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# Table of Contents

<b>I.</b>	<b>List of Acronyms</b>	
<b>II.</b>	<b>Executive Summary</b>	
1.0	<b>Introduction</b>	1
2.0	<b>Definition of Terms</b>	1
3.0	<b>Unique Characteristics of Aboriginal Individuals, Families &amp; Communities</b>	4
3.1	Aboriginal Peoples in Canada	
3.2	Demographics, Health Status and Need for Home Care	
3.3	Non-isolated, semi-isolated, isolated and remote residence	
3.4	Quality and Affordability of Housing	
3.5	Jurisdiction, Responsibility and Self-government	
3.6	Local access to Appropriate health Care Services and Providers	
3.7	Cost of Service Delivery	
4.0	<b>Planning Issues and Considerations</b>	11
4.1	Availability and Access to Services	
4.1.1	Limitations of Available Information and Accurate Costing	
4.1.2	Acuity and Staff Ratios	
4.2	Education and Health Care Providers	
4.2.1	Health Human Resources and Projected Shortages	
4.2.2	Appropriate Curriculum in Education and Training Programs	
4.2.3	Use of Internet based Education and Training Methods	
4.3	Cultural and Spiritual Considerations	
4.4	Public Education and Awareness	
4.5	Research – Health Management Policy Development	
4.5.1	Increasing Aboriginal Research Capacity	
4.5.2	Ethics, Values and Policy Related Challenges	
4.5.3	Health Care Delivery Models	
4.5.4	Identification of Facilities and Services Needed	
4.5.5	Canadian Virtual Hospice: Knowledge Development and Support in Palliative Care	
4.5.6	Clinical Guidelines and Standards	
4.6	Support: Family, Caregiver and Significant Others	
4.6.1	Health and Safety Concerns	
4.6.2	Lack of Local Expertise, Adequate Space and Equipment	
4.6.3	Respite and Personal Support for Caregivers	
4.6.4	Advance Care Planning	
4.7	Surveillance	
5.0	<b>Summary of Responses to Interviews and Questionnaire</b>	20
6.0	<b>Conclusion and Recommendations</b>	21
	<b>Bibliography</b>	
	<b>Appendix A - Five National Aboriginal Organizations</b>	

## List of Acronyms

ACP	Advance Care Planning
AFN	Assembly of First Nations
A.N.A.C.	Aboriginal Nurses Association of Canada
CVC	Canadian Virtual Hospice
CWIS	Community Workload Increase System
DIAND	Department of Indian Affairs and Northern Development
FNIHB	First Nations and Inuit Health Branch
FNIRHS	First Nations and Inuit Regional Health Survey
HRDC	Human Resources Development Canada
NAHO	National Aboriginal Health Organization
NAPELC	National Action Plan for End-of-Life Care
NCE	National Cost Estimates
NIHB	Non-Insured Health Benefits
OT	Occupational Therapy
PT	Physiotherapy Therapy
RT	Respiratory Therapy

## Executive Summary

The National Aboriginal Health Organization (NAHO) is pleased to present this discussion Paper on End-of-Life/Palliative Care for Aboriginal Peoples. This document, intended to contribute to the development of the National Action Plan for End-of-Life Care (NAPELC), is a starting point that identifies issues pertinent to Aboriginal Peoples.<sup>1</sup> This discussion paper is not an in depth study and only provides a general overview of issues. It is important to note that there is no Canadian standard for end-of-life and palliative care for Aboriginal peoples and each province is working independently.

This discussion paper is structured along the lines of the seven key areas identified by the NAPELC Steering Committee. The terms home care, palliative care, and end-of-life care are discussed and defined in Section 2. The unique characteristics of Aboriginal persons, families and communities are presented in Section 3 where barriers relevant to other health services delivered to Aboriginal Peoples are identified and discussed with respect to end-of-life care. Incidence of chronic disease and disability is higher among the Aboriginal population than the Canadian population. In addition, age standardized mortality rates show that the Aboriginal population in Canada has a shorter life span than the general population, and consideration of this difference would be beneficial during short and long term planning processes. Issues related to isolation, affordable housing, jurisdiction and access are highlighted as unique barriers that prevent equitable access to care.

Section 4 addresses planning issues: those unique and pertinent to Aboriginal Peoples and those shared with the general Canadian population. Section 5 highlights and discusses modest input secured during key focussed telephone interviews with national Aboriginal organizations and from a questionnaire distributed to select home and community care stakeholders. Data from Health Canada's 1999 Needs Assessment Summaries of the Home and Community Care program was not available at the time of writing this document. When this information becomes available, the identification and analysis of issues is recommended for your consideration.

For the development and implementation of a National Action Plan on End-of-Life Care the following is recommended. Firstly, that a consultation process which garners feedback from key Aboriginal stakeholders<sup>2</sup> at all critical stages of the action plan be undertaken. Secondly, research and a needs analysis may include community best

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<sup>1</sup> The term *Aboriginal Peoples* refers to both status and non-status First Nations, Inuit and Métis peoples of Canada (per section 35(2) of the *Constitution Act, 1982*).

<sup>2</sup> Key Aboriginal stakeholders include: Assembly of First Nations (AFN), Inuit Tapiriit Kanatami (ITK), Métis National Council (MNC), Native Women's Association of Canada (NWAC), Pauktuutit – Inuit Women's Association (IWA), Congress of Aboriginal Peoples (CAP), Aboriginal Nurses Association of Canada (A.N.A.C.), Native Physicians Association in Canada (NPAC), National Indian and Inuit Community Health Representative Organization (NIICHO), Canadian Aboriginal AIDS Network (CAAN), and the Native Mental Health Association (NMHA). See Appendix A for descriptions of the five national Aboriginal organizations.

practices that have proven practical and economical at the community level. Thirdly, policy modifications about the Home and Community Care Program should reflect the constitutional recognition of the Métis; this way, the Federal Government's evolving understanding and practice of addressing the needs of urban, non-Status and Métis in their community-based program planning requirements will become evident. Fourthly, standards of care, facilities and professional training require further development to address Aboriginal care settings at the community level. Finally, a co-ordinating mechanism is needed to resolve recurring jurisdictional issues at the community level and in federal, provincial and territorial governments.

# **National Aboriginal Health Organization (NAHO)**

## **Discussion Paper on End-of-life/Palliative Care for Aboriginal Peoples**

### **1.0 Introduction**

The purpose of this discussion paper is to contribute to the development of a National Action Plan for End-of-Life Care (NAPELC). Issues have been identified and strategies have been recommended to support and advance interests of Aboriginal Peoples. The identification and analysis of end-of-life care issues are limited due to lack of data. While data about First Nations are limited, the most significant gap exists with respect to Métis, non-status First Nations and urban Aboriginal people and to a lesser extent, Inuit people. While this paper focuses on End-of-Life and Palliative Care within the context of Home and Community Care, the interface between home and community care and institutional care has also been reviewed. The following seven key areas identified by the NAPELC Steering Committee have been used to structure this document:

1. Availability and Access to Services
2. Education and Health Care Providers
3. Ethical, Cultural and Spiritual Considerations
4. Public Education and Awareness
5. Research
6. Support: Family, Caregiver and Significant Others
7. Surveillance

### **2.0 Definition of Terms**

#### **Home Care**

The National Framework on Home Care for First Nations and Inuit Communities, developed by Health Canada and Indian and Northern Affairs Canada, provides the following definition of home care:

a system of service delivery encompassing a range of insured, extended and uninsured health and social services for all age groups, addressing the holistic, social and personal care needs of individuals who do not have, or have lost, some capacity for self care. These integrated services are designed to improve individual functioning, and provide culturally sensitive support and care in the community, where possible.<sup>3</sup>

This federal Home and Community Care Program is for First Nations and Inuit communities only and is not offered to Métis and non-status First Nations people or Aboriginal people living in non-First Nations or non-Inuit communities.

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<sup>3</sup> Laurel Lemchuk-Favel and Francesca Verhoeve, "First Nation and Inuit Home Care: Analysis of Costs Based on NCE Model," February 12, 1999, p. 1.

Health Canada categorizes three models of home care:

1. Maintenance and Prevention model-- allows persons to live independently with health and functional deficits and prevents institutionalization;
2. Long-term substitution model-- provides an alternative to long-term institutionalization; and
3. Acute care substitution model-- meets the needs of people who would otherwise have to enter or remain in acute care facilities.<sup>4</sup>

Components of the home care program offered as a public service or on a fee-for-service basis by private, not-for-profit and government providers vary significantly across the country. Most common components are as follows:

1. home nursing services
2. home care aid
3. occupational therapy (OT)
4. physiotherapy therapy (PT)
5. respiratory therapy (RT)
6. speech therapy
7. dressing, medications and related preparations
8. temporary use of health aides and/or equipment
9. personal care (personal bathing and assistance in activities of daily living)
10. home support services (heavy housework, handyman service, meals-on-wheels, and transportation).<sup>5</sup>

### **Palliative Care**

The Canadian Palliative Care Association defines palliative care as:

the combination of active and compassionate therapies intended to comfort and support individuals and their friends and families who are living with, or dying from, a progressive life threatening illness, or are bereaved.<sup>6</sup>

The World Health Organization defines palliative care as:

the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms and of physical, psychological, social, emotional and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families. Palliative Care also affirms life and regards death as a normal process and neither hastens nor postpones death. Palliative Care integrates the aspects of

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<sup>4</sup> Laurel Lemchuk-Favel and Francesca Verhoeve, "First Nation and Inuit Home Care: Analysis of Costs Based on NCE Model," February 12, 1999, p. 2.

<sup>5</sup> Laurel Lemchuk-Favel and Francesca Verhoeve, "First Nation and Inuit Home Care: Analysis of Costs Based on NCE Model," February 12, 1999, p. 3.

<sup>6</sup> [http://www.cPCA.net/menu\\_items/faqs.htm#faq\\_def](http://www.cPCA.net/menu_items/faqs.htm#faq_def)

care with coordinated assessment and management of each person's needs and continues after death to support the family in bereavement.<sup>7</sup>

The World Health Organization's definition is more compatible with traditional and holistic Aboriginal views that encompass spiritual, physical, emotional, mental and social attributes of people. Such a holistic view allows for balance and connectedness within individuals, families and communities in relation to the natural world. When death occurs 'in balance' all attributes of the dying and deceased are managed until the person 'passes to the other side' safely and family and loved ones are returned to a state of being in balance.

Recent policy changes reflecting a holistic approach to end-of-life care have been made by the American Medical Association. Elaboration of these may be found in Cassel and Foley (1999) who set out the following principles for end-of-life care<sup>8</sup>:

1. Respect the dignity of both patient and caregivers;
2. Be sensitive to and respectful of family's wishes;
3. Use the most appropriate measures that are consistent with patient choices;
4. Encompass alleviation of pain and other symptoms;
5. Assess and manage psychological, social and spiritual/religious problems;
6. Offer continuity (the patient should be able to be cared for, if so desired, by his or her primary care and specialist providers);
7. Provide access to any therapy which may realistically be expected to improve the patient's quality of life, including alternative or non-traditional treatments;
8. Provide access to palliative care and hospice care;
9. Respect the right to refuse treatment;
10. Respect the physician's professional responsibility to discontinue some treatments when appropriate, with consideration for both patient and family preferences; and
11. Promote clinical and evidence-based research on providing care at the end of life.

When these principles were reviewed by medical societies throughout the United States, a high degree of consensus was achieved. As a result the American Medical Association added eight elements to their policy statement.

Recent research initiatives by the Academy of Psychosomatic Medicine support a holistic approach to palliative and end-of-life care. The Academy of Psychosomatic Medicine issued a call for research about how patients and their families experience the end-of-life/palliative care and the nature of assistance required to decrease suffering and maintain quality of life throughout the process. Several other prominent medical societies involved in hospice, palliative care and pain management endorse the

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<sup>7</sup> Strachan-Tomlinson, *Discussion Paper (a working draft) in preparation for the National Action Planning Workshop on End-of-Life Care, March 2-4, 2002 Winnipeg, Manitoba*, for Health Canada Secretariat on Palliative and End-of-Life Care, Ottawa, p. 83.

<sup>8</sup> Christine Cassel, and Kathleen M. Foley, *Principles of Care of Patients at the End of Life: Emerging Consensus among the Specialties of Medicine*, Milbank Memorial Fund, December 1999, p. 3.

American Medical Association's principles and four other medical organizations have adopted these principles with modifications.<sup>9</sup>

Along these principles, the description of optimal palliative or end-of-life care for all Canadians presented in the NAPELC Discussion Paper includes the following:

1. integrated, accessible, coordinated and adequately funded services that could support patients in varied institutional and home settings in rural and urban communities;
2. financial coverage for drugs;
3. professional and non-professional care services;
4. access to community day programs;
5. 24-hour pain and symptom management teams;
6. support for families such as respite care and bereavement follow-up.<sup>10</sup>

Eligibility criteria, referral, assessment and case management processes also vary throughout Canada and between service provider agencies. Alternative and/or traditional care options and spiritual grieving supports alluded to in the American model are not included in the NAPELC model.

### **3.0 Unique Characteristics of Aboriginal Individuals, Families and Communities**

This section identifies specific characteristics of Aboriginal individuals, families and communities that may require targeted responses in future planning.

#### **3.1 Aboriginal Peoples in Canada**

Canada's Constitution identifies and recognizes three distinct categories of Aboriginal Peoples: Inuit, Métis, and First Nations. While a great deal of diversity exists between these peoples, they do share many experiences with and/or treatment by non-Aboriginal Canadian society and its federal and provincial orders of government, as well as the institutions they have created. Current issues of importance to Aboriginal communities include disparities between remote, rural and urban populations, negotiations for self-government, and the overwhelming needs of populations that have been served by a variety of programs and services that have often created conflict and alienation.

##### **Inuit**

Inuit have a holistic vision of the individual. A human being is one with his or her surroundings, a part of a whole that draws its meaning from the relationships that the human being has with whatever is living and whatever surrounds him – a

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<sup>9</sup> Christine Cassel and Kathleen M. Foley, *Principles of Care of Patients at the End of Life: Emerging Consensus among the Specialties of Medicine*, Milbank Memorial Fund, December 1999, p. 3.

<sup>10</sup> Janet Smylie, *A Guide for Health Care Professionals Working with Aboriginal Peoples*, Society of Obstetricians and Gynecologists, April 2001, p. 11.

strong connection with the environment. Well-being flows from balance and harmony among all elements of personal and group life.<sup>11</sup>

For Inuit, life in Northern coastal communities has created a people who rely heavily on each other and for whom strong bodies and good health has been a matter of life and death. Today, Inuit communities have minimal health services and there is a danger that cultural knowledge is being lost. Inuit are particularly concerned with addressing gaps in health services, ensuring Inuit knowledge forms the basis of programs, developing communities to ensure self-sufficiency and supporting a rapidly growing population.

Health is the whole person... we don't need to think that we have an addictions problem here, a problem with teens there, elders who are lonely, women who are depressed. We have to think: "people don't feel good. Why is that?"<sup>12</sup>

### **Métis**

The Métis are distinct peoples who have evolved from the union of European and First Nations cultures, combining their various traditions and traits. Métis history is one of adaptation and resilience in the face of continual change. Métis have struggled with a loss of culture and a lack of recognition with respect to Aboriginal-specific programs and services. Although 26% of the Aboriginal population in Canada identified as Métis in the 1996 Census, there is a veritable absence of information and knowledge concerning Métis health. There is an urgent need to prioritize and develop a successful strategy for the conduct of Métis-specific health related research, programs and services, and culture-based models of delivery in urban settings.

For a person to be healthy, [he or she] must be adequately fed, be educated, have access to medical facilities, have access to spiritual comfort, live in a warm and comfortable house with clean water and safe sewage disposal, be secure in cultural identity, have an opportunity to excel in meaningful endeavor, and so on. These are not separate needs; they are all aspects of the whole.<sup>13</sup>

### **First Nations**

First Nations people live in all parts of Canada and comprise about 53 distinct linguistic groups. While many First Nation individuals continue to live close to the land and maintain at least some traditional activities such as hunting, fishing and trapping, increasing numbers are moving to urban centres. Current issues of importance to First Nations communities include disparities between on- and off-reserve populations, the desire for self-government, and the burgeoning needs of a population that has not been particularly well served by a variety of programs and services in the past.

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<sup>11</sup> Pauktuutit, *The Inuit Way: A Guide to Inuit Culture*, p. 13.

<sup>12</sup> Métis family counsellor in Kinnon, 1994

<sup>13</sup> Henry Zoe, Dogrib Treaty 11 Council, RCAP, 1996

### 3.2 Demographics, Health Status and Need for Home Care

Demographics of Aboriginal populations are relevant when assessing and planning for future needs. According to 1996 Census findings, 1,101,960 people or 3.9% of the Canadian population reported Aboriginal ancestry; 210,055 for Métis, 41,085 for Inuit, and 535,075 for North American Indian (referred to as First Nations – both status and non-status in this paper). These numbers have increased since 1996.<sup>14</sup> Additional observations include:

- the age standardized mortality rate for First Nations people (182 deaths per 100,000) is slightly lower than the Canadian population (193 deaths per 100,000) as a whole;<sup>15</sup>
- life expectancy at birth is about seven to eight years less for registered First Nations members than for Canadians generally;<sup>16</sup>
- Aboriginal Peoples in Canada experience a disproportionate burden of health problems compared to the general Canadian population. Detailed, regionally specific knowledge about health problems is limited, especially for urban areas.<sup>17</sup>
- the incidence of degenerative diseases (heart, liver and lung diseases, cancers) is rising;<sup>18</sup>
- diabetes mellitus is increasing and affects 6% of Aboriginal adults compared to 2% of all Canadian adults;<sup>19</sup>
- the Aboriginal population is younger than the Canadian population as a whole, with the average age of 25.5 years compared to 35.4 in the general population (1996 Census). Children under 15 years account for 38 % of the Aboriginal population compared to 20% of the general population; and<sup>20</sup>

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<sup>14</sup> Laurel Lemchuk-Favel and Francesca Verhoeve, "First Nation and Inuit Home Care: Analysis of Costs Based on NCE Model," February 12, 1999, p. 20.

<sup>15</sup> Janet Smylie, *A Guide for Health Care Professionals Working with Aboriginal Peoples*, Society of Obstetricians and Gynecologists, April 2001, p. 11.

<sup>16</sup> Canada, Royal Commission on Aboriginal Peoples, *Report of the Royal Commission on Aboriginal Peoples Volume 3: Gathering Strength*, 1996.

<sup>17</sup> Laurel Lemchuk-Favel and Francesca Verhoeve, "First Nation and Inuit Home Care: Analysis of Costs Based on NCE Model," February 12, 1999, p. 9.

<sup>18</sup> Canada, Royal Commission on Aboriginal Peoples, *Report of the Royal Commission on Aboriginal Peoples Volume 3: Gathering Strength*, 1996.

<sup>19</sup> H.L. Macmillan et.al. "Aboriginal Health" IN *Canadian Medical Association Journal*, 155 (11), 196, pp. 1569-1578.

<sup>20</sup> Janet Smylie, *A Guide for Health Care Professionals Working with Aboriginal Peoples*, Society of Obstetricians and Gynecologists, April 2001, p. 11.

- the Aboriginal population is growing at a faster rate. The birth rate of Inuit women is the highest of all Aboriginal populations and is twice that of the national average.<sup>21</sup>

Findings about disability and chronic conditions from the First Nations and Inuit Regional Health Survey (1999), suggest 15% of respondents required assistance with personal care, required an attendant for short trips or were otherwise housebound.<sup>22</sup> The proportion of those respondents requiring palliative or end-of-life care is unknown.

Lemchuk-Favel and Verhoeve (1999) calculate an estimated average length of stay (ALOS) for both nursing care and home maker support to be 241 days/patient.<sup>23</sup> Specific reasons addressing why individuals were discharged from home care are not given. Based upon source documentation, Lemchuk-Favel and Verhoeve conclude that home care no longer meets the needs of clients, and recommend that other options be explored. Care is usually offered over a long period of time however, duration of palliative care is unpredictable. Many home care clients also exhibit co-morbidity meaning that they have been diagnosed with more than one chronic illness. This is an important consideration when designing service delivery and symptom management regimes for Aboriginal patients. Information about the end-of-life/palliative care needs of Aboriginal people living in various kinds of communities is not available and is required for comprehensive planning.

### **3.3 Non-isolated, Semi-isolated, Isolated and Remote Residence**

Aboriginal Peoples live in non-isolated (64.7%), semi-isolated (9.1%), isolated (24.6%) and remote-isolated (1.6%) communities with varying proximities to service and urban centres.<sup>24</sup> Access to health care services is directly correlated to the degree of isolation experienced by some communities. Research that would determine whether or not this is the case in urban and rural areas has not been undertaken. A significant number of communities are accessible only by air or seasonal road. Others are accessible by road, but are more than an hour away from a major service centre. One out of five Aboriginal people live in seven of Canada's metropolitan centres (Winnipeg, Edmonton, Vancouver, Saskatoon, Toronto, Calgary and Regina), and there is a trend towards increasing urbanization of Aboriginal Peoples in Canada. This includes non-status and Métis people who do not have reserve lands, with the exception of eight Métis

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<sup>21</sup> Janet Smylie, *A Guide for Health Care Professionals Working with Aboriginal Peoples*, Society of Obstetricians and Gynecologists, April 2001, p. 22.

<sup>22</sup> Please note the only Inuit people to participate in the First Nations and Inuit Regional Health Survey were the Labrador Inuit.

<sup>23</sup> This calculation is based upon Ottawa-Carleton data from 1997/98 and First Nations proportions of chronic conditions (diabetes, cardiovascular, respiratory and arthritis) and cited in Lemchuk-Favel/Verhoeve, 1999, p. 13.

<sup>24</sup> Laurel Lemchuk-Favel and Francesca Verhoeve, "First Nation and Inuit Home Care: Analysis of Costs Based on NCE Model," February 12, 1999, p. 7.

settlements in Alberta, established through provincial jurisdiction.<sup>25</sup> The majority of Inuit live in and around 53 communities, most of which are isolated and remote-isolated, in the Arctic and sub-Arctic regions of Canada and from the Labrador coast in eastern Canada to Tuktoyaktuk, in the far northwestern corner of the country.<sup>26</sup>

### **3.4 Quality and Availability of Housing**

The lack of quality housing is a fundamental consideration when planning for home based care, including end-of-life/palliative care. Aboriginal Peoples, including non-status and Métis, share proportionately greater problems of access to adequate housing than the general Canadian population. These problems have been acknowledged by DIAND:

Although housing conditions have improved, there is still work to be done. The lack of adequate, affordable housing is a great challenge for many First Nations. The average income in these communities is half the Canadian average. The birth rate is double the national average, which means an ever increasing demand for housing. The projected number of new households in First Nations will average 4,500 per year over the next 10 years. Too few housing results in overcrowding. Of the 88,570 houses in First Nations communities, about 11 percent are overcrowded, compared to one percent elsewhere in Canada.<sup>27</sup>

The status of housing in Inuit, non-status First Nations or Métis communities or the housing issues of Aboriginal Peoples living in urban centres is not reflected in the above quotation. Although the *1991 Aboriginal Peoples Survey* contains some references to housing, data is not available. However, it is likely that similar patterns would exist. Therefore, adequate housing and resources to renovate or modify homes for the provision of home care services is an essential requirement for good quality home care and home based end-of-life/palliative care. Where adequate housing is not available, care must be delivered in an alternative home, hospice or institution.

### **3.5 Jurisdiction, Responsibility and Self Government**

The provision of health care is complex. Provincial or Territorial governments provide insured health services to all residents. The *Canada Health Act* and federal funding provide important structural supports for a national system. The Federal Government provides community health services along with treatment services for Status Indians and Inuit in remote and isolated communities south of the 60th parallel.<sup>28</sup>

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<sup>25</sup> <http://www.ainc-inac.gc.ca>

<sup>26</sup> Linda Archibald and Roda Grey, *Evaluation Models of Health Care Delivery in Inuit Regions*, (Ottawa: Inuit Tapiriiksat Kanatami, 2000), p. 6.

<sup>27</sup> [http://www.ainc-inac.gc.ca/pr/info/info104\\_e.html](http://www.ainc-inac.gc.ca/pr/info/info104_e.html)

<sup>28</sup> As a general rule, status First Nations living on-reserve and Inuit (with some different rules and eligibility criteria) are the responsibility of the Federal Government. North of the 60<sup>th</sup> parallel some health responsibilities have been devolved to respective territorial governments owing to the creation of Nunavut and other health transfers in the Northwest Territories.

The Non-Insured Health Benefits Program (NIHB) delivered by Health Canada, covers transportation, pharmaceutical, medical supplies and equipment, optical services, mental health emergency care, and dental services. It is provided to status Indians and Inuit, regardless of residency (i.e., is provided to status Indians who reside on and off reserve). Benefits are based on schedules developed by Health Canada and are subject to cost control mechanisms. The NIHB program operates, for the most part, outside of the Health Transfer process except in the case of a limited number of pilot projects (fourteen) in select First Nations. Métis and non-status Indians are not provided for by the NIHB.

Since the early 1980s, *Health Transfer* has been the primary mechanism by which First Nations south of the 60<sup>th</sup> parallel have gained administrative control over some community health services formerly delivered by Health Canada. For First Nations, the health transfer process, south of the 60<sup>th</sup> parallel, has resulted in the transfer of responsibility for the delivery of federally funded community health services directly to about 46% or 276 First Nations communities as of March 31, 2000. Health Canada estimates that 90% of communities may be operating under Health Transfer arrangements and in addition, since 1994, other First Nations have opted for the *Integrated Community-Based Health Services* approach. This alternative approach is appealing to those First Nations that are neither interested in, nor ready for health transfer arrangements, but are nevertheless seeking to increase their community's control over health services.

Lastly, *Self Government*, as formally recognized by the federal government in the 1995 *Inherent Right to Self-Government Policy*, provides a high degree of autonomy to First Nations regarding community control of health services. The First Nations right to self-government is an existing Aboriginal right under Section 35 of the 1982 *Constitution Act*. Community control of health services is generally recognized as a major area through which First Nations can express self-government, through both design and planning of health services utilization, while building capacity to ensure that resources are managed at a pace determined by First Nations.

The federal Home and Community Care program however, remains outside of the scope of current transfer arrangements, and is exclusively targeted to on-reserve communities. In addition, as First Nations people move on and off the reserves and work through various transfer processes, jurisdictional issues become increasingly complex and can be a very significant barrier to accessing services.

There are conflicting views among the various levels of government concerning Métis people. Despite recognition under section 35 of the 1982 *Constitution Act*, Métis issues remain absent from the majority of federal policies, programs and legislation. For example, neither Health Canada nor DIAND claims specific responsibility for funding or delivery of direct community health programs to Métis or non-status First Nations. However, a number of Métis communities have successfully gained provincial funding for home care services.

Although existing Aboriginal rights are recognized and affirmed in the Constitution Act 1982, the federal government has not fully accepted jurisdiction on behalf of Métis as

Aboriginal Peoples. Neither the federal or provincial governments have assumed responsibility for Métis health services nor has a comprehensive government policy or strategy been developed to address Métis health issues. Métis are excluded from access to health care, education and social programs accessible to First Nations and Inuit.

Métis are accorded legal status under Section 35 of the Constitution Act 1982 where the term 'Aboriginal' is defined to include Métis, along with 'Indian' and 'Inuit' people. The Constitution Act 1867 gave Parliament exclusive jurisdiction with respect to 'Indians and Lands reserved for Indians'.<sup>29</sup> As of 1939, Inuit were judicially included under the scope of Section 91(24) of the *Constitution Act 1867*.

In 1996, the Royal Commission on Aboriginal Peoples stated, "We are convinced that all Métis people, whether or not they are members of full-fledged Aboriginal nations, are covered by section 91(24)." The Commissioners recommended that the federal government acknowledge that this section applies to Métis people and that the federal government accordingly base its legislation, policies and programs on that recognition.<sup>30</sup>

### **3.6 Local Access to Appropriate Health Care Services and Providers**

Many Aboriginal communities lack local access to health care services and providers. Often, patients must wait to be transported to a larger centre or for a visiting service provider to come to their community. Delays in access to care, including diagnostic tests and procedures can be very significant. The high cost of patient transportation, particularly in communities only accessible by air, generally limits access.

Access issues in urban centres are different than those experienced by Aboriginal Peoples living in more isolated areas. Home and Community Care Program criteria do not include Métis and non-status Indians. Even when home and community care programs do include Métis and non-status, most do not use the services due to access issues such as a lack of cultural relevancy, language issues, transportation support and other barriers. To fully understand access barriers experienced by urban Aboriginal people requires more focussed research.

### **3.7 Cost of Service Delivery**

In order to plan care related to community requirements, models for estimating costs to support funding requests must be developed and tested. The only specific resource document available that speaks to the cost of home care and palliative care in First Nations and Inuit communities is "First Nation and Inuit Home Care: Analysis of Costs Based on NCE Model," February 12, 1999 by Lemchuk-Favel and Verhoeve. This work is an initial attempt at estimating costs, therefore, additional investigation must be completed to validate cost, and to provide more detail upon which to develop estimates. Lemchuk-Favel and Verhoeve report the average range of long term home care costs were \$18.77 per day for "need help with personal care" to \$20.76 for "home activity

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<sup>29</sup> Canada, Royal Commission on Aboriginal Peoples, *Final Report*, 1996.

<sup>30</sup> Canada, Royal Commission on Aboriginal Peoples, *Final Report*, Volume 4, Ottawa, pp. 209-210.

limited by health problem”, while short term home care costs were estimated at \$12.41 per day. By comparison, palliative care costs specific to status First Nations and Inuit were calculated using end stage cancer rates and are estimated at \$28.43 per day for palliative care, significantly higher than the above-noted home care cost estimations.<sup>31</sup>

Average First Nations and Inuit per capita home care costs were estimated to be 24% higher than the Canadian average.<sup>32</sup> The funding for home care across Canada, particularly in Aboriginal communities is increasing for some communities under Health Canada’s Home and Community Care Program, however the funding level was established at a minimal rather than optimal level.

## **4.0 Planning Issues and Considerations**

Key issues and considerations for the development of the National Action Plan on End-of-Life Care are outlined below according to the seven areas or themes identified by the NAPELC Steering Committee.

### **4.1 Availability and Access to Services**

The availability of and access to a range of appropriate services, gaps, barriers and access issues are addressed in this sub-section. Note that information about specific service use is not available.

#### **4.1.1 Limitations of the Available Information and Accurate Costing**

There is a lack of current data that would highlight costs of home care and end-of-life/palliative care needs for the majority of Aboriginal communities. Lemchuk-Favel and Verhoeve use First Nations and Inuit data from the Community Workload Increase System (CWIS) and the FNIRHS for costing analysis.<sup>33</sup> Métis and non-status First Nations people are not factored into this for two reasons: a lack of data for non-status First Nations and Métis; and, Health Canada’s policy concerning its responsibility for the provision of home care services.

Factoring in increased costs associated with remoteness remains a challenge. The original NCE model meets this challenge in part by addressing diseconomies of scale. Diseconomies of scale refer to additional costs of service directly related to serving small populations with a variety of needs. For example, in a city with many patients with similar service requirements a staff of full time professionals can be hired to serve those needs. There is a degree of ‘economy of scale’ in serving more patients with more

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<sup>31</sup> Laurel Lemchuk-Favel and Francesca Verhoeve, “First Nation and Inuit Home Care: Analysis of Costs Based on NCE Model,” February 12, 1999, p. 25.

<sup>32</sup> Laurel Lemchuk-Favel and Francesca Verhoeve, “First Nation and Inuit Home Care: Analysis of Costs Based on NCE Model,” February 12, 1999, p. 26.

<sup>33</sup> Laurel Lemchuk-Favel and Francesca Verhoeve, “First Nation and Inuit Home Care: Analysis of Costs Based on NCE Model,” February 12, 1999, p. 5.

workers. There are also additional opportunities to better use specialists when more patients require services of the same specialist, thereby ensuring that specialist time is well used. In a small community, problems arise when the number of patients with similar needs require less than the equivalent of a full time worker in certain disciplines. For example, one full time nurse may provide too little service and two full time nurses may provide too much. Similarly, physiotherapy service demand may warrant one part-time physiotherapist. It is unlikely that a physiotherapist would relocate to a remote northern community for part-time employment. Depending on the location of the community and availability of professionals, the option to hire part time staff may not be feasible.

Isolated and remote-isolated communities in relatively close geographic proximity, linked by airline routes or roads may present opportunities for pooling resources and securing professional medical services through a 'travelling/visiting' service options model. This option may be less feasible where distances between communities are significant. For example, Lemchuk-Favel's and Verhoeve's application of the NCE model puts forth a method for costing remoteness and diseconomies of scale based on the Assembly of First Nations (AFN)/Berger Formula. A number of assumptions in their application may not be relevant when applied to small, geographically isolated communities. They state, "home care programs in remote and isolated communities have diseconomies of scale due to small population size, which can be alleviated to some degree by neighbouring small bands pooling resources to establish a shared program." Staff travel costs over a large geographic area are referred to as an important further consideration but the costs themselves are not identified.<sup>34</sup>

The feasibility for isolated and remote-isolated communities to develop regional service depends on many factors. First and foremost is the cost of travel and the time required for travel. Travel is more likely to occur from 'fly-in' communities located in northern provincial regions to regional centres than between communities due to limited air access between communities. In Nunavut, 'neighbouring' communities are often geographically far from each other with travel costs and time being prohibitive. Hence, the cost-effectiveness of various models of delivery needs to be researched and tested, in consideration of the availability of required health care practitioners/professionals, other health workers and the nature of support and supervision required as well as administrative jurisdiction.

#### **4.1.2 Acuity and Staff Ratios**

In the NCE model used by Lemchuk-Favel/Verhoeve, the ratio of home care aides to nurses as a whole is 9:1 and the ratio of home care aids to total health professionals is 6:4 in Canadian models of service generally. In the ratio for the number of home care aides relative to all health professionals, the 4 includes one nurse, one physiotherapist, one speech therapist and one occupational therapist. In the North Battleford Home Care program which serves 3,500 First Nations people in seven communities the ratio of home care aides to nurses is 2:1. Lemchuk-Favel/Verhoeve suggest the lower ratio

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<sup>34</sup> Laurel Lemchuk-Favel and Francesca Verhoeve, "First Nation and Inuit Home Care: Analysis of Costs Based on NCE Model," February 12, 1999, p. 7.

represents 1) a much higher acuity of care is present in home care programming 2) a much higher need for nurses than home care providers and/or 3) that nurses are performing some duties which could be assumed by health care aides or other health care professionals.<sup>35</sup> 3) Socio-political pressure for the provision of professional nursing services or lack of availability of rehabilitation professionals may also exist. A model which calls for a higher ratio of nurses to aides would require additional funding.

## **4.2 Education and Health Care Providers**

### **4.2.1 Health Human Resources and Projected Shortages**

Projected shortages in health human resources in Canada has been a subject of research over the last several years. Accumulating evidence predicts shortages in nursing, medicine, medical specialities and the rehabilitation therapies. More detailed studies such as *The Home Care Sector in Canada: A National Human Resource Analysis*, co-sponsored by Health Canada and Human Resources Development Canada (HRDC) are being undertaken. This study will gather information about formal caregivers (paid regulated and paid unregulated) and unpaid voluntary or informal caregivers. Indicated below are the study's objectives:

The objectives of the study include the development of an information base upon which decisions related to fundamental human resource issues and concerns (such as recruitment, retention, supply and demand, wage rates, implications of self-managed care, career choices, skills, training, mobility, training, work environment etc.) can be made. Particular attention is to be focussed on highlighting notable differences between provinces, urban and rural/remote communities, consumer groups, francophone and Aboriginal communities.<sup>36</sup>

Recent studies conclude there is a need to educate more health care service providers in a variety of fields.<sup>37</sup> Educational institutions across the country are responding, and once professionals are educated, the next challenge will be to recruit and retain these professionals in Aboriginal communities. *Survey of Nurses in Isolated First Nations Communities: Recruitment and Retention Issues* (2000), a recent study by the Aboriginal Nurses Association of Canada, found that Aboriginal nurses are more likely to choose to work and remain working in Aboriginal communities.<sup>38</sup> An extrapolation of this finding may indicate that the training of Aboriginal health professionals and other service providers will result in increased levels of retention. Finally, educational and

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<sup>35</sup> Laurel Lemchuk-Favel and Francesca Verhoeve, "First Nation and Inuit Home Care: Analysis of Costs Based on NCE Model," February 12, 1999, p. 9.

<sup>36</sup> Health Canada and Human Resources Development Canada, *The Home Care Sector in Canada: a National Human Resource Analysis Terms of Reference*, March 31, 2002.

<sup>37</sup> Kishk Anaquot Health Research and Program Development, *An Evaluation of the Indian and Inuit Health Careers Program*, March 31, 1999.

<sup>38</sup> Aboriginal Nurses Association of Canada, *Survey of Nurses in Isolated First Nation Communities: Recruitment and Retention Issues*, September 8, 2000, p. 6.

training programs for Aboriginal students should be developed and delivered in closer geographic proximity to Aboriginal communities in order to increase the number of Aboriginal health care providers in various health care professions.

#### **4.2.2 Appropriate Curriculum in Education and Training Programs**

Curriculum priorities within educational, training, orientation and continuing education programs for health service providers are another current issue. In order to improve the quality of palliative and end-of-life care, there are four areas that may require additional attention in Canada broadly to improve care of Aboriginal Peoples:

1. Cross-cultural orientation, cultural perspectives on death and dying; working with cultural and language interpretation services; palliative care models that work in Aboriginal communities of all sizes; death and dying in the Aboriginal family and community context; ethical guidance specific to Aboriginal values and belief systems;
2. Personal awareness and coping/processing skills; assisting and supporting the dying patient; pain management in various health care settings; symptom management at home and in “transit” between care locations;
3. Communicating with patients and families, including “bad news” in a culturally sensitive manner; supporting end-of-life/palliative care decision making; conflict resolution appropriate to Aboriginal families; and
4. Counselling support about grieving and bereavement; working with pastoral care staff, clergy and Aboriginal spiritual helpers; developing systems to provide access to traditional healing and medicine practices.<sup>39</sup>

In mainstream Canada, volunteer agencies are active and effective in supplementing paid service providers and family caregivers. Sufficient financial and curriculum support needs to be provided to hospice and palliative care/end-of-life care agencies for the provision of education, training, volunteer support and continuing education opportunities to volunteers. Appropriate volunteer selection and assignment systems also require additional development. The system of volunteer support in Aboriginal communities tends to rely less on formal agencies and more on family and extended family or Clan (in Nations that have Clan systems) support.

Family caregivers also require education and training in order to provide appropriate, safe, effective and compassionate care to their family members. Trainers need to be sensitive to emotions and personal barriers that may be experienced while training family members who are grieving. Family caregivers also need access to culturally appropriate anger and grief related healing support.

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<sup>39</sup> Aboriginal Nurses Association of Canada, *Survey of Nurses in Isolated First Nation Communities: Recruitment and Retention Issues*, September 8, 2000, p. 6.

### 4.2.3 Use of Internet-based Education and Training Methods

The availability of high speed internet is increasing to Aboriginal communities, although access to adequate and reliable telephone and cable service is an issue in some isolated communities. Internet-based education and training is an option that warrants consideration in communities with the required technological phone and cable service. The effectiveness of internet-based distance education must be analysed because Aboriginal Peoples generally have less formal education and access to technology than their Canadian counterparts. Many Aboriginal people prefer experiential or 'hands on' training where teaching methods employ demonstration and practice opportunities. In addition, although all levels of health service provider education and training and informal training have significant theory and informational components, more important aspects are manual and interpersonal skills that are best learned 'in person'. Finally, a review of training and education best practices for target groups should be undertaken and applied.

### 4.3 Cultural and Spiritual Considerations

Aboriginal Peoples have diverse cultural and spiritual belief systems. Programs must allow for the expression of beliefs and the practicing of individual and family traditions and ceremonies. Cultural and spiritual practices can be a significant source of strength when difficult times are encountered. Extended family and community supports can also be of great assistance.

For example, the Aboriginal Cultural Helper Programs at the University of Alberta Hospital and Royal Alexandra Hospital in Edmonton are similar to the First Nations Health program at the Whitehorse General Hospital in the Yukon. In addition, the St. Boniface Health Sciences Centre has made substantial progress in this area over the last fifteen years.<sup>40</sup> These services help Aboriginal patients and their families meet their cultural and spiritual needs by connecting patients with Elders, organizing spiritual ceremonies, arranging for interpretive services and building bridges between Aboriginal people and hospital staff with respect to culture and protocol.<sup>41</sup> Similar services need to be considered for implementation in home and community service environments.

Cultural values are a source of significant strength to individuals and families. Hospital policies should allow for hospitalized clients to access traditional healers and ceremonies. Beliefs about and ceremonies engaged in when someone dies are still practiced in a number of Aboriginal communities; these beliefs should be honoured by allowing for the practice of ceremony in medical institutions. In some communities, traditional methods of handling bodies are no longer practiced, therefore, the handling of a body where there are no funeral homes or coroners' offices is a challenge.

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<sup>40</sup> The degree to which similar programs exist throughout Canada is not known given that this discussion paper is not an in depth study.

<sup>41</sup> [www.cha.ab.ca/healthsite/pk2848sh.asp](http://www.cha.ab.ca/healthsite/pk2848sh.asp) In Strachan-Tomlinson, *Discussion Paper (a working draft) in preparation for the National Action Planning Workshop on End-of-Life Care, March 2-4, 2002 Winnipeg, Manitoba*, for Health Canada Secretariat on Palliative and End-of-Life Care, Ottawa, p. 14.

#### **4.4 Public Education and Awareness**

Information needs should be determined by Aboriginal governments and other stakeholder organizations. Then communication strategies should be undertaken in the respective languages used by communities. Whether the media are print publications, videos or radio, preparation in respective languages of Aboriginal Peoples is extremely important, particularly for Elders. Additional costs are associated with this, particularly for Inuit communities that require translation of materials into their Inuktitut dialect.

#### **4.5 Research – Health Management Policy Development**

Areas of specific concern and identified gaps in research and health management policy are as follows:

##### **4.5.1 Increasing Aboriginal Research Capacity**

Aboriginal people and communities need to oversee/conduct research based on their identified research priorities. Aboriginal researchers need to work in and with communities to learn and document traditional practices associated with end-of-life/palliative care. Evaluation is an important activity requiring training and development to build expertise needed to direct comprehensive and relevant program initiative evolution in home care and end-of-life/palliative care. Development of innovative service delivery models and best practice models, based upon traditional values are also important research priorities. Since 1999, First Nations and Inuit people have had access to relevant data gathered in the FNIRHS. Home and community care and end-of-life/palliative care will be studied in greater detail in the second wave of the FNIRHS which is being conducted in 2002 by the National Aboriginal Health Organization's (NAHO) First Nations Centre. It is a survey process that is First Nations mandated and controlled.

##### **4.5.2 Ethics, Values and Policy Related Challenges**

Development of methods for educating care providers in ethics, and designing mechanisms through which ethical problems may be solved require attention. Unique and diverse traditional and non-traditional values and beliefs held by Aboriginal Peoples present complex challenges in addressing ethical issues. Revision of policies will lead to the creation of required health care systems. Various provincial Ministries of Health have developed policies related to Aboriginal health (e.g., Ontario Aboriginal Health Policy), respecting and protecting rights and options related to tradition and culture within health care systems.

In Ontario, for example, policy allows for First Nations such as Akwesasne, Six Nations and Wikwemikong to have their own nursing home and chronic care services facilities licensed under provincial legislation. These communities provide these services through a combination of federal, provincial and personal funds. In Manitoba, there are at least six well-established personal care homes funded by the Federal Government. More research is required to determine what exists across Canada.

### **4.5.3 Health Care Delivery Models**

Research about the development and testing of new and innovative health care delivery models is a gap in current research. For example, it is unknown whether or not applying a scaled down urban model to a First Nation, Inuit or Métis communities would yield desired outcomes. Lemchuk-Favel and Verhoeve suggest a staffing profile for a community of 2,000 people: 2 nurses, 6 home health aides, 1 OT, .5 PT and .25 RT.<sup>42</sup> Small communities have been unsuccessful in finding and retaining part-time rehabilitation staff; health human resources to fill full-time positions are either unavailable or unwilling to relocate. Visiting rehabilitation teams may work in some locations but, in others, they may spend too much time travelling. Alternative delivery models, such as training of new rehabilitation personnel at varying levels to implement programs, therefore may need to be considered and tested.

Innovative models have been developed and tested in rural Canada. For example, there is a rural palliative home care project in Nova Scotia and Prince Edward Island. This project has developed a model for use in rural areas of those provinces, with primary care teams being supported by a regional mobile consultant team that provides expertise and advice in palliative advance-care planning and delivery. Specialist expertise for complex symptom management is provided through telephone and telemedicine linkages and/or through site visits.<sup>43</sup>

### **4.5.4 Identification of Facilities and Services needed**

The existence of end-of-life/palliative services available in Aboriginal communities has not been reviewed. Home based care and services provided in a home setting has, however, been made a focus by Health Canada's First Nations and Inuit Health Branch (FNIHB) through their Home and Community Care Program. Within its comprehensive guidelines, communities are able to make decisions about the design of services best suited to meet specific community needs.

Housing shortages in Aboriginal communities mean there is a need to develop small multi-purpose care facilities with a limited number of beds. Palliative care may be included in the range of services provided by these facilities. This way, opportunities for individuals to die in their home communities, accessible to friends and family, would exist. Costs related to service requirements, diversity of patient specific care needs, and diseconomies of scale would be considerations. The development of innovative ways to meet needs in Aboriginal communities requires further research.

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<sup>42</sup> Laurel Lemchuk-Favel and Francesca Verhoeve, "First Nation and Inuit Home Care: Analysis of Costs Based on NCE Model," February 12, 1999, p. 23.

<sup>43</sup> Health Canada, "A Rural Palliative Care Home Care Project", p. 1.

#### **4.5.5 Canadian Virtual Hospice (CVH): Knowledge Development and Support in Palliative Care**

Health Canada is funding research in palliative care through the Canadian Virtual Hospice (CVH). Terms of reference allow for a focus on work with 'vulnerable populations' including Aboriginal populations. Although use of web-based tools have the potential to affect knowledge transfer, decision-making and clinical practice, evaluative studies on their efficacy are not readily available. CVH makes information available to service providers, volunteers and family members. Documentation of best practices and mutual support mechanisms are planned.<sup>44</sup> Developing linkages between CVH and appropriate Aboriginal organizations are key activities for ensuring that information requirements of Aboriginal Peoples are met.

#### **4.5.6 Clinical Guidelines and Standards**

Clinical guidelines and standards targeting Aboriginal people should be developed in partnership with Aboriginal organizations. Along with being evidence-based, the applicability of clinical guidelines and standards to Aboriginal communities should be considered both prior to and during development. Individuals working in rural, remote and isolated communities without locally-available physician services require specific clinical guidelines and standards along with associated quality assurance systems to ensure that services provided are fully supported, thereby ensuring delivery of quality care. Recently, the clinical nursing supervision and support of nurses working in these locations was the subject of a recent study completed by the Aboriginal Nurses Association of Canada (A.N.A.C.), and the study identified significant gaps in clinical nursing supervision and related support available to nurses working in some Aboriginal settings.<sup>45</sup>

### **4.6 Support: Family, Caregiver and Significant Others**

#### **4.6.1 Health and Safety Concerns**

In addition to training-related support issues identified in the education section above, a second core concern is the health and safety of family members, caregivers and significant others. If the patient is actively infectious, these individuals need to be trained in precautions to limit the risk of infection. In addition, if caregivers are providing direct care, which involves lifting the patient, or working with oxygen, drugs and/or other potentially dangerous agents, training should be provided. Equally important is the availability of culturally and spiritually relevant holistic counselling support to assist family members and significant others in their grieving process. Counselling and

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<sup>44</sup> [www.hc-sc.gc.ca/english/media/releases/2001/2001\\_121ebk1.htm](http://www.hc-sc.gc.ca/english/media/releases/2001/2001_121ebk1.htm) IN Strachan-Tomlinson, *Discussion Paper (a working draft) in preparation for the National Action Planning Workshop on End-of-Life Care, March 2-4, 2002 Winnipeg, Manitoba*, for Health Canada Secretariat on Palliative and End-of-Life Care, Ottawa, p. 39; and, Health Canada, "Virtual Hospice: Knowledge Development and Support in Palliative Care", November 2001, p. 2.

<sup>45</sup> Aboriginal Nurses Association of Canada, "Survey of Nurses in Isolated First Nation Communities: Recruitment and Retention Issues", September 8, 2000, p. 4.

support services are vital in preventing 'burnout' and to reduce the potential for emotional problems resulting from being overwhelmed by the demands of the processes of death, dying and grieving.

#### **4.6.2 Lack of Local Expertise, Adequate Space and Equipment**

Unique and significant barriers exist in providing these supports to Aboriginal people. An initial barrier occurs when an individual does not speak the language of the Aboriginal person being served or is not familiar with traditional beliefs, values and practices around death and dying. Literacy levels and lack of written materials in the first language of the caregiver can result in further challenges. Problems with the space available for privacy and comfort in the delivery of patient care arise when, for example, the only place in a home with multiple residents for a hospital bed is in the living room. Lack of access to appropriate equipment or lack of space within the house to use it (e.g., a wheelchair) may further impact the available options. Access to basic sanitation, such as unlimited water and indoor plumbing may also be a concern in supporting caregivers in the home, as is access to affordable, wholesome foods. Prevalence of smoking and wood stoves in the home may also present problems in managing air quality and providing a safe environment where oxygen or other flammable agents may be used.<sup>46</sup>

#### **4.6.3 Respite and Personal Support for Caregivers**

Caregivers are under tremendous strain throughout the home care and palliative care process. Some stages of illness and the demands on the caregivers are more intensive than others. The unpredictability of the course of the illness and the length of the dying process creates a barrier to being able to plan and pace efforts in providing care. For these reasons and many more, caregivers need available, accessible and trained respite services to ensure that they are able to have time away from the active support role. In addition, they need compassionate support to be available to them to prevent exhaustion and promote active and effective grieving processes. Aboriginal caregivers may have unique support requirements, such as the need for Aboriginal respite workers, as well as ceremonial or spiritual support requirements.

#### **4.6.4 Advance Care Planning**

Advance Care Planning is a process of communication among patients, their health care providers, their families and others about care that will be considered appropriate when a patient is unable to make decisions. Advance Care Planning (ACP) may include advance care directives that are completed by a person when he or she is able. Within an Aboriginal context, the process of explaining the ACP process, finding mutual understanding and making decisions may well involve extended family members. The process may have to be redesigned to ensure consensus and appropriate respect for traditional forms of decision making.

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<sup>46</sup> Canada, Royal Commission on Aboriginal Peoples, *Final Report*, Volume 3, Gathering Strength: Chapter 3, Health and Healing, Ottawa: 1996, pp. 180-181.

## **4.7 Surveillance**

General trends affecting the overall Canadian population include the following:

1. Increased demand for services;
2. Decreased supply of informal caregivers;
3. Increased reliance on home care as an acute care substitution program;
4. Emphasis on consumer directed care and development of self-managed care programs;
5. Private versus public mix of home care services; and
6. Increased devolution of health care administration to regional authorities.

The way in which these and other significant trends are affecting Aboriginal Peoples is evolving. Therefore, surveillance mechanisms need to be developed in conjunction with Aboriginal Peoples to track emerging issues in Aboriginal communities. Baseline needs assessment work has been done in some status First Nations and Inuit communities under the umbrella of Health Canada's FNIHB Home and Community Care Program. Although the needs assessment process did not focus on palliative and end-of-life care specifically, needs were identified in this area, with needs assessment summaries provided to First Nations and Inuit Health Branch (FNIHB) as a contract deliverable. At the time of writing this report, FNIHB noted the importance of collating and analyzing these summaries, as means of gaining additional insights into concerns of Aboriginal communities. Again worth noting are those Aboriginal people that are not eligible for the Home and Community Care program, namely, off-reserve status First Nations living south of the 60<sup>th</sup> parallel, Métis, and all non-status First Nations.

## **5.0 Summary of Responses to Interviews and Questionnaire**

### **5.1 Brief Description of Interview and Questionnaire Process**

The research approach and data collection methods were designed to determine priorities and issues common among national Aboriginal organizations, Métis member organizations, Home and Community Care Coordinators, and health care workers. To augment a literature review, information from people providing direct care and support at regional levels was collected by telephone interview and by questionnaire.

Focused, telephone interviews were conducted with key national Aboriginal organizations, and a questionnaire designed to elicit the same information as the telephone interview was circulated to regional FNIHB Home and Community Care Coordinators for distribution to community advisors in order to garner local/regional input. Key Métis contact people at the regional level were also asked to distribute the questionnaire at the local level.

The questionnaire was designed to elicit input about three themes: priorities, ethics and cultural considerations. Concerning priorities in End-of-Life/Palliative Care, respondents noted the importance of spiritual and cultural respect, while encouraging greater involvement of Aboriginal communities and organizations to address access, services, and professional development issues.

When asked what they felt were the most important ethical concerns, respondents identified the importance of informed consent, involving patients and families in decision making, confidentiality, and encouraging options that meet the unique traditions of Aboriginal Peoples. Cultural considerations included the importance of respecting specific coping strategies used during death and dying by Aboriginal Peoples. Additional feedback elaborated upon treatment options that are not currently available in their area.

A final question asked about the nature of conflicts associated with death and dying processes. Broad recommendations were made to develop systems that would reduce the potential for conflict, enhancing honest and productive communications and relationships between various levels of service providers, patients, family members, extended family and the community.

## 6.0 Conclusion and Recommendations

The process of identifying and engaging in discussion and debate with regard to the quality and availability of home and community, end-of-life / palliative care for all Canadians is an exciting and interesting challenge. Numerous complexities arise in designing systems to deliver a consistent standard of care to Canadians in their homes wherever they live. This paper is only the beginning in addressing the need to identify, document and communicate the unique and diverse characteristics and the particular issues related to Aboriginal people, their families, communities and Nations. The overall goal of the completion of the National Action Plan on End-of- Life Care is admirable and important. The inclusion and full consideration of the significant issues related to the development and delivery of culturally-relevant and financially sustainable palliative care systems to Aboriginal people is fundamental to an inclusive plan.

### ***Recommendations:***

1. Ensure active and appropriate participation of relevant Aboriginal organizations in the development of the National Action Plan on End-of Life Care. Such participation would include support for:
  - developing and implementing a broad-based consensus process to identify, research and communicate the end-of-life / palliative care priorities and issues of Aboriginal Peoples
  - based on assessed needs, developing innovative end-of-life / palliative care delivery models that build on the strengths of Aboriginal people, families and communities
  - identifying, documenting and making available Aboriginal best practices in end-of life delivery models across Canada and internationally, specifically including those models that use both cultural and traditional strengths and methods.
2. To conduct necessary research to define responsible, competent, compassionate, appropriate, culturally relevant and ethically sound end-of-life / palliative care for First Nations, Inuit and Métis people.
3. Build on the needs assessments completed under the umbrella of the Home and Community Care program to ensure the end-of life needs are well defined for First Nations, Inuit and Métis populations; and to further include an assessment of the needs of urban Aboriginal people. An expected output is to identify the jurisdictional and other barriers to current end-of life / palliative care health services.
4. Develop and implement a strategy to ensure the education and training of the appropriate number of Aboriginal health workers in all fields necessary to provide culturally relevant and sensitive care to Aboriginal Peoples in all health care settings.
5. Develop strategies for appropriate provision, professional development and other supports to health care workers employed in Aboriginal communities to ensure an ongoing high standard of palliative care.

6. Create a coordinating mechanism that fully involves federal, provincial, territorial and Aboriginal governments and organizations to identify and resolve jurisdictional issues arising between governments, to achieve a coordinated approach to Palliative Care.

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## **Appendix A**

### **Five National Aboriginal Organizations**

#### **Assembly of First Nations (AFN)**

The Assembly of First Nations advocates and supports the diverse goals, rights, aspirations, traditional and spiritual values of First Nations citizens for all generations. The AFN Secretariat strives to improve the conditions of First Nations peoples in areas such as housing, social development, justice, health, education, economic development and land settlement. As a national organization, the AFN represents First Nations citizens from over 633 First Nations communities. The AFN also provides First Nations with information about government activities, policies and programs.

#### **Congress of Aboriginal Peoples (CAP)**

The Congress of Aboriginal Peoples' affiliates are open to over 800,000 off-reserve Indian, Inuit and Métis people living in urban, rural and remote areas throughout Canada. Founded in 1971 as the Native Council of Canada (NCC), the organization was formed to address the lack of recognition of Métis and non-status Indians (now First Nations) as Aboriginal Peoples and to challenge the exclusion of their constituency from federal responsibility. Affiliates and provincial territorial organizations include: Labrador Métis Nation, Federation of Newfoundland Indians, Native Council of Prince Edward Island, Native Council of Nova Scotia, New Brunswick Aboriginal Peoples Council, Native Alliance of Quebec, Ontario Métis Aboriginal Association, Indian Council of First Nations of Manitoba, Native Council of Canada (Alberta), United Native Nations (BC), Métis Nation Northwest Territories, The Council of Yukon First Nations and the CAP Youth Committee.

#### **Inuit Tapiriit Kanatami (ITK)**

The Inuit Tapiriit Kanatami was established in 1971 as the national voice for the Inuit of Canada. One of its objectives is to take measures at the national level, along with other national Inuit organizations, to protect and promote Inuit culture, language, values, health, education, justice and any other matter that impacts upon the ability of Inuit to shape the future of their society within Canada. Member organizations represent their respective regions; they are the Labrador Inuit Association (represents 5,000 Inuit of Labrador), Makivik Corporation (represents 9,000 Inuit of Nunavik (Northern Quebec)), Inuvialuit Regional Corporation (represents 5,000 Inuit of the Western Arctic) and Nunavut Tunngavik Incorporated (represents 21,500 Inuit of Nunavut).

## **Métis National Council (MNC)**

The Métis National Council is the national representative of the Métis Nation in Canada. Established in 1983 following recognition of the Métis as a distinct people with Aboriginal rights in the Constitution Act, 1982, the MNC has been recognized as the voice of the Métis Nation in constitutional negotiations at the national level, and acts as an advocate and negotiator for the Métis people with the Government of Canada and at national conferences. It also represents the interests of the Métis people on the international stage. MNC is composed of five provincial organizations: Métis Provincial Council of British Columbia, the Métis Nation of Alberta, the Métis Nation-Saskatchewan, the Manitoba Métis Federation and the Métis Nation of Ontario.

## **Native Women's Association of Canada (NWAC)**

The Native Women's Association of Canada is a non-profit organization incorporated in 1974 to enhance, promote and foster the social, economic, cultural and political well-being of First Nations and Métis women to First Nation and Canadian societies. Among its objectives are the assisting of Native women's organizations, as well as community initiatives to develop their local projects and to advance issues and concerns of Native women and to link with other organizations with common goals. NWAC has thirteen member organizations: one for each province and territory and Labrador.