>

- *rapidly growing* requiring careful planning to ensure that resources will be in place for a considerably larger population and making prevention of future health problems imperative:
  - the birth rate for First Nations people is twice that of the Canadian population in general; and
  - projected population growth among First Nations between 1998 and 2010 is 28%, or an additional 180,000 people;<sup>30</sup>
- *aging* requiring the development of promotion/prevention programs for older people who likely will carry a large disease burden:
  - while not presently a large proportion of the population, the number of Aboriginal people over the age of 65 is expected to triple between 1991 and 2016;<sup>29</sup>
- *increasingly concentrated in urban and inner-city areas, but also living in rural and isolated locales* requiring a variety of promotion/prevention strategies and ones that address cultural plurality, mobility and poverty;
- unevenly distributed across Canada requiring different approaches and levels of services:
  - 63% live in British Columbia, Alberta, Saskatchewan, and Manitoba;
  - 6% live in the Yukon and Northwest Territories where they make up 48% of the population; and
  - 6% live in the Atlantic provinces where they make up 1.6% of the population.<sup>29</sup>

#### **Cross-cutting Issues of Urban First Nations and First Nations Women**

This section describes the situation faced by unique subset groups of First Nations including those living in urban areas (a group of people who make up more than half of First Nations) and women.

Urban First Nations people face serious challenges in health. Often the reason for a specific illness factors outside the realm of medicine – social, emotional and economic conditions, as noted in our earlier chapter on Health Determinants. One of the fundamental inequalities that put First Nations people at risk for poor health is income. Statistic's Canada study on the health status of the First Nations population living away from First Nations communities across the country found that First Nations living in cities and town were more likely to have chronic health conditions, long-term activity restrictions and depression then their non-First Nations counterparts.<sup>31</sup> Some key findings include:

- In 2000/01, 20% of First Nations people living away from First Nations communities reported an unmet health care need, significantly higher than 13% for the non-First Nations population;
- the First Nations population living away from First Nations communities was 1.5 times more likely than the non-First Nations population to report fair or poor health;
- First Nations living away from First Nations communities were 1.5 times more likely than the non-First Nations population to experience a major depressive episode and to report at lease one chronic condition such as diabetes, high blood pressure or arthritis; and,
- the First Nations population living away from First Nations communities was 1.4 times more likely to report a long-term activity restriction than the non-First Nations population.

Because many First Nations women cannot access housing in First Nations communities, and have experienced discrimination, violence and disempowerment, women outnumber First Nations men in urban centers. Issues surrounding matrimonial property rights in First Nations communities, violence and discrimination result in increased urbanization, community breakdown, and ultimately serious health and safety issues, not only for women but also for the entire community.

First Nations women, who are often the primary caregivers in First Nations households, require healthy and nurturing environments. First Nations women and children are often at increased risk from infectious diseases and other health concerns.

Current resources available for municipal governments with First Nations populations are inadequate to deal with the extent of the problems described above. The complex and varied nature of programs and services for First Nations people dictate the need for a strong partnership consisting of all orders of government and the First Nations community. The same complexity will also Issues surrounding matrimonial require a good definition of roles and responsibilities but with sufficient program flexibility to adapt to unique needs in particular municipalities.

Jurisdictional issues have made urban First Nations people's access to services in increased urbanization, even more problematic. Intergovernmental disputes, federal and provincial offloading, lack of program co-ordination, exclusion of municipal governments and urban First Nations groups from discussion on policy and jurisdictional matters, and confusion regarding the political representation of First Nations people in cities have all contributed to a situation that has had negative impact on the ability of First Nations people to gain access to appropriate services in urban settings.

property rights in First Nations communities, violence and discrimination result community breakdown and ultimately serious health and safety issues not only for women but also for the entire community.

In cities across Canada, there are now housing projects, childcare agencies, education and training institutions, and other services available to some First Nations people. Urban First Nations people can try to access services from all orders of government, from mainstream service organizations as well as from non-profit Aboriginal organizations. In many urban areas with large First Nations populations (such as Toronto, Winnipeg, Regina, Saskatoon and Edmonton), services, agencies and provincial programs are instrumental in providing services in education, health, community development and training, child and family services, housing, social services, legal services and arts and cultural development. The complexity of accessing these services, and, in many cases, the poor awareness of the existence of these services, means that many First Nations people in need do not access these services.

# First Nations Living in the Territories

First Nations living in the Yukon and in Northwest Territories face a unique situation. There are no First Nations reserves in these territories and, as such, First Nations are not serviced by FNIHB. As a result of this arrangement, programs delivered by FNIHB are not available to First Nations in the Yukon or in the Northwest Territories. These include a wide variety of public health programs listed below.

#### Public Health Programs delivered by the First Nations and Inuit Health Branch

Regional Medical Officers of Health, with the support of community nurses and environmental officers of health, provide services to those First Nations living in First Nations communities. For communities that are transferred, the only mandated public health programs they must agree to provide to their communities are those of communicable disease, treatment and environmental health. These fail to recognize the importance of chronic disease and injury prevention, as well as the need for a coordinated approach to mental health and substance abuse.

There are, however, a number of programs and services that are eligible for transfer to the communities. While these appear to be a comprehensive list on paper, they fall under the issues raised in Chapter 3 with respect to transfer. The eligible programs include, but are not limited to:

- 1. Brighter Futures
- 2. Suicide Prevention
- 3. Aboriginal Diabetes Initiative
- 4. Head Start
- 5. Building Healthy Communities Mental Health Crisis Management
- 6. Building Healthy Communities Solvent Abuse
- 7. Canada Prenatal Nutrition Program
- 8. Community Health Representatives
- 9. Community Nursing
- 10. Nursing Training
- 11. Support Services to Community Health
- 12. Health Education
- 13. Dental Therapy (certain provincial restrictions apply)
- 14. Operations and Maintenance of Facilities and Residences
- 15. National Native Alcohol and Drug Abuse Program

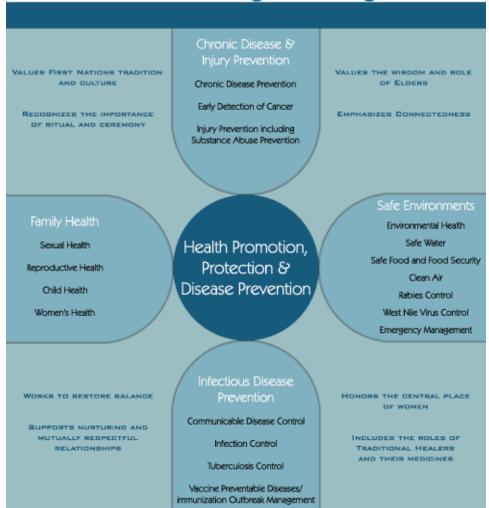
# The Proposed/Required Programs

When considering how best to improve public health delivery to First Nations, it is a critical step to first describe the scope of the health protection, promotion and disease prevention responsibilities required. The following list of program categories will set the stage for strategic direction and standards for public health services for First Nations. The precise nature and detailing of programs is beyond the scope of this document and requires a multitude of stakeholder input. These services should be available through provincial and territorial programs or by First Nations governments to their community members living away through specifically earmarked federally transferred funds. As described in the vision section above, these programs could be obtained through three methods; FNIHB, provincial/territorial services, or First Nations Health Authorities. Any of these three methods would need to include programs for:

- Chronic Diseases and Injury Prevention;
- Family Health;
- Safe Environments; and,
- Infectious Disease Prevention.

Each of these is illustrated in the visual map below described in somewhat more detail throughout the chapter, including the subset of programs under each of these broad categories. The word mandatory is used not to suppose that individuals must participate, but rather, that funding and guidelines need to be responsible for essential public health programs to successfully complement each other.

First Nations Public Health Programming



# 1. Chronic Diseases and Injury Prevention

# (a) Healthy Living

Nutrition is recognized as a key health promotion issue in First Nations communities. An unbalanced diet and food insecurity, changes in diet from traditional to processed food, environmental contaminants, and nutritional deficiencies are linked to increased susceptibility to disease, poor pregnancy outcomes, and mental health problems. Other contributing factors include poverty, loss of traditional food knowledge and traditional lifestyle, a move away from breastfeeding, a lack of physical activity and recreational opportunities. The related issue of overweight, especially the more risky fat centralization in the waist and hips, is emerging as a significant health problem among Aboriginal people. Deficiencies in iron, calcium and vitamin D, as well as obesity, are significant issues for children.<sup>29</sup>

Low levels of *physical activity* are attributed to a more sedentary lifestyle, reliance on store bought food, loss of traditional ways of life, and depression. Additional research is required in this area to document required levels of activity, preferred activities and interests and barriers experienced to remaining active.

The prevalence of *smoking* among First Nations is 62%, twice the rate for Canadians in general. Research among First Nations and Inuit show that many started to smoke as early as six to eight years of age (Health Canada, 1999). Tobacco use and exposure to second hand smoke are known risk factors for lung cancer, cardiovascular disease, pregnancy complications, and sudden infant death syndrome.<sup>29</sup>

*Diabetes* was virtually unknown in Aboriginal communities 50 years ago and is now a leading cause of disability and death. The prevalence rate of diabetes among First Nations is three times that of the general Canadian population. Currently, one in three elders over age 65 has diabetes and, with no intervention, more than one-quarter of First Nations adults are expected to have diabetes within 20 years. According to a Health Canada source, more than 90% of First Nations adults with diabetes will undergo lower limb amputations and more than half will be hospitalized with heart problems.<sup>29,30</sup>

A mandatory program will include guidelines that address each of these chronic diseases and healthy lifestyle issues in keeping with the cultural scope described in the introduction of Chapter 5.

## (b) Early Detection of Cancer

The present risk of cancer of the breast, colon, lungs, and prostate, are lower in Aboriginal people than Canadians in general. However, increases in cancer rates are predicted. Lung cancer incidence is already increasing in some areas. The vast majority of lung cancers are due to smoking. Lung cancer is the leading cause of cancer death in both First Nations men and women. Reflecting the widespread increase in smoking in women starting in the 1950s, lung cancer rates in First Nations women have been steadily increasing for the past 30 years.<sup>29</sup> Cervical cancer incidence and death rates among Aboriginal woman is also high and screening rates are low.<sup>29</sup>

As part of the public health infrastructure in First Nations communities, a mandatory program will include guidelines that address early detection and prevention of cancers.

# (c) Injury Prevention and Control

Injuries are the leading cause of death in the first half of the lifetime of First Nations.<sup>32</sup> Hospitalizations and short-and-long term disability are even more common outcomes. The direct and indirect economic costs of injuries are enormous. While many injuries may be unintentional, they are not "accidents." There are clear causes for the injuries that occur. Motor vehicle crashes are a leading cause of injury-related death and disability and public health efforts have advocated for greater seat belt and child seat use, better road design, and reduced drinking and driving.<sup>32</sup> The recognition of bicycle-related head injuries in children led to campaigns to increase the use of helmets. Among the elderly, falls are a major concern and public health has been active in assessing comprehensive strategies to modify a variety of contributing factors (e.g., adverse effects of medications, lack of muscle strength and balance, and cluttered living spaces).

The precise extent of *family violence*, *child abuse and sexual violence* in Aboriginal communities is unknown, but is thought to be of serious proportions. An analysis by the National Clearinghouse on Family Violence estimated that at least three quarters of Aboriginal women have been victims of family violence, and up to 40% of children in some Northern Aboriginal communities have been physically abused by a family member. Family violence has been linked to unemployment, overcrowded housing, and alcohol and drug abuse, and has a significant long-term impact on health status.<sup>33</sup>

A mandatory program in violence and injury prevention will include guidelines to address intentional and nonintentional injuries. The goal will be to reduce disability, morbidity and mortality caused by motorized vehicles, bicycle crashes, falls in the elderly and to prevent drowning.

#### (d) Mental Health and Addictions

There is little detailed research regarding *mental health and wellness* among Aboriginal people.<sup>34</sup> Mental health promotion is an emerging field and First Nations communities are experimenting with means of improving mental health and reducing mental health problems. Research is needed on components of mental health for First Nations people including cultural and spiritual aspects, effective approaches to promotion and links to other health issues such as FAS/FAE, violence, and unhealthy lifestyle choices.

Suicide in Aboriginal communities is considered by many to be a national crisis, with rates that vary from five to seven times the national average.<sup>32</sup> Some research has shown a link between decreased suicide rates among First Nations youth and indicators of self-determination/self-governance of the First Nations communities.<sup>69</sup> Alcohol and drug use is both a response to social breakdown and an important factor in worsening the resulting inequalities in health. People tend to turn to alcohol to numb the pain of harsh economic and social conditions. The same is true of tobacco. Social deprivation – whether measured by poor housing, low income, lone parenthood, unemployment or homelessness – is associated with high rates of smoking and very low rates of quitting. An ongoing concern is the emergence of new addictions such as that seen recently with the use of crystal meth. The impact that such a drug has goes beyond the individual to include the community at large.

Little statistical information is available on *alcohol and drug abuse*, *and the use of solvents* among Aboriginal people, although there is significant concern about the issue. Similarly, Fetal Alcohol Syndrome/Fetal Alcohol Effects (FAS/FAE) is thought to be a significant problem, although research is incomplete. Parental alcohol abuse is a leading risk factor for child neglect and abuse.<sup>33</sup>

A mandatory program will include a comprehensive approach to the maintenance of mental health and the targeting of risk factors known to contribute to mental unwellness and suicide prevalence for each community.

## 2. Family Health

#### (a) Sexual Health

**Sexually transmitted infections** are a particular concern, especially in the North among First Nations. For example, rates of chlamydia and gonorrhea were 15 and 25 times the national rates between 1989 and 1998. Sexually transmitted infections can lead to increased reproductive health problems, including infertility and increased risk of cervical cancer.

*HIV/AIDS* is an escalating condition in First Nations communities. First Nations cases represented 15% of total cases even though the First Nations population was 3% of the Canadian population in 1999.<sup>35</sup> First Nations people represented 26% and 43% of new HIV positive cases in Alberta and Saskatchewan in 1997. First Nations people are diagnosed earlier which suggests that they are likely also contracting the disease at an earlier age. First Nations women in particular are at risk. An ongoing study of pregnant Aboriginal women in British Columbia reported an HIV prevalence rate of 31.3 per 10,0000 pregnancies in 2002, 10 times higher than the nationally reported rate in Canada overall. In the case of rising rates among First Nation women in Prince Albert, Saskatchewan, there is some evidence demonstrating a link between sexual abuse as young girls and being infected with HIV later in life.

A mandatory program will include guidelines to address the prevention of STDs and the spread of current infections. These programs will focus on the establishment of healthy sexual relationships, personal but also community responsibility. The specific vulnerability of women and children must be emphasized in prevention and interventions.

# (b) Reproductive Health

Access to family planning services is a crucial component of good family health. First Nations women represent a group of people that are twice as likely to be poor and more likely to live in an environment where substance abuse and spousal violence are widespread. Supporting these women is essential.

A mandatory program will include guidelines to assist with comprehensive family planning that is culturally sensitive and will include access to contraception. The focus of this program will also be on planning for a healthy pregnancy and promoting healthy behaviours and environments before and during pregnancy.

# (c) Perinatal and Infant Health/Human Development

A number of issues relate to prenatal and infant health. About 15-23% of First Nations babies have high birth weights, which can be associated with birth injuries, developmental problems, gestational diabetes, and maternal overweight, and prolonged gestation. Low birth weight is an issue among low income, at risk and marginalized women. Infant mortality among First Nations is twice the Canadian rate and sudden infant death syndrome (SIDS) is more common among First Nations infants.<sup>29</sup>

Of the infants known to have contracted HIV though perinatal transmission in British Columbia between 1994 and 1999, 50% were Aboriginal.

The *teen pregnancy* rate is increasing dramatically and is a new concern because personal mobility, family separation and changes in community structures provide far less support to young parents than before. Pregnancies among young First Nations teens (under age 15) are 18 times more common than in the Canadian population.<sup>29</sup> The First Nations Regional Longitudinal Health Survey (RHS) 2002/3 reported that 21.8% of 17 year olds had been pregnant at some time in their life.

Fewer First Nations infants are breastfed.<sup>29</sup> The RHS has found that over 60% of First Nations children are or have been breastfed, and was more prevalent for better educated mothers and higher family incomes. This remains below the Canadian average of 79.9%.

A mandatory program will take into consideration the success of existing programs and other such ventures and aim to provide guidelines to improve the health and well being of unborn children and infants. This would include the expansion of Maternal Child Health (MCH) programs.

#### (d) Child Health

Observational research and intervention studies show that the foundations of adult health are laid before birth and in early childhood. Slow growth and poor emotional support raise the lifetime risk of poor physical health and reduce physical, cognitive and emotional functioning in adulthood. Good health-related habits, such as eating sensibly, exercising and not smoking, are associated with parental and peer group examples, and with good education. The RHS 2002/3 reported that over half of on-reserve First Nations children are either overweight (22.3%) or obese (36.2%).

Head Start programs, Brighter Futures and the Canada Prenatal Nutrition Program have had some success in addressing the needs of First Nations children. Far more needs to be done to ensure healthy role modeling, diets and environments exist to provide an opportunity for a lifetime of health.

A mandatory program will ensure all First Nations children have access to programs governed by guidelines that include a broad range of determinants of health as part of their framework. The expansion of Aboriginal Head Start (AHS) Programs would be included to target services for families with young children and complex needs.

## (e) Youth Health

First Nations youth require unique programs tailored to their concerns related to health as well as other essential determinants of health such as home environments, school and friends. In the RHS 2002/03 report, almost half of First Nations youth surveyed lived with only one parent or neither parent. More than 4 in 10 (42.9%) of youth households were defined as overcrowded.

The RHS also noted that among 15-17 year olds, First Nations smoking rates were three times the Canadian rates for boys (47% vs. 13%) and four times higher for girls (61% vs. 15%). More than 42% youth were overweight or obese.

A mandatory program will provide the needed support to First Nations youth and provide guidelines to communities to address the broader determinants of health that impact on their live and key risk factors.

#### (f) Dental Health

Dental health is currently a program that is serviced under non-insured health benefits (NIHB). The prevention of dental caries and the maintenance of good oral health should be considered as part of a public health program. Good oral health for children supports overall general health. There is a gap between the total dental health of First Nations and the Canadian population as a whole and it is widening. The current data suggests that 90% of First Nations have dental decay. Most of the dental decay seen is preventable. A current Health Canada supported initiative. The Canadian Oral Health Initiative (COHI) is attempting to shift the emphasis in the FNIHB oral health service from a treatment focus to both a prevention and treatment focus in line with the principles of public health.

A mandatory program will work together with NIHB to improve the state of oral health among First Nations with a renewed emphasis on prevention, and targeting an earlier age group.

#### (3) Environmental Health

The goal of environmental health is to promote health and quality of life by preventing or controlling those environmental factors that contribute to injury, diseases or death within a framework of sustainable development.

Environmental degradation affects the health and well-being of First Nations in three ways. First, pollutants and contaminants, especially those originating from industrial development, have negative consequences for human health. Second, industrial contamination and disruption of wildlife habitat combine to reduce the supply and purity of traditional foods and herbal medicines. Finally,

Erosion of ways of life dependent on the unity of the land, water, flora and fauna constitutes an assault on aboriginal mental and spiritual health. - Royal Commission on Aboriginal People

erosion of ways of life dependent on the unity of the land, water, flora and fauna constitute an assault on Aboriginal mental and spiritual health.<sup>23</sup>

Waste disposal is a significant problem, including dump sites, burning of wastes, potential contamination of ground water from orphan wells that have not been properly decommissioned etc. Presently, the Indian Waste Disposal Regulations that are in place are not being followed as many communities continue to use unregulated dumpsites with frequent burning instead of proper, regulated landfills or systems to haul garbage to regional sites outside of First Nations communities. This speaks to inadequate funding to enable these communities to bring waste disposal practices and water systems among others, up to modern standards.

The Convention on Biological Diversity (CBD) is a United Nations convention that recognizes the unique heritage and knowledge of Indigenous peoples with respect to ecological and environmental systems. Drafted in direct response to the global realization that "the Earth's biological resources are vital to humanity's economic and social development," the CBD was one of two binding agreements that came out of the UN Conference on Environment and Development or "Earth Summit" held in Rio de Janeiro in 1992. The CBD states that each contracting party to the CBD shall:

Subject to its national legislation, respect, preserve and maintain knowledge, innovations and practices of indigenous [sic] and local communities embodying traditional lifestyles relevant for the conservation and sustainable use of biological diversity and promote their wider application with the approval and involvement of the holders of such knowledge, innovations and practices and encourage the equitable sharing of the benefits arising from the utilization of such knowledge, innovation and practices.

The CBD has been signed and ratified by more than 168 countries, including Canada, in light of the "growing recognition that biological diversity is a global asset of tremendous value to present and future generations."

The natural and built environments are factors that contribute to health both directly in the short term, and indirectly in the longer term. A healthy environment also protects consumers from product related hazards by promoting the safe use of products. These factors can influence health practices and shape the opportunities we have to live healthy and productive lives. Children are particularly vulnerable to serious health risks from environmental hazards and biological, physical and chemical threats. At certain levels of exposure, contaminants in our air, indoor air quality, the design of transportation systems, urban planning that includes bicycle paths and parks, and the safety and security of residents significantly influence our health: creating healthy homes, schools, workplaces and communities, which play an important role in promoting healthy active living.

When we speak of urban planning, we are not just referring to buildings, but also to the notion of conservation. Furthermore, notions of heritage and conservation are linked to sustainability, not only of natural environments, but also of human communities. Health promotion, as detailed in the Ottawa Charter, is concerned with highlighting and building on the connection between ecologically sustainable development and human wellbeing, by fostering the creation of supportive environments and healthy public policy.

#### (a) Safe Water

Many of the initial public health measures in Canada focused on ensuring safe drinking water for communities. While the key lessons were learned over a hundred years ago, the risks of water systems will always remain, requiring sustained effort, commitment and vigilance. The recent experiences in Kashechewan, Ontario; Walkerton, Ontario; and North Battleford, Saskatchewan (see below) provide a tragic reminder of the serious impact that contaminated water systems can have on the health of communities.<sup>36,37</sup>

#### Kashechewan, ON, 2005

On October 12, 2005, a mechanical malfunction at the Kashechewan First Nation water treatment plant led to insufficient chlorine getting into the water treatment system, resulting in the presence of elevated levels of total coliform and E. coli bacteria in the water supply. There has been no action by the federal government even though the community has been under a boil water advisory since 2003. On October 25, 2005, Emergency Measures Ontario began the evacuation of members of the Kashechewan community to Sudbury.

#### Walkerton, ON 2000

The contamination of a community well with E. coli led to 1,346 reported cases and seven deaths. Multiple factors were involved in contributing to this outbreak including poor training and oversight of water treatment system staff and the lack of routine notification of the public health department of abnormal water test results.

#### North Battleford, SK 2001

An estimated 5,800 to 7,100 people (almost half the city's population) were affected by an outbreak of the Cryptosporidium parasite. This was due to a breakdown of the filtration system at the water treatment plant.

Aboriginal people, particularly children, have significantly higher incidence of *water-borne diseases* compared to the general population.<sup>38</sup> Contaminants in drinking water can include organisms such as giardia, salmonella and E. coli bacteria, dissolved metals, other compounds, pesticides, and industrial chemicals. Sources of contamination include human sewage, agricultural runoff, industry, mining, pulp and paper mills, and flooding.<sup>36</sup>

A 1995 INAC study found that one in four (24%) water systems and one in five (20%) sanitation systems in First Nations communities are substandard.<sup>39</sup> In July 2001, 47 First Nations communities were under boil water advisories.<sup>40</sup> In 1999, 22% of respondents to the RHS believed no progress has been made in improving water and sewage systems in First Nations communities.<sup>21</sup>

In May 2003, INAC released another report summarizing the state of water and wastewater systems in First Nations communities. Multiple problems were identified including 29% of the 740 community water systems posing a possible high risk to water quality and another 46% posing a medium risk to water quality.

Some efforts have been undertaken by the Department of Indian Affairs and Northern Development to work with the Assembly of First Nations in the creation of an expert panel that would advise the Minister and the National Chief on improving drinking water safety in First Nations communities through a regulatory framework. The 2006 federal First Nations Drinking Water Action Plan will go beyond the expert panel however, and include infrastructure development, upgrading of water treatment facilities and increased training in many communities, as well as efforts in local communities to improve sanitation and decrease contamination. There are bacterial and chemical drinking water monitoring programs overseen by Environmental Health Officers employed by both FNIHB and Tribal Councils under the First Nations Water Management Strategy. The lack of legislation in this area to mandate the specific requirements of a monitoring and response system and to require that all residents be assured of a supply of safe drinking water are gaps that need to be addressed.

A mandatory program that includes safe water as a legislated and enforceable program will exist that recognizes Regional Medical Officers of Health and First Nations Environmental Health Officers with authority to ensure safe water is available to all First Nations. The goal will be to reduce the incidence of water-borne illness in the population.

#### (b) Rabies Control

Many First Nations communities exist in isolated and remote settings that support wild and domesticated animals. Rabies continues to be a national problem with certain species. First Nations, by nature of their proximity with animals, are at a particular risk.

A mandatory program will include guidelines to ensure the safety of First Nations from zoonotic diseases such as rabies through access to national rabies eradication and other such programs.

# (c) Food Safety

Increased levels of contamination in the environment pose potential human health risks, especially to those practicing traditional lifestyles.

Environmental research in the North around the Great Lakes in Ontario and on the Saint Lawrence Seaway has uncovered environmental contamination in many communities, often not identified until the community initiates an investigation. For example a recent study in Ouje Bougoumou, a Cree community in Northern Quebec, has found high levels of arsenic, cyanide, lead, mercury and other heavy metals as a result of mining in the area. The lead researcher compared findings to those of the Love Canal in New York State.<sup>37</sup> Increased monitoring, advisories

The presence of contaminants in traditional foods (wildlife, vegetation and fish) has brought about a move away from traditional lifestyles (hunting and gathering) and increased rates of diabetes, obesity and heart disease.

on unsafe food and water, and further research on long-term effects of environmental contaminants throughout First Nations communities are needed.

The impact of the environment on health is recognized in the *Canadian Environmental Protection Act*. The presence of contaminants in traditional foods (wildlife, vegetation and fish) has brought about a move away from traditional lifestyles (hunting and gathering). There is also a need for harmonized regulatory frameworks to ensure food premises meet operational standards and to allow clearly defined mechanisms to deal with continued breaches of good public health practice in food premises on First Nations lands. The importance of food accessibility is also a population health issue. The urgent need for affordable and nutritious fresh food for all First Nations is a priority for communities. The use of traditional knowledge and food choice preferences combined with nutrient reference values should form the basis of policies on food and nutrition as it is delivered to communities.

A mandatory program is urgently needed that addresses not just the safety of food from a contaminant point of view but also takes on the unique, and as yet unprecedented role, of examining access to good nutrition including its abundance and affordability. Guidelines, as for safe water, will ensure authority for inspection of food premises are assured for First Nations Environmental Health Officers and Regional Medical Officers of Health. The goal will be to improve the health of the population by reducing the incidence of food-borne illness.

#### (d) Healthy Housing

Healthy housing remains a determinant of health that is poorly addressed by current programs. The issues are largely three-fold:

- overcrowding;
- poor construction with lack of legislative standards for home building inspections; and,
- lack of housing diversity to reflect the people that live in the homes.

Multiple studies have shown that overcrowding contributes to the increased prevalence of respiratory illnesses (including tuberculosis), conjunctivitis and gastrointestinal illnesses. Violence and exposure to second hand smoke are also more likely to occur in overcrowded homes.<sup>41</sup> The 2002 RHS has shown that First Nations are 25 times more likely to live in overcrowded homes compared to the rest of Canadians.<sup>21</sup>

The lack of training and financial support to incorporate routine maintenance and ongoing education activities aimed at occupants into the housing program is also a major issue. The goals of such an initiative would be to improve the maintenance and lifespan of the existing housing stock. For example, a program that incorporated housing educators who regularly visit occupants to advise them on basic maintenance activities necessary to maintain systems in the home would be invaluable and would allow timely interventions when necessary to prevent major damage that results when building systems are not maintained or when maintenance issues are not addressed in a timely fashion.

Plumbing inspections of public premises in First Nations communities are not currently provided by any agency. This is a service gap that results in inequities in development between those living in First Nations communities and those living away from First Nations communities. Another issue is that in many cases, the main users of resort developments in First Nations communities are non-Aboriginal - which leaves the question 'who is responsible for providing services?'

A mandatory program will include an approach to healthy housing that ensures building standards are inspected and supported by First Nations housing authorities. Overcrowding requires new funds to ensure the building of new homes for First Nations.

#### (e) Sanitation

Sanitation plays an important role in the control of infectious diseases. Environmental Health recognizes this as a guiding principle of the program. However, formalized mechanisms are needed to deal with situations where there is a health issue of concern. Examples include the need for permitting or licensing of public accommodations and swimming pools, as they are developed, based on recognized standards. The ability to set and enforce public health standards is also needed for facilities and operations of large public events such as First Nations Summer or Winter Games, powwows, or other traditional gatherings where large numbers of people rely on the host community to supply facilities for food preparation, drinking water, washrooms and garbage disposal.

A mandatory program requires the capacity to set standards, educate and manage the sanitation aspects of communicable disease and environmental health. The ability to set and enforce public health standards would be included in this function.

#### (f) West Nile Virus Control

The control of arthropod borne viruses relies on the control of the vector. Mosquito breeding grounds need to be properly monitored and managed and, in some cases, larviciding is appropriate. Similarly, control of the adult mosquito can occasionally require adulticiding. Personal protective measures are key in preventing the transmission of the virus to humans. To date, a comprehensive surveillance program has been operating under Health Canada in collaboration with the provinces and territories.

A mandatory program for vector-borne illnesses, such as West Nile Virus, need to be part of a larger environmental health program where the control of vectors potentially impacts the environment.

# (g) Emergency Preparedness and Response

Concerns for the intentional release of nuclear, biological or chemical agents were heightened during the anthrax attack in the U.S. as well as the terrorist attacks in New York City. Weapon development programs in several countries of the world over a period of many years make these agents a potential threat. As evidenced by the experience in the US, a country's public health system is on the front lines of defense and investigation in attacks of this nature. While Canada may not be a primary target, highly contagious diseases such as smallpox would not recognize political boundaries. Furthermore, the state of emergency preparedness and capacity for First Nations communities to detect and respond to a threat will be highly dependent on the extent of preparedness and existing system infrastructure.

Community preparedness for natural disasters and major communicable disease threats relies on community leadership and program people in the development and maintenance of these plans. INAC, FNIHB, and Environmental Health Officers need to be better coordinated and structured to deal with potential catastrophes in First Nations communities, with clear linkages with provincial/territorial preparedness plans.

A mandatory program for emergency preparedness should be under the auspices of Environmental Health as the services are most vulnerable to a range of emergency situations. The guidelines will include roles and responsibilities of the regional health authorities, the provinces, INAC, and FNIHB with central leadership assigned to the Environmental Health Officers.

# 4. Infectious Disease Prevention

#### **Control of Infectious Diseases**

During the early 1900s, infectious diseases were the leading cause of death worldwide. Now, as a result of health protection measures – such as immunization, sanitation, public health education and better living conditions – infectious diseases cause less than 5% of all deaths in Canada. This accomplishment places health protection measures, and, in particular, immunization among the greatest achievements in health care of the 20<sup>th</sup> century.

Nevertheless, emerging disease threats and complacency in immunization stresses the need for this role to remain a high profile one.

High prevalence rates of infectious diseases including hepatitis A, B and C, gastroenteritis, meningitis, gonorrhea and chlamydia have been reported among First Nations people. Childhood vaccination rates may be considerably lower than for the Canadian population. First Nations children have higher rates of respiratory tract infections (bronchitis, pneumonia, and croup) as well as severe otitis media (ear infection that often leads to hearing loss). Suggested increased risk factors include vitamin deficiencies, poverty and crowding, tobacco smoke, and wood fire smoke.<sup>34</sup>

Rates of tuberculosis among First Nations people in First Nations communities in 1999 were 18 times higher than the Canadian born, non-Aboriginal population.<sup>29</sup>

Injection drug use is contributing to a health crisis of HIV/AIDS rates among First Nations. Dr. Patricia Spittal, the lead researcher in a major new study into HIV/AIDS rates among young aboriginal drug users in British Columbia, said the figures show that the problem has moved out of the big cities into small towns, where health services are often minimal. If not addressed aggressively in small reserves and rural areas, it is believed that the virus could wipe out whole communities.

Injection drug use is also a major risk factor for developing hepatitis C. The majority of those infected with hepatitis C will have ongoing chronic infections with a proportion of these developing liver cirrhosis or liver cancer. Increasing rates of these outcomes are expected in future decades. Comprehensive public health approaches are required to prevent or reduce the risk of transmission of these diseases, including education to reduce risk behaviours, drug and mental health treatment programs, and harm reduction initiatives to reduce the risk of disease transmission.

The incidence of tuberculosis among First Nations in First Nations communities declined between 1991-1996, but remained more than six times than of non-Aboriginal population. Rates in 1999 were 18 times higher than the Canadian born, non-Aboriginal population.<sup>29</sup>

A mandatory program is urgently required that will have a broad mandate of infectious disease control and is not reliant on disease specific funding. Certain diseases are linked with varying high risk groups such as those that are incarcerated, homeless or engaging in intravenous drugs. They will be included as priorities in this program.

#### **Infection Control**

Infection control practices in nursing centres, long term care facilities and other health care centres require vigorous assistance in the area of infection control including clear guidelines in addition to qualified personnel to oversee the implementation and maintenance of these practices in any health care setting.

#### **Immunizations**

The use of immunization to prevent infectious diseases is the most cost effective medical intervention available to public health. Routine immunizations have resulted in dramatic reductions in the frequency of many serious diseases including polio, diphtheria, measles and several others. While these diseases have become rare in Canada, their presence in other parts of the world demands ongoing vigilance.

# Reinvigorating a National Immunization Strategy

The lack of continuity of publicly funded immunization across the country is based on individual provincial decision-making. The substantial diversity in the publicly funded program and legislations cause substantial confusion and unequal coverage rates for First Nations whose own jurisdictional boundaries may cross more than one province or territory.

Recognizing the importance of immunization, practitioners have called for a National Immunization Strategy that would be comprised of an immunization registry, improved vaccine safety monitoring, improved vaccine procurement, harmonization of immunization schedules, and improved education for health care providers and the public. The 2003 First Ministers' Accord on Health Care announced that a National Strategy would be pursued. This stands to benefit First Nations.

The mandatory program will include recommendations to work closely with the province/territory in developing immunization registries and strategies to increase immunization uptake for First Nations living in and away from First Nations communities. Links should be made within the province with First Nations organizations that service First Nations people living away from First Nations communities as key partners in the delivery of vaccination clinics, as required.

# The Gaps

The lack of a formally defined public health program for First Nations that details out the scope of service inclusion means that many essential components are omitted. Taken alone, public health programs will have little impact on community health if the broader determinants of health are not considered and a more politically responsible approach to preventing disease and enhancing health is not taken. To date, decisions such as the role of the Public Health Agency of Canada, the National Collaborating Center for Aboriginal Health, and other health promotion activities have not included First Nations in the formative stages of discussion.

The three potential mechanisms for obtaining public health services, namely FNIHB, provincial/territorial services or First Nations Regional Health Authorities, are all worthwhile options to consider. Having said that, each has inherent pros and cons and no perfect body exists to deliver public health services to First Nations communities. Nevertheless, one gap is obvious: the flexibility for First Nations to decide for themselves which provider of public health best suits their needs, this does not exist for many communities.

For services provided by Provincial and Territorial Regional Health Authorities, such as in British Columbia, there are varying degrees of quality and suitability as well as commitment to provide public health services to First Nations communities who are requesting it. There is little mechanism to assure quality services are provided.

Health programming that is linked to government accountability in short term cycles makes long term projects, such as health promotion and disease prevention, virtually impossible.

Current staffing ratios are insufficient to ensure services are delivered in a fiscally responsible manner to a minimal critical mass. This "ideal" number of nurses, physicians and other para-health professionals has yet to be determined but will require cooperation among First Nations communities to share services where their population numbers are small.

Different locations afford varying degrees of access to healthy environments, food, services, amenities, health information, education, employment, housing, and opportunities to experience a sense of community and a sense of place. A wholistic approach to delivering population health must be adopted to ensure that the inter-relationships between all major issues impacting on individuals and families within the context of their local communities are taken into account. Location should not be an excuse and funding needs to be made available to ensure continuity and accessibility.

#### Recommendations

In accordance with the Ottawa Charter, the aim of our recommendations is to assist communities to build healthy public policy, create supportive environments, strengthen community actions, develop personal and collective skills by providing learning opportunities, and reorient health services. This will require, at the minimum:

- public health leadership;
- creating a vision and goals;
- promoting First Nations-led harmonized planning, participation and community development;
- promoting partnerships with FNIHB and provincial/territorial Regional Health Authorities; and,
- creating more widely available opportunities for communities who are interested in creating their own Regional First Nations Health Authorities to oversee public health.

**Recommendation #49:** A commitment to design a comprehensive public health system, as described above, by those deemed responsible for the delivery of public health programs to First Nations, needs to begin as a priority item. This includes FNIHB, provincial/territorial public health service providers, First Nations Regional Health Authorities and First Nations community leaders. The purpose of such a commitment would be to agree on connecting diverse services led by regional centers which would be linked to ensure the health of First Nations is protected under such unique circumstances. The set of mandatory programs, identified based on existing and new research evidence, should form the basis for the comprehensive public health system's programming.

**Recommendation #50:** Joint policy development needs to begin between First Nations and the Public Health Agency of Canada in areas related to its roles in supporting public health services delivery in First Nations communities and to First Nations people living away from their communities.

**Recommendation #51:** Population health strategies must be elaborated by studying and discussing the health outcome of the full range of determinants of health, encompassing social, environmental, cultural and economic factors. This can only be achieved through cross-Ministerial and Departmental policies that encourage public health impact evaluations be at all governmental decisions.

**Recommendation #52:** Critical mass numbers need to be taken into account when describing the public health services that will be supported in communities. It is highly likely that many First Nations communities will need to link together in the sharing of public health services where their population numbers are small.

**Recommendation #53:** Health promotion is a long-term activity that requires a longer-term planning approach not bound to the annual planning cycle of the federal government.

**Recommendation #54:** Research must be an integral component of evidence-based health protection and promotion programming and an enhanced and more recognized role for current First Nations researchers needs to be highlighted and encouraged.

**Recommendation #55:** The successes of public health programs in communities and outside of First Nations communities need to be carefully evaluated by new measurements. Communities need to identify public health priorities and strategies that include specific health targets, benchmarks for progress towards them, and collaborative mechanisms to maximize the pace of progress. New indicators of progress may be a return to traditional ways, housing quality and so on.

**Recommendation #56:** New federal funding for public health should be explicitly tied to these strategies and plans, with process and outcome reporting, and structured as contributions that are subject to audit as per Recommendation #55.

**Recommendation #57:** Chronic diseases are the leading cause of death and disability in Canada and many chronic diseases are preventable to a very large extent. The federal government, in collaboration with First Nations, the provinces and territories, in consultation with major stakeholders, should give high priority to the implementation of a First Nations National Chronic Disease Prevention Strategy.

**Recommendation #58:** The *First Nations Public Health Act*, outlined in Chapter 3, will include a commitment to chronic disease prevention as it will reflect an emphasis on an enabling, rather than a prescriptive, legislative framework.

**Recommendation #59:** Local governments are well positioned to promote community health and wellbeing across their municipality for First Nations living in urban settings. They also have a leadership role in community building and have the ability to build capacity, by implementing strategies to enhance community health status and health equity outcomes. Strategies, such as the Aboriginal Healing and Wellness Centers in Ontario could be viewed as potential collaborating partners in a seamless delivery of public health programs for First Nations across the country.

**Recommendation #60:** Individuals, community groups, government departments, and other agencies need to participate in health planning, not only to ensure a match between local needs and priorities, but because participation itself promotes health. Individuals and the wider community need to participate meaningfully to ensure appropriateness, individual/community ownership of processes, programs and outcomes, and the promotion of accountability to the community for decisions about priorities and resource allocation.

**Recommendation #61:** An annual report, detailing out the health of First Nations, is an invaluable resource to early planning for public health and should be supported by Health Canada.

**Recommendation #62:** A variety of agencies, organizations and charities currently offer public health and public health related services to First Nations people living away from First Nations communities. A list cataloguing each of these providers is required to assist with the development of a map linking the services in a meaningful way. This will also provide a list of potential collaborative partners for the delivery of community health programs.

**Recommendation #63:** Greater First Nations control should extend not only to health services, but also to environmental stewardship to address key health determinants.

**Recommendation #64:** Elders need to play a key role in the detailing of population health programs to ensure that traditional knowledge and wisdom is preserved in the long term planning of the future of public health programs.



# **Supporting Public Health**

# **Chapter 6: Capacity and Financing**

"Today, seven generations later, you turn to us as your own culture is failing. The land you took from us, tricked us out of, is becoming too poisoned to feed you. Your rivers and streams are dying. I wonder, why do you turn to us now? Is it because through it all we never stopped praying? Never stopped beating our drums, dancing and singing songs to the Creator? And that somehow, somehow, you couldn't silence us?" Sioux Elder cited in Johnson and Budnick

Planning for health is about planning to enhance the community's capacity to achieve positive health outcomes. Capacity building involves developing "sustainable skills, organizational structures, resources, and commitment to health improvement in health and other sectors [to] prolong and multiply health gains many times over."<sup>42</sup>

Capacity building can occur within programs, but also within systems. It can lead to greater capacity of people, organizations and communities to promote health. This means that a capacity building activity may be developed with individuals, groups, teams, organizations, inter-organizational coalitions, or communities.<sup>43</sup> In this context, capacity can include adequate knowledge and skills among decision-makers, managers and service providers; staffing; resources, physical infrastructure and computer and telecommunications technology. It is developing and applying abilities to govern and manage, make informed and evidence-based

Capacity building not only can occur within programs, but also within systems. It can lead to greater capacity of people, organizations and communities to promote health. This means that a capacity building activity may be developed with individuals, groups, teams, organizations, interorganizational coalitions, or communities.<sup>43</sup>

decisions, plan strategically, identify and set priorities, evaluate, make human and fiscal resources effective and efficient, and take responsibility for the successes and failures of health interventions. Capacity also implies the capacity for working with external agencies.

# The Vision

Each First Nations community has sufficient funding and capacity to support a health system infrastructure that has grown from an illness and treatment driven system into a wellness model based on a protective model of health promotion, disease prevention and health protection.

# **Public Health Care Funding**

The federal government, with respect to national health care funding, supports health care through the Canada Health and Social Transfer (CHST). It provides provinces and territories with cash payments and tax transfers to apply as they see fit to their health and social programs on condition that they are provided according to the principles laid out in the *Canada Health Act*. From time to time, the federal government also provides funding for specific health initiatives, most recently, primary or home care. Funding levels for public health services are not explicitly identified in health system financial transfer arrangements between the federal and provincial/territorial governments. With the exception of some limited program areas (e.g., perinatal nutrition program, sentinel surveillance systems), there is no direct federal funding of the governmental public health system in provinces/territories or regions. With the exception of the small field epidemiology program, the secondment of public health personnel to provinces does not occur in Canada.

Provincial and territorial governments provide funding to their respective health authorities predominantly through grants. In Ontario, municipalities share a 50% responsibility for the funding of most local public health programs although this will increase over the next 5 years to 75%. In 2002, approximately \$80 billion was spent on health by the federal, provincial, territorial, and municipal governments. There is no standardized definition of public health, and it is therefore difficult to obtain a precise estimate of what is spent on public health spending.<sup>2</sup>

The result of the transfer of funding and responsibility to regional structures has meant that smaller regions were more likely to have discontinued or reduced health surveillance, health promotion, disease and injury prevention, and health protection programs than larger regions.

This distribution by the provinces to their regions or municipalities has resulted in the transfer of most resources and much of the responsibility for public health programs to regional structures. However, regions depend on federal and provincial/territorial governments as important sources of population health data and targeted funds for specific initiatives that would not otherwise be funded within the region (i.e., diabetes prevention, immunization), as well as coordination with other regions and public health professionals.

Over time, there has been a decrease in resources available at the provincial and territorial level to support regions' knowledge and skill development, strategic planning abilities and leadership to address longer term goals for health promotion, disease prevention and health protection. The result of the

transfer of funding and responsibility to regional structures has meant that smaller regions were more likely to have discontinued or reduced health surveillance, health promotion, disease and injury prevention, and health protection programs than larger regions. Resources have been curtailed, diverted or not replenished in line with ongoing and emerging requirements.<sup>2</sup>

When we turn our attention to First Nations, we are subject to the federal government setting priorities and allocating funds on our behalf. Just as with the provinces and territories, resources for First Nations public health services face conflicting policy influences and demands for resources. As long as public health remains poorly understood by decision makers and policy makers, this conflict will continue. The health system in Canada is still illness-and-treatment driven, with little indication of a commitment to change funding priorities toward disease prevention, health promotion and health protection.

A considerable portion of funding for First Nations promotion/prevention efforts is provided by the federal government through targeted funds. While targeted funds may enable a community to focus on a particular issue, raise awareness of certain health issues and, in some cases, overcome resistance to change, problems with targeted funding include:

- activities may be fund-driven rather than the community's priority (chasing money);
- projects are short-term and usually involve a grants competition, requiring repeated investment of time and resources;
- programs must deal with multiple sources of funding that have different requirements and expectations;
- there are restrictions on how money is spent that may not fit with the communities' vision or time frame; and,
- the commitment to spend money on staff training is not always evident.

Rather than developing a community wellness program that is wholistic and integrated, efforts are project-driven, short-term and focused on the funding organizations' priorities. Urban First Nations health programs may have one or more provincial sources of funding, all with different spending restrictions and reporting mechanisms and separate evaluations.

Many First Nations organizations, both in and outside the federal government health transfer process, have been frustrated by the amount of time required to prepare for and negotiate funding agreements for promotion/prevention programs, accompanied by what is seen as inadequate capacity development and support for communities. It is also noted that government program staff themselves require additional capacity to be effective in assisting First Nations communities while streamlining the process. In some circumstances, there is

Rather than developing a community wellness program that is wholistic and integrated, efforts are project-driven, short-term and focused on the funding organizations' priorities.

Funding levels are not considered adequate to address the high rate of health and social problems in First Nations communities, especially Northern and remote communities. a lack of capacity within First Nations communities to develop a solid proposal and often they do not have funding to consult expertise outside the community.

Finally, funding levels are not considered adequate to address the high rate of health and social problems in First Nations communities, especially Northern and remote communities. In some cases, the ways in which money is spent may not be the most cost effective approach to

health care spending. For instance, federal investments are required to provide higher levels of continuing care in First Nations communities. Provincial health reforms which have, in some cases, resulted in hospital closures, introduction of early discharge programs and other changes, have placed serious pressures on First Nations communities. Population demographics and health status trends also raise the critical need for continuing care services.<sup>30</sup>

New funding, not re-alignment of existing resources, needs to be made available to First Nations communities who have the wisdom, insight and best interests of their people at the forefront.

New funding, not re-alignment of existing resources, needs to be made available to First Nations communities who have the wisdom, insight and best interests of their people at the forefront. This new funding will be to support the infrastructure (described in Chapter 5) that will ensure a comprehensive public health system in First Nations communities. This should not be via provincial or territorial transfer but rather directly to First Nations communities via a regional or sub-regional First Nations structure.

Similarly, new funding needs to be allocated to allow for dedicated public health programming for First Nations people living away from First Nations communities. This funding should not be put in an envelope together with other health dollars transferred to provinces: it needs to be a program priority and funded as such. The program design should be regionally flexible (in keeping with best practices described in Chapter 5) and should include First Nations leaders in their design. The accountability should be primarily to First Nations leaders who have these peoples as part of their Band lists, and secondly, to the federal government that will have supported these programs.

New funding needs to be allocated to all provincial governments to allow for dedicated public health programming for First Nations people living away from First Nations communities.

# **Capacity Building**

Capacity development is more than just training and knowledge of specific skills; it is building capacity in self-determination and governance in health care that builds upon an individual and community development process. It develops and applies abilities to govern and manage, solve problems, respond to new situations, make informed, evidence-based decisions, to strategically plan, to identify and set priorities, to evaluate, to effectively and efficiently manage resources (human and fiscal), and to take responsibility for the success or failure of health interventions. Capacity development also implies the capability of working with internal and external agencies to share knowledge and experience.

Capacity and funding are closely linked. Without resources, capacity is profoundly limited. Without capacity, funding may be irresponsibly allocated and accounted for. However, First Nations have been at severe disadvantages with both capacity and funding. Wage disparities, lack of training, little support to communities and the overall social and

economic disadvantages faced by First Nations have contributed to the lack of capacity. Moving forward, there are three dimensions for building capacity:

1. Health infrastructure or service development:

Capacity to deliver particular programs that are in response to particular health problems. This usually refers to the establishment of minimum requirements in structures, organizations, skills and resources in the health sector.

Capacity and funding are closely linked as without resources capacity is profoundly limited and without capacity funding is irresponsibly allocated and accounted for.

# 2. Program maintenance and sustainability:

Capacity to continue to deliver a particular program through a network of agencies, in addition to, or instead of, the agency that initiated the program. This capacity must also compensate for delivery of the program based on growing demand and evolving needs.

#### 3. Problem solving capability of organizations and communities:

The capacity of a more generic kind to identify health issues and develop appropriate mechanisms to address them, either building on the experience with a particular program or as an activity in its own right.<sup>42</sup>

Public health in many countries has become a priority and generally the capacity to develop public health remains, in many cases, a challenge. Many countries have taken action to define the essential function of their public health systems (see Chapter 8) and developed mechanisms to assess their implementation. National level leadership

In all of the countries reviewed, the national level of government funds a substantial portion of the public health system infrastructure. has been critical to support the articulation of the key issues and challenges facing public health and to implement comprehensive strategies to address the deficiencies in the system's infrastructure. In all of the countries reviewed (see Chapter 8), the national level of government funds a substantial portion of the public health system infrastructure. A robust central public health institute to support the essential public health function was observed in the US and England, as well as other European nations (e.g., Norway, Netherlands).

The scope of a public health system and the required programs are outlined in detail in Chapter 5 and address item 1 above (health infrastructure or service development). The capacity to support these programs and the funding required to do so is outlined in the recommendation section of this chapter and addresses item 2 (program

maintenance and sustainability). The role of addressing the basic determinants of health is crucial. The success of the proposed public health programs will be severely limited if economic disparities, education and employment opportunities and activities related to self-governance and self-determination are not recognized as equally vital in creating healthy communities. Finally, item 3 is addressed in Chapter 3 on surveillance.

#### The Potential Role of Telehealth

Although health human resources will be examined in more depth in the next chapter, it is a crucial component to capacity building. Without health professionals, there is little need for funding to pay them. At this time, there is an alarming shortage of health care professionals with an expertise in public health. As a result, other means of accessing care through telehealth, for example, should be explored. Furthermore, if communities are to pool resources where critical mass numbers within their Bands are small, telehealth may be a vital link.

#### **Previous Reports**

The Royal Commission on Aboriginal Peoples' proposed a system of healing centres and lodges under First Nations control to bridge jurisdictions and individual ministries and to pool resources from all sources (federal, provincial, territorial, municipals and First Nations) i.e., "block funding." The Romanow Commission similarly proposed Aboriginal Health Partnerships with these key elements:

- per capita funding based on number of sign-up residents and consolidated funding from region/province/ territory;
- operation through a fund-holder model where the partnership is responsible for organizing, purchasing and delivering services; and,
- a not-for-profit community governance structure with a board composed of representatives from the funders and other individuals (organizers, users, providers).<sup>23</sup>

In developing other models of funding, other factors that should be considered include:

- total population base;
- age and gender of population base;
- socio-economic composition of the population base;
- services communities provide to residents of other communities;
- remoteness factor;
- local cost of living;
- population growth;
- level of need; and,
- self-government interests.

#### **Partnerships**

A strong governmental public health system is an essential but insufficient factor to address population health issues. Inter-sectoral partnerships are a common component of public health initiatives in other countries. (see International Models, Chapter 8)

They are the basis of the multi-state Turning Point project in the U.S., and form the basis for several recommendations contained in the recent US Institute of Medicine's Report on their public health system. In England, addressing inequalities in health outcomes is an explicit goal of the national health system and inter-sectoral partnerships will be critically important. In Australia, the state and federal governments and other partners came together to work towards improving the public health system's infrastructure (see International Models Chapter). Public health systems in many jurisdictions are searching for ways to ensuring a formal partnership with NGOs, community agencies, and other sectors (e.g., education).

# The Accountability Framework

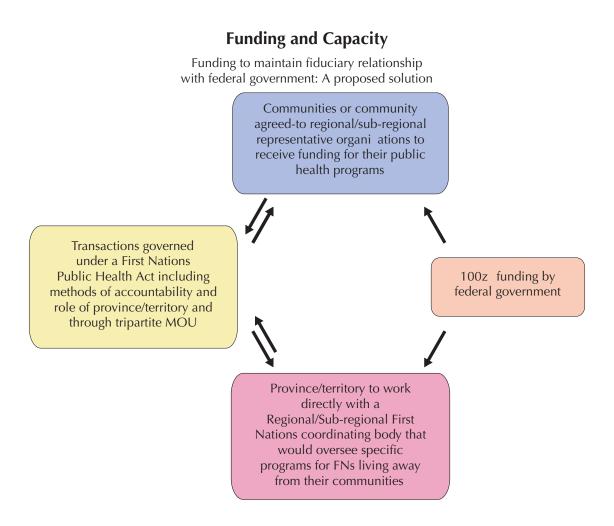
The current accountability framework reflects the complexity of the administrative environment in which FNIHB and First Nations organization now operate. It is fragmented and produces a large number of reports on financial expenditures and activities. It produces little information on the administrative and capacity building needs of First Nations and only limited information on outcomes. Although data is being produced, FNIHB has limited functional capacity to assemble this data into information upon which to base strategic decisions. The result is a very expensive system that has undermined Regions' capacity to support First Nations organizations. The same framework is shifting First Nations administrators and health services providers' time from program planning and management to the writing of reports that serve few purposes other than monitoring.

As a response to the 2003 First Ministers Health Accord, the AFN elaborated a First Nations Health Reporting Framework (FNHRF), as an alternative approach to the pan-Aboriginal Health Reporting Framework proposed by FNIHB and the provinces/territories. The FNHRF aimed at identifying key indicators on which federal/provincial/territorial/First Nations governments would report to measure their performance with respect to First Nations health. Founded on the principle of reciprocal accountability, the FNHRF was reviewed during a National Dialogue in Toronto in February 2006. It was determined by dialogue participants that regional dialogues should take place to further define indicators. A key conclusion was ensuring that all reporting-related initiatives be aligned to minimize the administrative and research burden on First Nations communities and organizations. For instance, FNIHB's new Results Based Accountability and Management Framework (RMAF) should be complementary to the First Nations-driven health reporting framework.

#### **Health Services Accreditation**

Health services accreditation through the Canadian Council on Health Services Accreditation (CCHSA) is one avenue that is increasingly pursued by First Nations to assist in the development of their organization infrastructures. It is one component of a quality assurance program. For example, the Nunee Health Authority is currently pursuing accreditation as a means to ensure high quality health services and to support ongoing capacity building of service providers and administrators.

One organization interviewed by the National Evaluation of the Health Transfer Policy group received their accreditation with the International Standard Organization (ISO 9000) for all Band programs including health. They now have a Quality Assurance Coordinator who works with all programs managed by Chief and Council. This accreditation has given the Band a new status and increased opportunities for economic development. Banks are now more likely to do business with them. The process was funded through INAC.<sup>24</sup>



#### The Gaps

The recommendations that follow are in keeping with the gaps identified in this chapter, namely adequate funding with respect to formulas for deriving funding amounts that include all the necessary factors to consider; the lack of federal funding directly to First Nations for their membership that include monies to provinces earmarked specifically for First Nations living away from First Nations communities; the need for support to communities wishing to become accredited for health service delivery; lack of efficient and transparent mechanisms for dispute resolution; performance indicators that are irrelevant to First Nations community planning.

#### Recommendations

**Recommendation #65:** The federal government and First Nations must develop minimal requirements for sustainable public health programs. Funds should be transferred directly to communities via Regional First Nations Health Authorities or other proposed means that would permit Public Health Programs to be delivered or purchased by First Nations communities.

**Recommendation #66:** If communities choose to govern their own public health services by creating collaborative agreements (e.g. inter-community economies of scale) then funds should flow to Regional and sub-Regional First Nations Health Authorities with a governing board composed of representatives from the communities, Health Directors, and Chiefs as well as other individuals as deemed necessary.

**Recommendation #67:** Public health in the first instance is a local enterprise. Provinces and territories in turn must fund, support, and coordinate local activities for First Nations in their jurisdictions through their own agencies and ministries. Specific funding from Health Canada needs to be transferred to mandated First Nations Health Authorities and/or, pursuant to agreement of First Nations leaders, to provinces/territories who in turn will ensure that First Nations living away from First Nations communities have specific public health programs of high quality. Another option is for First Nations communities to receive funding for their entire membership and engage with the province or territory to purchase services on behalf of their membership living away from the community.

**Recommendation #68:** Accreditation processes for interested communities should be funded.

**Recommendation #69:** Program reporting will be based on the achievement of pre-set national indicators or benchmarks to ensure that outcomes, rather than activities are used to monitor the use of federal funds which will reinforce accountability of the federal government based on its fiduciary obligation.

**Recommendation #70:** Assessing the degree to which FNIHB are achieving their goals and responsibilities of delivering and/or assuring public health programs to First Nations needs to have outside auditing on an annual basis through a third-party and non-governmental expert group.

**Recommendation #71:** Funding needs will be determined by a set of predetermined criteria including Northern and remote factors, total population base, age and gender of population base, socio-economic composition of the population base, services communities provide to residents of other communities, local cost of living, and population growth.

**Recommendation #72:** Not all funding needs to be new. We see opportunities for First Nations public health initiatives to participate in programs already announced, such as the massive investment in Canada Health Infoway, and the 4-year \$100 million AHHRI.

**Recommendation #73:** The new funds would be implicitly tied to implementing the *First Nations Public Health Act* and the contents of the Act that would assume the responsibility of health protection and promotion as a means for better coordination and regional First Nations collaboration.

**Recommendation #74:** The time required to build capacity within First Nations communities will be considerable. Meanwhile, other alternative means of developing capacity, such as telehealth, can to be explored, as an option to First Nations.

**Recommendation #75:** Telehealth needs to be funded as a program with human resource capacity and not solely a tool for delivering a range of public health services to First Nations communities. This is essential so that it does not create a new burden on existing nursing and other health care staff.

# **Chapter 7: Health Human Resources**

There are very few other crises currently facing First Nations communities so severe as that of health human resources. This chapter will focus broadly on health human resources with some specificity to public health. Four main issues in staffing of promotion/prevention/protection programs are apparent:

- the need to address the acute shortage of health professionals, especially nurses, in First Nations communities;
- the need for more First Nations health care providers and promotion/prevention workers;
- the need for skill and knowledge development among current health workers; and,
- the need for trained health program administrators, managers and health information technicians.

# The Vision

To motivate First Nations children and support them in recognizing that they are capable of becoming a health care professional, to nurture them through their education, to see them reap the benefits of their work and commitment, and to see that they recognize the great value in serving their communities.

# **Background**

# The Acute Shortage

The Naylor report lamented the lack of solid quantitative data on the state of human resource supply in health protection and promotion activities. Nonetheless, it was categorical in its affirmation that "no attempt to improve public health will succeed that does not recognize the fundamental importance of providing and maintaining in every local health agency across Canada an adequate staff of highly skilled and motivated public health professionals." This point was reinforced by witnesses who testified to the Committee that the SARS crisis had revealed just how thin on the ground the country is with respect to health human resources in general, and health protection human resources in particular. Also, the Committee was struck by the fact that the serious shortage of nursing personnel has grave implications for Canada's ability to protect and promote the health of its population.<sup>2</sup>

Staff turnover results in discontinued services, uneven service delivery, gaps in knowledge development and loss of momentum. It also places communities in more vulnerable situations where staff may not have the experience for early identification of outbreaks and other public health emergencies.

Staffing capacity is even more of a critical issue in First Nations communities prompting several initiatives related to health worker recruitment, training and retention. Long-standing staff shortages in many remote communities are well known but shortages also exist in some communities located in or near urban reserves. Staff turnover is a major concern. This results in discontinued services, uneven service delivery, gaps in knowledge development, and loss of momentum. It also places communities in more vulnerable situations where staff may not have the experience for early identification of outbreaks and other public health emergencies.

Community Health Representatives (CHRs) were the first First Nations health workers to undertake formal health education and prevention activities in First Nations communities, through funding from the federal government. The community of CHRs has grown to more than 900 workers employed by 577 Bands. Their role in the health system

has evolved over the years and includes promotion, prevention, and protection functions related to environmental health, immunization, screening, pre and post natal care, health education, community development, and mental health. CHRs may be the only source of stability and reliability in a health service system that otherwise experiences high staff turnover among nurses and physicians. The Royal Commission on Aboriginal Peoples identified the CHR program as one of the most successful programs involving First Nations people in promoting health.<sup>23</sup> However, a number of challenges exist in making full use of this resource. The National Indian and Inuit Health Representative Organization (NIICHRO) has identified continuing regional disparities in salary levels, and availability and access to training certificate/diploma programs.<sup>33</sup> Issues related to working conditions for CHRs include: lack of funding for training and for community programs, misunderstanding/misinterpreting the CHR role, lack of career opportunities, unrealistic work loads, fluctuating salaries and benefits, and job insecurity.

CHRs may be the only source of stability and reliability in health services that experience high staff turnover among nurses and physicians.

FNIHB has initiated a National Nurse Retention and Recruitment Strategy to address the severe shortage of nurses working in First Nations communities. The strategy addresses improving both working and living environments to encourage nurses to stay in First Nations communities, and recruiting the best possible nurses for those communities. Follow-up activities include promoting better clinical support and supervision, addressing housing and community safety concerns, more active recruitment efforts in the regions, and a focus on attracting First Nations nurses. FNIHB is also looking at a funding process in

transferred communities that takes into account the rising cost of nursing services. Nevertheless, turnover, under staffing and vacant positions remain critical issues in nursing programs. The reality is that technical and professional skills will have to be imported in First Nations communities for many years to come. Public health is focused on the health of populations. To do so effectively requires a critical mass of technically expert staff.

#### The Need for First Nations as Health Professionals

The Royal Commission on Aboriginal People reported that in 1996, there were only 40 to 50 Aboriginal physicians in Canada.<sup>23</sup> This represents 0.1 % of all physicians. Presently the number of physicians is estimated to be around 150-200. There are about 200 Aboriginal registered nurses, or 0.1 % of the total. The number of traditional healers, midwives and Elder advisors is not known. RCAP recommended that governments and educational institutions undertake to train 10,000 Aboriginal people in health including professional and managerial roles, from 1996-2006.<sup>23</sup>

Although the number of health professionals has increased since the RCAP report, the proportion of First Nations health professionals remains far below what it should be. In September 2004, at the Special Meeting of the First Ministers with Aboriginal Leaders, the federal government announced a commitment of \$1.3 million over the next five years for an Aboriginal Health Human Resource Initiative (AHHRI). Three objectives were identified: increasing the number of Aboriginal health workers; improving retention of health workers in Aboriginal communities; and adapting curricula to be more relevant.

Many strategic partnerships already exist among the potential participants, including professional associations and university institutes. Faculties of Nursing in colleges and universities offer collaborative programs at the bachelor's level, and some of these programs are delivered by distance modalities to remote, northern, and rural communities.

Colleges and First Nations educational institutions work together to offer para-professional programs and continuing education. In some areas of the country, First Nations Elders and healers are included in support programs within colleges and universities, and there are positive linkages between First Nations communities and local education institutions. Some health researchers work in close partnership with First Nations communities. All of these existing partnerships provide models for expansion across institutions and communities. It is likely that many more strategic partnerships can arise from the proposed priorities in this Public Health Framework.

The commitment of Canada's medical schools to social accountability was documented in Social Accountability: A Vision for Canadian Medical Schools with the support of Health Canada and the Association of Faculties of Medicine of Canada (AFMC).<sup>44</sup> From this activity, an Aboriginal Task Group was formed which, among other objectives, will explore and define methods, resources, and strategies to increase the number of First Nations medical students, residents and physicians, and enhance the cultural competence of non-First Nations medical graduates. A set of overarching principles and values has been articulated by the Task Group with several recommendations to medical schools that include issues regarding admissions, curriculum development, and faculty support. Currently, Canadian universities that offer designated seats to First Nations students entering health careers include Queens University (four seats), University of Toronto (five seats), University of Western Ontario (three seats), University of Saskatchewan (three seats), University of Manitoba Pre-Med initiative (35 graduates in medicine since 1987), and University of Alberta (37 graduates since 1993 with more than three seats allocated). The Northern Ontario Medical School opened in September 2005 with two campuses in Sudbury and Thunder Bay and five designated seats for First Nations students. McMaster University has no designated seats. The University of British Columbia has five designated seats. To the knowledge of this Advisory Committee, there are only two First Nations medical graduates with a specialty in Community Medicine.

# Skills and Knowledge Enhancements to Current Health Care Providers

Increased skills and knowledge are recognized as necessary for the improvement of health promotion/prevention efforts at the national, provincial, territorial, regional, and community levels. First Nations, as well as non-First Nations nurses, physicians, Community Health Representatives, addictions workers, counselors and others would benefit from a better understanding of:

- cultural knowledge of health and wellness;
- the strengths and current challenges facing First Nations communities;
- key issues and connections among them;
- population health, health promotion and disease prevention theory and practice;
- community development, client participation
- empowerment practice; and,
- best practices in program planning delivery and evaluation.

Culturally sensitive care can only be achieved by First Nations people, both in terms of developing services and providing services.

This can only be achieved by a vigorous examination and revision of current health education curricula across the country and within several institutions. Nevertheless, there are limitations in what one can expect to teach non-First Nations health care providers. The office visit is far from ideal for providing culturally sensitive care when the First Nations way of healing occurs outdoors or in ceremony. Culturally sensitive care can only be achieved by First Nations people, both in terms of developing services and providing services.

#### **Health Information Technicians and Health Administrators**

Generally, when First Nations communities and organizations need to gather information and data relevant to their citizens or communities, they must rely on what is made available from the federal and provincial/territorial departments and research institutions who hold the information about their communities. Developing the capacity to manage, analyze, and implement a health surveillance system requires investment in human resource development. Academic training of First Nations people in the area of health research and information science is urgently needed. Several universities, such as Manitoba and Alberta, currently provide specialized access and support programs to encourage First Nation students to pursue careers in medicine and allied health fields. Although some First Nations physicians pursue additional training in epidemiology and health services evaluation, particularly at the University

The focus on the recruitment and training of Aboriginal health care professionals has perhaps overshadowed the concurrent need for trained health administrators. of Manitoba, more career development in this area is required. First Nations students need to have the same support options available to them for graduate studies in the population health field, as they currently do in medicine, nursing, dentistry, etc. Continued career development of First Nations health research professionals at the post-doctoral and academic levels must also be supported, building on successes to date achieved through the Institute of Aboriginal Peoples' Health Research's Aboriginal Capacity And Research Development Environments (ACADRE).

A second stream for developing First Nations capacity in health surveillance can be achieved through continuing education opportunities. Most First Nations organizations and communities employ Health Technicians who are generally responsible for health policy development, program planning, and evaluation. Acquiring specialized skills in the effective use of health information must be a priority for this cadre of health professionals. One example of the kind of continuing education opportunities that need to be provided is the "Summer Institute in First Nations Allied Population Health Research," offered at the University of Manitoba. This institute developed a program in partnership with the Assembly of Manitoba Chiefs. It allows participants to become familiar with various relevant health datasets derived from surveys, and provincial and federal administrative data.

The focus on the recruitment and training of First Nations health care professionals has perhaps overshadowed the concurrent need for trained health administrators. Health management careers are one area where there is a severe shortage of trained First Nations professionals, a need which becomes particularly acute in many communities working toward transfer of health services.<sup>45</sup>

# Recommendations

**Recommendation** #76: Students need to have better academic preparation in elementary, junior high, and senior high schools with expanded mathematics and sciences programs. Creative, innovative and culturally significant science ventures for children need to be added to their current curricula.

**Recommendation #77:** Life skills programs should be introduced at all elementary and secondary levels to attract youth to careers in health.

**Recommendation #78:** Partnerships must be created between First Nations communities and organizations and provincial academic institutions to earmark spots for undergraduate sciences, nursing, medical and paraprofessional training.

**Recommendation #79:** Funding for post secondary health careers should increase and go directly to students with additional support including mentors and access to Elders to assist them with issues around isolation and distance from home. There needs to be separate funding streams available for health professional programs for students.

**Recommendation #80:** New training programs and positions specific to First Nations in various public health-related fields need to be created that can have recognized accreditation across Canada. This would allow the creation of secondments to, and from, other First Nations communities, with arrangements for mutual recognition of seniority and a range of collaborative opportunities for advancement.

**Recommendation #81:** New training programs should be developed based on virtual models of learning to allow First Nations students to learn closer to home. These training modules should be developed in collaboration with First Nations health professional and paraprofessional associations.

**Recommendation #82:** The creation of a First Nations School of Public Health in Canada, possibly as a 'virtual' school that would draw on the resources of several institutions that are already engaged in some of the teaching and training required, should be explored. A 'virtual' school would also have the advantage of linking both university-based and community college-based programs so that students receive both theoretical and practical training.

**Recommendation #83:** Colleges and universities must adapt the present health care professional curricula to reflect First Nations cultural and traditional needs and knowledge. This could be done through support of the Social Accountability initiative of the Association of Faculties of Medicine of Canada (AFMC).

**Recommendation #84:** College and university entrance requirements should be reviewed to ensure that they are receptive to First Nations students. Certain prerequisite examinations, such as the MCAT for medical school, place some First Nations students at a disadvantage. A dialogue should begin with universities to examine the cultural biases and discrimination these examinations present.

**Recommendation #85:** Post-secondary preparatory programs, such as summer programs, should be developed by colleges and universities to support incoming First Nations students.

**Recommendation #86:** First Nations communities should be encouraged to create practicum opportunities for First Nations and non-First Nations students in their communities.

**Recommendation #87:** Certification and standards for innovative public health para-professionals should be considered to support public health activities that currently demand qualifications that are irrelevant to the First Nations community context.

**Recommendation #88:** Provincial, territorial and federal departments that currently offer a range of health and education related programs should be encouraged to consider the transfer of these programs to education institutions where the support and expertise for successful learning among First Nations students/professionals may reside.

**Recommendation #89:** Colleges and universities must be lobbied to increase the number of designated seats to First Nations in health programs, and to understand that a pan-Aboriginal is not as effective. Specifically, working in close partnership with First Nations communities, will increases the likelihood that First Nations students will return to those communities upon completion of their training. Ultimately, this will enhance the sustainability of the health human resource capacity available to support First Nations communities' public health systems.

**Recommendation #90:** Accreditation programs at colleges and universities should have their criteria expanded to include First Nations cultural competency and First Nations inclusion criteria and goals. This needs to be developed by First Nations people and not non-First Nations faculty.

**Recommendation #91:** New sub-specialties in the areas of First Nations health both for the health care provider and for the health care administrator should be created.

**Recommendation #92:** In addition to conventional health care careers, emphasis should also be on encouraging First Nations to develop training in health information and technology, as well as other key professions such as nutrition.

**Recommendation #93:** Provincial academic institutions should have, at a minimum, community representatives on their governing boards to begin assisting with partnership creations between First Nations communities and organizations with First Nations education interests.

**Recommendation #94:** Consideration should be given to providing credentials for certain types of public health practitioners through competency-based learning needs assessment tools. This would mean that public health specialists could become competency based rather than discipline-based.

**Recommendation #95:** Increases are required to bursaries, scholarships and grants for students in health professional and paraprofessional programs.

**Recommendation #96:** Where communities currently receive funding through transfer or where communities in the future may receive such funding, there must be targeted funding available for ongoing training, recruitment and retention of staff.

**Recommendation #97:** Key players should be identified with a single leader to develop a strategy for a sustainable First Nations Health Human Resources (e.g. wage parity). The strategy should be based on a partnership involving governments, academic stakeholders, institutional partners, and professional associations. A subset function of this group would focus specifically on public health human resources. Budget for this purpose needs to be built into projected public health needs.

**Recommendation #98:** The developed strategy should aim to make First Nations self-sufficient with regards to public health personnel by enhancing inter-jurisdictional collaboration between First Nations, provincial/territorial and federal human resources on a continuing basis.

**Recommendation #99:** Creative designing of new positions within the public health profession should be developed for introduction to the currently unemployed in order to attract them to health careers. Roles in disease surveillance are one example.

**Recommendation #100:** Funding should be made available for assisting in developing on-the-job training programs that would allow for the cross-training of other health professionals so that they could acquire the skills needed to be able to bolster surge capacity in public health emergencies in all jurisdictions.

**Recommendation #101:** FNIHB regions should examine their hiring policies which often support internal hiring rather than looking more broadly at First Nations for available qualified workers, such as licensed practical nurses.



# **Partnering in Public Health**

# **Chapter 8: International Models**

The pervasive concern regarding Canada's First Nations public health system prompted a review of alternative international models for organizing and funding essential public health programs and services that other countries use for their residents and where appropriate, their Indigenous populations. Background documents were reviewed for the following countries: England, Australia, New Zealand, and the United States (U.S.). Information was sought on the following infrastructure issues with specific reference to Indigenous populations where applicable:

- Essential functions of public health;
- Legislative organization and governance structures;
- Accountability mechanisms;
- Budget allocations for government funded development;
- Information management;
- Research and development;
- Supporting capacity of smaller/remote agencies; and,
- Specific efforts to develop public health infrastructure.

Concern for public health systems was present in all of the jurisdictions reviewed. As expected, these concerns were even greater for relevant Indigenous populations. No perfect system was identified in the search, however, certain aspects of other countries' public health systems might be worth considering for First Nations in Canada.

All countries had the following similar stories: the impact of health system restructuring, chronic system under-funding and inattention, a shift in focus from communicable to chronic diseases, as well as the need to address emerging

Countries with Indigenous populations have repeatedly published reports highlighting the gaps that exist between these unique groups and the rest of the country with respect to public health.

threats such as bio-terrorism. Many jurisdictions have embarked on a process to identify the essential functions of their public health systems. One of the main incentives of this work is that a country can use the list to clarify areas of government responsibility.

Countries with Indigenous populations have repeatedly published reports highlighting the gaps that exist between these unique groups and the rest of the country with respect to public health. However, success stories exist and optimism for opportunities abound. In New Zealand, the Maori participation in various health action plans has resulted in positive outcomes not seen in other countries. In the US and England, highly visible plans for improving the public health system were encountered. In Australia, a national partnership between the federal and state governments had been formed to explicitly address the public health system's infrastructure. Highlights of the analysis of the information gathered from the literature review and key recommendations are described below.

# Background

Many researchers now use the terminology "epidemiologic transition" when they are referring to Aboriginal populations making a health transition relative to their level of development in their respective national societies. According to this theory, "societies experience over time three stages of development with regard to their pattern of disease dominance." The first, second and third stages experience the ages of 'pestilence and famine' (by ancient societies), the age of 'receding pandemics' (before the 20<sup>th</sup> century), and the age of 'man-made and degenerative diseases' (by Western, modern societies) respectively.

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According to one leading researcher on Aboriginal populations, Frank Trovato, the health status of most Aboriginal populations tends to lag behind that of their larger nation. This indicates that Aboriginal populations are in a health transition. Trovato states that all three Aboriginal populations in New Zealand, Canada, and the U.S. are in the second stage of epidemiological transition, where their more developed nation-states are in the third stage.

In the U.S., New Zealand, and Canada, Aboriginal birth and death rates are higher, and they have a greater prevalence of infectious and parasitic diseases, especially among infants and children. The incidence of premature death from accidents, suicide, and violence are "disturbingly high," says Trovato.<sup>46</sup> The research is significant insofar as it dictates health research must proportionately and adequately measure the shifting state of the health status of Aboriginal peoples. A disproportionate amount of research focuses on much healthier groups in these three countries.

The causes of disproportionate health status rates between Aboriginal populations and non-Aboriginal populations originate from historical events. After contact with Europeans, Aboriginal peoples' position in society became marginalized, where social disorganization now presently influences their health and social problems.

Statistics on Aboriginal populations of Canada, New Zealand, and the U.S. are not consistent; there are some similarities but there are differences as well. Based on differences in the mainstream societies, each Aboriginal population will vary by reference to specific health indicators. Trovato points to some differences such as New Zealand having a lower per capita income but income is distributed more evenly throughout the population compared to the U.S. and Canada. New Zealand has a smaller population in relation to the U.S. and Canada, but the Maori population represents a much larger proportion of the population. Also, the Maori only speak one language and have a more unified political presence in New Zealand, while there are several language groups of the Aboriginal peoples of North America. The New Zealand Maori also have a strong political presence throughout the social hierarchy in government.<sup>46</sup>

The Aboriginal peoples of Canada are considered to be highly disadvantaged in social and economic terms as well as for American Indians and Alaska Natives in the U.S. Most Aboriginal groups in Canada and the U.S. are recognized by the federal government and receive provisions for health care, and thus, should have a health status that is similar to that of the New Zealand Maori.

# New Zealand

#### 1. Indigenous Demographics

New Zealand is a constitutional monarchy with a parliamentary democracy. It is an island state that is comprised of two major islands and other smaller islands. New Zealand is responsible for the self-governing states of the Cook Islands and Niue, administers Tokelau, and claims the Ross Dependency. New Zealand has a land mass of 268,860 square kilometeres, comparable in size to Japan and slightly larger than Colorado in the U.S. Since 1876, there have been no subnational entities such as provinces, states or territories apart from its local government. New Zealand's local government structure is comprised of a two-tier structure of regional councils (the top tier) and territorial authorities (the bottom tier). The population of New Zealand numbers over 4 million. About 80% of the population is of European descent. Maori people make up 14.7% of the total population. New Zealand has a high standard of living; the country ranks 18th on the 2004 United Nations Human Development Index.

The Maori are the only Indigenous groups out of the U.S., Canada, Australia and New Zealand that are guaranteed

political representation in their state parliament commensurate with their population share. <sup>46</sup> The Maori represent a powerful political force in New Zealand government structures. However, the Maori populations suffer from the same plaguing social indicators as First Nations including higher rates of unemployment, incarceration, suicide, and lower incomes and rates of educational attainment. The Maori are also younger and have a faster growing population than the general population of New Zealand. The Maori are considered to be more culturally homogenous than First Nations: they all speak the same language, but have different dialects, and think of themselves as belonging to the same culture. Their most important form of social organization is the hapu, a sub-tribe or kinship society. Hapu are grouped together into iwi or tribes.

Despite their political clout, the Maori are not exempt from political problems; for example, there are differences in interests between the urban Maori and those residing in traditional lands and the issue of proper "mandating" political representation. 80% of Maori now live in large urban centers, but still have strong ties with other urban Maori and with their iwi and hapu. Maori culture has survived due to the strength, persistence, and resilience of the people. A few supportive government policies have been helpful.

There are many differences between New Zealand and Canada. Unlike Canada, New Zealand's Maori populations were left without reserves, the Maori have less clearly mandated political bodies to negotiate self-government/receive settlements, and the hapu and the iwi have no formally recognized powers. There is no commitment by New Zealand to provide for Maori self-government<sup>46</sup> In New Zealand, there are no provincial governments as there are in Australia, Canada, and the U.S. Thus, there are no federal-provincial issues to complicate the government's relationship with Maori. As Indian and Northern Affairs Canada has noted, "In Canada, the U.S. and Australia, these issues blur the lines of accountability for service delivery and complicate the negotiation of the transfers of land, grants and/or jurisdiction." There are also no issues of unextinguished Aboriginal title in New Zealand and there are no non-treaty Maori. Maori claims to land and settlements arise from the violation of the Treaty of Waitangi and the injuries caused by such violations.

The Treaty of Waitangi, signed in 1840, is the founding document of New Zealand. It provides a framework of rights and responsibilities, and articulates a relationship between Maori and the Crown. The Treaty of Waitangi recognizes Maori peoples as "peoples of the land" (*tangata whenua*). This relationship is based on three key principles: partnership, participation and protection. Action to reduce inequalities in health in New Zealand is taken within a Treaty of Waitangi framework.

It is estimated that, by the year 2050, the Maori population will have reached over 800,000 or increased to 22% of the total New Zealand population from 14%. The patterns of disease are changing in the Maori populations with an emphasis on non-communicable diseases, injury, and youth suicide among others. The infant death rate has decreased from 94 in 1929 to 18 in 1991 per 1000 live births. Life expectancy for males has increased from 33 in 1905 to 61 in 2001/02. The life expectancy for females has increased from 30 in 1905 to 73.2 years in 2001/02.

The mortality ratios of Maori and Pacific Island peoples are higher than that of European populations, but rates have improved. The gap between the life expectancy rates of Maori and non-Maori peoples is getting less wide, with gains being made every census year. However, the Maori life expectancy rate still lags behind that of the general population even with a lower proportion of the total population of New Zealand.

The last decade has seen a number of changes in the approach to overall health by the government in New Zealand through a re-focus on public health and its integration with primary care. With respect to their approach to Maori health, a number of important initiatives have culminated into several successful outcomes:

- Government health policies: The Treaty of Waitangi and the *New Zealand Public Health and Disability Act*, the New Zealand Health Strategy, the Primary Health Care Strategy, and District Health Board obligations;
- Maori Health Leadership: from three Maori health initiatives in 1984 to over 300 providers funded by the
  District Health Boards in 2004, health promotion, traditional healing, primary health care, disability
  support, Maori Health Strategy;
- Maori Health Leadership Workforce Development: training, health professions, cultural advisors, community health workers, recruitment and retention, the cultural/clinical interface, over 200 Maori medical practitioners;
- Health services responsiveness: most Maori use conventional health services, cultural awareness and competence of staff, early intervention through primary health care, proactive outreach, performance indicators to assess gains in health, ethnicity recording and measures of effectiveness;
- Integrated development: cultural affirmation, devolution, reduced dependence on the state, tribal (iwi) and Maori delivery systems;
- Maori research: Maori health research council capacity, Maori health research units (six), Maori
  methodological paradigms, Center of Research Excellence, Academy for Maori Research and
  Scholarship.

Results have shown that there have been increasing improvements over the last 30 years such as reduced life expectancy disparities, improved smoking cessation and immunization, strengthened primary health care infrastructure, increased capacity in professions and research, and access to care.

To implement these changes, the health sector had to undergo numerous changes and the Maori had to develop specific initiatives to address their health status. It is the health and disability sector of New Zealand that has responded to growing Maori leadership. There have been changes to ensure a voice for Maori in the decision-making process. And ground-breaking legislation (the *New Zealand Health and Disability Act*, 2000) is the first of its kind in New Zealand that "requires health agencies to recognize and respect the principles of the Treaty of Waitangi and to explicitly address Maori health issues."

The *Maori Public Health Action Plan* for 2003/04 is an interim plan that will be replaced by an overarching strategic framework, Achieving Health For All People, focusing largely on the processes for improving Maori involvement and participating in the public health sector. The latter is linked to the broader *Maori Public Health Action Plan* 2002/03 and the Inequalities Framework. It identifies objectives and associated areas for action. The objectives are:

- 1. building strong public health leadership at all levels and across all sectors;
- 2. encourage effective public health action across the whole of the health sector;
- 3. promote healthy communities and healthy environments;
- 4. make better use of research and evaluation in developing public health policy and practices; and,
- 5. achieve measurable progress on public health outcomes.

Public health actions, thus, focus on a framework, implementing a vision, priorities, infrastructure, and progress on outcomes. Interestingly, the Inequalities Framework is described as developing and implementing comprehensive strategies at four levels:

- structural tackling the root cause of health inequalities, that is, the unequal distribution of the social, economic, cultural, and historical factors that fundamentally determine health;
- intermediary pathways targeting material, psychosocial, and behavioural factors that mediate the impact of structural factors on health;
- health and disability services undertaking specific actions within health and disability services; and,
- impact minimizing the impact of disability and illness on the socio-economic position.

The key strategies outlined by the Ministry of Health in improving Maori outcomes are mainstream effectiveness, focusing on health priorities, reducing inequalities, and investing in Maori provider and workforce development. The health and disability sector also teams up with other sectors when working on the wider determinants of health.

#### 2. Structure of Health Services Delivery and Public Health

The New Zealand Public Health and Disability Act (NZPHDA), 2000, effectively dismantled Hospital and Health Services and the Health Funding Authority and replaced them with District Health Boards (DHB) and a Ministry of Health (MOH) with divided responsibilities. DHBs are responsible for service agreements where the MOH is responsible for inter-district and national personal health services, mental health services, Maori health services, and Section 88 (quarantine and isolation) notices, public health services and disability support services.

One of the key objectives of the public health legislation is to reduce disparities between population groups. The NZPHDA acts as the mechanism to achieve this aim and establishes DHBs to take a population health approach and apply it to their geographically defined populations.

The NZPHDA is concerned with entities and arrangements across the health and disability sectors and has implemented 21 DHBs responsible for services to geographically defined areas and for needs assessment service planning.

The MOH has a role in monitoring the funding and provision of services by DHBs and also provides policy advice and ministerial duties. DHBs are Crown entities and, therefore, are required to give effect to government policy. Each DHB has up to 11 members, with seven elected from the communities, and four appointed. Within the appointment process, the MOH must ensure that the Maori membership on the board is proportional to that DHBs Maori population, with at least two members of Maori on the board. DHBs need to consider all needs and services including prevention, early intervention, treatment and support services, and how these services can be provided to best meet the needs of the population within the funding provided.

To meet the health and disability needs of their populations, DHBs can deliver services themselves or arrange for other providers to deliver services. DHBs work collaboratively and cooperatively to ensure proper service delivery for their own populations. The Primary Health Organization (PHO) Initiative represents a new development in service delivery. "PHOs will encompass the range of primary care and practitioners that will be funded by DHBs to provide of a set of essential primary health care services to those people who are enrolled in that PHO." Many of the health care practitioners who will be involved in PHOs already operate under existing organizational arrangements such as Independent Practitioner Associations (IPAs), Maori Provider Organizations, and rural trusts.

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The NZPHDA recognizes the principles of the Treaty of Waitangi and adopts measures to ensure them including: minimum membership on DHBs, provision for Maori membership on DHB committees; training board members on treaty issues, Maori health issues, and Maori organizations and groups in the DHB; requirements that ensure the establishment of a process to include Maori participation and contribution to strategies affecting Maori health; requirements to foster development of Maori health capacity for participating in health and disability sector and providing for their own needs; and the provision of relevant information to Maori to enable effective participation.

DHBs have a range of accountability mechanisms such as district strategic plans, district annual plans, and regular monthly and quarterly reports. Transparency is provided by the DHBs by ensuring the communities have opportunity to be involved in board deliberations. DHB board meetings are open to the public and the public can be involved in the planning process through consultation on documents such as the district strategic plan. Planning is undertaken within the parameters of the New Zealand Health and Disability Strategies. "Each DHB is required to consider the full range of services which its population needs, while recognizing that some services are still funded by the Ministry of Health." The accountability framework is important for ensuring that DHBs do not favor certain services (the public hospital) over others delivered by non-Crown owned providers (such as primary health care services, disability support services, and by Maori-for Maori services).

New Zealand's public health system is undergoing dramatic change, both structurally and philosophically. According to the New Zealand Public Health Advisory Committee, the creation of DHBs has significantly altered the health sector, giving more responsibility to communities to identify health priorities. In addition, newly emerging Primary Health Organizations (PHOs) are required to address both the health of the individual patients and the health of their communities.

There have been new players added to the mix of public health including local government and PHOs. Local government has a new statutory responsibility to "promote the social, economic, environmental, and cultural wellbeing of communities." PHOs are "required to include approaches directed towards improving and maintaining the health of the population." In addition, Public Health Units (PHUs) now are related to DHBs, which replaced their relationship with Crown Health Enterprises and Hospital and Health Services.

New approaches to public health in New Zealand include addressing the wider determinants of health and increased intersectoral collaboration. This is on the agenda because of increased players in public health in addition to the traditional ones. These approaches give the New Zealand government the impetus to develop new skills and organizational capacities.

#### **Public Health Units**

There are 12 Public Health Units (PHUs). They are the key vehicles for delivery of public health services. There is usually one PHU for every DHB, although some PHUs can provide services across many DHBs. PHUs can be located in one of three categories within a DHB: in the "planning and funding," "service provision" arms, or "report directly to a CEO," which makes their role ambiguous. These PHUs can provide a mix of services or functions where they can be direct providers of services and programs or they can provide a strategic function such as provide

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advice on the health needs of populations. Regardless of the variation in roles of PHUs, the activities of the units are said to cover all three main aspects of public health:

- health protection;
- health promotion; and,
- health education.

PHUs may also represent DHBs in other intersectoral collaborations and initiatives.

DHBs want devolution of funding for public health to effectively address the needs of their communities. However, public health units are weary of such devolvement because of the risk of public health money being "siphoned off" to the hospital system. Around half of funding for public health services goes to PHUs within DHBs to provide services in communities. Some report directly to the Chief Executive (CE) of the DHB, whereas others are under the management of the General Manager of DHB planning and funding. The remaining PHUs are provider arms of DHBs, a carry over from the purchaser-provider split model. Those reporting to the CE or to planning and funding capitalize on synergies and experience more DHB understanding of public health. Those in provider arms tend to feel more marginalized and experience a conflict of roles between planning and funding and public health. Most PHUs have responsibility for more than one DHB region but have a primary relationship with one DHB where they have a contract for delivery of public services and one with the MOH.

There are two layers for contracts of delivery of public health services by PHUs. One contract is held with the MOH and the other is held with DHBs. Contracts that are with the MOH are related to the Minister's priorities. Contracts with DHBs related to DHB priorities that reflect the needs of their communities. There is thus potential for tension between the two layers. In addition, there is usually a component of each contract that requires the delivery of services to Maori and other ethnic populations.

#### **Local Government**

Traditionally, local government has played a key role in public health activities; however from the passage of the *Local Government Act*, 2002, local government's scope for action has increased from that of just health protection to promoting "the social, economic, environmental, and cultural well-being of communities, in the present and for the future." Local government is also mandated by the Act do an assessment on how an action will impact on these different forms of well-being. Again, public health is not referred to in this clause; however, there is an implication for strong relationships to develop between the personal and public health sectors and local government. The 2002 legislation changed local government health action from prescriptive models to enabling models. "Legislation now sets out specific things that councils must do or provide specific actions that councils cannot take, but within these boundaries authorities have extensive freedom and flexibility." In addition, local government councils are required to consult with community and other bodies to identify desired outcomes and develop Long Term Council Community Plans that outline how these desired outcomes will be achieved. However, this is only considered a potential role for local government councils and they are not obligated to address public health needs.

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#### **Primary Health Organizations (PHOs)**

PHOs were established under the 2001 New Zealand Primary Care Strategy. They are groups of providers who are mainly concerned with the primary health needs of "the people enrolled with them." The group always includes a General Practitioner, may include nurses, Maori and Pacific providers, pharmacists, dieticians, mental health workers, community health workers, and dentists. The PHO model is considered a wholistic one where public and personal health care are included within an overall population healthcare approach. There is a funding formula which allocates specific monies for health promotion activities. These activities can be carried out alone by PHOs or in collaboration with other providers and organizations. DHBs monitor and approve funding for health promotion activities.

#### Non-Governmental Organizations (NGOs)

NGOs are considered the third sector in public health that provide one of two main roles: provide specific health promotion and education services, such as tobacco control or well child programs (funded by MOH contracts) or provide public health services independently of the Ministry (with no government funding). In addition, they also play an advocacy role which links policy networks surrounding public health by providing information and leadership on specific issues (highlighting and commenting on relevant issues in the media and to policy-makers, monitoring public health performance, undertaking and commissioning research, providing a collective voice for practitioners and those whose needs they serve, and providing advice on policies that may impact on their areas of concern). The other half of public health services funding goes to over 200 NGOs.

#### Maori and Iwi Providers

Maori and Iwi providers are considered part of the NGO sector; they deliver services from a Maori perspective and are usually specifically "by Maori for Maori." Public health programs designed and delivered by Maori are done so in a culturally appropriate manner and thus effective in addressing Maori public health needs. In addition to dealing with specific issues, they operate within a wider model of Maori-centered health and development. Maori and Iwi services fuse personal and public health services together because traditional Maori concepts of health do not differentiate the two.

There are currently 240 Maori health providers contracted to 21 DHBs throughout Aotearoa. Maori health providers tend to deliver health and disability services primarily, but not exclusively, to Maori clients in a way that adheres to Maori principles and philosophies (or "kaupapa") and that is delivered through a distinctively Maori delivery framework. There are also other providers offering services to Maori.

#### 3. Review of relevant major documents

The New Zealand Health Strategy (NZHS) is the overarching framework for action on health. This strategy does not specify priorities or objectives; the details are specified in other action plans or detailed strategies. Other strategies include the Disability Strategy, the Primary Health Care Strategy, the Palliative Care Strategy, the Maori Health Strategy, the Pacific Health and Disability Action Plan, the Health of Older People Strategy, the Youth Strategy, Oral Health Strategy, and Sexual and Reproductive Strategy and many others. "The New Zealand Health Strategy develops the framework for action, identifies the Government's [sic] key priority areas, provides District Health Boards with the context within which they will operate, and identifies the way forward."<sup>49</sup>

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The NZHS is a living, breathing document that will be altered over time as issues change and new ones emerge. It focuses on issues that the MOH, DHBs, and health service providers must address. It provides the contextual environment for DHBs, which is reflected in the funding arrangements between the MOH and the DHBs. The funding agreements stipulate what services DHBs are required to deliver to ensure access to equitable and comprehensive health care. The future role of the NZHS is to strengthen intersectoral links, add specific strategies, and provide toolkits to DHBs to help them meet their populations' needs.

In New Zealand, the health system is considered to be strong; however, the government believes that the work of its many stakeholders has been hampered by the commercial focus of health care. The New Zealand government has admitted that they are slipping behind other developed countries even with improvements in health status. The Maori and Pacific peoples of New Zealand live in worse conditions than the general population when it comes to housing, nutrition, and access to clean water.

The combined goals must be the improvement in the health of our community, reduced disparities in health outcomes for all New Zealanders, including Maori and Pacific peoples, and the highest quality care for people who are sick or disabled, within the money available. – New Zealand Ministry of Health, 2000.

The NZHS aims to change the way the system works so that they can address these issues. The Commonwealth Government has set out to work collaboratively towards common goals giving the health sector incentives to work with other sectors, rather than by competing for the largest share of health dollars. "The combined goals must be the improvement in the health of our community, reduced disparities in health outcomes for all New Zealanders, including Maori and Pacific peoples, and the highest quality care for people who are sick or disabled, within the money available." 50

Through the use of the intersectoral work program, the New Zealand government has given priority to reducing social and economic disparities for all, including Maori and Pacific peoples, to make sure there is actual identifiable progress. According to the NZHS, the intersectoral approach is one that is in line with the

Maori Model of Health, the four cornerstones that contribute to Maori wellbeing. Policies and programs to reduce those inequalities, once they are identified, are developed by the Ministry of Health and the DHBs.

# **Maori Health Strategy**

The Maori Health Strategy (MHS) provides direction and guidance for the health sector in implementing the commitments in the NZPHDA. "As part of the New Zealand Health Strategy, DHBs will have to take the Maori Health Strategy into account when developing their strategic district plans and meeting their Maori health objectives and functions.

The NZHS has seven underlying principles. Of particular concern is the principle acknowledging the special relationship between the Crown and the Maori under the Treaty of Waitangi. This principle is to be incorporated into any health strategy across the health sector. "The nature of this relationship has been confirmed through interpretations of the Treaty of Waitangi, which stem from decisions of the Waitangi Tribunal, the Court of Appeal and the Privy Council."<sup>51</sup>

Central to this treaty relationship is the understanding that the Treaty of Waitangi principles will be adhered to and that Maori will have an important role in implementing Maori health strategies; the Crown and Maori will relate to each other in good faith, cooperation, and trust. This relationship also allows the Maori to define and develop their

own priorities for health so that they can develop the capacity for delivery of services to their communities. This also needs to be aligned with the Crown's responsibility to govern for the whole New Zealand population.

To date, the relationship between Maori and the Crown in the health and disability sector has been based on three key principles:

- participation at all levels;
- partnership in service delivery; and,
- protection and improvement of Maori health status.

With respect to reducing inequalities for Maori, the short to medium term objectives include:

- improving the quality and effectiveness of health promotion and education programs targeted at Maori;
- forming effective partnerships at all levels under the Treaty of Waitangi;
- enhancement of mainstream providers;
- increased Maori participation at all levels of the public health sector;
- improving an established matrix of relationships vertically and horizontally throughout the health sector;
- increased participation and involvement of Maori health providers across the health sector;
- improved mental health services to Maori, which take into account Maori healing;
- an increased number of Maori in the health workforce, particularly in mental health;
- promotion of smoking cessation programs; and,
- increased resources for Maori health providers delivering sexual and reproductive health services.

The already existing health gain areas will continue to be action areas as well for Maori:

- immunization;
- hearing;
- smoking cessation;
- diabetes:
- asthma;
- mental health;
- oral health; and,
- injury prevention.

There are also targets to improve Pacific peoples health:

- strengthening primary health initiatives for Pacific peoples;
- improving the health of Pacific children;
- improving mental health services for Pacific peoples;
- enhancing screening programs to improve the health of Pacific peoples; and,
- increasing the number of Pacific peoples in the health workforce.

In addition to priority population health objectives there are also service priorities. The sector must concentrate on and provide available funding to public health, primary health care, reducing wait times for public hospital elective services, improving the responsiveness of mental health services, and accessible and appropriate services for people living in rural areas.

To be able to improve the impact that public health can have on Maori people, there should be further development of Maori public health providers and organizations, development of the Pacific peoples health services, increase the delivery of health promotion programs in community and primary care settings, increase focus on health education, increase coordination with Territorial Local Authorities and other agencies that have a public health role, and improved access to public health protection services in rural areas, with a focus on clean water, sewage and housing. Maori and Pacific health have strong relationships with all five areas and the population health priorities.

#### Implementing the Maori Health Strategy: The Maori Public Health Action Plan

The *Maori Public Health Action Plan* (MPHAP) sets out what the government will do to implement the MHS, which has clear linkages to other Maori health strategies and plans ensures consistencies.

There is the expectation that the MOH, DHBs, and other agencies (the whole of the publicly funded health and disability sector) are responsible for improving Maori Health. As new issues arise over time, new areas for effort will be identified and incorporated into the agenda of other sector organizations.

The MHS is the overarching document and framework for Maori health where it provides guidance for the development of improved mainstream health and disability services. The MHS is also linked with the Maori Mental Health Strategic Framework, the Disability Action Plan, and the *Maori Public Health Action Plan* just as improved health outcomes and reducing inequalities are key objectives in government strategies such as the NZHS.

Working collaboratively with the MOH, DHBs and other agencies such as the Public Health Association are integral to improving and monitoring the outcomes of whanau, hapu, iwi and Maori communities and providers. The whole health sector is responsible for improving Maori health. Many of the objectives and projects of the MHS are built into the MOH work programs and DHB annual and strategic plans. The MOH, DHBs and other publicly funded health organizations have the following responsibilities regarding the implementation of the MHS and MPHAP:

# MOH:

- provide leadership and support to DHBs, providers and Maori organizations in advancing the strategy and to help coordinate activities;
- ensure other sectors collaborate to address wider issues affecting whanau health;
- lead in development projects;
- progressively update the strategy and action plans, advise the government on other ways to improve Maori health;
- manage DHB funding and performance;
- monitor implementation of the strategy and evaluate impact with iwi and Maori communities;
- advise government on ongoing strategic and operational policy development; and,
- lead in development projects.

DHBs have specific statutory responsibilities to:

- recognize and respect the principles of the Treaty of Waitangi;
- improve Maori health and reduce inequalities;
- involve Maori in their planning and decision-making;
- build Maori capacity to provide for their own needs;
- have Maori membership on the boards; and,
- ensure all board members are skilled and knowledgeable about Treaty of Waitangi and Maori health issues and local Maori communities.

DHBs, in the first year, had built the aims and pathways of the MHS into their planning and operations by establishing necessary capacity and processes to plan and fund services for Maori health improvement including: involving Maori in needs assessment, planning and prioritization, developing the skills and capacity of the DHB workforce (both Maori and non-Maori) improving ethnicity data collection, providing and funding high-quality services for population health improvement, taking over the administration of Maori provider contracts previously funded by the MOH, and leading implementation by incorporating the MPHAP throughout their business. It was expected that within two to three years, the DHBs were expected to realize the full potential of their relationships with iwi and Maori, and to demonstrate sustainable results in improved access to services and better health and disability outcomes for Maori and their whanau.

#### Other publicly funded agencies:

- National level funding organizations such as PHARMAC, the Health Research Council, the Health Sponsorship Council, and the Clinical Training Agency are all responsible for prioritizing their resources to improve Maori health and reduce disparities. The Clinical Training Agency (CTA) aims to facilitate the development of a professional health and disability workforce that can meet the future requirements of the health and disability services in New Zealand by purchasing post-entry clinical training with a budget of approximately \$85 million per year (includes training for Maori and Pacific health).
- Other institutions such as health professional colleges and councils, national bodies such as the National Heart Foundation, and NGOs including national, regional, and local-level providers receiving public funding all have critical roles implementing the MPHAP. It is expected that the MPHAP is to be included in their service agreements and monitoring arrangements.

All DHBs, the MOH, and other funders and providers are expected to allocate resources for Maori health within their funding allocations. Investments by these agencies are expected to reduce demand for some hospital and disability services, with a focus on prevention, while increasing demand for secondary and other referred services. Maori needs are built into the population-based funding formula that will be used to fund DHBs. DHBs are required to develop priorities using new available funding and by reallocating existing funding, where the spending on Maori health will be monitored. It was also expected that funding be increased to DHBs for developing the primary health care sector, where Maori health improvement must have priority. DHBs are also subject to regular reviews of how they use existing funding to evaluate the fairness and effectiveness of those allocations. DHBs are also required to fairly fund Maori services equivalent to that of New Zealand services.

# **Consultation Policy**

In adhering to their commitment to reducing health inequalities between Maori and other New Zealanders, the New Zealand government has devised a consultation policy that provides guidelines in establishing effective relationships with Maori communities and organizations to identify health needs, priorities, and strategic directions for service to improve the Maori health status. DHBs are the main entry point in achieving Maori health gains. There are four key factors, which provide the context to build and maintain effective relationships with Maori:

- the legislative framework: It is a legislative requirement (NZPHDA) that DHBs adhere to the Treaty of Waitangi and provide mechanisms to enable Maori to be a part of decision-making.
- health sector policy: While the government has a duty to govern on behalf of the total population, it also acknowledges that Maori should be able to define and provide for their own priorities. The NZHS, the NZDS, and the MHS all raise issues that are of relevance to DHBs and for Maori communities and groups: they must acknowledge the special relationship between Maori and the Crown and they must improve the health status of Maori.
- Treaty of Waitangi: DHBs must be aware of treaty and related policy principles that underpin their various functions and responsibilities as Crown entities.
- Maori Health Strategy. The MHS is based upon the relationship between Maori and the Crown and the hree treaty principles, which were articulated in the Royal Commission's Social Policy of 1988.

In addition to providing considerations for consultation with Maori communities and organizations (Ko Tatou), the MOH has produced a document that profiles formal DHB/Maori relationship models and indicative success factors (Whiringa). Most DHBs have responded to the legislated requirement by creating relationships and formal documents (including Memorandums of Understanding and/or Agreement) with Maori.<sup>52</sup>

# **United States**

# 1. Indigenous Demographics

According to the Institute of Medicine (IOM), today there are over 2 million self-identified American Indians and Alaska Natives (AI/AN) living in the U.S. The IOM states that while the majority live in Western states, only 38% actually reside on federal trust lands where the others reside primarily outside of reservation lands or in urban communities. Most AI/AN moved away from reservation lands in the 1950s because of poor economic conditions.

Health disparities have been persistent with AN/AI populations in the U.S. from the time of European contact continuing over 400 years. Early contact severely decimated and depopulated tribal populations with communicable diseases and warfare. According to research, health disparities have changed over time, but some diseases have had a continued impact on surviving tribes after they were removed from and resettled on federal reservations.

Today, there still exists a lack of information (evidence based) on disparities between AI/AN and all other races and the general American population, as well as information on the quality of health care that AI/AN receive. The IOM documents; however, that general information does exist on the health care disparities of AI/AN. Some factors that contribute to health care disparities in AI/AN populations include geographic, cultural, education, and financial barriers to adequate health care.

Educational barriers are underscored by the fact that AI/AN populations have fewer years of education and are three times more likely to live in poverty and be uninsured than the general population. Only one in three AI/AN had private health insurance, compared with 80% for Americans, 52% for African Americans, and 50% for Hispanics. Many of those AI/AN that reported they were uninsured identified that they depended solely on the Indian Health Service (IHS) for their health care.

AI and AN populations are classified as people having origins in any of the original peoples of North and South America (including Central America), and who maintain tribal affiliation or community attachment.<sup>53</sup> Those who identify as AI or AN as "race alone" make up 0.9% of the total U.S. population, or approximately 2.5 million people. However, the 2000 U.S. Census (U.S. Census Bureau) which the total AI and AN population is estimated at 4.1 million or 1.5% of the total U.S. population (281.4 million). Hence, 1.6 million individuals account for those who identified as AI/AN as well as one or more other races.

Because the minority AI/AN population is estimated to grow in proportion to the U.S. population, the Department of Health and Human Services (DHHS) and the Center for Disease Control and Prevention (CDC) have taken up many initiatives to improve the health of AI/AN by having a national focus on disparities in health status.

AI/AN males have a life expectancy rate 7.8 years less than that of American males; AI/AN females 5.8 years less than that of American females. AI/AN populations have an infant death rate two times greater than the American

There are many suspected and known reasons why the AI and AN populations have the poorest health among other groups: geographic isolation, economic factors, suspicion towards traditional spiritual beliefs, cultural barriers, and inadequate sewage disposal among others.

population, with the infant mortality rate being 7.2 per 1000 live births. AI/AN have a diabetes rate almost two times greater, and have disproportionately high death rates from unintentional injuries and suicide. "American Indians/Alaska Natives exhibited lower age-adjusted death rates than Americans for most causes of death; exceptions were suicide, diabetes, HIV, and homicide." 54

The smoking rate of AI/AN is 36% higher than that among Americans. When compared to the Indigenous populations of New Zealand, "[t]he highest prevalence of obesity was found among Americans, with 44% and 57% of male and female American Indians/ Alaska Natives, respectively, being obese." The diabetes prevalence rate was also higher for AI/AN populations (15.3%); and almost three times higher than the American population.

The top ten leading causes of death in the AI/AN population are heart disease, cancer, unintentional injuries, diabetes, stroke, chronic liver disease and cirrhosis, chronic lower respiratory disease, suicide, influenza and pneumonia, and homicide. In addition, AI/AN suffer from a disproportionately high prevalence of mental health issues, obesity, substance abuse and Sudden Infant Death Syndrome.

There are many suspected and known reasons why the AI and AN populations have the poorest health among other groups: geographic isolation, economic factors, suspicion towards traditional spiritual beliefs, cultural barriers, and inadequate sewage disposal among others.

# 2. Structure of Health Services Delivery and Public Health

DHHS is the U.S. government's principal agency for protecting the health of all Americans. The Department has more than 300 programs and services ranging from Medicare (health insurance for elderly and disabled Americans) and Medicaid (health insurance for low income people) to disease prevention, immunization services, health and social science research, health information technology, preschool education and services, improving maternal and infant health, and comprehensive health services for Native Americans.

DHHS administers more grant dollars then any other federal agency. Medicare is the nation's largest health insurer and Medicare and Medicaid together provide insurance for one in four Americans. Many DHHS funded services are provided at the state and local level by state or county agencies and private sector grantees.

Eleven operating divisions administer DHHS programs. Eight of those operating divisions are agencies of the U.S. Public Health Service and three are human service divisions. For a description of the organization of those services see Appendix 1 and 2.

Public health is delivered by each State through the DHHS. Each State has a Director for Public Health Services and the State is divided into counties, each of whom is responsible for the delivery of public health services. AI/AN have their health services delivered by the federal government through IHS. Another key partner in health care for both AI/AN and Americans, in general, is the US CDC.

The US CDC has an international reputation for excellence in public health. Over 2,000 of the approximately 8,600 full-time equivalent employees work outside the CDC headquarters in Atlanta; this includes postings to 47 state health departments.

Although it is best known for investigating disease outbreaks, the CDC is actually a broad public health agency; and much of its budget is directed to an extensive system of federal grants and transfers to states and municipalities in support of public health infrastructure. The CDC works with states to set and monitor standards. It oversees a national health alert and surveillance system, a national workforce development and continuing education initiative for public health practitioners and related laboratory personnel, and a public health information network. The CDC's National Public Health Laboratory System develops policies and public-private partnerships for improved and timely reporting of laboratory results.

As a matter of policy, CDC generally requests state health department authorization to conduct activities within their borders. CDC requests this authorization whether the activity involves one state or several, whether CDC staff presence is actual or "virtual", and whether the invitation to participate comes from within the state or from an outside agency or organization. This policy is based upon the Constitutional relationship between the federal and state governments. While states are reserved the 'police powers,' i.e., the authority of all state governments to enact laws and promote regulations to safeguard the health, safety, and welfare of its citizens within its borders, the federal government retains authority to regulate matters of interstate commerce.<sup>58</sup>

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U.S. essential public health services were identified in 1994. They have had several positive impacts:

- giving the public health community a clear and consistent phrasing of the functions of public health;
- facilitating identification of public health roles relative to other players in the system;
- improved accountability of the system;
- framework for assessing whether the public health system is fulfilling the functions (i.e.; performance assessment);
- framework for expenditure assessment of public health system;
- framework for organizing, assessing and developing public health core staff competencies; and,
- potential framework for new/revised public health legislation.

Healthy People 2010 has been the nation's health promotion and disease prevention agenda for the last twenty years; it is designed in such a way that it is simple and easy for diverse groups to combine their efforts and create teams to meet health objectives. Healthy People 2010 is designed to meet two overarching goals:

- increase quality and years of healthy life; and,
- eliminate health disparities.

The second goal relates to eliminating health disparities among segments of the population including differences that occur by gender, race or ethnicity, education or income, disability, geographic location, or sexual orientation. Out of the 28 *Healthy People 2010* focus areas the CDC and the Agency for Toxic Substances and Disease Registry (CDC/ATSDR) have co-lead responsibility for 18 of those focus areas, including all six areas identified in a DHHS initiative to eliminate health disparities. Focus area number 23 of *Healthy People 2010* is to ensure that federal, tribal, state, and local health agencies have the infrastructure to provide essential public health services effectively.

The DHHS and the CDC established separate Offices of Minority Health (OMH), in 1985 and 1988 respectively, in response to the *Report of the Secretary's Task Force on Black and Minority Health*, which identified large gaps in the health status of different racial and ethnic peoples in America. Subsequently, the U.S. Congress passed the *Disadvantaged Minority Health Act of 1990* to improve the health status of under-served populations. However, substantial disparities continued to exist.

Today, the OMH works collaboratively with state, tribal, and local governments to improve the health status of America's racial and ethnic minorities.

The CDC has cooperative agreements with 33 of the 569 tribes to address issues such as cancer screening, tobacco use, and HIV within these communities. CDC is also attempting to establish dialogue with all tribes by establishing a CDC Tribal Consultation Policy. The Office of Minority Health held open consultations with tribal leaders in the U.S. in 2002.

"CDC embraces the concept that consultation is 'an enhanced form of communication which emphasizes trust, respect and shared responsibility," and "[c]onsultation is integral to a deliberative process which results in effective collaboration and informed decision-making." "True consultation is not agencies telling indigenous [sic] peoples what they think is best for them. Instead, the CDC must encourage tribal collaboration from the ground up." "60"

There are 11 operating divisions within the DHHS who have a responsibility to "coordinate, communicate, and consult" with tribal governments on issues that will affect them. It is the DHHS policy that all 11 operating divisions have their own tribal consultation policies in place.

# CDC/ATSDR Minority Initiatives Coordinating Committee (CAMICC)

CAMICC coordinates all the DHHS departmental minority health initiatives within CDC/ATSDR, including activities which target all racial and ethnic groups. CAMICC meets monthly to discuss progress in implementing the plans. The committee is comprised of representatives from CDC Centers, Institute, and Offices (CIOs) and ATSDR.

#### Health Resources and Services Administration (HRSA)

HRSA directs programs that improve the nation's health by expanding access to comprehensive, quality health care for all Americans.

# Department of Health and Human Services (DHHS) Office of Minority Health (OMH)

HHS OMH develops effective health policies and programs that help eliminate racial and ethnic disparities in health. In addition to maintaining the Minority Health Resource Center, DHHS OMH advises the secretary and the Office of Public Health and Science (OPHS) on public health issues affecting minority populations.

#### Indian Health Service (IHS)

IHS was established in 1955 by the federal government to address the health needs of AI/AN peoples, including medical, dental, and preventive health services. OMH works with IHS on a variety of projects relevant to Indian tribal health. These projects include:

- 1. IHS Area Offices and Facilities;
- 2. Baseline Measures Workgroup;
- 3. Public Health Support Workgroup;
- 4. Tribal Epidemiology Centers; and,
- 5. National Epidemiology Program.

Those tribes who are federally recognized and to whom the IHS provide health services have a special relationship with the federal government, a government-to-government relationship, where tribes exist as sovereign entities and are

The federal responsibility for American Indian/Alaska Native (AI/AN) health care is grounded in treaty obligations, case laws, the Snyder Act of 1921 (P.L. 83-568), the Indian Health Care Improvement Act (P. L. 94-437), as well as historical obligations for the health of AI/AN people.-IHS, Baseline Measures Workgroup Report, 1996

recognized as such by the federal government. The establishment of the IHS is seen as congruent with the federal government's responsibility to regulate commerce with AI nations as provided in the Constitution. The IHS operates a series of inpatient and ambulatory care facilities across the U.S. and Alaska, where AI/AN tribes and organizations now manage many facilities, as noted previously.

The IHS provides health care directly by subsidizing health care services via contracts with private providers and for other specialized services not provided by the IHS direct care facilities via Contract Health Services. Today, the IHS has a user population of 1.51 million, where the users of the services are primarily young (median age of 24.2) compared with the general American population (32.9). While the IHS user population is young, those experiencing higher mortality from diseases are older. For example, the IOM indicates the two leading causes of death for AI/AN are heart diseases and cancer for women, and heart diseases and accidents for men.

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One of the barriers preventing access to care is transportation and the long distances needed to be traveled to access medical providers. In addition, there are limitations to IHS sponsored services. In contrast to other health programs like Medicare and Medicaid, the IHS is not an entitlement program - IHS funds are acquired from annual appropriations of the U.S. Congress. Essentially, this means that there are no additional annual funds available to the IHS even if the service is needed. Secondly, IHS services are not distributed evenly across the 12 Regional Areas. Previously, the resource allocation method was based on historical funding patterns where there has now been a new model introduced based on need to achieve greater parity in funding across IHS services. Contract Health Services is also severely under funded and access to care provided by these providers may be delayed or denied if the funding is not available. The IHS has had to look to other health care organizations for health services because of these resource limitations. This can include contracting with private health care organizations such as health maintenance organizations (HMOs) to provide health service delivery to IHS recipients in a given area.

Thus, some IHS users are forced to obtain private insurance in addition to their publicly funded health services. By law, the IHS is only considered to be a "residual" provider of health services, where it provides services that are not available by other providers. However, many of the IHS users depend solely on the IHS for their primary care, and because of low-income or location, many AI populations experience lower access to non-IHS services. According to the Henry J. Kaiser Foundation, AI/AN receiving federal IHS or tribal health services are three times as more likely to experience poverty than all other Americans. Furthermore, the Supreme Court has ruled that special programs for AI/AN are not racially based, but based upon a unique political relationship between the Indian tribes and the federal government.

Since federal funding for Indian health programs is discretionary, there has been no consistent long-term planning for Indian health care improvement; instead, resources for health care improvement have been allocated on a piecemeal approach. The *Snyder Act*, 1921, recognized the need for ongoing federal support for Indian health care, yet the wording of the act remains vague: provisions provide for ".relief of distress and conservation of health and for employment of physicians."

The *Indian Health Improvement Act of 1976* was considered the second milestone, after the *Snyder Act* of 1921, in addressing AI/AN health care disparities. The statute was based on two principles: 1) since the federal government has a unique, historical, and legal relationship with the Indians, it are required to provide federal health services to maintain and improve the health of Indians, 2) a major national goal of the U.S. is to provide the quantity and quality of health care services which would permit the health status of Indians to be raised to the highest level possible and to encourage the maximum participation of the Indians in the planning and managing of those services. The Act also provided funding in: 1) improving health services, 2) improving the health infrastructure, 3) providing more scholarships for the training of AI/AN healthcare providers, 4) allowing for Medicare and Medicaid reimbursements to IHS or to tribal health programs, 5) formally recognizing the health care needs of tribal members living away from reservations or in urban areas.

The health care system for AI/AN is seen to be very complex. The IHS has had to respond to dramatic changes taking place inside and outside the government including budget reductions, greater involvement of AI and AN governments in the health care system, and technological innovations. Issues facing the IHS continue to be the same as twenty years ago: an increasing number of beneficiaries requiring health services; demand for all health services; costs for health care, goods and staff; numbers of elderly increasing; and increasing mandates for cost containment.<sup>63</sup>

The IHS has also seen a change in patterns of disease with a shift to more chronic conditions affecting the social and economic health of AI and AN. These pressures have been intensified by intense budget reductions and the transfer of many federal programs and resources for AI/AN to individual states, decreases to discretionary programs in the federal budget, and the overall erosion of resources. States do not necessarily take into account the needs of the Indian populations when developing their programs; however, States will count Indians as part of their population base for revenue generation, similar to Canada's health and social transfers. Thus, it is increasingly important for tribes and Indian organizations to be included in discussions about health care at the State and federal levels.

#### **Twelve Area Offices**

These are the basic health organizations for a geographic area served by the IHS program (similar to a how a county or city health department is the basic organization in a state health department). Depending on the size of the reservation, there are few or many service units representing reservations.

Service units are grouped into larger cultural-demographic-geographic management jurisdictions administered by Area Offices.

The federal government attempts to meet its commitment to provide health care for AI/ANs through a system of hospitals and clinics on or near reservations, managed by the IHS and, more recently, by Indian tribes. IHS facilities provide primary care services free of charge, and limited free specialty services are available through contracts with private providers. However, services available through the IHS vary widely across tribes, and IHS hospitals are not available in all service areas. Many communities have small clinics and must contract out for all specialty care, x-ray services, and other diagnostic tests and routine preventive care such as mammograms. Services can vary and may be limited by significant shortfalls in funding.<sup>61</sup>

# **Indian Health Boards**

The changing nature of the U.S. health system had prompted new ideas for changing AI/AN health delivery. For tribal, urban and IHS programs, collections from third party payers like Medicaid, Medicare, and private insurance programs will be the only new revenue sources for AI/AN programs. "New ideas in delivery methods and funding sources are now a necessity. To meet this challenge, tribal governments can opt to exercise their sovereign rights in three ways: through P.L. 93-638 (Title I) contracts, P.L. 93-638 (Title III) compacts, or by retaining federally operated health programs."<sup>60</sup>

Indian Health Boards (national, local, and regional) bring medical and public health services to AI/AN populations. They are vital to implementing federal programs among native peoples in reservations and elsewhere. The National Indian Health Board (NIHB) advocates on behalf of all tribal governments and AI/AN (all 558 federally recognized tribes) in their efforts to provide quality health care. Since 1972, the NIHB has advised Congress, IHS federal agencies, and private foundations on health care issues.

NIHB represents tribal governments that operate their own health care delivery systems through contracting and compacting, as well as those receiving health care directly from the IHS. The NIHB, a non-profit organization, conducts research, policy analysis, program assessment and development, national and regional meeting planning, training and technical assistance programs, and project management. These services are provided to tribes, Area Health Boards, tribal organizations, federal agencies, and private foundations. The NIHB presents the tribal perspective while monitoring federal legislation and opens opportunities to network with other national health care organizations to engage their support on Indian health care issues.<sup>59</sup>

Because NIHB represents all federally recognized tribes, there is a need for the work of the NIHB to "reflect the unity and diversity of tribal values and opinions in an accurate, fair, and culturally-sensitive manner." This is accomplished through the NIHB Board of Directors and Area Health Boards. There are also various regional and local health boards. There are also various regional and local health boards.

The Board of Directors consists of representatives from each of the twelve IHS Areas. Each Area Health Board elects a representative and an alternate to sit on the NIHB Board of Directors. In areas where there is no Area Health Board, tribal governments choose a representative.<sup>60</sup>

#### **Baseline Measures Workgroup**

Subsequently, to deal with increasing complexity of the IHS and scarce resources, a Baseline Measures Workgroup (BMW) was created to justify national funding, monitor the performance of the health program and provide direction for change in the health care program over time. The BMW is composed of IHS employees, compacting tribes, contracting tribes, and tribes with federally operated health care systems.

It should be noted, however, that the recommendations of the BMW are neither binding nor regulatory; they are essentially guidelines for community based primary care models that integrate public and personal health. The database created from the BMW is essential in providing information needed to set national policy directions and make funding decisions. Participation in the database is optional, but strongly encouraged to preserve recognition of AI/AN at the federal level.

#### The BMW has the responsibility to:

- define the public health responsibility of the IHS under self-governance. (IHS public health responsibilities are not residual, thus, this initiative should begin and remain at the tribal (local) level. Also the BMW recommends that public health functions be viewed in three major categories: assessment, policy development, and assurance). These are directly related to the *Healthy People 2010* objectives.
- develop a process to identify, test and disseminate a set of health status indicators that are to be used to monitor the performance of Self-Governance Tribes. (Existing resource documents were used to devise a recommended set of standards. To be able to incorporate a wholistic approach to health programs in addition to traditional health status indicators, the BMW developed 6 categories of measures that are applicable to all health care systems: (1) health promotion, (2) health protection, (3) preventive services, (4) access, (5) resource management and utilization, and (6) strategies for the community's health.
- define the relationship between the IHS data reporting requirements, in particular, the core data set requirements and the responsibilities of Tribes participating in a Self-Governance Demonstration Project (SGDP).

#### **Public Health Support WorkGroup**

In order for the IHS to fulfill its residual function as providing essential public health services, it developed an integrated public health framework, provided by the Public Health Support Workgroup (PHSWG) of the IHS. The

Executive Leadership Group of the IHS established the PHSWG in July of 1998. "The [PHSWG] defines the core public health functions and essential public health services that are relevant for all local, regional, and national service levels, functions which are necessary for continued improvement in the health status of Indian people and communities."

# **Tribal Epidemiology Centers**

Tribal Epidemiology Centers "are a critical element of the CDC/ IHS partnership to improve the health and well-being of AI/AN populations. Activities include surveillance for disease conditions, epidemiological analysis, interpretation, and dissemination of surveillance data, investigation of disease outbreaks, development and implementation of epidemiological studies, development and implementation of disease control and prevention programs, and coordination of activities with other public health authorities in the region." There are six centers: NorthWest Tribal Center, Alaska Native Center, the Great Lakes Inter-Tribal Center, the Inter-Tribal Council of Arizona Center, the United South and Eastern Tribes Center, and the Urban Indian Tribal Center.

Tribal Epicentres are linked to the Baseline Measures Workgroup initiative. The Great Lakes Inter-Tribal Council of Wisconsin and the Inter-Tribal Council of Michigan participate in a Cooperative Agreement Epidemiology Project. "The Epi-Centers developed tribal-specific community health profiles based on health indicators by making use of the IHS's baseline measures, a needs assessment, and *Healthy People 2000*. Data in the community health profiles serve as baseline measures and descriptions of changing health status for the Tribes in the project service area." 63

# The IHS National Epidemiology Program

The National Epidemiology Program encompasses the following public health goals:

- prevention of epidemics and the spread of disease;
- protection against environmental hazards;
- prevention of injuries;
- promotion and encouragement of health behaviors;
- responding to disasters & assisting communities in recovery; and,
- assuring the quality and accessibility of health services.

The objectives of the National Epidemiology Program of the IHS are to describe causes of morbidity and mortality, identify risk factors for disease, and prevent and control disease. Services available by this program include: data management and reporting, community surveys, emergency response, surveillance, liaison, training, and consultation to clinicians. Most services are at no cost and applied epidemiological research and policy development are also available.

#### **National Council on Urban Indian Health (NCUIH)**

NCUIH serves as the national voice for AI/AN living away from reservations. NCUIH According to NCUIH, approximately 60% of AI/AN live away from reservations, with 53% of those living in urban centers of cities. Urban Indian Health Programs have been established in eight regions reaching 19 states.

The IHS Urban Indian Health Program supports contracts and grants to 34 urban health programs funded under Title V of the *Indian Health Care Improvement Act*. Approximately 100,000 American Indians use 23 Title V Urban Indian health programs and are not able to access hospitals, health clinics, or contract health services administered

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by IHS and tribal health programs because they either do not meet IHS eligibility criteria or reside outside of IHS and tribal service areas. Another 49,000 AI/AN use 11 Title V programs in cities that are located in IHS or tribal service delivery areas.

#### U.S. Census Bureau

The U.S. Census is required by law to collect data on race and ethnicity to satisfy legislative and program requirements. According to the U.S. Census Bureau, data on race are used in the legislative redistricting process carried out by states in monitoring local jurisdictions' compliance with the *Voting Rights Act*, for evaluating federal programs that promote equal access to employment, education, and housing, and for assessing racial disparities in health and exposure to environmental risks. Public and private organizations also use the race information to develop special programs and services in those areas where they are in high need in the areas of education, housing, and health.

#### Australia

# 1. Indigenous Demographics

Whereas the Canadian, New Zealand, and U.S. governments have signed treaties with Indigenous peoples, there have been no formal treaties signed between the Aboriginal and Torres Strait Islander (ATSI) peoples and the Australian Commonwealth. The common law principle of terra nullius has been applied to the relationship between the Aboriginal and non-Aboriginal peoples of Australia. The absence of any treaty is said to be the cause of ill health and social disadvantage of Indigenous peoples in Australia.

A public health report card on the health of Aboriginal and Torres Strait Islander peoples documents that there have been few gains attained compared with the Australian general population.

Infant Mortality was 14/1000 live births for Indigenous populations and 5.2/1000 live births for the general Australian population (close to three times less). Infant mortality for Indigenous populations has considerably decreased since 1965, but only through gradual improvement. Indigenous Australians are two times more likely to have a low birth weight baby (less than 2,500 grams). Between 1997 and 1999, Indigenous life expectancy was 20 years less than for the Australian population. Median age of death for Indigenous females and males was 58 and 49 respectively in 2000, compared to the general population at 82 and 76 for men. Hospital admissions for Indigenous Australians are two times higher than for the general population and Indigenous people experience a higher burden of disease and illness resulting in higher hospitalization rates: diabetes rates are three times higher, respiratory deaths four times higher, and circulatory conditions almost three times higher than the rates of the general population.

#### 2. Structure of Health Services Delivery and Public Health

Australia is a federation, comprised of six states and two territories: the Northern Territory and the Australian Capital Territory (ACT). Australia is a large, sparsely populated continent which is comparable in size to the U.S. but has a population of only 18-20 million, in which about 460,000 are Indigenous Australians (2%).<sup>64</sup> The majority of people live in coastal urban settings and enjoy a high standard of living. According to the Australian government, public health activities are both numerous and advanced in Australia. Australia spends approximately 8-9% (\$30 billion) of their Gross Domestic Product annually on health.<sup>64</sup>

When the Australian government was first established in 1901 it had very little involvement in public health, with the exception of quarantine. The Australian government consisted of a large governmental sector with states taking major responsibility for health services through a network of public hospitals. The health sector was mainly private until a 1946 amendment to the Constitution and the *National Health Act*. Australia now has a publicly funded health system very similar to that of Canada's, where Medicare is the national health insurance program.

Australia's public health activities did not start until the 1980s, when it responded to the World Health Organization's *Health for All By the Year 2000* agenda. The Australian Institute for Health and Welfare (AIHW) and the National Health and Medical Research Council (NHMRC) advocated for a statutory base for public health activities and federal responsibility. In addition, the *Kerr White Report* and the *Better Health Commission* of 1985 began investigating into issues of public health.

The culmination of a National Public Health Partnership (NPHP) emphasized the shift away from programs directed at specific diseases towards a "whole of system" approach to public health. It emphasizes the importance of a coordinated public health system and is the first national health effort that clarifies the roles and responsibilities of the Australian government and the states and territories as the principal partners.

In Australia, the federal government pays for half of public health services: 30% via direct expenditures and 22% via transfers to states and territories. The NPHP has clear priorities where separate workgroups are charged with issues such as: improving public health practice; developing public health information systems; reviewing and harmonizing public health legislation; implementing public health workforce initiatives; strengthening national public health research and development capacity; enhancing coordination of national public health strategies; and developing standards for the delivery of core public health strategies. The NPHP reports to the Australian Health Minister's Advisory Council.

Federal transfers occur through Public Health Outcome Funding Agreements that have targets and reporting requirements. A national program for public health education and research funds Australian tertiary institutions to strengthen post-graduate education and training.

Each party within the partnership must adhere to principles within a Memorandum of Understanding.<sup>65</sup>

- Each community or population sub-group should have access to strategies, services and activities and to a healthy and safe environment including clean air and water, and adequate food and housing.
- Public health efforts must proceed in partnership with public health sectors, non-health sectors and in collaboration with international partners to optimize population health outcomes.
- A supportive legal and political environment is integral to the public health effort.
- Priority-setting and decision-making should be based on scientific evidence as far as possible, on
  optimum capacity to scan and monitor health determinants, and on criteria that are open to public scrutiny
  and debate.

In Australia, federal and state public health activities include:

- health protection;
- illness prevention;
- health promotion; and,
- infrastructure development.

Local government plays the main role in service delivery, having a central role in public health surveillance and action. Activities are usually carried out by multidisciplinary teams with highly specialized expertise with the cooperation of national agencies.

Australia, as a federal state, is very similar to Canada. According to Indian and Northern Affairs Canada, the Commonwealth government of Australia, and their states and territories, have roughly the same powers as the Canadian provinces. Like Canada, the states deliver health care and education but depend on financial assistance from the Commonwealth or federal government. The Australian Commonwealth distributes conditional and unconditional grants to the states and territories and local governments: general purpose grants to the states, specific purpose transfers to state and local governments, and additional monies transferred directly to local governments.

Australia has a very similar equalization program to that of Canada, but it differs in some aspects. In addition to securing financial capacity of the states to provide uniform services to populations, the Australian government "measures differential service costs as well as revenue capacity and tax effort" in the calculation of state entitlements. States with relatively high Aboriginal populations receive relatively higher equalization grants to service Aboriginal peoples living in remote locations; however, there are no conditions mandating that the monies be spent on those populations. There is no way to measure that those funds are addressing the Aboriginal needs.

Independent Commissions, Commonwealth Grants Commissions and Local Government Grants Commissions, are charged with overseeing the entire state and local grant transfer system, which determine the amount of monies distributed among governments, where the terms of reference are set by the governments themselves. INAC indicates that "government-like" bodies are emerging in Aboriginal communities which provide services to Aboriginal peoples as either contractors to government or to supplement government services. These government-like bodies receive funding from grants-in-lieu of resource revenues, property taxes, and fees for access to land. These bodies also receive federal funding, which are administered by the Aboriginal and Torres Strait Islander Commission (ATSIC), considered a Commonwealth body. Some Aboriginal communities are considered local governments and have access to the same support as non-Aboriginal local governments.

#### **Federal Government Role**

The federal government provides the national regulatory framework for public health. The Public Health Division (Department of Health and Family Services) and the Office of Aboriginal and Torres Strait Islander Health (OATSIH) perform public health work. The National Health and Medical Research Council, Australian Institute of Health and Welfare, and the Health Insurance Commission carry out legislation and other functions. The federal government also adheres to the World Health Organization's international treaty obligations.

#### Core functions include:

- developing national public health policy;
- facilitating planning, monitoring, reporting, research, training and evaluation of public health activities;
- ensuring national consistency in policy standards, legislation and regulation, workforce competencies, environmental protection, disease prevention and outbreak control methods;
- fostering/financing new population health programs;

- conducting national programs in public health;
- maintaining a population health constituency with key players and with the public; and,
- adhering to Australia's international obligations in consultation with other partners.

#### **State and Territory Governments**

Under various health acts, they have the following core public health functions:

- identify public health issues via epidemiological surveillance;
- intervention and health outcomes;
- develop policy related to communicable diseases, environmental health, immunization, food, radiation safety, workplace risk, water quality, drugs and poisons, and emergency management;
- organize preventative and early detection programs;
- support population health literacy and health promotion behavior;
- develop new strategies for new health problems;
- enable government to act quickly in public health emergencies; and,
- monitor the effectiveness of, and collaborate with, all government and non-government public health sectors and relevant authorities to address public health issues, and provide for an appropriately skilled public health workforce.

Goals have recently been developed in four categories that are consistent with national health priority areas and which focus on chronic disease burden reduction. The four priority categories are:

- preventable mortality and morbidity;
- healthy lifestyles and risk factors;
- health literacy and health skills; and
- healthy environments.

#### 3. Review of major relevant documents

Because the Aboriginal peoples of Australia have no formal treaty relationship with the Commonwealth, they have no special rights or status, but nevertheless base their political and economic aspirations on making claims to Aboriginal title. The Mabo and Wik decisions and the *Native Title Act* provide the context within which claims to land are reconciled between the ATSI peoples and the Commonwealth government. In addition, a Council for Aboriginal Reconciliation was established to bring about a national reconciliation with Aboriginals.

There has been recognition, by the Australian government, of disparities in the level of services to Aboriginal Australians reported in the *National Commitment to Improved Outcomes in the Delivery of Programs and Services for Aboriginal People and Torres Strait Islanders* (National Commitment). In this report, specific areas of disparity are identified and it is iterated that all three levels of government take initiative to address them.

In 1991, the Commonwealth officially transferred program responsibilities for Aboriginal peoples from the Department of Aboriginal Affairs to the newly founded Aboriginal and Torres Strait Islander Commission (ATSIC) as a result of its delivery mechanisms being inappropriate for Aboriginals.

In February 2002, the Australian NPHP published "Approaches and Recommendations pertaining to Guidelines for the development, implementation, and evaluation of the National Public Health Strategies in relation to the Aboriginal and Torres Strait Islander (ATSI) people." The project was undertaken in three phases: 1) compilation of the literature to reveal contextual factors and issues; 2) comprehensive consultation process (semi-structured interviews with over 200 people, mainly service providers from all state and territory government health services and the Aboriginal Community Controlled Health Service sector); 3) Synthesis of findings and development of recommendations guided by a National Strategies Coordination Working Group of the NPHP (representative of Commonwealth and state health departments and the National Aboriginal Community Controlled Health Organization, chaired by Associate Professor Ian Anderson, Director, VicHealth Koori Health Research and Community Health Development Unit, University of Melbourne).

The NPHP identified the negative and positive aspects of implementing a national public health strategy with regard to Aboriginal health. While a national strategy had the positive aspects of being a regulating power necessary to forge strategies targeting specific health problems and has the ability to give out necessary resources and promote inter-sectoral collaboration, it also lacks real political commitment, has insufficient resources committed, and has implemented fragmented, short-term programs.

Apparently, the absence of ATSI health issues on the agenda has been due, in part, from a lack of available health data and political leverage. Other problems include not having the proper primary care network available (limited in coverage and severely under-resourced) to support the implementation of public health strategies. The NPHP recommends the use of regional ATSI health plans.

#### Mainstream, Specific, or Both?

In Australia, there is considered to be a "dissonance" between ATSI concepts of health and the nature of public health policy, where ATSI concepts tend to be more comprehensive and wholistic and focused on community health, and public health policy concepts tend to be more individualistic and focused on personal health. There has been a failure to improve the health of ATSI peoples and the cause is said to be the dissonant nature of the health system in Australia and its health initiatives.

The NPHP investigated possible strategies to address the dissonance between mainstream and Indigenous community concepts. Taking an Indigenous specific approach makes clearer claims for the ATSI health needs and allows for greater consultation and inclusion. On the other hand, the mainstream approach can have a tendency to mesh Indigenous issues in with the issues of other groups which may result in Indigenous issues being overlooked. As a result, if an Indigenous strategy is to be aligned alongside the mainstream approach, Indigenous issues must be given due priority and commitment through consistent funding.

The third approach incorporates the best of both the Indigenous specific and mainstream strategies. The strategy could produce Indigenous specific strategies that are structured as "companion" strategies to mainstream public health strategies. Apparently, this approach was widely accepted in the NPHP consultations.

Three recommendations were given by the NPHP to resolve this incongruence between health policy and ATSI health concepts. Any framework to resolve Aboriginal health issues should:

- project a broad view of health with both individual and community dimensions, influenced by social, cultural and economic factors as well as health services;
- provide a structure for integrated, long term commitments that link national strategies with targeted public health programs; and,
- deliver the critical mass of funding required to implement and sustain these programs through the provision of adequate service delivery infrastructure and resources.

#### Other Events in Aboriginal and Torres Strait Islander Health Policy and Strategy

In 2003 and 2004, other events and strategies aimed to develop ATSI health. These include the:

- National Strategic Framework in Aboriginal and Torres Strait Islander Health;
- National Strategic Framework for Aboriginal and Torres Strait Islander Peoples Mental Health and Social and Emotional Well Being 2004–2009;
- National Aboriginal and Torres Strait Islander Health Performance Framework;
- roll-out of the Primary Health Care Access Program; and,
- National Aboriginal and Torres Strait Islander Social Survey and the National Indigenous Health Survey.

The *National Aboriginal Health Strategy*, 1989, and the corresponding *National Strategic Framework for Torres Strait Islander Health* have been the guiding documents in the field of ATSI health on the national level. The national strategy relating to Aboriginal health in Australia has focused on health sector reform and development of intersectoral strategies to improve health outcomes for Indigenous peoples.

The key mechanisms implemented with the national strategy include: <sup>66</sup>

- Framework Agreements in Aboriginal and Torres Strait Islander Health (multi-party agreements between the Australian government; state and territory governments; the Aboriginal and Torres Strait Islander Commission and the Aboriginal community controlled health sector);
- Joint Planning Forums (established at a jurisdictional level with responsibility for the developing state and regional Aboriginal and Torres Strait Islander health plans).

Since 1995, the health portfolio has assumed responsibility for Indigenous health government programs, which was previously the responsibility of the Aboriginal and Torres Strait Islander Commission (ATSIC). Under the new administration, new mechanisms were put in place to ".provide a platform for collaborative, intergovernmental planning, engaging with both the Aboriginal community sector and the non-health sectors of government." 66

Post 1995, ATSI health reform has focused on:

• the capacity of primary health services to respond to Aboriginal and Torres Strait Islander health needs (with a particular focus on financing and workforce);

- disease and risk strategies that aimed to improve Aboriginal and Torres Strait Islander health outcomes;
   and,
- the evidence base for policy and practice in this sector (through strategic research and improvements in the quality of health and related data).

In 2004, the Australian government proposed a new framework for Indigenous governance and program delivery. As a result of structural problems with the previous governance and delivery system, a new framework was developed and announced by the Australian government in April of 2004. The government announced it would abolish ATSIC, the National Board of Commissioners, Regional Councils, and ASTIS. In their place, the government would embark on a new governance structure with new arrangements for the administration of Indigenous affairs.

The new arrangements were to restructure the machinery of government and introduce new structures that would operate in a whole-of-government manner. This new structure would involve:

the transfer of Indigenous-specific programs to mainstream government departments and agencies, improved accountability for mainstream programs and services, the establishment of the Ministerial Task Force on Indigenous Affairs, the establishment of the Secretaries Group on Indigenous Affairs, the establishment of the National Indigenous Council, the creation of an Office of Indigenous Policy Coordination, movement to a single budget submission for Indigenous affairs, the creation of Regional Indigenous Coordination Centers, the negotiation of agreements with Indigenous peoples at a regional and community level, support for Regional Indigenous representative structures, a focus on implementing the commitments of the Council of Australian Governments, and impact of changes on Torres Strait Islander people.

In contrast to the new arrangements, the National Strategic Framework is supposed to be a policy guide for Indigenous health until 2013. "It is a guide for local, regional and state/territory planning by health sector planning forums established under the Framework Agreements for Aboriginal and Torres Strait Islander Health in each state and territory."<sup>67</sup> The original partners of the planning process include the Commonwealth (Office of Aboriginal and Torres Strait Islander Health), the state/territory (the relevant department of Health), the state/territory affiliate of the National Aboriginal Community Controlled Health Organization (NACCHO), and ATSIC. NACCHO has concerns that abolishing ASTIC will remove the Aboriginal representative voice from planning forums, thus reducing those bodies to a minority position. NACCHO advocates that Framework Agreements they have put in place are supposed to address "buck-passing" between the Commonwealth and the states. Once ATSIC is replaced, there will be no formal mechanism for ensuring ATSI participation at the national level. Thus, NACCHO had recommended that a National Health Partnership Agreement be created to establish a place at the table for Indigenous representation and planning. The OIPC was supposed to be the mechanism to replace ATSIC.

# The National Strategic Framework for Aboriginal and Torres Strait Islander Health: Framework for Action by Governments

"The crucial mechanism for improving ATSI health is the availability of comprehensive primary health care services" and these services should "maximize community ownership and control, and be adequately funded, have a skilled

appropriate workforce and be seen as a key element of the broader health system."

Initiatives that address four key issues have been established by agreement between all partners at the state and territory level. They are:

- increasing the level of resources to reflect the higher level of need of Aboriginal and Torres Strait Islander peoples;
- improving access to both mainstream and ATSI specific health and health related programs to reflect the higher level of need;
- initiating a joint planning process which allow for full and formal ATSI participation in decision-making; and
- determining priorities, and improved data collection and evaluation.

Health does not just mean the physical well being of the individual but refers to the social, emotional, spiritual, and cultural well being of the whole community. This is a whole of life view and includes the cyclical concept of lifedeath-life.- National Aboriginal Health Strategy

The *National Aboriginal Health Strategy* that was implemented in 1989 was never actually put into effect, but was, nonetheless, a landmark document that guided health care service providers and health services in their endeavors with policy-making and planning. The Strategic Framework agreement builds on the NAHS and works within the current policy and planning environment to address issues with primary health care and population health.

Like similar frameworks included in this chapter, the Strategic Framework outlines nine principles to consider when implementing any health strategy. Within this group of principles is the commitment to recognize that "health

As with any population health approach, the approach to health status pertaining to Indigenous peoples must be one that is considerate of their worldview (a wholistic worldview) and enables them to participate in decision-making and take control over their own affairs.

promotion and illness prevention is a fundamental component of a comprehensive primary health care system and must be a core activity for specific and mainstream health services." As with any population health approach, the approach to health status pertaining to Indigenous peoples must be one that is considerate of their worldview (a wholistic worldview) and enables them to participate in decision-making and take control over their own affairs.

enables them to participate in decision-making and take control the best practice model to use for implementing the national strategic framework. NAACHO sees an Aboriginal community controlled service as one that is an "incorporated Aboriginal organization, initiated by an Aboriginal community,"

based in a local Aboriginal community, governed by an Aboriginal body which is elected by the local Aboriginal community, and delivering a wholistic and culturally appropriate health service to the community who controls it."<sup>67</sup> According to the strategic framework, this definition is one that truly represents community control and best practice. However, there are other current governance structures that are viewed as stepping-stones that help communities develop, by definition, a complete community controlled best practice service. Services are continually provided by other provider groups in the mainstream system along side the ACCHS to maintain capacity-building and to account for local circumstances.

A series of objectives and action areas have been developed in the National Strategic Framework to elevate the health status of ATSI people so that it is equal to that of the general population in three main areas. This requires:

- 1) Strengthening comprehensive primary health care:
- 2) Strengthening emotional and social well-being:
- mental health problems/suicide;
- prevention of child abuse and sexual abuse/violence, protection of children;
- alcohol, smoking and drug misuse; and,
- male health.
- 3) Focusing on pre-determinants of chronic disease:
- nutrition/physical activity;
- child/maternal health;
- oral health:
- improving health of ATSI peoples in custodial settings; and,
- data availability and quality.

Results areas/objectives are developed for health and non-health sectors, as well as for providing infrastructure to improve health status. Non-health sectors are responsible to take actions in education, employment, transport and nutrition if health gains are to be achieved by: improving standards in environmental health (including housing and essential services); and aiming to develop partnerships with, and commitment, from other sectors whose activities impact on health.

Results areas for providing the infrastructure to improve health status include:

- the development of a strategic approach to improving health information about the how well the health sector is meeting the needs of the ATSI peoples (including data collection, evaluation of interventions, and research processes by improving data quality and availability, data development, information management and utilization at the primary health care level; research; and knowledge translation);
- the recognition that accountability is reciprocal and both communities and governments are accountable for health services delivery and effectiveness of health outcomes (based on improved transparency of resource allocations and decision-making and reciprocal sharing of information); and,
- providing for optimal resources available for ATSI health commensurate with levels of need (based on real costs of services and capacity to deliver health outcomes including integrated funding models).

# England

In England, the National Health Service (publicly funded national health care) reforms have prompted the establishment of a large number of Primary Care Trusts. The development of regional networks to pool skills sets across Trusts, as well as the formation of a national health protection agency to pool communicable disease control staff, appear to at least be partially motivated as compensatory mechanisms. Concern has also been expressed regarding the inefficient sizes of some local public health agencies that may have spread public health staff too thinly.

In England, public health activities are contained within national service frameworks that have been developed for a variety of health conditions and population groups. Each of the Primary Care Trusts will be performance managed by one of the Strategic Health Authorities, most of which contain public health specialist staff. In addition, the high-level performance indicators for the NHS contain a variety of public health-related measures, which in effect hold the health care system accountable for public health outcomes.

## Health Development Agency (HDA) - England

The HDA gathers evidence of what works, advises on standards and develops the skills of all those working to improve people's health. The HDA was established in April 2000 and has a staff of approximately 120 and an estimated annual budget of \$10 million.

In partnership with other organizations, the HDA will develop and maintain:

- an accessible evidence base;
- guidance on how to translate evidence into practice;
- the skills of those working to improve the public's health;
- the standards and tools to measure the results; and,
- resources to help those working locally.

Between 2001 and 2002, the United Kingdom developed and put in place two national targets meant to focus on recent increases in health inequalities. These targets include the reduction of differences in life expectancy and infant mortality across social classes by 10% by the year 2010. In order to attain these targets, a program for action has been implemented including a strategy and recommended priority interventions along four theme areas:

- supporting families, mothers, and children;
- engaging communities and individuals;
- preventing illness and providing effective treatment and care; and,
- addressing underlying determinants of health.

#### **Conclusion**

In all four countries reviewed, the federal government's role in public health is strongly reinforced by the fact that it funds a substantial portion of the public health system. This contrasts distinctly with the experience in Canada where it is the responsibility of the provincial and, in some cases, local governments, to fund the public health infrastructure.

Even in Australia, which has the most similar constitutional structure of Canada, the federal government pays over half of the overall public health system's budget. In the U.S., substantial funds (and human resources) flow from the CDC to individual states. Only in the US is there reliance on local governments to fund a portion of local public health departments' budgets and this is the component of their system that is widely acknowledged as the weakest element. The experience in New Zealand in the late 1980s, – when the public health system lost up to 40% of its funding when placed in competition with immediate-focused acute care services – provides caution to such approaches. Other countries' funding transfer mechanisms earmark public health-specific funding to protect them from diversion to other services.

Apart from lessons in public health funding mechanisms, it would appear that Canada has a lot to learn including other countries' approaches to health data collection, Indigenous populations, and governance and accountability mechanisms, as well as their views on cross-ministerial policy making.

#### Recommendations

**Recommendation #102:** There is a need to consider the feasibility of creating a First Nations public health infrastructure that would include the legislative recognition and accountability in a similar style to that taken in New Zealand. Legislation regarding the roles and responsibilities of public health agencies and First Nations governments would create the impetus for First Nations and non-First Nations stakeholders to work together at all levels and develop working relationships. In the case of New Zealand, public health legislation provides the basis for these with Indigenous groups in all sectors and across all levels of health, and has improved the whole process of self-governance and self-determination for Maori groups.

**Recommendation #103:** A policy of joint federal/First Nation development and meaningful First Nations engagement at the national, provincial, regional and local levels needs to be created. This will address First Nations needs within the broader system. An official consultation policy has been developed and implemented in the U.S..

**Recommendation #104:** There is a need to consider and analyze the feasibility of implementing the District Health Board model of New Zealand in Canada. In doing so, there should be an evaluation of the effectiveness of implementing service provider contracts between provincial District Health Boards/Regional Health Authorities and newly created First Nations public health agencies to provide more comprehensive, coordinated and integrated approaches to the delivery of public health services to First Nations populations.

**Recommendation #105:** The possibility of fusing public health with the primary health care models in communities has been identified where critical mass does not allow for resources dedicated to both. This concept is being used by New Zealand, with both the U.S. and England considering adopting this system where resources in small communities are being spread too thinly.

# **Chapter 9: Conclusion**

One of the major challenges faced by public health is that it argues for action now to prevent something in the future. This is a difficult case to make when there are many more voices requesting action to address a problem today. The

child walking down the street who did not get polio is not a news story, but the waiting lines for a treatment service are. If one frames the question to ask what will happen in the future as a result of today's actions, however, preventative efforts and their impact become more recognizable.

The Advisory Committee to the Assembly of First Nations has crafted a roadmap of immediate and long-term actions required to address critical public health needs of First Nations. These actions are required not only to deal with communicable diseases, health determinants and emerging and longstanding he

There is a need for expanded human resources, modern information systems, more equitable funding arrangements and a recognition of First Nations jurisdictions.

communicable diseases, health determinants and emerging and longstanding health problems, from specific crises such as diabetes, to broad inequalities in health between First Nations and the rest of Canadians.

This Framework has outlined the need for strong leadership, accountability and legislated coordination for the delivery of public health programs for First Nations in Canada. This includes a need for expanded human resources, modern information systems, more equitable funding arrangements and a recognition of First Nations jurisdiction.

Following the review of findings from other countries, it is apparent that several steps could be initiated between jurisdictions and within each jurisdiction to improve the infrastructure of First Nations public health. These have been grouped under six main headings and were described in further detail in the previous chapters. There are a variety of options on how these actions could be pursued. Some items may work best with a specific level of First Nations government taking the lead, while others could work with a variety of approaches (e.g., regional/community public health partnership, lead non-governmental agency, etc.).

As a form of collective action, First Nations governments have a critical role in providing the formal public health system infrastructure. While a strong governmental public health system is essential, it is insufficient to be able to address population health issues at the community level. Collaboration with, and active participation of, community groups, non-governmental organizations (NGOs), business, and public sector agencies (e.g., schools) are also needed to improve health. The focus of this paper was on the federal/provincial/territorial/First Nations governmental component, which is the backbone of the public health system. It provides the infrastructure upon which programming and inter-sectoral collaboration can be built.

A key requirement for dealing successfully with future public health crises is a truly collaborative framework and ethos among different levels of government. The rules and norms for a seamless public health system must be sorted out with a shared commitment to protecting and promoting the health of First Nations. This includes the availability of services for First Nations whether living on or away from First Nations communities.

The rules and norms for a seamless public health system must be sorted out with a shared commitment to protecting and promoting the health of First Nations.

#### **Determinants of Health**

Chapter 2 reinforced the connection between the broader determinants of health. Many of the factors influencing health of First Nations lie in the complex social, economic and physical environments in which First Nations live, and therefore, when embarking on a health reform mission it requires a more social view of health. While healing and wellness programs have their place in the short term, it is economic and social reform that will bring lasting change. Societies that enable all citizens to play a full and useful role in the social, economic and cultural life of their society will be healthier than those where people face insecurity, exclusion and deprivation.

It is the goal of this framework to ensure that all of the chapter recommendations have inherent goals based on these determinants of health. The recommendations are:

**Recommendation #1:** Opportunities to develop and maintain personal life skills and a sense of life control and effectiveness, must be available to all First Nations including the critical importance of self-government.

**Recommendation #2:** Resources and supports in society must be implemented to enable and maintain healthy lifestyles through government policies on the fair distribution of income, the removal of barriers to health care and affordable housing, and the reduction of social stratification.

**Recommendation #3:** Opportunities for all people to live with dignity would see the elimination of poverty and its ramifications.

**Recommendation #4:** Reduction of preventable illness, injuries, disabilities and premature deaths must be a priority, particularly in a population with a large and growing youth cohort.

**Recommendation #5:** A new strategic approach to a First Nations health system administration that fosters a wholistic system and encourages multi-sectoral partnerships within communities (linkages with education, justice and other essential community services) are favored by First Nations, as demonstrated in the recommendation to create a First Nations Wholistic Health Strategy in the 2005 Blueprint on Aboriginal Health, as well as in the First Nations Wholistic Policy and Planning Model proposed by the Assembly of First Nations.

#### **Organization and Jurisdiction**

Chapter 3 discussed the need for a modern piece of legislation that facilitates harmonization across all jurisdictions, including recognized First Nations jurisdiction. Included in this is the need for an effective governance structure to ensure clear decision-making authority, public accountability and clarity of roles and responsibilities within the system. Taken together, the appropriate delivery structure to accomplish public health functions will require a unique architecture not yet seen in Canada.

Crucial non-government partners need to be included in this architecture to allow for effective communication with the public, appropriate consultation and increased visibility for public health.

Finally, public health performance indicators need to be created and annual reports (parallel to Hospital Report Cards) need to be available. The public health system exists to protect and promote the health of First Nations. There needs to be accountability mechanisms in place to assess public health system performance for First Nations.

The following recommendations address the issues surrounding public health jurisdiction, authority and governance. These recommendations propose an organized approach to the delivery of public health services to First Nations that overcomes current legislative and jurisdictional hurdles. The structure will need to respect the variations in First Nations communities across the country.

**Recommendation #6:** FNIHB should assume the role of assurance and facilitator, and when decided upon by First Nations' plans, provider of public health to First Nations communities. Their facilitator role should consist of their participation in tripartite agreements with provinces and territories interested in providing public health services to First Nations communities. Their facilitator role should also consist of enhancing the capacity of communities interested in assuming governance of their own public health services, such as through First Nations Regional/Subregional Public Health Authorities. Their assurance role would ensure the fulfillment of the pre-agreed upon role of other provinces and territories.

**Recommendation #7:** Smaller First Nations communities of less than a critical mass number (as yet to be defined) should have access to flexible mechanisms of accessing services. Economies of scale and First Nations political structures will need to be considered when determining best ways of providing public health services. Collaboration between First Nations communities will likely be essential in ensuring the success of community health programming that is both feasible and sustainable.

**Recommendation #8:** Wellness Centers, Friendship Centers, and other First Nations organizations, agencies and community programs need to be included as key stakeholders in the delivery of public health programs. Many of these existing agencies and services have the knowledge and experience but lack the funding capacity to enhance their services and to reach more First Nations. Of critical importance, these service delivery centres must solidly connect to their First Nations government and not usurp First Nations government capacity to deliver public health programs to their membership living both on and away from their communities.

**Recommendation #9:** A more significant role of the Public Health Agency of Canada in program development and evaluation may be better achieved through the creation of a First Nations Public Health Secretariat within each of the provinces and territories, or by supporting a new national First Nations Public Health Agency.

**Recommendation #10:** The enactment of new federal legislation, entitled the First Nations Public Health Act, should be considered. This Act will include a description of the authority of the provincial and territorial Public Health Acts in addition to unique laws relevant to First Nations. This act would also describe a well-defined Public Health System with core basic programs. Included in the Act would be the option of extending the authority required to have public health programs governed by First Nations communities either through regional/ sub-regional First Nations Public Health Authorities or other proposed means. Communities that opt not to govern their own public health programs will have the option of having them provided by FNIHB. Such services will need to be protected from the realities that most public health professionals face with acute health care often calling them away from public health activities.

**Recommendation #11:** Regional/Sub-Regional First Nations Public Health Authorities described in Recommendation 10 should be governed by a Board of Directors that would consist of Chiefs from each community (or their designates). A CEO of the Health Authority would report to the Board, and Health Directors from the communities would act as an advisory body to the Board.

**Recommendation #12:** Clear descriptions of roles, responsibilities, funding and accountability protocols need to be annexed to any proposed *First Nations Public Health Act* to ensure effective, efficient, sustainable service delivery structures. This Act would also detail out the fiduciary role of FNIHB in facilitating tripartite agreements and assisting in the assurance and evaluation of services provided to First Nations communities.

**Recommendation #13:** The new proposed *First Nations Public Health Act* would endeavour not to complicate the delivery of public health in Canada. Rather, it would attempt to harmonize and formalize the way in which public health is most effectively regulated and delivered – that being at the local level. This would include a review of other relevant/conflicting legislation, such as that which governs the licensing of food premises.

**Recommendation #14:** Intergovernmental Agreements or Memoranda of Understanding should be struck between the federal government, First Nations governments, and the provinces and territories. These agreements should outline the unique relationship the federal government has with First Nations under a potential new *First Nations Public Health Act.* For example, where provincial Regional Health Authorities or Boards of Health fail to comply with service delivery of public health programming to First Nations, the MOU between federal, First Nations, and provincial governments will enable the provincial ministries to enforce their authorities that govern Regional Health Authorities and Boards of Health, and therefore ensure that services are provided with as little interruption as possible to First Nations living on or away from their communities.

**Recommendation #15:** With respect to surveillance, rules governing the following: case identification (e.g., uniform criteria for diagnosis and laboratory testing), data sharing (e.g., timelines and procedures for reporting new cases and norms governing the protection of privacy), and information dissemination (e.g., responsibility for communicating to national and international audiences and the content of such communications), need to be incorporated into both the intergovernmental agreements as well as any potential *Public Health Act*. These rules, first and foremost, must respect the principles of Ownership, Control, Access and Possession (OCAP) of First Nations to their collective and individual health data.

**Recommendation #16:** The federal government must continue to honour its fiduciary relationship with First Nations communities as part of the new public health programming arrangement. A clear statement to this effect must be made in any proposed *First Nations Public Health Act*. The federal government's role is especially important for communities who opt not to govern their own public health services.

**Recommendation #17:** A dialogue should begin between the Assembly of First Nations, First Nations regions, and the federal government to explore the federal government's relationship with provinces under the *Canada Health Act*. This dialogue should specifically explore the possibility of unique funding arrangements to provinces so that they can offer access to quality public health services unique to First Nations living away from First Nations communities but with some direct accountability to First Nations governments who also represent these individuals

**Recommendation #18:** The role of INAC in the delivery of public health relevant services, such as housing, water and sewage, should be detailed under the *First Nations Public Health Act*.

**Recommendation #19:** In order to achieve healthy housing for all First Nations, recognition of complete First Nations jurisdiction in the area of housing and infrastructure and the acceptance of First Nations as equal partners in government-to-government based decision-making processes related to housing and infrastructure must be guaranteed.

**Recommendation #20:** Provincial Regional Health Authorities and Public Health Units should have First Nations representation on their public health governing bodies, especially in urban communities with large First Nations populations.

**Recommendation #21:** New methods of creative accountability on the part of the federal government to First Nations should be developed, including the possibility of third party auditors that are non-government employees. Similar changes need to happen on the part of First Nations accountability to include assessment based on outcomes of population health versus outputs of programs i.e., reporting that enhances First Nations capacity to effectively plan and monitor public health services instead of impeding this capacity due to a high administrative burden.

**Recommendation #22:** Additional funding will need to be made available for the new programs, as defined under the proposed *First Nations Public Health Act*. This is particularly relevant for communities that have already negotiated Health Transfer Agreements or for those that fall under other funding arrangements with the federal government such as James Bay Cree, self-governing First Nations and the territories.

**Recommendation #23:** Medical Officers of Health (currently named Regional Medical Officers of Health) who service First Nations communities must be granted full authorities under the provincial legislation where they work. They should be allowed the same rights as all other provincial and territorial Medical Officers of Health, and invited to participate in all provincial and territorial meetings and consultations. The proposed new act would scope out their responsibilities including their relationship with FNIHB. These Medical Officers may be employed by FNIHB, or by First Nations or by the province.

**Recommendation #24:** An official consultation policy should be adopted by the federal government and used by all federal ministries and departments when any potential policy decision is being discussed that would impact First Nations and their public health. The aim of this recommendation would be to achieve the meaningful consultation that is expected under a fiduciary obligation.

**Recommendation #25:** Any changes to the current way in which public health is delivered to First Nations can not adopt a Pan-Aboriginal approach, nor can the funding envelope be a Pan-Aboriginal one. Instead, a specific First Nations approach and funding for public health need to be assured.

#### **Surveillance**

Harmonizing emergency preparedness and response frameworks at the First Nations, federal, provincial and territorial levels are important not only in the concept of organization and jurisdiction but also for the purposes of disease surveillance. Building an integrated federal/provincial/territorial/First Nations planning, training and exercising platform for responding to all-hazard disasters, including public health emergencies created by large scale disease outbreaks is also required.

The federal government should give priority to infectious disease surveillance, including provision of technical advice and funding to First Nations Regions to support the development of the infrastructure including training of personnel required to implement surveillance programs. The agency should facilitate the longer-term development of a comprehensive health surveillance system that will collect, analyze, and disseminate laboratory and health care facility data on infectious disease and non-infectious diseases to relevant stakeholders that can be linked with regional systems whilst not jeopardizing the principles of OCAP.

#### Recommendations

Recommendation #26: First Nations Health Information Institutions (FNHII) should be developed immediately. They should be driven by the needs, priorities and interests of First Nations people, under the complete ownership of First Nations and not under the ownership of federal, provincial, territorial or other governments. A national coordination office will act as the facilitator and supporter of Regional/Sub-regional FNHII in each of 10 or more participating regions/sub-regions. In turn, community resources will be determined by a needs assessment completed by the community itself, with the assistance of regional coordinators. To ensure that the FNHII keeps pace with other Canadian health infostructures, adequate community infrastructure (including physical space such as facility modifications, information and communications technology, security) will be required as will a periodic increase in resource levels to evaluate the infostructure and accommodate technological changes and advancements.

Needed is a national public health surveillance system that will collect, analyze, and disseminate laboratory and health care facility data on infectious disease and non-infectious diseases to relevant stakeholders that can be linked with regional systems whilst not jeopardizing the principles of OCAP.

Recommendation #27: Tripartite agreements should be developed between each First Nations Region or Sub-Region (such as a treaty area), the provincial or territorial government, and the federal government to build a coordinated national health surveillance system (in keeping with Phase 2 described above). It is highly likely that a great deal of regional variance will exist as each region decides on its surveillance needs. The only pre-requisite should be that the system design ensures national interoperability and health language applications. Such a system would include improved co-ordination between public laboratories and other public health surveillance bodies as well as a requirement to share data that is currently collected by federal/provincial/territorial governments that should include, but is not limited to, hospital stays, emergency room visits, reportable disease lists, patient billing lists and other patient registries where current First Nations identifiers exist. These lists should be of aggregate data only and prevent the identification of individuals, but should be of sufficient breakdown that the information is meaningful to communities whose population health is being evaluated. It is vitally important that health data be shared across all jurisdictions to create a national picture of health risks and health outcomes.

**Recommendation #28:** New federal funding for public health should be explicitly tied to these surveillance strategies and plans, with process and outcome reporting. These new federal funds should not displace existing health commitments.

**Recommendation #29:** Pan-Canadian investments in Health Research, Electronic Health Records and Telehealth need to include First Nations as equal partners in the development of strategies and program design.

**Recommendation #30:** First Nations leaders should consider supporting the current efforts behind the development and implementation of the Pan-Canadian i-phis replacement across the nation to ensure their inclusion in a national system, recognizing the flexibility of data ownership that such a system could provide.

**Recommendation #31:** First Nations leaders should consider supporting the current efforts behind the development and implementation of the pan-Canadian i-phis replacement "Panorama" across the nation to ensure their inclusion in a national system, recognizing that First Nations data ownership can be provided by such a system.

**Recommendation #32:** FNHII must be designed to improve public health surveillance capacity in First Nations communities under First Nations control. Health Canada must support and negotiate with First Nations national, regional, and sub-regional institutions, a concerted approach to public health information gathering, use and dissemination contrary to the current fragmented approach of building disease/domain-specific registries with minimal First Nations engagement.

**Recommendation #33:** Agreements will be made with other government jurisdictions, agencies, research institutions and others for the opportunity to share and have access to First Nations data collected by the institutions described in Recommendation #26.

**Recommendation #34:** Health Canada and Canada Health Infoway must work with First Nations in developing federal, provincial and territorial client registries to establish linkages with federal/provincial/territorial electronic health records that are flexible and appropriate to the needs of each First Nations community. First Nations communities must determine independently the information exchange and access protocols that are acceptable and valuable to them. Personal identifiers should be developed for the purposes of health care delivery, including electronic health records, but these identifiers should be drawn and approved by First Nations governments and held by the FNHII to protect individual privacy.

**Recommendation #35:** Band membership lists or lists of members under self-government agreements need to include those First Nations living away from First Nations communities to be included in the surveillance system and given personal identifiers.

**Recommendation #36:** The Government of Canada must fulfill recommendations of the Advisory Council on Health Infostructure, the National Broadband Task Force, the Romanow Commission and subsequent federal commitments to address, as a matter of priority, the broadband infrastructure needs of First Nations communities, especially as these needs relate to high-speed health communications/applications.

**Recommendation #37:** FNHII must be regularly evaluated in terms of their contribution to measurable improvements in First Nations health and well-being. These recommendations must also be understood to be evolving based on First Nations priorities and experiences.

**Recommendation #38:** First Nations institutions should be encouraged to establish a network of community-based health service/program expertise and urban community centers such as the Wellness Centers that could be connected to the FNHII for the purposes of First Nations living away from First Nations communities' disease surveillance capture.

**Recommendation #39:** The development of FNHII and the development of public health surveillance systems must be given higher priority. Resources must be made available on an equitable and sustainable basis. Not only are health surveillance activities a fundamental component of self-government, but the erosion of a coordinated health surveillance capacity in the context of health transfer is both dangerous from a public health perspective and seriously undermines the health planning process at a time when resources are inadequate to meet health needs.

**Recommendation #40:** A review of the capacity and protocols needed by public health laboratories to respond effectively to routine and emergency infectious disease investigations on behalf of First Nations needs to be evaluated and the potential for a direct link with FNHII explored.

**Recommendation #41:** A scan of the current acceptability by First Nations of First Nations personal identifiers under the control of First Nations infostructures needs to be determined, with follow-up education on the pros and cons of such identifiers applied to personal health information.

**Recommendation #42:** Health care professionals need to be included as stakeholders in the development of a surveillance tool to ensure early buy-in and acceptability.

**Recommendation #43:** Any system to be developed for health data collection needs to be flexible and compatible with a range of health systems and health system languages so that additional modules may be added with minimal disruption and costs.

**Recommendation #44:** Any data sharing agreement with provincial/territorial or federal governments needs to clearly outline the responsibilities that each has with respect to responding to any alerts generated by the data in both the urgent and non-urgent setting. Clear communication protocols should also be detailed at the same time.

**Recommendation #45:** Any proposed infostructure needs to include funding resources for community based computers, training and software as well as ongoing maintenance and evergreening costs.

**Recommendation #46:** Any future potential *Public Health Act* will need to explicitly address First Nations personal health information identification.

**Recommendation #47:** Determinants of health should be addressed as variables to be surveyed, collected and analyzed as part of the surveillance system.

**Recommendation #48:** There is an urgent need for First Nations Leaders and Health Planners to work with their communities, INAC, Regional Medical Officers of Health, and provincial counterparts to create integrated protocols for outbreak management followed by training exercises to test the protocols and assure a high degree of preparedness to manage outbreaks. Protocols must include:

- agreement on roles and responsibilities;
- agreement on data ownership, custody, sharing with the aim of facilitating greater sharing of data;
- security and privacy mechanisms;
- prior agreement on the use of data for publication and authorship; and,
- clear identification of persons responsible for: (a) management of the outbreak; (b) data management; and, (c) communications.

#### **Health Promotion**

The starting point should be to define the essential function, programs and services that will fall within the system clearly scoped out. These pre-agreed upon programs and business processes are to include a streamlined and enhanced capacity to assist with the management of outbreaks of disease and threats to health, including linkages to clinical systems. At the minimum the scoping exercise should include:

- standards and best practices;
- research related to population and public health;
- a central resource for knowledge translation and evidence-based decision-making including the identification of research needs (possibly through the Public Health Agency National Collaboration Center for Aboriginal Health); and,
- evaluation of population and public health programs.

A follow-up step to the development of core functions for public health is to identify the corresponding programs and services that should be delivered. The focus here is on the "minimum" or "basic" set of programs recognizing that communities may decide to cluster additional programs with public health at the services delivery level and individual communities may have specific public health needs that need to be addressed.

This scheme illustrates first and foremost that there are no great mysteries in the organization of an effective public health system. Most of these functions are self-explanatory. It will ultimately strengthen and integrate the five essential functions of the Canadian public health system:

- population health assessment;
- health surveillance;
- health promotion;
- disease and injury prevention; and,
- health protection.

#### Recommendations

In accordance with the Ottawa Charter, the aim of our recommendations are to assist communities to build healthy public policy, create supportive environments, strengthen community actions, develop personal and collective skills by providing learning opportunities, and reorient health services. This will require, at the minimum:

- public health leadership;
- creating a vision and goals;
- promoting First Nations-led integrated planning, participation and community development;
- promoting partnerships with FNIHB and provincial Regional Health Authorities; and,
- creating more widely available opportunities for communities who are interested in creating their own First Nations Health Authorities to oversee public health.

**Recommendation #49:** A commitment to design a comprehensive public health system, as described above, by those deemed responsible for the delivery of public health programs to First Nations, needs to begin as a priority item. This includes FNIHB, provincial/territorial public health service providers, First Nations Regional Health

Authorities and First Nations community leaders. The purpose of such a commitment would be to agree on connecting diverse services led by regional centers which would be linked to ensure the health of First Nations is protected under such unique circumstances. The set of mandatory programs, identified based on existing and new research evidence, should form the basis for the comprehensive public health system's programming.

**Recommendation #50:** Joint policy development needs to begin between First Nations and the Public Health Agency of Canada in areas related to its roles in supporting public health services delivery in First Nations communities and to First Nations people living away from their communities.

**Recommendation #51:** Population health strategies must be elaborated by studying and discussing the health outcome of the full range of determinants of health, encompassing social, environmental, cultural and economic factors. This can only be achieved through cross-Ministerial and Departmental policies that encourage public health impact evaluations be at all governmental decisions.

**Recommendation #52:** Critical mass numbers need to be taken into account when describing the public health services that will be supported in communities. It is highly likely that many First Nations communities will need to link together in the sharing of public health services where their population numbers are small.

**Recommendation #53:** Health promotion is a long-term activity that requires a longer-term planning approach not bound to the annual planning cycle of the federal government.

**Recommendation #54:** Research must be an integral component of evidence-based health protection and promotion programming and an enhanced and more recognized role for current First Nations researchers needs to be highlighted and encouraged.

**Recommendation #55:** The successes of public health programs in communities and outside of First Nations communities need to be carefully evaluated by new measurements. Communities need to identify public health priorities and strategies that include specific health targets, benchmarks for progress towards them, and collaborative mechanisms to maximize the pace of progress. New indicators of progress may be a return to traditional ways, housing quality and so on.

**Recommendation #56:** New federal funding for public health should be explicitly tied to these strategies and plans, with process and outcome reporting, and structured as contributions that are subject to audit as per Recommendation #55.

**Recommendation #57:** Chronic diseases are the leading cause of death and disability in Canada and many chronic diseases are preventable to a very large extent. The federal government, in collaboration with First Nations, the provinces and territories, in consultation with major stakeholders, should give high priority to the implementation of a First Nations National Chronic Disease Prevention Strategy.

**Recommendation #58:** The *First Nations Public Health Act*, outlined in Chapter 3, will include a commitment to chronic disease prevention as it will reflect an emphasis on an enabling, rather than a prescriptive, legislative framework.

**Recommendation #59:** Local governments are well positioned to promote community health and wellbeing across their municipality for First Nations living in urban settings. They also have a leadership role in community building

and have the ability to build capacity, by implementing strategies to enhance community health status and health equity outcomes. Strategies, such as the Aboriginal Healing and Wellness Centers in Ontario could be viewed as potential collaborating partners in a seamless delivery of public health programs for First Nations across the country.

**Recommendation #60:** Individuals, community groups, government departments, and other agencies need to participate in health planning, not only to ensure a match between local needs and priorities, but because participation itself promotes health. Individuals and the wider community need to participate meaningfully to ensure appropriateness, individual/community ownership of processes, programs and outcomes, and the promotion of accountability to the community for decisions about priorities and resource allocation.

There is an urgent need to ensure equitable funding arrangements that do not leave First Nations relying solely on Provincial, Territorial and local government coffers and questionable Federal government commitment and resources.

**Recommendation #61:** An annual report, detailing out the health of First Nations, is an invaluable resource to early planning for public health and should be supported by Health Canada.

**Recommendation #62:** A variety of agencies, organizations and charities currently offer public health and public health related services to First Nations people living away from First Nations communities. A list cataloguing each of these providers is required to assist with the development of a map linking the services in a meaningful way. This will also provide a list of potential collaborative partners for the delivery of community health programs.

**Recommendation #63:** Greater First Nations control should extend not only to health services, but also to environmental stewardship to address key health determinants.

**Recommendation #64:** Elders need to play a key role in the detailing of population health programs to ensure that traditional knowledge and wisdom is preserved in the long term planning of the future of public health programs.

#### **Capacity and Funding**

These structural factors have important flow-on effects. Sufficient purchasing power to feel secure and included in society is central to the health of individuals in any community. Individuals and households need sufficient disposable income to afford stable, adequate housing, educational opportunities and effective, available and acceptable health care.

There is an urgent need to ensure equitable funding arrangements that do not leave First Nations relying solely on provincial, territorial and local government coffers and questionable federal government commitment and resources.

Consideration should be given to public health system funding for First Nations to be shared by the federal and provincial/territorial governments. The formula could be agreed upon by all three levels of government with clear accountabilities consistent with their relative roles. Public health agencies require sufficient, stable and predictable

funding especially since many preventive programs need to be planned and implemented on a multi-year basis. While it is critical to maintain local input into decision-making, funding of core public health services is not consistent with the current funding characteristics. In the absence of greater infrastructure development (i.e., defined functions, performance measurement system, etc.), establishment of explicit funding targets for the public health system is not feasible.

Public health actions depend upon active collaboration with other partners. For example, one strategy to address childhood obesity is to ensure daily physical activity in schools. This cannot be accomplished without the active participation of schools, school boards, parent council, students and provincial ministries of education. Currently, inter-sectoral partnerships are often developed to a greater extent at the regional/local level where public health services are delivered rather than at provincial or national levels. Partnership at these levels is needed to develop the public health system and its programming. The multi-agency initiatives to systematically address chronic diseases (e.g., Chronic Disease Prevention Alliance of Canada) are examples of emerging national partnership models.

#### Recommendations

**Recommendation #65:** The federal government and First Nations must develop minimal requirements for sustainable public health programs. Funds should be transferred directly to communities via Regional First Nations Health Authorities or other proposed means that would permit Public Health Programs to be delivered or purchased by First Nations communities.

**Recommendation #66:** If communities choose to govern their own public health services by creating collaborative agreements (e.g. inter-community economies of scale) then funds should flow to Regional and sub-Regional First Nations Health Authorities with a governing board composed of representatives from the communities, Health Directors, and Chiefs as well as other individuals as deemed necessary.

**Recommendation #67:** Public health in the first instance is a local enterprise. Provinces and territories in turn must fund, support, and coordinate local activities for First Nations in their jurisdictions through their own agencies and ministries. Specific funding from Health Canada needs to be transferred to mandated First Nations Health Authorities and/or, pursuant to agreement of First Nations leaders, to provinces/territories who in turn will ensure that First Nations living away from First Nations communities have specific public health programs of high quality. Another option is for First Nations communities to receive funding for their entire membership and engage with the province or territory to purchase services on behalf of their membership living away from the community.

**Recommendation #68:** Accreditation processes for interested communities should be funded.

**Recommendation #69:** Program reporting will be based on the achievement of pre-set national indicators or benchmarks to ensure that outcomes, rather than activities are used to monitor the use of federal funds which will reinforce accountability of the federal government based on its fiduciary obligation.

**Recommendation #70:** Assessing the degree to which FNIHB are achieving their goals and responsibilities of delivering and/or assuring public health programs to First Nations needs to have outside auditing on an annual basis through a third-party and non-governmental expert group.

**Recommendation #71:** Funding needs will be determined by a set of predetermined criteria including Northern and remote factors, total population base, age and gender of population base, socio-economic composition of the population base, services communities provide to residents of other communities, local cost of living, and population growth.

**Recommendation #72:** Not all funding needs to be new. We see opportunities for First Nations public health initiatives to participate in programs already announced, such as the massive investment in Canada Health Infoway, and the 4-year \$100 million AHHRI.

**Recommendation #73:** The new funds would be implicitly tied to implementing the *First Nations Public Health Act* and the contents of the Act that would assume the responsibility of health protection and promotion as a means for better coordination and regional First Nations collaboration.

**Recommendation #74:** The time required to build capacity within First Nations communities will be considerable. Meanwhile, other alternative means of developing capacity, such as telehealth, can to be explored, as an option to First Nations.

**Recommendation #75:** Telehealth needs to be funded as a program with human resource capacity and not solely a tool for delivering a range of public health services to First Nations communities. This is essential so that it does not create a new burden on existing nursing and other health care staff.

#### **Health Human Resources**

The Canadian government, together with the Public Health Agency of Canada, has been tasked with the ominous job of developing a National Public Health human resource strategy. This needs to have a specific section dedicated to the urgency of health human resources for First Nations. At the minimum this will need to consider:

- appropriate number of staff;
- standards for qualifications and competencies;
- health human resource planning for public health;
- accessible and effective training programs in a number of formats;
- lifelong learning and career-development opportunities; and,
- an extensive program of secondments to and from First Nations/provincial/territorial and local health agencies, with arrangements for mutual recognition of seniority and a range of collaborative opportunities for advancement.

Many of these practitioners are public health nurses, but also include staff from many other disciplines (e.g., health inspectors, nutritionists, health promoters, community development specialists, health administrators and information specialists etc.). The public health system appears to have too few graduate-level public health professionals (i.e., holding Masters degrees, as well as physicians who are certified specialists in community medicine) and those that do exist are not equitably distributed across jurisdictions. There are virtually no resources currently dedicated to address the continuing education needs of public health staff. Public health systems in other jurisdictions have developed specific training programs to improve leadership skills (e.g., joint initiatives between schools of public health and schools of business administration). Central public health agencies have also taken on the task of developing plans to address skill levels of staff and are working with existing academic providers on this project.

To these categories one can add another. It should include highly technical or scarce expertise, facilities or equipment that constitute a specialized reserve or surge capacity that is best provided or organized nationally, and formal international liaison activities.

Considering the breadth of public health issues, the relative population sizes of First Nations within provinces and territories, and their relative wealth, it will never be feasible to have comprehensive centres of public health expertise for each First Nations community. Even if one achieved this, there would increasingly be issues of unnecessary duplication among Regions. Perhaps this is another key area where the Public Health Agency could play a role.

#### Recommendations

**Recommendation #76:** Students need to have better academic preparation in elementary, junior high, and senior high schools with expanded mathematics and sciences programs. Creative, innovative and culturally significant science ventures for children need to be added to their current curricula.

**Recommendation #77:** Life skills programs should be introduced at all elementary and secondary levels to attract youth to careers in health.

**Recommendation #78:** Partnerships must be created between First Nations communities and organizations and provincial academic institutions to earmark spots for undergraduate sciences, nursing, medical and paraprofessional training.

**Recommendation #79:** Funding for post secondary health careers should increase and go directly to students with additional support including mentors and access to Elders to assist them with issues around isolation and distance from home. There needs to be separate funding streams available for health professional programs for students.

**Recommendation #80:** New training programs and positions specific to First Nations in various public health-related fields need to be created that can have recognized accreditation across Canada. This would allow the creation of secondments to, and from, other First Nations communities, with arrangements for mutual recognition of seniority and a range of collaborative opportunities for advancement.

**Recommendation #81:** New training programs should be developed based on virtual models of learning to allow First Nations students to learn closer to home. These training modules should be developed in collaboration with First Nations health professional and paraprofessional associations.

**Recommendation #82:** The creation of a First Nations School of Public Health in Canada, possibly as a 'virtual' school that would draw on the resources of several institutions that are already engaged in some of the teaching and training required, should be explored. A 'virtual' school would also have the advantage of linking both university-based and community college-based programs so that students receive both theoretical and practical training.

**Recommendation #83:** Colleges and universities must adapt the present health care professional curricula to reflect First Nations cultural and traditional needs and knowledge. This could be done through support of the Social Accountability initiative of the Association of Faculties of Medicine of Canada (AFMC).

**Recommendation #84:** College and university entrance requirements should be reviewed to ensure that they are receptive to First Nations students. Certain prerequisite examinations, such as the MCAT for medical school, place some First Nations students at a disadvantage. A dialogue should begin with universities to examine the cultural biases and discrimination these examinations present.

**Recommendation #85:** Post-secondary preparatory programs, such as summer programs, should be developed by colleges and universities to support incoming First Nations students.

**Recommendation #86:** First Nations communities should be encouraged to create practicum opportunities for First Nations and non-First Nations students in their communities.

**Recommendation #87:** Certification and standards for innovative public health para-professionals should be considered to support public health activities that currently demand qualifications that are irrelevant to the First Nations community context.

**Recommendation #88:** Provincial, territorial and federal departments that currently offer a range of health and education related programs should be encouraged to consider the transfer of these programs to education institutions where the support and expertise for successful learning among First Nations students/professionals may reside.

**Recommendation #89:** Colleges and universities must be lobbied to increase the number of designated seats to First Nations in health programs, and to understand that a pan-Aboriginal is not as effective. Specifically, working in close partnership with First Nations communities, will increases the likelihood that First Nations students will return to those communities upon completion of their training. Ultimately, this will enhance the sustainability of the health human resource capacity available to support First Nations communities' public health systems.

**Recommendation #90:** Accreditation programs at colleges and universities should have their criteria expanded to include First Nations cultural competency and First Nations inclusion criteria and goals. This needs to be developed by First Nations people and not non-First Nations faculty.

**Recommendation #91:** New sub-specialties in the areas of First Nations health both for the health care provider and for the health care administrator should be created.

**Recommendation #92:** In addition to conventional health care careers, emphasis should also be on encouraging First Nations to develop training in health information and technology, as well as other key professions such as nutrition.

**Recommendation #93:** Provincial academic institutions should have, at a minimum, community representatives on their governing boards to begin assisting with partnership creations between First Nations communities and organizations with First Nations education interests.

**Recommendation #94:** Consideration should be given to providing credentials for certain types of public health practitioners through competency-based learning needs assessment tools. This would mean that public health specialists could become competency based rather than discipline-based.

**Recommendation #95:** Increases are required to bursaries, scholarships and grants for students in health professional and paraprofessional programs.

**Recommendation #96:** Where communities currently receive funding through transfer or where communities in the future may receive such funding, there must be targeted funding available for ongoing training, recruitment and retention of staff.

**Recommendation #97:** Key players should be identified with a single leader to develop a strategy for a sustainable First Nations Health Human Resources (e.g. wage parity). The strategy should be based on a partnership involving governments, academic stakeholders, institutional partners, and professional associations. A subset function of this group would focus specifically on public health human resources. Budget for this purpose needs to be built into projected public health needs.

**Recommendation #98:** The developed strategy should aim to make First Nations self-sufficient with regards to public health personnel by enhancing inter-jurisdictional collaboration between First Nations, provincial/territorial and federal human resources on a continuing basis.

**Recommendation #99:** Creative designing of new positions within the public health profession should be developed for introduction to the currently unemployed in order to attract them to health careers. Roles in disease surveillance are one example.

**Recommendation #100:** Funding should be made available for assisting in developing on-the-job training programs that would allow for the cross-training of other health professionals so that they could acquire the skills needed to be able to bolster surge capacity in public health emergencies in all jurisdictions.

**Recommendation #101:** FNIHB regions should examine their hiring policies which often support internal hiring rather than looking more broadly at First Nations for available qualified workers, such as licensed practical nurses.

#### **International Models**

The pervasive concern regarding Canada's First Nations public health system prompted a review of alternative international models for organizing and funding essential public health programs and services that other countries use for their residents and, where appropriate, their Indigenous populations.

In addition to funding lessons, it would appear that Canada has a lot to learn including other countries' approaches to health data collection, Indigenous populations, and governance and accountability mechanisms, as well as their views on cross-ministerial policy making.

#### Recommendations

**Recommendation #102:** There is a need to consider the feasibility of creating a First Nations public health infrastructure that would include the legislative recognition and accountability in a similar style to that taken in New Zealand. Legislation regarding the roles and responsibilities of public health agencies and First Nations governments would create the impetus for First Nations and non-First Nations stakeholders to work together at all levels and develop working relationships. In the case of New Zealand, public health legislation provides the basis for these with Indigenous groups in all sectors and across all levels of health, and has improved the whole process of self-governance and self-determination for Maori groups.

**Recommendation #103:** A policy of joint federal/First Nation development and meaningful First Nations engagement at the national, provincial, regional and local levels needs to be created. This will address First Nations needs within the broader system. An official consultation policy has been developed and implemented in the U.S..

**Recommendation #104:** There is a need to consider and analyze the feasibility of implementing the District Health Board model of New Zealand in Canada. In doing so, there should be an evaluation of the effectiveness of implementing service provider contracts between provincial District Health Boards/Regional Health Authorities and newly created First Nations public health agencies to provide more comprehensive, coordinated and integrated approaches to the delivery of public health services to First Nations populations.

**Recommendation #105:** The possibility of fusing public health with the primary health care models in communities has been identified where critical mass does not allow for resources dedicated to both. This concept is being used by New Zealand, with both the U.S. and England considering adopting this system where resources in small communities are being spread too thinly.

## **Summary**

Experience in other countries as well as in Canada has generally indicated a lack of sustained interest in public health infrastructure by decision-makers unless faced by a crisis. The circularity of the argument is evident since one will not be able to adequately respond to the crisis unless the necessary infrastructure is already in place. Incremental system development by public inquiry and royal commissions is not a preferred option. Addressing the deficiencies in the "system" is challenging since there are varying points of accountability for First Nations. Since the system's functions and performance are not clearly defined, it is difficult to explicitly address systematic gaps. Considering that the purpose of the system is to protect First Nations and improve their health, a lack of clear accountabilities is not in our collective interest.

On an ongoing basis, governments periodically announce initiatives for specific issues such as smoking, physical activity, and obesity. At the local level, one needs the capacity to deliver the programming for these various initiatives and do so in an integrated fashion. It is the formal governmental public health agenda (e.g., provincial public health departments, regional/local public agencies) in collaboration with community partners (e.g., NGOs) that are the stable delivery vehicle. Without this structure in place, one is faced with propping up temporary, unsustainable, issue-specific structures. Many multi-sectoral initiatives currently in development assume and will depend on the existence of a strong public health system infrastructure upon which to build (e.g., Healthy Living Agenda; Chronic Disease Prevention Alliance of Canada; Emergency Preparedness). The reality is that a strong, consistently and equitable resourced and integrated system does not exist at all within First Nations communities.

Recognizing the differences in geography and health care systems across the country, flexibility in how services are delivered will need to be maintained. However, whether it is individual communities themselves, or in collaboration with each other, or via provincial/federally delivered programs, this should not be a barrier to ensuring that essential functions are delivered.

The changes that need to occur across the country are substantial and will not occur without a dedicated process to achieve the vision outlined above. While there are many potential places one could start, for discussion purposes, some immediate recommendations have been made above.

Action must be taken at all levels of the framework, by all parts of the First Nations sector, nationally, regionally and locally. There is a role for all of us to play in reducing health inequalities for First Nations. The wider social sector also has a significant role, but here we have focused on what the health and disability sector is responsible for, and how it can work with other sectors to effect results. Key players in our sector are:

- National Chief;
- Chief's Committee on Health;
- Regional Health Directors and Health Technicians;
- policy advisors and decision-makers, especially the Ministry and Departments of Health, the minister of Health and Cabinet colleagues;
- funders and providers of health services, including District Health Boards, hospitals, non-government organizations and primary health care organizations;
- local government; and,
- communities, through generating community action.

Clearly, the task is not solely one for governments. We all have a role to play – as individuals, groups, organizations, and employers. Good health does not just happen; it is created in our homes, communities, schools and workplaces, through organizational actions and supportive policies that contribute to healthy social and physical environments and influence the choices we make as individuals. This framework is only the beginning and reflects many of the commitments made by First Ministers in Kelowna in November, 2005. We envisage that this will assist with laying the foundation that ensures the healing of First Nations communities to provide an environment that guarantees opportunities for all to achieve good health.

# **Glossary**

#### **Community Health**

A perspective on public health that assumes community to be an essential determinant of health and the indispensable ingredient for effective public health practice. It takes into account the tangible and intangible characteristics of the community – its formal and informal networks and support systems, its norms and cultural nuances, and its institutions, politics, and belief systems.

#### **Communicable Disease**

An illness due to a specific infectious agent or its toxic products that arises through transmission of that agent or its products.

#### **Determinants of Health**

The range of personal, social, economic and environmental factors that determine the health status of individuals or populations.

#### **Disease Prevention**

Disease prevention covers measures not only to prevent the occurrence of disease, such as risk factor reduction, but also to arrest its progress and reduce its consequences once established.

#### **Health Promotion**

The process of enabling people to increase control over, and to improve, their health. To reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and realize their aspirations, to satisfy needs, and to change or cope with the environment.

#### **Health Protection**

This refers to actions that protect Canadians against health and safety risks. Science (providing evidence), surveillance (monitoring and forecasting health trends), risk management (assessing and responding to health risks) and program development (taking action) form the basis of health protection activities.

#### **Health Status**

A description and/or measurement of the health of an individual or population at a particular point in time against identifiable standards, usually in reference to health indicators.

#### **Health Surveillance**

Surveillance is the ongoing, systematic collection, analysis and interpretation of health data essential to the planning, implementation, and evaluation of health practice, closely integrated with the timely dissemination of these data to those who need to know. The final link of the surveillance chain is in the application of these data to prevention and control. A surveillance chain is in the application of these data to prevention and control. A surveillance system includes a functional capacity for data collection, analysis and dissemination linked to public health programs.

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#### **Infectious Disease**

A clinically manifest disease of humans or animals resulting from an infection.

#### **OCAP**

Ownership, Control, Access, and Possession (OCAP) of information are principles that affirm First Nations rights to self-determination in the area of research. Ownership affirms that First Nations have a right to own their cultural knowledge and all information that is produced from this knowledge. They have the right to control information and research about them and they must have access to information about themselves and their communities without facing any barriers. They must have access to their information for their communities without facing any barriers. While ownership describes the relationship between a people and its information in terms of a right, possession is the physical control over the information.

## **Population Health**

This refers to the health of a population as measured by health status indicators and as influenced by social, economic and physical environments, personal health practices, individual capacity and coping skills, human biology, early childhood development, and health services.

#### **Public Health**

The combination of sciences, skills, and beliefs that is directed to the maintenance and improvement of the health of all the people through collective or social actions. The programs, services, and institutions involved emphasize the prevention of disease and the health needs of the population as a whole<sup>1</sup>

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# **Appendix 1: Department of Health and Human Services Operating Divisions**

#### **National Institutes of Health**

Premier medical research organization, supporting over 38,000 research projects nationwide in diseases including cancer, Alzheimer's, diabetes, arthritis, heart ailments and AIDS. Includes 27 separate health institutes and centers.

FY 2005 Budget Allocation: \$28.6 billion

## Food and Drug Administration

Assures the safety of foods and cosmetics, and the safety and efficacy of pharmaceuticals, biological products, and medical devices

FY 2005 Budget -- \$1.8 billion

#### Centers for Disease Control and Prevention/Agency for Toxic Substances and Disease Registry

Working with states and other partners, CDC provides a system of health surveillance to monitor and prevent disease outbreaks (including bioterrorism), implement disease prevention strategies, and maintain national health statistics. Provides for immunization services, workplace safety, and environmental disease prevention. CDC also guards against international disease transmission, with personnel stationed in more than 25 foreign countries. The CDC director is also administrator of the Agency for Toxic Substances and Disease Registry, which helps prevent exposure to hazardous substances from waste sites on the U.S. Environmental Protection Agency's National Priorities List, and develops toxicological profiles of chemicals at these sites

FY 2005 Budget -- \$8 billion

#### **Indian Health Service**

Working with tribes, the IHS provides health services to 1.6 million American Indians and Alaska Natives of more than 550 federally recognized tribes. The Indian health system includes 49 hospitals, 247 health centers, 348 health stations, satellite clinics, residential substance abuse treatment centers, Alaska Native village clinics and 34 urban Indian health programs.

FY 2005 Budget -- \$3.8 billion

#### **Health Resources and Services Administration**

HRSA provides access to essential health care services for people who are low-income, uninsured or who live in rural areas or urban neighborhoods where health care is scarce. HRSA-funded health centers will provide medical care to almost 14 million patients at more than 3,700 sites nationwide in FY 2005. The agency helps prepare the nation's health care system and providers to respond to bioterrorism and other public health emergencies, maintains the National Health Service Corps and helps build the health care workforce through training and education programs. HRSA administers a variety of programs to improve the health of mothers and children and serves people living with HIV/AIDS through the Ryan White CARE Act programs.

FY 2005 Budget -- \$7.4 billion

#### **Substance Abuse and Mental Health Services Administration**

SAMHSA works to improve the quality and availability of substance abuse prevention, addiction treatment and mental health services. Provides funding through block grants to states to support substance abuse and mental health services, including treatment for more than 650,000 Americans with serious substance abuse problems or mental health problems. Helps improve substance abuse prevention and treatment services through the identification and dissemination of best practices. Monitors prevalence and incidence of substance abuse.

FY 2005 Budget -- \$3.4 billion

#### Agency for Healthcare Research and Quality

AHRQ supports research on health care systems, health care quality and cost issues, access to health care, and effectiveness of medical treatments. It provides evidence-based information on health care outcomes and quality of care.

FY 2005 Budget -- \$319 million

#### **Other Agencies (Human Service)**

#### **Centers for Medicare and Medicaid Services**

Administers the Medicare and Medicaid programs, which provide health care to about one in every four Americans. Medicare provides health insurance for more than 42.1 million elderly and disabled Americans. Medicaid, a joint federal-state program, provides health coverage for some 44.7 million low-income persons, including 21.9 million children, and nursing home coverage for low-income elderly. CMS also administers the State Children's Health Insurance Program that covers more than 4.2 million children.

FY 2005 Budget -- \$489 billion

#### **Administration for Children and Families**

ACF is responsible for some 60 programs that promote the economic and social well-being of children, families and communities. Administers the state-federal welfare program, Temporary Assistance for Needy Families, providing assistance to an estimated 5 million persons, including 4 million children. Administers the national child support enforcement system, collecting some \$21.2 billion in FY 2003 in payments from non-custodial parents. Administers the Head Start program, serving more than 900,000 pre-school children. Provides funds to assist low-income families in paying for child care, and supports state programs to support foster care and provide adoption assistance. Funds programs to prevent child abuse and domestic violence.

FY 2005 Budget -- \$47 billion

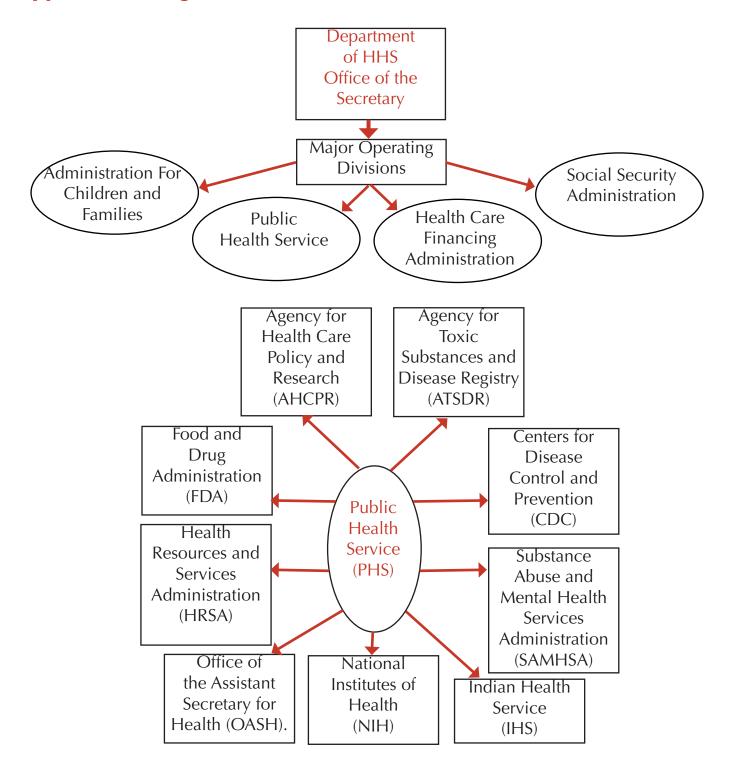
#### **Administration on Aging**

AoA supports a nationwide aging network, providing services to the elderly, especially to enable them to remain independent. Supports some 240 million meals for the elderly each year, including home-delivered "meals on wheels." Helps provide transportation and at-home services. Supports ombudsman services for elderly, and provides policy leadership on aging issues.

FY 2005 Budget -- \$1.4 billion

Departmental leadership is provided by the Office of the Secretary.

# **Appendix 2: Organization of U.S. Health Services**



# **Appendix 3: Baseline Measures Workgroup**

10 Highly Recommended Measures

The ten highly recommended (not mandatory) measures are:

- 1. Age specific overweight and obesity prevalence rates;
- 2. Prevalence of tobacco use;
- 3. Prevalence of alcohol and drug dependence of adults, youth, and pregnant women;
- 4. Rate of family violence (child, spouse, Elder abuse and neglect);
- 5. Number and percent of homes (existing and new) with deficiencies in sanitation of drinking water and waste disposal, by community;
- 6. Rate of hospital discharges and ambulatory clinic visits for injury;
- 7. Proportion of population screened for cancer of the uterine cervix, breast cancer; and for colo-rectal cancer;
- 8. Immunization rates of all age groups in accordance with Advisory Committee on Immunization Practice (ACIP) recommendations;
- 9. Incidence and prevalence of diabetes mellitus; and,
- 10. Collaboration or incorporation of community values or spiritual healing at facility, with respect for individual beliefs.

# **Appendix 4: Regional Focus Group Feedback**

This report is a summary of discussions occurring during various focus groups held at the regional levels. These focus groups were held in each of the 10 Regions between February and May, 2006. More than 250 participants attended.

The purpose of these focus groups was to attain feedback on the First Nations Public Health Framework. A consultation guide was forwarded in advance to the participants. However, the focus groups were not strictly directed by this guide. Rather, participants were allowed to raise issues of importance to them. Thus, the importance of these focus groups lies in the fact that they are derived from a First Nations perspective.

# Summary of identified issues in the Yukon

In a discussion on self-governing First Nations (SGFN), participants in this focus group noted several important issues. One participant pointed out for example that they want to set their own objectives in addition to wanting their own responsibility in the development of land claims agreement implementation policy, including health reform. It follows that First Nations have the authority to design a diversity of forms for their governing institutions so that these institutions will reflect their diverse traditions, needs and preferences. In the view of one participant, the Government of Canada has no role to play here. More specifically, in the area of health, one participant made the suggestion that middle-men need to be eliminated from the process so that expenditures go directly to First Nations communities. This participant believes that as a result, there would be more dollars and consistency of planning, hence, SGFN would have the authority to decide for themselves on what the important issues are.

Other participants reiterated these sentiments to varying degrees, for example, one participant noted that each and every community must have a say in what happens, there needs to be a body that is advised by communities. This participant noted that rather than having a secretariat, there should be a First Nations public health agency, a northern office for example. Another participant strongly urged that if a northern office were to be established, there would need to be input on how it would be developed from a First Nations point of view.

Another participant further pointed out that SGFNs have realized that they simply cannot do everything by themselves and it is essential that they discuss issues collaboratively. Participants further agreed they somehow needed to be more visible in rural areas, where collaboration with agencies and governments remains non-existent. Similarly, one participant noted that these concerns are related to what occurred with child welfare in relation to the cogovernance model. Governments have continued with the status quo, while First Nations are advocating for change. One participant continued to point out that this type of collaboration has not been well received. PSTA cautioned on the types of relationships that are developed and if they are compromised when they are negotiated. For SGFN, they look to the Assembly of First Nations (AFN) for advocacy, however other participants argued that in a perfect world, SGFN would have their own jurisdiction and would go directly to the source without the consultation and aid of the AFN. One participant felt that PSTA individuals should look at a framework, there may be a position paper worth examining. There was also some concern that the AFN had gone too far down with the Framework development without sufficient regional consultation. Another participant noted that the blueprint needs to be taken into consideration. The blueprint speaks to key principles that were agreed to by leadership and this needs to be built into the framework.

SGFN also raised concerns on how the proposed Public Health Act would affect them given that they have the right and authority to create their own laws, moreover, they have jurisdiction for all citizens, but this jurisdiction needs more leverage.

Other participants also spoke of health human resource issues in a First Nations health system. Here, lay people and different types of training are required, thus the blueprint needs to acknowledge how a First Nation accesses health care, i.e., CHR. One participant believed that there has been no regional support for para-professionals. Another participant pointed out that it is often the North that is the most severely affected in terms of shortages and upcoming shortages. There needs to be assurance that community perspectives will be more valuable to the process.

Participants believed more efforts should be made to convey the definition of community as it is different in the Yukon and therefore another option should come into play. SGNF deliver services to entire communities, i.e., home care and then bills the Yukon Territorial government (YTG). Thus, as one participant noted, it makes sense to go through with an agreement for services and make it official. Another participant noted that a further option is to have the YTG purchase services from SGFN.

# Summary of identified issues in the Atlantic

Those participating in the Focus groups in the Atlantic region raised similar concerns to those in the Yukon. For example, one participant noted that there was a lack of a coordination approach, thus, communities do not feel well connected with each other. More communication and collaboration needs to occur amongst communities. Another participant discussed the lack of health data. While there is a substantial amount of information, it is often difficult to gather. This participant pointed out that data needs to clearly define the illness rates.

A further issue that arose during discussions was the lack of health human resources, for example, a nurse has the responsibility of conducting public health and acute public health care. One participant noted that a single individual can consume the majority of the nurse's time, thus it is unreasonable to expect nurses to conduct public health nursing in addition to their other responsibilities. Most participants agreed that there needs to be more dedicated health resources and that communities need to network as it is essential to get feedback. Communities need to be linked together in the system in addition to being a part of a broader system. Participants agreed that they need to look at how and what would be needed to support this type of infrastructure. A public health system is a long term agenda, it does not compete on a yearly basis for new funds. Some participants also raised concern over how to manage "the system" and where to access the expertise.

With respect to community services, participants pointed out that a lengthy review of programs are offered to the provinces but not First Nations communities. The participants listed the following programs offered to the provinces:

- Belledune Soil Sampling;
- Health Learners in Schools:
- Information Handbook for Health Care Providers; and,
- Nutrition Programs delivered by social workers.

Participants pointed out that in New Brunswick, there are twelve communities that are all at different stages while others appear to be more organized. Participants agreed that people need to be further educated on matters. In Nova Scotia, there is a relationship between public health and First Nations communities. One participant noted that for resource material, First Nations living in Nova Scotia need to purchase their material from public health, complimentary training is also provided through public services and resources are purchased through the First Nations and Inuit Health Branch (FNIHB). These fall under community health resources through FNIHB.

Participants further pointed out that immunization is a problem in New Brunswick. Communities have complained that they do not have automatic information to know what is available and therefore it is difficult to find out what is new for immunization. One participant noted that the problem is now knowing what to ask for. Communication links, provinces and FNIHB should be the ones advising on new vaccine protocol for each province, participants agreed that communication is simply not there.

In Cape Breton, issues have been focused around the needs of the communities as funding has not been available. They have been using existing resources to meet those needs and have had to be creative with their finances. For example, one participant argued that there is not sufficient funds for nutrition available in smaller communities and hoped that a transfer would give more flexibility. Larger communities have more opportunities to apply for funding and resources. A further issue that was discussed amongst participants is the lack of Aboriginal nurses. One participant noted that FNIHB does not hire Aboriginal nurses and that a Masters degree is often required to be hired at their office.

Some participants have pushed for a memorandum of understanding (MOU) between the District Health authorities, as this currently does not exist. When trouble does occur, jurisdictional issues come into play. One participant has noted that this is an old issue that needs to be urgently addressed. This participant further noted that provincial services are provided to them for hospitals and specialists, however, not everyone may agree to deal with it. In the more progressive communities, they have moved on to make things happen. Another participant has noted that concern revolves around access and safety for First Nations people. Further collaboration is needed for access and services. Participants agreed that communities need to receive money directly or let the provinces handle these issues. They pointed out that it was important not to give to FNIHB as communities will not get what they need, this would just involve more workers who are not involved at the community level. One participant argued that in Cape Breton, FNIHB provided services whether First Nations lived on or off reserve. They even provided services to nonnative community members that live on reserve, non-natives are counted under CWIS. Participants noted that in the ADI program, those who are living on reserve have a coordinator to work closely with, there needs to be a similar system in place for those living off reserve. There is currently no framework in place to ensure that those living off reserve are receiving the same services as those living on reserve. Participants argued that there needs to be more clarification on who is going to provide off reserve services. One participant noted that the Friendship Centre does not have sufficient resources. More funding and services to the Friendship Centers in every province are required if they are to be part of the system of delivering public health services. Individual communities need to know what programs exist for their off reserve members.

A further area of discussion centered around smaller, more isolated communities. One participant suggested that video conference for isolation work may be valuable and worth promoting. According to most participants, if all health centers are linked, this will provide more opportunities to network and share with others. In Newfoundland,

they have an MOU with public health services in NFLD and pay a minimum fee per year. They work in partnership to provide services to the communities and are working well together. A similar process is also occurring in Labrador. Participants agreed that Newfoundland and Labrador are positive examples of what can be done.

One participant indicated that in New Brunswick, political will is unpredictable. This participant continued to point out that there are two political organizations, MAWI and UNBI. MAWI is responsible for the three larger communities while UNBI is responsible for the remaining twelve communities. This participant argued that geographically, this arrangement does not make sense. In terms of money, this participant has noted that it appears to be a waste of resources. Ten to fifteen years ago, this type of arrangement would have made sense with no future changes to be made.

Suggestions were made for home and community in the Atlantic to split up the region, i.e., to have one for Nova Scotia, Newfoundland and Labrador and one for New Brunswick and Prince Edward Island. These participants pointed out that this appears to be working well in the communities with the size of the geographical area. One participant noted that it would be useful to link these with the province and FNIHB and anyone else that would be beneficial in making this process work. Participants agreed that this would work well because Health Canada would provide the funding. Participants further noted that it would be worth having an MOU between the four provinces. In the end, partnerships would develop and sharing of resources could occur.

One participant also argued that data collection in communities should be mandatory. Data needs to be collected in order to have numbers to support various programs. Other participants agreed that if this were to occur, this would have to be legislated as to who would own the data and where it would be managed.

Participants also raised concerns about funding. One participant noted that in order to get funding, communities are required to do way too much for way too little. Communities would like to take their own initiatives without support from FNIHB.

Participants also noted the following concerns:

- First Nations in Nova Scotia are demanding that more health promotion activities are needed. This is especially important in schools;
- It is important to realize that smaller communities are faced with different priorities than those coming from larger communities. These differences need to be acknowledged;
- The Nurse specialist in Ottawa and the nurse specialist in the region need to collaborate and communicate more effectively;
- There needs to be more MOU between First Nations communities, the federal government and the provinces;
- More communities need to implement telehealth;
- Under the Public Health Act, there needs to be emergency preparedness training of staff. This should be the responsibility of Indian and Northern Affairs Canada; and,
- It is not necessary to have a regional MOH from FNIHB, instead, it is worth exploring a secretariat option. Similarly, it is worth hiring a provincial MOH to be specific to the needs of First Nations.

# Summary of identified issues in British Columbia

It is important to point out that this focus group was not provided with the facilitation guide prior to the meeting unlike other regional focus groups an as such felt that they were unable to participate fully without consultation with their communities and leadership.

This focus group began the discussion by pointing out that British Columbia First Nations provide their own services with regard to Nursing Services and need to continue to do this whenever possible. This service includes all Communicable Disease Control. These participants noted that the ability to provide more nursing time in the communities creates disease prevention and health promotion. Participants further agreed that concern lies with the determinants of health. The discrepancies created are with INAC funding for housing and maintenance in addition to the provincial guidelines for what constitutes a health home. This needs to be worked out so that policy on reserve may reflect some of the provincial policy and First Nations communities are not allowing elders and others to stay in homes that should be condemned. One participant pointed out that health issues appear to get caught between the Band and INAC. Participants argued that again INAC plays a large part in the safety of the water, many times it becomes a further financial restraint because of wells, lines and sewers. Health again is in the middle with no way to contribute until the Bands and INAC come to a decision about what needs to be done.

One participant believed that injury surveillance is not adequately funded for community members and needs to be funded for communities to begin to address prevention. Participants agreed that programming in the communities is increasing, but fear of getting a program started and funding being cut, is always a reality. First Nations are at the mercy many times of the election process. Participants further suggested that First Nations need to lobby for telehealth and the ability to gather their own statistics. This is similar to the concerns raised by participants in many of the other regions. Participants agreed that they would prefer to see each community have their own system, however, a regional level would work better than a national level. First Nations need to push forward gathering statistics at all provincial organizations. It is not sufficient to only have statistics that the provincial health officer provides.

Participants agreed that First Nations do not want anymore levels of funding, they need to continue to lobby on behalf of funding that comes in from the community levels. FNIHB has provided funding to the CHC for Advocacy on behalf of NIHB. Many of the participants believed that this does not make sense as they are dealing with the concerns at the grassroots level. There needs to be education on behalf of community members on what is available and how to access NIHB. Participants noted that this is simply not happening. Participants maintain that FNIHB needs to communicate the changes and updates quarterly. All First Nations children and Youth should have costs to their health care fully covered with no exceptions until the age of 19. This may result in more positive outcomes of health for the future generations if it is combined with prevention. Participants noted that the next step is to continue to collaborate with the provincial government and the federal government programs while continuing to increase the capacity in communities by assisting members in receiving education and training for their positions and further develop a strong human resource capacity. Participants also noted that it is important for the funding formula to change and reflect the age, gender and total population base. It is important to point out that every band is at a different level of socio-economic development and funding should reflect income levels, remoteness, cost of living and population growth.

Participants agreed that four key issues have been identified as challenges to healing First Nations peoples mental health funding remains the same and needs to be increased. These four areas include residential school experience, suicide, abuse in all forms and alcohol and drug abuse. Participants pointed out that the ability to collaborate with provincial programs is increasing, however, the knowledge and understanding is imply not there. Many suggested that community based health initiatives need to be in place.

Participants pointed out that the First Nations on Vancouver Island are engaged in the strategic planning initiatives with the VIHA and are demanding more input and direct representation on the VIHA Board of Governance. This position is a challenge in overcoming greater understanding of varying government roles and how they could compliment one another. This is a further opportunity for using the Integration Funding available. Some participants felt that purchasing services creates an immediate two tiered privatization system that could further isolate and estrange First Nations from access to publicly funded healthcare that they have a right to under the Canada Health Act. Some participants suggested that this could be an option without an exchange of money. First Nations direct the services from local Regional Health Authority or Public Health Unit. It could be from Regional Has, from the FNIHB or a combination. First Nations would direct what the service (within an approved framework) will be and it is delivered by a combination of existing and enhanced resources. Some concerns were also raised with regard to option 2, i.e., providing their own services. Participants agreed that this could put communities in direct competition with one another and would leave smaller communities to fend for themselves. They pointed out that it is the smaller communities that have the poorest health conditions and health outcomes.

Surveillance is also a concern because of the lack of information flowing across a continuum of care that First Nations would access from Public Health to Acute Care or Continuing Care. The vision for British Columbia is the continuum across jurisdictions of F/P/T and First Nations and addresses the full spectrum of Public Health in the broadest sense, while at the same time speaking to other parts of the healthcare system of acute, community and the other social determinants (housing, education, economic, employment, and social safety). Participants pointed out that for a client registry, informed consent for each piece of health information gathered, the First Nations member should be informed of exactly what the information is being used for, where is being stored and who has access to it. The layers of data collection would also need to be provided as part of the informed consent (numbers, gender, age groups) and where it is stored, who has access to it and why. Participants raised the following questions concerning surveillance: What and whose purpose does the health information collected by First Nations on services provide within First Nations communities and health information collected by provinces and territories serve by provincial and territorial public health facilities serve? How would it be regulated and safeguarded? How would "buy in" occur from both the First Nations and the provincial/territorial public health facilities to collect this data? How would this be coordinated?

Participants further noted that public health for British Columbia First Nations is a mandatory program that many First Nations have provided very successfully for decades. It is a program with many strengths and often offers better coverage than provincial programs. These participants pointed out that the options list seems out of touch with what is occurring in public health for First Nations. They agreed that it does not seem that the service delivery at the community level needs changing. Participants further pointed out that it is necessary to use more resources, particularly more nursing hours. Many of the smaller communities lose many nursing days a year to train, attend meetings and work on projects, for example, assisting in developing the pandemic plan. One participant spoke of their particular nurse who must attend the same number of sessions as a full time nurse, thus smaller communities

experience a proportionately larger loss of service hours. Participants agreed that the funding formula must address these shortfalls for smaller communities. They recommended increasing days of work by 10-15 days per year for the time the nurse is away from the community.

In their discussion on the use of data, participants noted that First Nations want their own data to be kept and controlled at the community level. This data is required across programs and is best collected and kept within communities. They recommended collecting generic date from each community which identifies program delivery and outcomes. Participants agreed that imposing a one size fits all model would not be effective. Participants further felt that another agency and/or bureaucracy is not necessary. Participants strongly believed that health funding should be directed to the community level rather than toward another bureaucracy. The federal government could support program delivery by reducing bureaucratic requirements. It could support off reserve members by allowing the members who access on reserve services to be included in the CWIS data and therefore be funded. Participants also recommended coordinating and simplifying governance to ensure equity and reduce time consuming unproductive negotiations, meetings and reporting.

In their discussion on the Public Health Act, participants agreed that unless there is an obvious benefit, a further set of laws may not be helpful but will just add to the requirements for First Nations health services. There needs to be a support initiative and flexible educational opportunities for members to develop accredited training in the health field. Participants recommended offering laddered education or part time accredited education.

Participants agreed that option 2 for service delivery supports the concept of self-government while option 3 encourages relationship building and shared capacity resources. There is some concern about a residual approach to health. Participants noted that off-loading without adequate administrative and financial resources to sustain change is bound to fail.

Participants agreed that the status quo option does not support self-determination or self-government. The status quo will continue to perpetuate "ill-health" for Aboriginal people. Participants believe that Aboriginal people cannot continue to deal with primary health in isolation of the social determinants of whole health, there needs to be a multifaceted and coordinated approach, one that listens to and addresses the needs of those that health is trying to serve.

In their discussion on programs and services, participants recommended streamlining and enhancing programs that have been successful in both on and off reserve settings. There needs to be stronger communication with one another across regions, provinces, territories and jurisdictional boundaries. This needs to occur in a respectful way in order to discover what has already been done, what works best and to recognize where capacity exists so that a process can begin of downsizing the supervisory role of government which can continue to reach towards the objective of self-government. Participants also noted that it would be useful to visit other regions to see what they have done to enhance self-determination. Participants strongly stated that Health Canada, INAC and FNIHB should not be controlling the services, communities have the capacity and would like that responsibility for themselves. However, another participant wondered whether if First Nations are going to take over, is there going to be enough funding available to meet the needs of the community? Would this funding come out of the blueprint? It was also stated that it is not the population size, rather the needs of the community that needs to be further examined.

Participants also stated the following questions and concerns:

- Will the pilot provincial health program turn to First Nations for proposals?;
- There is a need for an MOU with federal/provincial government and First Nations organizations to list deliverables:
- There is concern with regard to isolated communities, these communities have frustrations with access to services. People are dying on the way to the hospital because of the long drive. This needs to be acknowledged and addressed; and,
- Health Canada needs to increase their funding when costs increase.

# Summary of identified issues in Manitoba

This focus group briefly discussed the gaps identified in the current public health programs. Participants identified the following concerns:

There are poorly defined CDC programs as far as follow up goes. Child health clinics are still not based on good evidence practices. Community postpartum and midwifery services including prenatal classes are lacking in Manitoba. There are some nursing services that do not even have the capacity to do pregnancy testing, thus, these services need to be acknowledged and addressed. There is also a lack of inclusion of traditional healers within communities. Traditional healers are often difficult to access because of distance and costs. It was pointed out that mental health workers come in one day a week, however, participants feel that this is useless as they do not get to know members of the community.

Participants agreed that population numbers used by FNIHB to fund programs do not reflect what the true population is. For example, one community suggests that there are 2, 500 diabetics in that particular community, however, FNIHB acknowledges that the entire population of that community is only 1000. Participants agreed that there needs to be more diabetes screening clinics in their communities. Participants also noted that Manitoba has had the same budget for the last 15 years for their tribal councils to do health promotion. They are always proposal driven and there appears to always be more proposals than dollars.

There appears to be a lack of community ownership in the area of community wellness.

Participants noted that CHRs have too many programs to deliver. Participants also pointed out that training dollars are not part of transferred dollars. The impact of Bill C-31 is still having an impact on community funding. Participants noted that the remoteness factor of some communities does not take into consideration distance from the airport, winter roads or boats. Participants agreed that while equalization payments exist, there is no accountability to First Nations for money received on their behalf. Participants argued that there needs to be an establishment of a regional health and social commission with a linkage to the PHAC. Participants also believe that there needs to be a First Nations led with similar policies and procedures by central role of elders and traditional healers. Participants also noted their concerns around the framework. One participant asked how the current debt would be handled – in Manitoba the debt runs as high as 15-20 million dollars. Participants also recommended increasing the role and numbers of EHOs Participants concluded the session by suggesting that more people need to be included in the focus group session particularly in the area of the Public Health Act.

# Summary of identified issues in Saskatchewan

Participants in the Saskatchewan focus group pointed out many gaps that they have been confronted with in relation to public health programs. Participants identified the following concerns:

- There appears to be a lack of science teachers which are desperately needed in schools, funding has often been tied to qualified personnel;
- Participants also noted that breast screening tests need to exist in more communities;
- Fetal Alcohol Spectrum Disorder programs are also desperately needed in communities;
- Participants noted that speech language services are also needed;
- Occupational health is needed in communities;
- Traditional health and healers are also needed in communities and need to be integrated into programs; and.
- Participants also agreed that more diabetes and cancer prevention programs as well as treatment centers are also needed. While these services are available, the quality is often poor.

Participants were also concerned for remote communities as they do not have access to many of the services discussed above. Participants also noted that urban programs are not funded to be specific for First Nations living away from their communities. There is a lack of awareness of programs away from communities as well. Participants further noted that NIHB needs to be enhanced to maintain health and prevent illness to reduce burden on Bands. Traveling from home to where the services are located, are presenting major barriers for First Nations and the Band who has to fund this. Participants noted that there also appears to be a lack of human resources to support the needed programs. It is often the nurse who decides in many cases which programs she wants to run. One participant made the important point that services need to acknowledge First Nations with disabilities with respect. Similarly, wheelchair accessible programs that respect the needs and not just the population alone are needed.

In their discussion on options for seamless delivery, participants agreed that Boards of Health should be established. They further suggested that friendship centers and forum directions in Regina may be centers to provide urban health. There should also be a regional body with appointments at the national level to work with OAHC. However, the renewal system that exists now is opposed to new initiatives which takes away from the expertise and dollars currently being spent on communities. One option may be for the Public health secretariat to go through the existing First Nations health bodies and to advocate at the national level.

In their discussions on the Public Health Act, participants believed that there could be a sense of unity for First Nations that is more reflective of the needs across the country. Participants also argued that water standards, CDC, and housing all need to be included in the Public Health Act. The act should also be federal because of treaty rights, however as one participant observed, reference to the province would be essential as they deliver to hospital services.

In discussions on surveillance systems, participants felt that these systems could potentially illustrate that First Nations are in fact using health services at a much higher rate than what they are being funded. Participants agreed that communities would need to be very clear about the type of information that would need to be collected, for what purpose and who would own it before a client registry could be developed.

Participants also raised concerns about the framework. RHA deals with their own shortages, thus, they would unlikely be able to increase service provisions to First Nations. Concerns were also raised by participants that private suppliers may not provide value for dollars. Issue of enforcement was also raised as a concern, participants noted that there is a need for the Chief in council to provide their blessing. Cost sharing should be provided as a fifth option with health districts or First Nations communities that have their own services that they could sell. One participant suggested that the tribal health council should be the RHA so that individual agreements would not confuse the delivery of public health as many communities have different CA and are either transferred or not. Participants in Saskatchewan preferred the third option if the Tribal health council were used as the lead.

Concern was also raised as to how NIHB services would be affected, i.e., mental health, dental, vision and transportation. The question was posed whether or not the Public Health Act guaranteed accessibility and would it permit enforcement? Another participant wondered how conflicts would be handled when the Chief was meant to close a restaurant he owned?

## Summary of identified issues in Alberta

Participants in Alberta agreed that a holistic approach to developing this particular structure and being aware of all of the different cultures in the province is necessary. They noted that the definition of "health" also differs in every community and these issues need to be identified and addressed. These participants noted that there needs to be more money allocated to the First Nations communities. The responsibility needs to reside with the First Nations communities, not within the government. There also needs to be more serious discussions regarding treaties. Participants argued that there needs to be recognition of section 35 (1) of Canada's Constitution Act, 1982 and thereby moving policy based programs and services to the obligation of these programs and services by the government through treaty rights.

Participants also agreed that there needs to be a collaboration of all proposed framework options and there may be some communities that want to purchase services but may also want to provide other services to their own respective community. Participants agreed that there should be an ability to 'pick and choose' what each specific community wants in regards to services. This would allow them the freedom and responsibility to administer their own tailored programs and services. Participants continued to point out that funding can be addressed by creating an obligation to put these issues in place for First Nations. Again, participants noted that this process could take place under section 35(1) of Canada's Constitution Act, 1982. One participant asked how regional authorities are funded to create First Nations formulas and premiums for specific programs and services. This participant questioned the costs, specifically funding and finances available to implement these options.

Concerns were also raised amongst participants with regard to privacy issues. One participant argued that there are no policies or oaths in place with respect to confidentiality when it comes to information that is being gathered on reserve. Participants agreed that trust has to be built within health centers on reserve and there should be small programs that build on this and grow from there. Consent needs to be discussed with community members and how these goals can be achieved.

There needs to be mechanisms in place to address these concerns and they are as follows:

- Oaths of Confidentiality;
- Surveillance records;
- Repercussions or sanctions imposed for release of personal information;
- The doctor on reserve should ultimately be the one with access to personal files of the community members; and,
- Communities should be managing their own data and then sending reports directly to Ottawa.

Participants also discussed connectivity as an issue. First Nations in each community would like to be able to discuss issues with each other, however, one participant pointed out that more funding for equipment and training would be necessary to make this happen. Participants also noted that there should be a more focused approach that comes from a grassroots sector that will include a more holistic approach that integrates all of the principles of the First Nations communities. All participants agreed that there needs to be development and implementation processes that will allow people who know what is going on within First Nations communities to have input on this entire process from start to finish.

## Summary of identified issues in Ontario

Participants in this group began the discussion by raising concern over the work of the stakeholder as opposed to the key informant. There is the issue around the need to be part of the system, often First Nations are forgotten. Participants noted that when you look at the health status of First Nations across Canada, the situation is not positive. When the provincial and federal governments make decisions, First Nations are always left out of the equation. There was further concern that if a recommendation goes forward, First Nations do not want to get lost in the system.

Participants were also concerned around inclusion of LHIN. Chiefs are currently becoming involved in the LHIN structure now that it is in provincial legislation. These participants perceive that being involved in the LHIN area will diminish treaty rights to health care. In some cases, people simply do not have a choice such as the Northern Diabetes Network and collaboration for those services that are with the general population. Participants noted that people will not have a choice and they will fall within LHIN automatically. One participant observed that in the south, there would have to be approval first and Chiefs state that by doing so, you are watering down your treaty rights.

Concern was further raised around financial resources involved. Participants noted that problems exist with keeping the status quo as an option as FNIHB does not have the authority or the mandate to do option 4. One participant noted that if this document were to be shared nationally, decisions would need to be made about public health for First Nations, and if you look at status quo in Ontario it becomes a problem and it is not highlighted anywhere here. Participants agreed that the status quo needs to be explained more fully.

Participants in this focus group were also concerned that many people are saying that this is a great plan, however, there needs to be reassurance that it is realistic and attainable. One participant noted that there is no point talking about options that cannot become a reality especially at this point in time in our history. One participant stated

that "we can talk about all kinds of things but unless it's realistic and attainable why discuss it." There were also concerns raised around the title of the document. One participant pointed out that it should be by First Nations and not for First Nations. Participants agreed that the message that First Nations want to create this for their own communities should be stronger. Participants also suggested strengthening the language to state that First Nations want to pursue this initiative themselves, i.e., the human resources, capacity, purchasing and shared responsibility. This is especially important for northern communities. In the northern communities there is no one to share with - you are by yourself.

Under Option 1, one participant noted that one of their communities had a signed agreement with public health units and they have withdrawn from that because they were paying \$15,000 for very few pamphlets. With regard to self-government initiatives, participants noted that some communities have done this however, it is almost a 20 year initiative to investigate and look at. There is also the reality that there are simply no funds to implement self-government initiatives.

Further concern was expressed by one participant who noted that as she read the document and the facilitation guide, her concern as a First Nation was the lack of traditional approaches expressed in the document. This participant suggested that it should be included in the "Gaps" section as missing a First Nations approach to public health. Programming also needs to embrace holistic health that also involves traditions Another participant stated that First Nations people are always being talked to about accountability and clarity. It seems strange money would be given on behalf of Aboriginal people to a provincial government or organization and there is no accountability back. This strengthens the argument for money to go directly to communities so that First Nations can have access to the services and benefits being provided. Concerns were raised over responsibilities for provincial public health units to provide vaccinations. Participants noted that it would appear that the province pays for the service they are not delivering. One participant asked wither or not there is any mechanism or discussions for a one time adjustment payment to First Nations for services they have not received? This would go a long way in providing infrastructure to start up. It may not happen, but certainly if either party, the offending or initiated party would agree. One cannot take on responsibility without funding.

Concern was also raised over talking about dollars specific to certain programs and which programs are included under those budgets. Many communities do not have primary care service and most of the funding is used for primary care. Issues also came up in this discussing on whether or not this framework would jeopardize funding and there would be a decrease in the amount available to communities. Participants agreed that they do not want to create the allusion that First Nation communities are getting lots of money and no help.

Questions were raised by participants as to why Saskatchewan and Manitoba were chosen to participate in the next stage of the framework – a pilot and the need for Ontario to be allowed to participate.

There was also a request by one participant for public health expenditures according to FNIHB budget. There is the issue of wage disparity and what is transferred from FNIHB and the Bands. With respect to the pilot, it was felt by many participants that if you are going through this process, you should be able to bring something tangible and say this is what we have learned in these five years. Also, that it is functionally appropriate for this to be put into legislation to cover First Nation public health.

One participant also stated that because communities are doing so much, they do not have the time to sit down and conduct solid program planning by developing their own programs and resources for certain programs. This participant continued to point out that as a front line worker, he does his best, but there is no time to develop even a manual on maternal child health services. "He noted we have piece meal work. We don't have time to develop it more fully and we are delivering services to the community the best we can. From a front line worker, we could do more but we don't have time to do it all. That's where we then turn to the local public health unit to develop resources and to perhaps tap into that. Sometimes even to purchase their material, we need the supporting dollars to do that."

Another participant noted the following: "I think that our community's vision in north-western Ontario for all the public health is needing access and viability for primary care and for there be dedicated resources for public health. We need to play catch up to bring our system on par with the rest of Ontario and Canada. It needs to be whatever we think the best practice and standards should be. It has to meet the needs of the community and be based on the needs of our communities. It has to be First Nations driven and we have to have First Nations in the system. We have to have appropriate language and culture components to it and our traditional practices have to be a part of the program. Ongoing support system and inflation considerations for programs must be considered as our community health programs do not receive any increases. They are not based on actual needs. When you look at the equity of salaries with the workers, it's insane. Why are our communities being treated like that? It has to stop."

Participants also raised the question about the importance of traditional beliefs. One participant noted that "in our Association, as I said yesterday, we created a framework with compensation fitting into holistic health care and with policies. We will be finished that soon and have mental, physical and spiritual aspects done. In the area of spirituality, it is inclusive of traditional beliefs. It is inclusive to utilize traditional medicines which is very important to us. We need to strengthen that whole area because people are using traditional medicine when all else fails. We need to see a strengthening of traditional roles. We are seeing some new areas coming up and to give you an example a recipient of our health award has their PhD in traditional healing. He has to be in the traditional healing area, the sweat lodges and conduct volunteer work. This is being built into educational institutions. It's really great to see. In that area, how does the important role of traditional beliefs fit in? It is very real and we need to strengthen that." There was also a general concern amongst participants that much of the language in the document is public health language. One participant pointed out for example that "when we talk about disease from a First Nations perspective, it is not disease oriented, it is wellness orientated which is holistic and takes into account traditional healing and determinants of health. It's part of the problem and we're looking at it from a different perspective from public heath. The ultimate ideal goal would be to improve the health status. I don't see the language within public health addressing that. We're talking more about disease prevention and dealing with disease."

Participants also agreed that in public health per se, there is an inherent problem of definition, who provides the services, what is the mandate for providing services and ensuring that the services are provided. Questions were asked as to how First Nations communities look at surveillance and the outcomes to improve health? Participants agreed that this is part of the problem for the federal government to improve delivery. It is because of jurisdictional problems, it is not First Nations driven.

In terms of looking at goals, one participant maintained that the public health framework for First Nations would need to have a community based initiative and that whatever they needed for resources it would go outside of what they do not have, for example, the existing infrastructure in Sioux Lookout. One participant noted that "there has to be some power given to the government, an Act that will be consistent and that will remain for a long time for those government models you are going to set up long term. Right at the highest level possible to incorporate an Act that will provide long term delivery or program or structure for the long term. You will have to create a mechanism, which could be legislative and put it in action. At this point, it won't work if you are doing it as a pilot project here and there. Also, whatever is there now, you will always have planning meetings, but you will have to say we are going to deal with this at the highest senior level and that it will have to be done. First Nations do not have adequate public health and for it to be done it must be done at a level that the Premiers and the government of Canada will agree on."

In creating a national framework, participants noted that it should not dictate regional functions. Many of the participants agreed that First Nations in Ontario want to be the ones to define what public health means and to define the priorities and how it will be delivered without punitive damages. The national framework needs to convey the voices of First Nations communities and not the other way around. It is important to recognize the need to leverage from the national processes. One participant suggested that the other option is the "opt in opt out" option. What movement or flexibility is there if you do not want a framework? This participant continued to point out that there needs to be more analysis and numbers, where the funding sources will come from and whether it is new money. Participants pointed out that no matter what kind of framework and policies are ultimately produced, in the end it is the health of First Nations communities and primary health which will always take precedence over public health.

Participants also noted that there are not enough resources to deal with acute care needs. There is a need to take it from holistic perspectives and address it. One participant observed that it is also timely because there are a number of reforms happening, including the immunization system being implemented in the province. The hospitals will be doing the initial phasing of that. It was noted that it is not mandatory right now, if individuals want to take advantage of it, they can. Participants agreed that communities need to be aware of it as a tool. Another participant spoke of registries - not having nurses input into a variety of systems. This participant noted that the out is with the province and feds about new immunization system and there is a First Nation unique identifier. There has been a pan Canadian group looking at that. That is a great concern coming from the community.

There is also concern of the speed at which people are making decisions on behalf of First Nations. Communities need to be part of that identification. IBM has already been contracted to put a flag in that system. One participant noted that "we have our Chiefs who say we will take care of people no matter where they are. Our Chiefs have always said if there was a way to give us the dollars so that we can provide services for people living off reserve and have a fee for service arrangement. I don't know if it could be done but it's been ongoing that they wish that could be done. Give them the dollars and the onus is on First Nations where the membership is for utilizing any services off reserve and then they bill us. Strictly from the AIAI position, our Chiefs have discussed this but it hasn't happened."

Participants also spoke of a push for legislative changes or amendments. One participant stated that "the bottom line is if we don't push for them we don't get them. By virtue of the fact, lobbying makes it more effective for policy and those sitting on the other side know we are serious. We should go there so the feds will know we are serious."

In a discussion on the Public Health Act, participants noted that there should be federal enabling legislation for public health because if you leave it to the provinces it won't happen. Jurisdiction and fiduciary responsibility lies with FNIHB. Participants also noted that the federal government is responsible for health on First Nation territories. Participants agreed that FNIHB has stated that they do not have enabling legislation for them to proceed. They said they fall under the province and they make it clear it is not in their mandate.

One participant noted that the problem is that "we fall between the cracks because FNIHB says they don't have the mandate. With enabling legislation we would have to ensure it is a First Nation driven process, that it is a community process and our concerns are a part of the legislation. So in other words, traditional, holistic approaches are part of that. That would be my recommendation to my political leaders."

Moreover, participants noted that public health surveillance should it be part of the legislation to have a protection mechanism available that they can convey to First Nations as to how information would be inclusive to the OCAP principles. They agreed that there needs to be reassurance in the legislative piece. Surveillance centers should not be an incorporated body that becomes a product not led by First Nations. Participants agreed that this is a problem as it becomes an incorporated body at arms length that becomes the main concern. There are some communities who are reluctant and they insist on guarantees where their information is not going to get abused. Participants noted that they have tried to overcome that and still have communities that are like that.

At the community level, participants agreed that a system needs to be in place that will support the work being done in terms of service delivery. The community maintains ownership and control of the information and how it gets used. The fiduciary obligations are with FNIHB and Health Canada. People want to see FNIHB as a central connector to a system linking with communities and Health Canada.

With respect to governance First Nations communities need to be a key element. Participants noted that the problem with Option 3 is with those who work regionally, and One participant pointed out that "we fail to realize it's the nuts and bolts where the rubber hits the road and it's not the intention that there be a disconnect. Sometimes being advocates we miss that and I don't want to create another entity which becomes an incorporated body that floats. What I want is to have a body which effectively connects to communities." For governance, it should be a combination of Option 1 and 3 to have enabling legislation with a mandate for First Nations. A combination of 1 and 3 might be something people could live with. Ultimately the fiduciary responsibility still lies with FNIHB. Participants argued that FNIHB should not be delivering programs but they have the expertise and capacity that First Nations communities simply do not have. Participants agreed that they need a transfer of the skills and knowledge that NFIHB has. The province always has the mandate. We are challenging them and saying, "What are you doing on our behalf?" FNIHB always sheds the responsibility.

Participants noted that it goes beyond FNIHB and should be a cross-Ministerial issue and priority. It is the federal government that has to be responsible to make sure public health and population health is being delivered at the community level.

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