Sustaining the Caregiving Cycle: First Nations People and Aging

A Report from the Assembly of First Nations to the Special Senate Committee on Aging

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EXECUTIVE SUMMARY

This report from the Assembly of First Nations is presented to the Special Senate Committee on Aging. The Senate Committee is mandated to examine issues related to the aging of Canadian society and implications for federal government policies and programs.

As part of the Senate Committee's work, evidence and presentations submitted in the fall of 2006 have been referenced in an Interim Report published in March 2007. The Interim Report raised a number of questions to guide the second phase of the Committee's work, including issues around diversity of seniors and specifically with regard to Aboriginal issues. The alarming statistics on the lower life expectancy of First Nations and other Aboriginal populations suggested the need for additional commentary from these groups.

This submission provides additional information related specifically to First Nations in Canada. It offers alternative definitions of aging from a First Nations cultural perspective, along with detailed information related to health status and determinants of health. First Nations people face higher rates of chronic health conditions; for example, diabetes is three to five times higher than the Canadian population. Health and social security programs and services are problematic for First Nations people in many respects.

Cost containment measures have had detrimental effects on First Nations health services. Programs targeted to seniors e.g. the First Nations and Inuit Home and Community Care Program (FNIHCC), are being utilized more by clients under age 65 in First Nations communities. Only 0.5 percent of First Nations communities have long term care facilities, forcing most First Nations seniors requiring care to leave their home and community. A major effort is required to develop a comprehensive approach to continuing care for First Nations. There is only minimal funding for seniors' participation programs. Far fewer First Nations seniors are accessing the Guaranteed Income Supplement and more support is required to ensure they are aware of, and assisted in, the process of applying for these benefits.

Much work is required to address the wide-ranging needs of First Nations seniors. More importantly, there are critical implications for the youthful First Nations population on the horizon. Through dedicated efforts to improve health care, long term care and healthy living now, the future for tomorrow's aging First Nations people can be a positive and vibrant one.

1. INTRODUCTION

The Assembly of First Nations (AFN) is a national organization that works on behalf of, and with, over 630 First Nations in Canada on joint efforts to recognize, restore and enhance First Nations rights, jurisdiction, development and well-being. The AFN works jointly with First Nations through a range of initiatives and processes that reflect the Treaties, Constitutional rights under section 35, and other legislation, policies, programs and services of First Nations and governments within Canada.

The purpose of this report is to share information with the Special Senate Committee on Aging, specifically regarding First Nations people in Canada. This input from the AFN is intended to assist the Committee by providing a First Nations lens that adds to, and expands upon, the evidence already submitted on behalf of First Nations. This report speaks only on behalf of "First Nations", specifically those individuals, communities and Nations recognized to be First Nation ("Indians" or Registered Indians under the *Indian Act*) through the Treaties, Canadian Constitution and/or legislation of Canada (as distinct from Métis and Inuit, also recognized as Aboriginal peoples within the Constitution).

The Special Senate Committee on Aging is looking broadly at the issue of aging in Canada and the implications for future programs and policies, given current needs and gaps in health care, social development, housing, transportation, financial security and other areas. A series of key questions have been raised in the Interim Report of the Committee (March 2007), including how is old age defined and the extent to which current federal programs address the diverse needs of seniors. This report will address selected questions and their implications in relation to First Nations peoples. It concludes with a number of recommendations for the consideration of the Committee.

2. FIRST NATIONS DEMOGRAPHIC PROFILE

There are approximately 748,371 First Nations people in Canada.[1] First Nations population growth will be significant over the next several decades.

First Nations people currently make up about 3.3 % of the population in Canada. Statistics Canada projections show that the general population over the age of 65 will grow by 11.3% between 2006-2036 (from 13.2% in 2006 to 24.5% in the year 2036).[2]

The First Nations population age 55- 64 will increase by 236% and the 65+ group by 229% over the next several decades. Life expectancy is also anticipated to improve. By 2010, First Nations males' life expectancy will increase from 59.2 to about 72 years and from 65.9 to 79 years for First Nations females. As a result, there will be 57,000 more First Nations members aged 65 and older in 2021.[3] These projections are further supported by the recent report by Statistic Canada which indicates that the "North American Indian senior population is projected to grow from 28,200 in 2001 to 59,500 in 2017.[4]

At the other end of the scale, approximately 50% of the First Nations population is under the age of 25, compared to Canada's median age of 37.5. This dominant young population cohort will have a major impact in the next 30 years as it moves into the 55th year.

As well, migration back to First Nation communities will cause the population living in First Nations communities to increase by 34%:

"The total Registered Indian population could increase by 34%, from approximately 703,800 in 2001 to slightly less than 940,000 in 2021. Over the same period, the on-reserve population could grow quite substantially if the migration assumption (net inflow to reserves) proves correct over time. The proportion of Registered Indians living on reserve could increase from an estimated 60% in 2001 to 75% in 2021. Conversely, the off-reserve proportion and corresponding five-year annual growth rates could decline during the period."[5]

Contrary to what is commonly assumed regarding the outflow of First Nations residents from First Nations communities into the urban areas, there is also a significant influx in urban-to-reserve/community migration producing a consistent net inflow or gain of migrants to reserves and communities.[6] It was estimated that in 2001 most of the First Nations population lived in their communities (48%) and in large cities (41%). These estimates are expected to remain consistent with a projected increase of 57% among those living on reserve by 2017, mostly at the expense of rural areas. With this movement, it is expected that more demand will be placed on vital resources within these communities, including the demand for continuing care services.

Projections based on current population data predict that the longevity of First Nations people in Canada will increase in future, and parallel to this, there will be an increase in the prevalence of chronic health conditions and in the demand for the full range of services in First Nations communities. A recently completed Continuing Care Synthesis Report states that:

"Overall, between 1996 and 2001, the First Nations population grew by 15.2% . . . (Statistics Canada, 2004a) . . . the largest increase has been in the 65 and older age group. Between 1996 and 2001, the number of First Nations 65 years of age and older living on reserves grew by 34% (Statistics Canada, 2003). If this trend continues, the implications for housing, social services and health care will be substantial (Statistics Canada, 2003). It is also noted that, currently, there is a "youth bulge" that may have an impact on the need for continuing care services in the future due to potential increases in morbidity rates for accidents, diabetes, etc. Hull (2006) noted that 54.0% of First Nations living on reserve were between 0 and 24 years of age, 14.3% were between 25 and 34 years of age and 4.7% were 65 years of age or older. . . Thus, 68.3% of First Nations... are under the age of 35."

3. AGING IN A FIRST NATIONS CONTEXT

In this section we will respond to the following key questions raised in the Interim Report: Is age 65 a realistic age of eligibility for First Nations seniors to access seniors' programs, and given the poor health of First Nations populations, can alternative measures be used? What are the critical determinants affecting the participation, health and well-being of First Nations seniors, and which health determinants are most influential in improving health and ensuring that seniors live full lives?

3.1 Definitions of Aging

There are many definitions of aging. From a biological perspective:

"Aging is a complex biological process in which changes at molecular, cellular and organ levels result in a progressive, inevitable, and inescapable decrease in the body's ability to respond appropriately to internal and/or external stressors."[8]

From a First Nations cultural perspective, aging is part of the cycle of life, a natural process that culminates in old age and finally passing to the spirit world. With aging comes wisdom and understanding; elders are respected for their knowledge and the guidance they can offer. Many First Nations in Canada share a common understanding of the "medicine wheel", a circle with four quadrants relating to the four cardinal directions, the physical, mental, emotional and spiritual aspects of the self, and life stages of infant/child; youth; adult; and elder.

There are some common biological misconceptions about aging. For example, it is generally assumed that our bodies continue to function at the same level of efficiency until old age. In fact, the best available evidence says that most of our physiological processes reach their maximum capacity prior to, or during, early adulthood and then gradually start to decline. It is also assumed that adults "age" through a standard series of physical changes and at the same rate, whereas according to the evidence, age-related physical changes do not occur according to a strict timetable but at differing rates.[9] This implies that there are some real opportunities to improve the aging of First Nations people in the future by addressing those health conditions now emerging in the First Nations cohort age 30 to 55 years.

3.2 The First Nations Perspective

The Interim Committee heard evidence that suggests utilizing age 55 as being equivalent to 65 when referring to First Nations seniors. The AFN concurs with this recommendation, which coincides with recent studies by First Nations health organizations. In its June 2006 report on First Nations seniors' health, the First Nations Regional Longitudinal Health Survey (RHS) used a cut-off of age 55 to identify seniors, citing lower life expectancy and earlier onset of chronic conditions experienced by First Nations living in their communities.

Another report entitled, "Our Nations' Elders Speak – Ageing and Cultural Diversity: A Cross-Cultural Approach"[10] also refers to First Nations and Inuit seniors as any person 55 years of age and older, noting that First Nations and Inuit have the lowest life expectancy of all groups in Canada. This report defines old age as "whenever health and functioning deteriorate to a level that results, as we age, in decreasing independence and mobility."[11] In this definition, the level of functioning is primary; chronological age is secondary. The report also connects aging with elders' ability to access services and resources, which can be impacted by social and political status, poverty, cultural disruption and racism.

First Nations elders are more likely to suffer degenerative diseases associated with old age and to experience the social and psychological consequences of old age such as loss of friends, spouse or relatives earlier in their lives.[12] Many First Nations elders have experienced a loss of self-esteem and independence as a result of the negative impacts of residential schooling and the loss of traditional ways of life. The RHS found that 47% of First Nations seniors aged 50-59 years and 43.3% percent of First Nation seniors aged 60+ had attended residential school and had frequently experienced negative impacts such as isolation from family and community, verbal or emotional abuse and loss of cultural identity.[13]

3.3 Aging Well

The NIICHRO report notes that "to Age Well is to Feel Whole." Essential elements of healthy aging include: physical, mental, emotional, social and spiritual well-being; empowerment (ability to make decisions about one's life); awareness of, and access to, information about existing programs and services; easy access to medical, social and other support services; aging in place, with respect and dignity, for as long as possible (independent and interdependent living); a supportive social environment; continued community involvement and participation; financial security; adequate and affordable housing; and accessible and affordable transportation.

When these pre-requisites of aging well are applied in today's First Nations socio-economic context, it is apparent that very few First Nations people are aging well. This is even more significant given the earlier evidence presented to the Committee[14] stating that in roughly twenty years' time, the percentage of Aboriginal seniors will triple. Major efforts are required now to ensure that all of these essential elements are in place so that the burgeoning First Nations population will age well over the next several decades.

3.4 Cultural Perspectives on Health

From a First Nations cultural perspective, aging well also has to do with the teachings of the inherent value of growing old and the wisdom of our elders who have earned the respect of their communities and Nations by virtue of their advanced years. In the "medicine wheel" model of understanding life noted earlier[15], it is said that as we enter the fourth quadrant of the life cycle, the "north", we enter the time of wisdom and understanding in our lives, the time of teaching and sharing our wisdom with others. This denotes a strong, vital role for the elders and the recognition of their intrinsic value and contribution to the well-being of their communities and the world beyond.

A wholistic approach takes into account and integrates all aspects of health – physical, mental, emotional-social and spiritual. This approach views the individual in relation to the family, the family in relation to the community, and the community in relation to the larger society. In contrast, the bio-medical model assumes that one can take a piece of a person and mend it, without reference to the whole person or the social environment."[16]

First Nations cultures take an approach to health, well-being and disease which is concerned with the whole person and not merely the part of the person that is injured or diseased. Good health means more than the absence of disease or illness; rather it emphasizes the whole person and the harmonious functioning of body, mind, emotions and spirit. Over the last few decades, this view of health has become accepted by the modern health care establishment. Notwithstanding, despite strong evidence showing greater effectiveness of a population health versus a biomedical approach, Canada lags behind other nations in matching theory to practice. Adopting a population health lens for the Canadian health care system highlights, even more dramatically, the gap between First Nations' and non-First Nations Canadians' well-being.[17]

Figure 1: First Nations Wholistic Policy and Planning Model

Bonding
Relations within the community
Bridging
Relations with other communites
Linkages
Relations with formal institutions

Self Determination
Environmental Stewardship
Social Services
Justice
Gender
Life Long Learning
Languages, Heritage & Culture
Urban/Rural
Lands & Resources
Economic Development
Employment
Health Care
On/Away from Reserve
Housing

Self Government / Jurisdiction
Fiscal Relations/Accountability
Collective & Individual Rights
Capacity/Negotiations

Elders
Child
Youth
Adult

Cultural
Economic
Social
Environmental
Physical
Mental
Spiritual
Emotional
Community

Legend
Medicine Wheel
Lifespan
First Nations Self-Government
Health Determinants
Social Capital

In 2005, federal, provincial, territorial and First Nations governments endorsed a First Nations Wholistic Health Strategy at the First Ministers meeting on Aboriginal issues. A First Nations Wholistic Policy and Planning Model (Figure 1) has been proposed by AFN which addresses the determinants of health that are most relevant to First Nations and which emphasizes the significance of self-government in looking at potential new investments and partnerships in promoting positive health outcomes.[18]

This population health approach focuses on the interrelationship of the determinants of health, addresses health issues, explores community initiatives and may be used in making recommendations around First Nations seniors' health and well-being.

3.5 Health Status Historically and Today

Historically, First Nations have enjoyed robust health, as described in many of the early accounts of explorers, missionaries and traders throughout North America. This shifted over time, as noted in the time span represented below:

> *"Skeletal remains of unquestionable pre-Columbian date . . . are, barring a few exceptions, remarkably free from disease. Whole important scourges [affecting Europeans during the colonial period] were wholly unknown. There were no plagues, cholera, typhus, smallpox or measles. Cancer was rare, and even fractures were infrequent. . There were, apparently, no nevi [skin tumours]. There was no trouble with the feet, such as fallen arches. And judging from later acquired knowledge, there was a much greater scarcity than in the white population of. . most mental disorders, and of other serious conditions."*[19]

> *"the Indians in general exceed the middling stature of Europeans; are straight and well-made people, large-boned but not corpulent . . . Their constitution is strong and healthy, their disorders few . . ."(a fur trader, 1767)*[20]

> *"The Indians are in general free from disorders; and an instance of their being subject to dropsy, gout or stone, never came within my knowledge. . ."(18th century explorer Alexander Henry)*[21]

> *"(The Indians are) far below the average size and weight of the white man . . . Their muscles and bones undeveloped; stature stooping, with a long, narrow, thin chest."(northern Ontario physician, 1905)*[22]

The health status of First Nations people in Canada today is far below the national average and decreases with age usually beginning with those aged 30 and older. Life expectancy is shorter although improving progressively. As noted in the Interim Report, Health Canada data for 2001 showed the male life expectancy for registered Indians at 70 years compared with 77 for Canadian males, and the rate for female registered Indians was 76 compared with 81 for Canadian females.[23]

3.5.1 Chronic Conditions

In comparison with Canadian health data, First Nations people have higher rates of chronic illnesses such as diabetes, cardiovascular disease, arthritis and functional/activity limitations. These conditions place First Nations populations at increased risk of requiring on-going medical and personal care throughout their lifetime.

The RHS has found the following with respect to long-term health conditions reported by First Nations according to age group:

> *"There is an almost perfectly linear drop by age group in the prevalence of those who reported having none of the conditions, declining from 67.2% in the youngest age group to 13.6% among First Nations seniors 60 years and older. Among First Nations seniors, 40.8% reported four or more such conditions compared with only 1.8% in the 18–29 age group. The reporting of two or three conditions increases with age until age 60 and older, after which it is more common that respondents will report four or more conditions. The prevalence of one long-term condition holds relatively constant regardless of age, ranging from 18.9% to 25.6%."*[24]

Simply put, seniors are nearly twice as likely to report one or more chronic health conditions (85.2% vs. 47.8%) and nearly three times as likely to report two or more conditions (66.9% vs. 24.7%).[25]

Diabetes is a significant health concern among First Nations. The prevalence of diabetes among the general Canadian population is 3%, comparable to 8.5% for First Nations living in their communities. The age-adjusted rate for First Nations is roughly 3 to 5 times higher than that of the general Canadian population.[26] Prevalence rates for diabetes increase with age and are higher among those living in isolated communities. In the First Nations population, 35.2% of those aged 65 years and older are diabetic compared to only 10% of that age group in the Canadian population.[27]

In addition to the high prevalence rates, major complications are associated with diabetes. The most common are heart disease, hypertension, stroke, lower limb amputation, kidney disease, and eye disease. These usually require on-going medical treatments in the form of complex care to counteract related side effects. The prevalence rate is expected to increase over time as a function of incidence, survival of people with diabetes, and aging of the population. Incidentally, the need for preventative and on-going care will be necessary in order to counteract the rise of associated complications.

3.5.2 Limitations on Active Living

Many chronic conditions result in serious functional/activity limitations both if the individual is not provided with adequate treatment at an early stage and as the individual ages. For example, arthritis is a serious condition which results in lifelong disability from joint deterioration regardless of age and requires support in the home and with personal care. Arthritis affects 45.5% of First Nations individuals over 60 years of age.[28] Furthermore, more than half (52.2%) of First Nations adults with disabilities reported arthritis or rheumatism compared with 14.6% of their non-disabled counterparts.[29]

According to the RHS, the age-adjusted prevalence of disability amongst First Nations adults ranges between 27.8% and 28.4% and between 1.1 and 1.6 times the prevalence of disability in the general population.[30] First Nations seniors with disabilities are more likely to report fair or poor health (64.5% of First Nations seniors 60 years and older with disabilities, compared with 18.3% of First Nations seniors without disabilities).[31] Injury prevention is another critical area of concern. The First Nations population with disabilities resulting from injuries represents the highest rate of injured over any other ethnic group in the country.[32]

The disability rate among young adults is almost three times higher for Aboriginal peoples than for non-Aboriginal people. Sixty-six percent of Aboriginal adults with disabilities are affected by a mild disability, 22% by a moderate disability and 12% by a severe disability.[33] Again, the long term implications of these figures are significant given the increasing longevity of First Nations people and the growth rates of the youth population.

Recent research on continuing care[34] predicted an increase in the need for continuing care in First Nations communities in Manitoba and Quebec; "…all of the individuals in the study had chronic conditions that are expected to worsen over time, it is reasonable to expect that there will be a substantial number of continuing care clients with moderate to high care needs, in the future." National level research also supports this finding. Almost half (47%) of First Nations seniors are in need of one or more homecare services according to the RHS, however, only one third (34%) of those in need received the care (see Table 2 below).[35] Issues with regard to continuing care and other priority programs and services will be discussed later in this report.

Table 2. Proportion needing homecare services age group

Type of assistance needed	Age group				
	18-29	30-39	40-49	50-59	60+
Home maintenance	8.2%	11.3%	11.7%	25.3%	40.0%
Light housekeeping	3.1%	3.7%	5.7%	16.6%	38.7%
Care from a nurse	*	*	1.7%	6.1%	16.6%
Palliative care	*	*	*	*	*
Personal Care	1.5%	*	*	2.4%	9.9%
Meals prepared or delivered	1.0%	*	*	4.0%	13.6%
One or more services needed	8.9%	11.9%	13.6%	30.4%	47.7%
One or more services received	2.8%	2.6%	3.3%	9.8%	34.2%
Need for home modifications	2.0%	3.8%	5.1%	16.7%	29.4%

*value suppressed due to small cell size

3.5.3 Determinants of Aging and Health

A paper produced by Social Development Canada provides a comprehensive list of issues related to longevity including low income; poor housing; inadequate health care and supports for independent living; and economic well-being pre- and post-retirement.

Psychological and social factors are also known to be important determinants of human longevity.[36] Biological processes can be affected by socio-cultural dynamics in several ways, e.g. depression is related to physical ailments.[37] Researchers have found that depression among men and women 65 and older nearly triples their risk of stroke.[38]

Poverty has a profound impact on health. American studies have shown that people living below the federal poverty level have a death rate from cancer twice that of the rest of the population. African American men, who outnumber Caucasian Americans in poverty 3-to-1, were found to have a 25% higher cancer risk.[39]

A survey completed by over 50 First Nations elders in 2002 [40] identified numerous issues that affect elders' health: diabetes, heart disease and arthritis being primary, as well as cancer, poverty/money issues, alcohol and drug abuse, housing, and loneliness, neglect and physical abuse. To address health issues and problems they identified a number of strategies such as:

- Establishing legal rights and supports to prevent and address elder abuse;
- Addressing housing problems and providing better housing for elders;
- Providing more information on health issues;

- Addressing health funding cutbacks;
- Increasing community knowledge of, and involvement in, elder issues;
- Increasing family involvement and support;
- More training of First Nations in the health professions;
- More programs, activities and centres for elders;
- Increased access to home care for elders;
- More funding for transportation; and,
- Teaching First Nations youth the traditional ways including respect for elders.

Housing

Numerous studies have catalogued the serious problems associated with housing and infrastructure for First Nations. The 2005 First Nations Housing Action Plan prepared by the Assembly of First Nations details problems such as shortages leading to severe overcrowding; lack of plumbing and electricity; poor insulation; toxic mold; substandard construction and major repair. Overcrowding is a recurring problem; 19% of dwellings on reserve have more than one person per room in comparison to 2% in the general Canadian population.[41] This last statistic shows a rate of overcrowding close to 10 times greater among First Nations than Canadians.

Over a third of First Nation adults live in homes requiring major repairs, which includes defective electrical wiring, plumbing, and need of structural repairs to walls, etc. Eighteen percent of First Nation homes do not have a telephone with service, and almost 4% do not have hot running water. Many live in crowded conditions, with the average occupant density of the First Nations communities reaching 4.8 persons per household, compared to 2.6 for the rest of Canada. Fifty-eight percent of seniors (aged 55+) live in band-owned housing and over a third of seniors reported have mold or mildew in their homes in the past year (2003). Nearly fifteen percent of First Nation seniors (aged 55+) do not have access to garbage collection services.[42]

Supportive housing or assisted living units would provide a viable option for some First Nations elders; however there is limited capacity at the community level to provide this type of facility. INAC placed a moratorium on the construction of new care facilities for seniors in the late 1980s which has since been lifted and replaced with very restrictive terms for approval of new facilities. In most cases, First Nations communities cannot access provincial funding for seniors housing because the Province takes the position that First Nations are a federal responsibility or funding is limited and local municipalities and urban centres are given priority.

The availability of supportive housing or similar facilities, with some on-site services for the elderly, would ensure that appropriate care is available to individuals based on assessed need and would help to alleviate problems associated with overcrowding, family/informal caregiver burnout, and may help to prevent complications arising from inadequate care of individuals with chronic conditions.

The correlation between the lack of housing and chronic health conditions also remains significant and requires a system where proper care can be delivered by trained health professionals in the most appropriate setting.

Education

Seventy-one percent of First Nation seniors did not graduate from high school. Although education levels are better among younger First Nations individuals, still about half of First Nations adults age 18 – 54 did not graduate high school.[43] Since educational outcomes are tied to future employment opportunities, it is important to consider investments in educational

attainment for First Nations youth and adults today, to prevent rising reliance on income assistance with the aging of the First Nations population.

Poverty and Income Assistance

Many First Nations seniors appear to be living at or below the poverty line. The RHS found that adults who were under age 30 and over 59 had lower personal incomes than those in the middle range. The median personal income in 2001 for adults in First Nations communities was $15,667.[44] This compares with the low income cut-offs identified by Statistics Canada in 2004 for a family of four at $26,015 for rural areas up to $37,791 for large urban areas (over 500,000).[45]

Specifically among First Nations seniors, those aged 60 and over had a median personal income of $12,991 and a median household income of $24,650.[46] Nearly 80 percent of First Nation seniors rely on income from Government sources, including EI, Old Age Security and social assistance. Seven percent of First Nation Seniors (aged 55+) received a disability allowance in 2001.[47]

A number of items are critical in working to eradicate poverty among First Nations. These include[48]: the need for adequate capital, operating and training resources for overall community economic development and job creation, as well as active measures that support and encourage individuals to make the transition from income assistance into paid employment. Active measures include child care, but also long term care for seniors whose children must stay home as caregivers due to lack of services within the community.

3.6 Summary

All of the information shared here supports the notion of the onset of old age at 55 rather than 65 within First Nations populations in general, and a corresponding need for governments to support this understanding in their programs and policies. A more culturally-relevant framework than the biomedical model is also required to inform program and policy-making as these relate to addressing the needs and interests of First Nations seniors.

The many determinants of health and aging that affect First Nations populations in Canada include poverty, poor housing and infrastructure in First Nations communities, lack of employment and education, inadequate health care, lack of supportive housing and adequate continuing care/long term care services and the need for more advocacy to assist elders in receiving benefits and supports that will allow them to live as well as possible.

4. EXISTING SUPPORTS AND FUTURE POLICY IMPLICATIONS

In this next section, we will respond to the key questions: What needs to be done to reduce the higher rates of chronic illnesses among First Nations seniors? What are the public policy implications, the costs and benefits of moving toward an active aging/life course approach to aging? What needs to be done to reduce the incidence of core housing needs among First Nations seniors? What should INAC and Health Canada be doing to improve support services for seniors on reserve?

4.1 General Fiscal Imbalance in Federal Funding

Since 1997-98, the Government of Canada has maintained an arbitrary 2% cap on spending increases for core services which includes all social programming provided to First Nations communities. Similarly, in 1996-97, the Indian Health Envelope, containing all core programs of the First Nations and Inuit Health Branch (FNIHB) of Health Canada has been generally

capped at 3% annually. These caps ignore basic cost drivers such as population growth, aging, and inflation.

These caps also represent less than one-third of the average 6.6% increase that most Canadians enjoy through the Canada Health and Social Transfers until 2013. When adjusted for inflation and population growth over time, the total budget for INAC has decreased by 3.5% since 1999-2000. Core program budgets, such as social development and capital facilities and maintenance, have decreased by almost 13% since 1999-2000.

This health and social fiscal imbalance has resulted in a gradual impoverishment of community budgets. If communities had been funded in alignment with population growth and inflation, their budgets would be 45.5% higher than they are today. Hence, this imbalance severely impacts the ability of First Nations governments to address the needs of their population, including First Nations seniors.

4.2 Health Programs and Services: Issues and Gaps

First Nations communities offer fewer health services to seniors than other communities in Canada. Significant gaps and barriers exist which make it more difficult for First Nations seniors to access proper medical care, increasing the likelihood that they will experience poorer and more acute health conditions.

4.2.1 Continuing Care

Existing Federal Programs

The Assisted Living program, funded and managed by Indian and Northern Affairs Canada (INAC) consists of three components: in-home care which assistance with homemaking services, foster care (supervision and care in a family setting to individuals requiring supervision); and facility (institutional) care, which reimburses expenses for Type I and Type II social care in facilities. In 1988, because of escalating costs and INAC's unclear authorities in this area, INAC instituted a national moratorium on the construction and operation of personal care homes. The moratorium has since been lifted and replaced by very restrictive terms for approval of new personal care homes.

The *First Nations and Inuit Home and Community Care* program (FNIHCC) was subsequently implemented by Health Canada in 1999. FNIHCC is intended to complement and not duplicate existing services such as those provided by INAC's Assisted Living program. The FNIHCC provides funding for basic home and community care services, including case management, nursing care, in-home respite care and personal care. At the present time, 92% of eligible communities have implemented FNIHCC, representing about 95% of the total First Nations and Inuit populations. However, some First Nations communities do not have any Home and Community Care services and, in some communities, FNIHCC is not fully implemented or effectively providing the needed services.

Continuing Care Research

Within the general Canadian population, continuing care services offered in the provincial and territorial health systems are accessed primarily by individuals over 65 years of age. However, conditions within First Nations communities demonstrate a different portrait of First Nations continuing care service users: children and youth with assessed needs; adults with chronic diseases and conditions; adults with mental illnesses; and the elderly (55 years and older), noting again the earlier onset of many age-related illnesses within the aging First Nations population. **In fact, 50% of clients accessing Health Canada's FNIHCC are under age 65.**[49]

FNIHCC has responded reasonably well to the identified home care needs of First Nations. The Assisted Living Program provides social support services that meet some of the needs of ill and disabled First Nations clients. However, the number of personal care homes currently operating in First Nations communities is severely limited. As a result, there remains a dire need for expanded services in the whole area of continuing care/long term care for First Nations.

There are 633 First Nations communities across Canada, but only 30 have a personal care home that provide facility-based care with funding received from INAC. This represents less than a total of 900 beds for First Nations living in their communities. **There is, therefore, a ratio of 1 bed per 99 individuals aged 55 and over for First Nations living in their communities compared to 1 bed per 22 individuals aged 65 and over in the general Canadian population.**[50]

In the current situation, many First Nations residents are forced to leave their homes and family to be placed in a provincial facility located outside their community. The low income of most First Nations seniors limits their ability to access "private pay" facilities out-of-community or to pay the resident co-payment required in publicly-funded facilities.

In the case of northern and remote communities, this essentially means that the person must move to a facility that is located hundreds of miles from their home, often in an urban setting. First Nations feel isolated in provincial facilities and are often situated long distances from their families. This has a detrimental effect on their health and quality of life.

In a study carried out in 1999, 85% of respondents indicated that some community members were residing in out-of-community, extended care facilities and that there were major drawbacks to these arrangements including: isolation from family and friends, loss of opportunity to participate and contribute to the cultural life of their community and loss of their role as an Elder.[51] Thus, emotional stresses on the individual and their family, as well as a negative impact on their health, are often the products of such displacement.

"Terminally-ill Aboriginal people or elders, uprooted from their communities in a traumatic medevac flight to a city hospital all alone died sooner than those who went home to die, an Alaskan palliative care expert is telling Thunder Bay medical professionals".[52]

First Nations living in remote and isolated areas experience many impediments to accessing services such as the lack of roads and efficient transportation, high cost of transportation for medical supplies, inability to access rehabilitative services, adequate palliative or respite care and the lack of available health professionals necessitating frequent travel to urban centers, the incurrence of greater financial expenses, and lengthy wait times.

Provincial health reforms that have been occurring across the country since the 1990s have had a severe impact on First Nations health services and systems. With the significant cutbacks in hospital and in-patient services, shorter hospital stays and the general deinstitutionalization of both acute and long term care clients, First Nations individuals are being discharged from hospital earlier and return to their communities, where care and services are limited and sometimes altogether absent.

Jurisdictional issues also have an impact on First Nations continuing care. Despite some consolidation of care services between the two programs provided by Health Canada and INAC, serious gaps exist in the provision of higher levels of in-community care services. The federal government has taken the position that these types of services should be covered by the provinces under the general transfer provision of the Canada Health and Social Transfer (CHST).

The CHST is based on a per capita formula and includes First Nations living on reserve and in designated communities (North of 60). Therefore, continuing care services are intended to be accessible and available to all Canadian citizens regardless of residency. However, the reality is that most provinces do not provide continuing care services to First Nations living on reserves citing jurisdictional responsibilities attributed to the federal government. To further complicate the issue, according to Health Canada and INAC, neither department claims to currently have the authority or mandate to provide higher levels of care to First Nations (such as 24-hour nursing care or institutional care).

Health Canada and INAC recently funded a major research project to gain a better understanding of the continuing care services currently provided and identify new services needed by First Nations and Inuit. The research, conducted jointly with First Nations and Inuit organizations and completed in October, 2006,[53] provides evidence that supports the need for increased funding and significant improvements in the continuing care services currently available in First Nations communities.

One of the key findings was that over 95% of clients interviewed would prefer to receive continuing care in their own community; however current services are not sufficient to meet existing and projected need as the population ages. Most clients currently access lower levels of care but since most have some form of chronic illness, the need for higher levels of care will rise.[54]

Recommendations

It is critical to close the gap between existing continuing care services provided to First Nations and those accessible and available to the general Canadian population. In doing so, aid in maintaining the continuity and vitality of cultural and linguistic traditions within communities is also required.

To this end, the AFN and First Nations regional representatives are currently working jointly with Health Canada and INAC to develop a comprehensive continuing care program that is intended to address the gaps in services and seek federal authority and funding for the higher levels of care for First Nations residents living in their communities. The Joint Working Group will be preparing a Business Case to support this initiative which is expected to be completed in the Fall 2007 and will eventually be submitted for Cabinet and Treasury Board approval.

It is strongly recommended that this initiative receive the support from Members of Parliament and that appropriate funding be allocated to ensure that continuing care services for First Nations are increased to a level and standard equal to the services available to all other Canadians.

There have been some preliminary estimates of cost for the needed improvements to continuing care for First Nations. Based on the research and work done to date, approximately $432.4 million will be required to meet the needs of home care and facility care clients (excluding Non-Insured Health Benefits and capital costs). It is important to note that this estimate does not include costs for supportive housing or assisted living facilities which could provide more affordable and cost effective alternative living arrangements to allow the elderly members to remain in their communities.

The Continuing Care Research report from October, 2006[55] contains fifty recommendations covering various issues such as access to needed services, funding shortfalls, recruitment, retention and training, importance of cultural context in program design and operation, needs of family caregivers and accountability and standards.

This report concludes that future continuing care services need to be designed to meet higher care needs and has identified a number of gaps in service and key areas of needed improvements which are summarized as follows:

- Physiotherapy, social and recreational activities, and specialized education services for children and youth with special needs;
- Mental health services, palliative care services, resources for family caregivers and services for people with disabilities;
- Long term facility care, short term facility care, and supportive housing units.
- Increase in the services and hours of availability into the evening and weekends to meet the critical need for care and to provide respite care to clients and caregivers;
- Various housing options should be considered including assisted living settings, Elders' lodges, homes for the physically challenged and homes for the mentally challenged;
- Adequate resources to ensure that culturally appropriate services are provided that maintain and reinforce First Nations and Inuit cultural traditions including the ability to provide interpreters where necessary;
- Palliative care and end of life care should be supported and recognized as an essential in continuing care;
- Funding formulas should not be based on per capita or per diem funding. Funding allocations and existing funding formulas need to be reviewed to ensure that they are based on fairness and need, address the specific concerns of small/ remote & northern communities take into account case mix, community size and location and are based on up to date population figures;
- Support and needed services for families, family caregivers and communities caring for individuals with continuing care needs; and
- Federal government policy should be amended to include the provision of services for Types 3, 4 and 5 clients in facility care.

4.2.2 Informal Caregivers

The growing trend towards the provision of home care by family and friends, known as informal caregivers, is addressing some of the needs and gaps in services caused by the lack of nursing and personal care available in First Nations communities. This trend is largely due to the strong family and community ties embedded within First Nations culture.

The Continuing Care Research report, described earlier, showed that 60% of individuals in receipt of home care also received informal care, including assistance with meal preparation, personal care, and medical and nursing-type care.[56] Due to their role as caregivers, it is not uncommon for these informal caregivers to experience an increase in unpaid absences from work which is problematic for many families who rely solely on those earnings to survive.

Recommendations
The importance of accessing informative resources for support is vital in better educating informal caregivers on medical conditions and related symptoms, or potential health issues that may arise. Increased support for informal caregivers is needed through additional respite care, training on how to provide the right care, information on specific medical conditions, and increased nursing and personal care hours.

4.2.3 Non-Insured Health Benefits[57]

Health Canada also funds the Non-Insured Health Benefits Program (NIHB) for First Nations status members. The NIHB Program provides a limited range of medically necessary, health-related goods and services which are not provided through

other private or provincial/territorial health insurance plans. NIHB are complementary to provincial and territorial insured programs and community-based health programs and services funded by Health Canada.

The requirement that NIHB comply with thirteen different provincial and territorial jurisdictions often results in significant inequities in benefit access for First Nations. There are also serious concerns with regional inconsistencies in processes relating to adjudicating benefit requests; this adds to the potential for inequities in the program.

The NIHB Program has been the subject of several cost management measures during the 1990s. These have included: delisting of benefits; changes to eligibility for benefits; reductions in pharmacist service costs (mark ups and dispensing fees); enforcement of low-cost pharmaceutical alternatives (generic drugs); prior approval requirements for limited use/special authority drugs; and pre-determination (prior approval) of some dental services.

In addition, the Program is affected by reductions in provincial benefits since FNIHB views itself as "a payer of last resort". The most recent example of a provincial policy change affecting the NIHB Program is the Ontario government's delisting of vision benefits as of November, 2004. Experience in First Nations communities suggests that these cost containment measures have had an adverse impact, for example on decreased quality of service, longer waits, and denial of service if transportation access is not available.

All of these issues have major impacts on health care services for seniors. The AFN has been made aware of a number of specific situations such as:

- A senior with diabetes is having difficulty getting reimbursed for the cost of a laser surgery/corneal implant procedure that was necessary to prevent blindness. She was required to pay for the procedure herself and this required her, an individual on very limited income, to use her whole year's savings of $350 which she needed to cover her heating costs. She will also need to have her other eye done but does not have the funds to cover the cost and Health Canada has still not approved coverage under NIHB.

- Certain categories of service providers – mainly dentists and orthodontists – have moved First Nations individuals to a cash basis due to delays in receiving payment from the NIHB Program. Instituting a cash basis for remuneration is an immediate deterrent to care, as many seniors requiring service may not have the resources to pay up front and, therefore, do not seek treatment. This process also requires the person to fill out forms for reimbursement which is an added impediment for many seniors that may not have the capacity to understand and complete complicated government forms.

- There is particular concern with the changes imposed through the National Medical Transportation Policy Framework under NIHB. Regions have reported unreasonably restrictive medical transportation benefits, for example, denial of an escort to accompany elderly and disabled First Nations residents to medical appointments. Without access to medical transportation, many seniors cannot get to their doctors since they may not have any alternative form of transportation and are unable to afford a taxi service. There are also concerns with communications since many senior First Nations members may not be able to speak or read English very well so they require the assistance of an escort to ensure that they can communicate effectively with health professionals.

The input received by the AFN from First Nations regional organizations and communities in 2004-05 in relation to a national action plan for seniors also identified the following health related issues that need to be addressed:[58]

- Access to psychosocial and mental health (psychologist, social workers, addiction workers, etc.);
- Para transit and medical transportation;
- Family support and respite services;
- In home foot care;
- Palliative care programs distinct from home care programs;
- Adapted equipment;
- Prescription medication and alcohol addiction specialists;
- Adequate training for workers;
- Traditional nutrition programs;
- Assistance/ prevention of over-prescription and/or misuse – improved management of prescriptions and pharmaceuticals and the potential complications arising from use of traditional medicine;
- Training for physicians/pharmacists/community health workers;
- Lack of home support provision in rural small northern communities.

4.3 Social Security Programs: Issues and Gaps

The Interim Report of the Special Senate Committee on Aging estimated that 3% of Canada's seniors are not receiving the Guaranteed Income Supplement (GIS), despite being eligible to receive it. Among First Nations, this is a much greater problem, with an estimated 10-30 % of eligible First Nations seniors not receiving GIS. A study conducted in 2006 for the Assembly of First Nations, although limited in size, revealed two main barriers to take-up of the OAS and GIS programs: lack of useful information (i.e. simple, easy to understand information in accessible formats, reflecting language and comprehension levels), and complications with the application process.[59]

This same study found that First Nations service providers had requested training on the GIS Program in order to assist seniors with their applications and questions; however, training was not readily available from either Human Resources and Social Development Canada (HRSDC) or INAC. The study concluded that, based on the issues and obstacles seniors face with the rules-based approach of the federal government, language barriers and complexities around non-taxable income and income earned in the United States, it is quite likely that First Nations seniors living both in and outside of their communities face similar issues and are missing out on receiving this benefit.

In addition to difficulty accessing these programs, First Nations across Canada have identified concerns regarding the inadequacies of the Old Age Security Program and GIS Programs. Further research and study is required in this regard.

In consideration of the significantly high unemployment rate of 27.7 % among First Nations nationally – double the rate of the general population – it is unlikely that many First Nations seniors have access to any form of pension other than the Old Age Security Pensions that are accessible as of age 60.[60]

There is also very limited access among First Nations to the Canada Pension Plan (CPP) since it requires contribution payments. First Nations Band members working in their communities were not allowed to contribute to CPP in earlier years; therefore, they have not been able to accumulate any significant amount of CPP benefits. This is especially true for many elderly First Nations women who stayed at home to raise their children.

Consequently, many First Nations seniors must rely on social assistance benefits to sustain their livelihoods. However, the amount paid in benefits is not sufficient to cover the high cost of living in remote communities where First Nations seniors are faced with significantly high costs for healthy food and heating.

A recent study by Statistics Canada indicates a major gap in pension contributions pre-retirement between families at the top of the earnings scale and those at the bottom. This trend is predicted to continue and the gap will widen, meaning that low income earners (whether individuals, single parent or two-parent families) will reap the least benefits in pension income in the future.[61]

4.4 Social Participation Programs: Issues and Gaps

First Nations across Canada have informed the AFN of the need for more funding to provide programs for seniors that ensure their social participation and active involvement in the community. Some of the needs identified are:[62]

- Forum for sharing knowledge and traditional culture by Elders;
- Information sharing on Elder abuse and prevention;
- Day centres so that Elders can participate in various activities;
- Friendly visits and opportunities to socialize;
- Recreational and social outings; and
- Exercise programs.

The New Horizons Seniors Program, which is currently being funded by HRSDC, would provide funding (maximum of $25,000) for some of the types of projects listed above. The program supports local projects across Canada that encourage seniors to contribute to their communities through social participation and active living. It also promotes involvement of seniors in their communities to reduce the risk of social isolation. It is not clear to what extent this program is promoted other than information being available on the HRSDC web site. If this is the only source of information, then it is unlikely that many First Nations communities would be aware of the program since many do not have easy access to the internet.

Another issue is that the program is proposal-driven which can cause some difficulties for First Nations access. Most communities do not have the staff or the capacity to develop detailed proposals to access funding. The federal government must be cognizant of these barriers to accessing programs and develop communication tools and practices that will ensure that all First Nations communities are aware of, and have equal opportunity to, access available programs and support services.

4.5 Communication on Federal Programs: Issues and Gaps

In 1997, Health Canada's Division of Aging and Seniors undertook a study to identify effective approaches and strategies for informing Aboriginal seniors about federal programs and services. According to this report,[63] some of the key findings and recommendations of the study were:

- Respondents showed a very limited understanding and awareness of federal programs and services for Aboriginal seniors;
- Current practices and methods used by the federal government to disseminate information are not successful in expanding the use of such programs and services;

- Respondents consistently preferred personal contact, either face-to-face or by telephone, as the best method of communicating with seniors;
- Key informants (caregivers, administrators and community leaders) expressed the greatest need for more programs and services for Aboriginal seniors;
- Consider that the needs of seniors to "connect" with people directly affect their health. This should be taken into consideration in designing strategies for information dissemination and health promotion;
- Create partnerships between the federal government and communities for the purpose of overall strategy development and for the development of specific responses to the information needs of Aboriginal seniors.

4.6 Other Issues and Gaps in Programs and Services

The input received by AFN from First Nations regional organizations and communities also identified the following senior's related requirements:[64]

- Assistance with filling out pension forms and advocacy;
- Resources to identify First Nations seniors issues, such as research and ongoing data gathering;
- Adequate social facilities/structures and related resources in Yukon communities (rural remote and small) for engaging Elders in the community and supports to assist them with activities of daily living, recreational and social and other pursuits;
- Assistance with various home maintenance activities such as snow removal, lawn care, spring cleaning, wood splitting & carrying into house;
- Friendly visits and social contact;
- Transportation and assistance with groceries, shopping, bill payments;
- Affordable respite care;
- Emergency response for Elders;
- Remuneration for family caregiving – Elders in need of support at various times, would feel more comfortable if a paid family member was the caregiver instead of a stranger;
- Financial assistance for medication and high cost of living; and
- Improved supports for Elders/seniors living outside their communities – who often do not qualify for the same benefits and programs that Elders living in their communities receive.

5. CONCLUSIONS

First Nations Elders are those people, usually older, who are recognized by the community as possessing great wisdom and who are called upon as an authority to advise or act on important family and community matters. The term "Elder" in some cultures, refers to older persons and indicates respect, honor, and special status as aging in many cultures is associated with experience, wisdom, the transmission of cultural heritage and language, leadership roles in the community, and in some cases, spiritual knowledge.[65]

It is a term that has come to mean many different things to Elders themselves. It may mean frail elderly or it may signify wisdom and experience and/or spiritual knowledge; it may define a state of being to achieve. The term Elder rather than senior celebrates the vitality, knowledge, experience and positive contribution of our Nations' Elders to our common future. There is a positive future for our Elders if programs in health and social care, supportive housing and continuing care are supported to the extent that they should be. As well, if current generations aged 30-55 and even our youth and children

today, are supported to live healthy lifestyles and maintain optimal health, our future as First Nations peoples will be more prosperous and contribute to Canada's overall prosperity.

A healthy, vibrant aging population in First Nations communities could potentially contribute significantly to the planning and implementation of First Nations community economic development, education, language revitalization, cultural and historical interpretation, and coordination of community events, in addition to other roles within their families and clans. More advocacy and support of today's First Nations seniors is required to ensure they are receiving the benefits to which they are entitled. One element of this is to ensure the administration of income security benefits is simple and efficient. There must be recognition of the special status of First Nations people emanating from their inherent and Treaty rights. There must be more work done in conjunction with First Nations governments and health organizations to address health care needs. Improving health status especially starting at age 30 will prevent future health care costs from spiraling as the current youthful First Nations cohort ages.

Current social security programs must be adjusted to support those in need, such as low-income First Nations seniors. This supports one of the findings in the Prime Minister's Task Force and their report, Creating a National Seniors Agenda.[56]

A community-based, wholistic approach to First Nations seniors health and social programming, involving the meaningful engagement of First Nations governments in related federal, provincial and territorial initiatives, is required. Strategies focused at multiple levels to address significant disparities due to non-medical determinants of health are required. For instance, working within a First Nations Wholistic Health Strategy, a program such as Brighter Futures should be considered for development targeting the specific needs of the aging First Nations population, with components for the age 30 to 55 group and age 55 plus.

Several improvements are required immediately to bring health and social budgets up to required levels before beginning to address major reforms of entrenched First Nations poverty and concomitant poor health which shows in lower life expectancy in addition to many other indicators. The arbitrary 2% cap on core community services provided by INAC should be removed and replaced with stable annual budget growth based on cost drivers (such as inflation, population growth, aging and health status burden).

The severe lack of long term/continuing care services and supportive housing facilities currently available to First Nations must be addressed to close the gaps in services provided to First Nations and those accessible and available to the general Canadian population. This will serve to ensure that First Nations seniors will remain healthy and can live in dignity as active members of their community.

Little information has been gathered to date from First Nations seniors regarding their needs. As this population increases, it will be important to have comprehensive plans in place that reflect the full range of needs. Thus, regional consultations are recommended that would encourage input from First Nations seniors. HRSDC should support this undertaking with First Nations through the AFN and First Nations regional organizations, for the purpose of building an agenda for the future.

5.1 SUMMARY OF RECOMMENDATIONS

1. Work on improving health promotion and service delivery to the largest age cohort 30 to 55 year old First Nations people, as well as to those 55 years and over. Improving the health status of the middle age cohort today will have major cost savings in future health care. This includes implementing a First Nations Wholistic Health Strategy, as described in

the First Nations Framework of the Blueprint on Aboriginal Health (2005), endorsed at the First Ministers Meeting on Aboriginal Issues.

2. Remove the 2% cap on core INAC services that provide for non-medical determinants of health such as safe drinking water, housing, education and social supports.

3. The joint project (First Nations/AFN/INAC/Health Canada) to develop a comprehensive Business Case and Continuing Care program is nearing completion. The proposed Business Case will clearly outline the major gaps in services to First Nations and identify the needed enhancements in existing services or new services required to improve the continuing care services available to First Nations. Once the work is completed, Health Canada and/or INAC will seek Cabinet approval and funding for a continuing care program for First Nations communities. It is strongly recommended that this initiative be supported and adequately funded by the federal government as a means of investing now for future cost-savings to Canada.

4. Increased support for informal caregivers through additional respite care, training on how to provide the right care, information on specific medical conditions, and increased nursing and personal care hours.

5. The Non-Insured Health Benefits (NIHB) Program, a key priority in the AFN-Health Canada Workplan signed by National Chief Fontaine and Minister Clement in December 2006, must be granted a stable annual growth rate that enables basic cost drivers to be met. Currently, although one-year only short-term relief funding has been provided, these temporary measures do not provide enough security to lift cost containment policies which limit benefits for First Nations seniors as noted.

6. Programs designed to support improved coordination of health services between jurisdictions and enhanced health human resources must be flexible and First Nations-driven in order to meet the goal of improving First Nations health status.

7. Beyond health care and existing community health programs, new, comprehensive programs, designed and delivered by First Nations, in food security, mental health and injury prevention are needed – these are key issues impacting the health and well-being of First Nations seniors.

8. A detailed analysis should be undertaken of financial support programs for First Nations seniors including American pension plans and RRSP, and a practical, easy to understand manual or toolkit be produced for the use of First Nations staff and seniors when applying for OAS, GIS and CPP. These documents should explain eligibility and why an individual may not be eligible for certain benefits. Training materials and supports be developed and delivered to First Nations service providers to enable them to assist seniors in applying for, and receiving these benefits.

9. Federal government should incorporate a biological age approach to determining eligibility for OAS and GIS. Look at adding an exceptions clause to OAS and GIS that identifies special circumstances in which individuals who have age-related conditions, but are between ages 55 to 65, be considered eligible for OAS and GIS.

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