

# **ELDER CARE ENVIRONMENTAL SCAN IN SIOUX LOOKOUT ZONE FIRST NATIONS**

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*Prepared for the Sioux Lookout Meno Ya Win Health Centre*

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## 1.0 INTRODUCTION

On January 26, 2009, Sioux Lookout Meno Ya Win Health Centre (SLMHC) issued a Request for Proposals to conduct an Elder Care Continuum Environmental Scan. Meno Ya Win is part of a group of Elder care stakeholders that identified the need for an Elder care review in the Sioux Lookout District First Nations. The scan was required to lay the foundation for the establishment of a continuum of care to support Elders and ensure their equal access to community-based and institution-based services. The Research contract for the Scan was awarded to a team consisting of Florence Woolner, Joyce Timpson, Laurel Wood and Lois Mombourquette. Research was conducted between the end of February and April 30, 2009.

The Elder Care Continuum Environmental Scan has focused on the following research questions:

- Based on demographic data available what is the Elder population, gender, age, and health status in the Sioux Lookout District?
- What is the level of independence or dependence and care requirements for Elders in the North?
- What services are available for Elders in their communities including hours, breadth and scope of services?
- Who is providing care for Elders in their home communities?
- What resources may be accessed to enhance existing service and create partnerships for Elder care?
- Based on the input of existing service providers and stakeholders and governing bodies, what are the recommendations for Elder-friendly initiatives to improve access to existing services, enhance existing services and develop new services.

There is little data readily available concerning First Nations Elders' health in general and even less in the Sioux Lookout District communities. This Scan delivers a snap shot of the demographic and health status situation of Elders in the north, the services available in the communities and the service gaps, and the challenges of Elders living in SLMHC catchment First Nations. The overall objective is to collect first stage information for a sustainable continuum of care for Elders consistent within the provincial Aging at Home Strategy.

Elders have been a small, but growing percentage of the total First Nation population in the district, albeit a much smaller proportion when compared with the general population. A growing First Nations population and access to improved health care has increased their life expectancy. Using projections based on the general population in 1995, a population projection suggested that the

numbers of persons over 65 in the Sioux Lookout First Nations would triple by 2015 from 1991<sup>1</sup>. With the limitations of the population data, it is difficult to say whether this had occurred, although it does not appear to be so, at least not for those living on reserve. However, whatever the population, the marked increase in chronic illnesses related to changing lifestyle and diet among the northern population could result in Elders today and into the future requiring much more care than their predecessors. Indeed, with the rise in chronic illnesses among increasingly younger persons, it is anticipated that supportive care for older adults will be a major direction in the health care continuum in the future. With minimal data available, the aforementioned realities rendered this environmental scan relevant. It points to directions for further in-depth analysis of how the health care system continuum can respond to the needs of Elders both now in the future.

We are grateful to the Project liaison staff at the Hospital, as well as those staff who collected and shared data for the team. We are also grateful to Chiefs and Councils for their support and interest and, in particular, to the many key informants – health care professionals and leaders, Elders and family members and health experts who gave their valuable time and insights during the research.

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<sup>1</sup> Sioux Lookout First Nations Health Authority, Participatory Research Project, 1995.

## 2.0 METHODOLOGY

The research team in consultation with the SLMHC Project Representative developed a research design that accommodated the limited time frame, the vast territory, and the ethical and practical realities of information gathering for the target population. The team worked with key stakeholders at the tribal council and community level including political leaders, health care administrative and service personnel, and Elder service recipients and their families. By necessity, team members relied on their working relationships developed over the years to gain expeditious access to primary and secondary data. The presentation and interpretation of the technical information such as medical data was discussed with the informant to ensure accuracy, and avoid making conclusions outside the expertise of the researchers.

Research in First Nations required methods that engaged and respected individuals and communities and conformed to established ethical guidelines developed by National Aboriginal Health Organizations (NAHO). Culture-specific ways of obtaining information were employed and conventional research methods were adapted to respect the esteemed position of First Nations Elders.

Four key elements were the focus of the research:

1. Demographic, health status and care requirements in the First Nations communities of the Sioux Lookout District;
2. Inventory of currently available services for Elders;
3. Utilization of services and support systems;
4. Identification of available and collaborative potential to establish sustainable services.

The following steps were taken:

1. Letter of introduction and information to Chiefs.
2. Gathering of demographic data from the websites of Statistics Canada and Indian and Northern Affairs.
3. Interviews with key stakeholders with expertise in, or who oversee programs for, specific illnesses or conditions. Confirmation of community specific information with Elder, and health care personnel in the communities.
4. Review of hospital admission data for admission numbers and diagnoses.
5. Scan of Federal and Provincial programs for Elders.

6. In-depth interviews with 30 northern health care personnel – Health Directors, nurses, home care coordinators, etc
7. In-depth interviews with 21 Elders
8. Focus group session with one group of Elders who are recipients of service in Sioux Lookout
9. Tele-meeting and follow-up interviews with members of the Meno Ya Win Elders Council.

As a first step, the study team developed and distributed an introduction and information letter to each First Nation Chief in the catchment area communities. The communiqué explained the background and the reasons for the research, invited feedback and suggestions, and offered to share the study results with First Nations Chiefs and Councils in the district once they are available. Communication documents were also developed consisting of a summary and description of the project to share with Health Directors and other community stakeholders that were interviewed.

Demographic information was gathered using Census data from 2001 and 2006 and Indian Affairs and Northern Development (INAC) population statistics. A community-by-community compilation of the 60-years and over age groups was developed but it is significant to note that the data available and the scope of this work did not allow for the collection of accurate community by community demographic and health status data. A search of primary health data was conducted for prevalence of diabetes, tuberculosis, mental illnesses, cancer and other chronic illnesses. Further health status information was collected through interviews with key informants in select communities and organizations, e.g. Nurses in Charge (NICs) in northern nursing stations, Home Support and Home Care Coordinators, and Tribal Council (TC) health personnel. Health status information was collected by SLMHC staff and used by the study team to compile diagnoses for hospitalized persons 60 and over for a five-year period.

The research team studied Elders services in the northern communities by conducting an Internet scan of Federal and Provincial programs with follow-up questions directed to the appropriate government and health care agencies. Key informant interviews were conducted with selected health personnel and Elder care professionals in Tribal Councils and select communities.

To collect information to the extent to which available services are being utilized by Elders and their families, the team conducted in depth interviews with 11 communities aiming for a cross section based on size, Elder population, level of service development, and tribal council affiliation. A survey instrument was developed and after trial testing and revision, was administered by phone to northern health, home support and home care providers, including NICs, Home & Community Care (HCC) Coordinators and Nurse Managers, Community Support Service (CSS) Coordinators and some Health Directors. Four Tribal Council

health departments were also interviewed using this questionnaire and some of them provided additional community specific numbers and information. Results of all Elder care professional interviews were compared and analyzed for emerging and recurring themes and to develop recommendations to improve and/or develop sustainable services including collaborative potentials with new or existing partners.

Interviews were conducted with Elders and their family caregivers using a different survey instrument. Twenty Elders were interviewed in individual formats, 13 in person and 7 by telephone. Twelve were women and 8 were men; five were couples. The youngest Elder interviewed was 60; the oldest, 89. Six were in their 80's; 8 in their 70's; and six in their 60's. The Elders came from 12 different communities. Four were hospital inpatients or residents in extended care. Ten required translators and in two cases, one partner translated for a spouse. The Elders represented a wide range of health conditions, from fairly fit to being on dialysis three times a week. A couple were interviewed in Sioux Lookout after being medevaced for serious health concerns, some had knee or hip replacements in the past, two suffered strokes, one was an amputee, one suffered from early dementia and one claimed to be "just old". Several of the Elders evidenced great determination to continue to be independent despite their health conditions.

The study team also interviewed 11 Elders in a focus group with a translator while participating in a weekly social gathering of the Life Long Care program at the Sioux Lookout Nishnawbe-Gamik Friendship Centre. These participants originally came from seven northern First Nations but have relocated to Sioux Lookout, the majority to be closer to health care services.

Three members of the study team also participated in a videoconference of the SLMHC Elders Council in which seven communities were represented. A number of council representatives were contacted by phone after the videoconference for personal follow-up interviews. Elders were questioned about their health status, living situations, the extent to which relatives and others assist them, the types of services they know about and access and additional services which might enhance their daily lives.

Through its interviews with key stakeholders and Elders, the team endeavoured to determine which resources might be accessed to enhance existing Elders services, create partnerships for Elder care and provide outreach to Elders and care providers. The team looked for constructive examples of service structures/relationships with nursing stations, and between home support and home care to build a series of recommendations of Elder friendly initiatives for northern communities.

### 3.0 EXECUTIVE SUMMARY

The Sioux Lookout Meno Ya Win Health Centre is part of a group of Elder care stakeholders in the district who identified the need for an Elder care review in First Nations. The review or environmental scan is to be a part of the work required to lay the foundation for the establishment of a continuum of care to support Elders and ensure their equal access to community-based and institution-based services.

This Elder Care Environmental Scan provides a snap shot of the demographic and health status situation of Elders in the north, the services available in the communities and the service gaps, and the challenges of Elders living in SLMHC catchment First Nations. The overall objective of the scan is to collect first stage information for a sustainable continuum of care for Elders consistent within the provincial Aging at Home Strategy. The study research team members were Florence Woolner, Joyce Timpson, Lois Mombourquette and Laurel Wood.

The research team conducted in-depth interviews with 30 northern health care personnel from 13 communities and interviewed 21 Elders from the north. The team met by video conference with the MenoYa Win Elders Council and did follow-up interviews with some of the members of the Council. They also held a focus group with Elders who are recipients of services in Sioux Lookout. Demographic information was gathered from the websites of Statistics Canada and Indian and Northern Affairs and a scan of Federal and Provincial programs was done. Health status information was collected from interviews with key stakeholders with expertise in, or who oversee programs for, specific illnesses or conditions. A review of hospital admission data was done to obtain admission numbers and main and secondary/co-morbid diagnoses.

The Environmental Scan estimates that 1045 people age 60 and over are living in the 29 Sioux Lookout District First Nations and an estimated 702 people, age 65 and over. One hundred and eighteen people are 80 years of age or over. This means that people 60 and over represent 6.5% of the total population on-reserve, and people 65 and over represent 4.4%.

In terms of health status, a large but unknown proportion of people over the age of 60 have Type 2 diabetes in the north and possibly one third of Elders have debilitating arthritis. There are many Elders with latent tuberculosis, and cancer appears to be on the increase. Renal failure requiring dialysis is now the end result of a number of illnesses and an increase in the prevalence of renal failure can be predicted. Mental health of Elders is an important matter; care for Elders in this area is largely unexplored and cannot be overlooked in the overall health care system. Dental care and possible other conditions that are seemingly unrelated, require consideration in the health care continuum of all ages.



The report provides an overview of government funding protocols for Elders in the north. There are three main government programs providing home and community-based services: Home and Community Support Services (provincial); Homemaking and Nurses Services Program (80% provincial; 20% federal); and the First Nations and Inuit Home and Community Care Program (federal). There is no formal coordination among the agencies that fund these programs. The people in the communities are the only ones who know exactly how the three programs are being used locally, and service implementation, priorities and administration differ from one community and one Tribal Council area to the next.

In assessing services to Elders in the communities, health care personnel interviewed singled out the Home and Community Care program as the most useful home-based service for Elders with the Home Support program also seen as important. A number of respondents indicated they think the HCC program does reduce the number of Elders seen at clinics and the number of Elders who can come home earlier from hospital or stay at home longer. The home-based support provided by these programs is thought to work best when there are close working relationships between the community nursing and health staff, and the Home Care and Home Support staff and when the service supports rather than replaces family care of Elder relatives. There are still a significant number of families in the north who are caring for their parents and grandparents and respondents felt that all efforts should be made to support these caregivers at critical times so that they can continue to do so. Repeated mention was made of the various positive uses of telemedicine to provide social, health promotion and health care.

Gaps to services described during the scan include: inadequate and under skilled respite and palliative care; lack of or insufficient services in physiotherapy and occupational therapy; problems related to the operating and sustaining of seniors housing and making Elders homes accessible; scarcity of Elder- appropriate services in mental health support, health prevention and diabetes education; need for increased physical and recreational activity for Elders; communications barriers between Elders and young workers and some problems with transportation availability for Elder clients and staff in the community.

Three main themes emerged relating to factors limiting the quality of service provided in the communities. It was felt that there is insufficient training and skills development for Personal Support Workers and home support staff. Resource limitation problems were raised, as well, evidence of which are cramped and inaccessible office space; need for more staff and staff training; more Home Care Nurse time in the communities; waiting lists to receive service; inability to provide after hour service, need for additional trained respite staff; inadequate housing for Home Care Nurses; and the inability to do all required house repairs and accessibility construction in Elders' own homes. Issues related to the need for and the benefits of better coordination of services on the ground and in funding protocols were repeatedly raised during the study as well.

Elders interviewed want to stay at home as long as they can and also want to assist their peers to stay in the community. Most prefer to remain in their own homes but some Elders see the advantages of living in a seniors facility in their community which, though difficult, is mostly preferred to having to live elsewhere. They are aware and now accepting and appreciative of the home care and support services available to them. Many Elders are recipients of some kind of home care or support service. Depending on the community, Elders comprise from two thirds to eighty percent of the clients of home support programs. About a quarter of the Elders interviewed do not use any home support or home care service in their communities and are happy to keep living independently with the support of their families for as long as they can.

Elders did speak eloquently about some of the real challenges they face living at home. Of primary concern are the health and disability challenges they face which includes as well as physical problems, loneliness and unresolved grieving and worry. Many Elders feel helpless and discouraged when they see their children or grandchildren become involved in alcohol or drug abuse. A basic concern is money, having enough to get through the month for food and other necessities and to keep wood on the fire. For Elders who do not have substantial family and/or band support for it, the buying and paying for wood to be split and brought into the home is onerous. And some are concerned about their values and traditions and how important it is to pass these on to the community.

Elders had good ideas for how to improve services to help them stay in their homes longer. These include increased help with wood; installation and upgrading of homes for accessibility; better trained and evaluated staff; meals on wheels or at least assistance with meal preparation at critical times; more education and support for diabetes; provision of respite care, more foot care and physiotherapy; staff who speak the language and have the skills to advocate for and support Elder clients to access services they require in the healthcare system; and Elder mental health counsellors. Increased and enhanced Elders housing on reserve was a frequently repeated suggestion by Elders and caregivers.

## 4.0 DEMOGRAPHICS

### 4.1 OVERVIEW

The following summarizes the population estimates for the 60 and over on-reserve population of the 29 Sioux Lookout District First Nations. It is considered with confidence to be a minimum estimate.

1. An estimated 1045 persons age 60 and over, 513 males and 532 females currently living in the Sioux Lookout District First Nations communities.
2. An estimated 702 persons are age 65 and over.
3. An estimated 118 persons are 80 years of age and over.
4. Although the percentage of the population in the north who are 65 years of age and over appears to have stable at 4% since reported in the early 1970s, with the population distribution, it can be expected that this percentage will likely grow in future decades
5. Given the limitations of the data available the age groups as a percentage of the on-reserve population is listed below. The bracketed number is the respective percentage for the general population:
  - (a) 60 and over: 6.5% of the population (11.3%).
  - (b) 65 and over: 4.4% of the population. (13.5%)
  - (c) 60-64: 2.1% of the population (4.7%)
  - (d) 80 and over: 0.7% of the population (3.6 %).

## 4.2 ELDER POPULATION

There are three sources of population data each with its own limitations:

1. Statistics Canada which details population by age group, although some First Nations data is estimated;
2. Indian and Northern Affairs Canada (INAC) which keeps updated population figures for all First Nations by on-and off reserve designations but reports age group data from the Census; and,
3. Health clinics and Band offices which often keep updated on-reserve population records access to which is sometimes difficult.

Historically, the determination of accurate demographic data for Aboriginal people has been problematic, partly as a result of resistance to participation in the national census. Although First Nations have participated more in the census since 2001, problems of isolation and language continue to pose difficulties.

Determination of the accurate numbers of Elders in First Nations communities, particularly from isolated communities, poses even more challenges. For these reasons, the population data included in this study is believed to be underestimated.

Despite its limitations, 2006 Census data is considered the most reliable data for comparison and projection purposes. To test the potential size of the discrepancy, for three communities, a comparison of current data obtained from local health professionals was compared to 2006 census data for those aged 65 and over. The discrepancy ranged from 33% less (from 15 to 10) to 30% more (from 20 to 26). An overall underestimation is supported by the fact that the diabetes program, which updates its data regularly on every diabetic in the north, has in its data base more registered diabetics 60 and over group that are recorded in the 2006 census data for the group. The study team considers the numbers presented in this report to be the best possible, although minimal, estimation. Where it was necessary to estimate a specific number, the number and methods are noted.

Table 1 compares the on-reserve population data in 29 communities north of Sioux Lookout as determined from 2006 census data and 2009 INAC data showing an increase of 7% in the on-reserve population over that time. The increase is a result of both improved data collection by INAC and population increase.

**Table 1: On reserve populations, 2006<sup>(a)</sup> and 2009<sup>(b)</sup>**

Community	On Reserve	
	2006 <sup>(a)</sup>	2009 <sup>(b)</sup>
Aroland	325	325
Bearskin Lake	459	431
Cat Lake	492	514
Deer Lake	680	888
Fort Hope	1144	1250
Fort Severn	492	492
Kasabonika	681	895
Koochiching	30	30
Keewaywin	370	370
Kingfisher Lake	460	460
Kitchenuhmaykoosib Inninuwug	905	905
Lac Seul	821	748
McDowell	—	—
Mishkeegogamang	896	896
Muskrat Dam	252	193
Neskantaga	265	294
New Saugeen	—	—
Nibinamik	362	325
North Spirit Lake	259	417
Pikangikum	2100	2132
Poplar Hill	457	443
Sachigo Lake	450	428
Sandy Lake	1843	2285
Slate Falls	164	172
Wapekeka	350	379
Weagamow	700	698
Webequie	614	668
Wunnumin Lake	482	489
Wawakapewin	21	41
<b>TOTAL</b>	<b>16074</b>	<b>17168</b>

<sup>(a)</sup> Statistics Canada Community Profiles for 2006, [www12.statcan.ca/census-recensement/2006/](http://www12.statcan.ca/census-recensement/2006/).

<sup>(b)</sup> Indian and Northern Affairs Canada, Search by First Nation, [inac.gc.ca/fnp/Main/Search/SearchFN](http://inac.gc.ca/fnp/Main/Search/SearchFN).

— No data available, populations known to be small

Table 2 shows the breakdown by age of the on-reserve population of 60 years of age and over.

**Table 2: On reserve populations aged 60 and over, 2006 data<sup>(a)</sup>**

Community	On Reserve	Aged 60 and over					
		Total	Males	Female	60-64	65-79	Over 79
Aroland	325	30	15	15	5	20	5
Bearskin Lake	459	30	10	20	5	20	5
Cat Lake	492	15	10	5	10	5	0
Deer Lake	680	25	15	10	15	5	5
Fort Hope	1144	60	35	25	30	30	0
Fort Severn	492	26*	13*	13*	9*	15*	3*
Kasabonika	681	55	25	30	15	30	10
Koochiching	30	—	—	—	—	—	—
Keewaywin	370	20*	10*	10*	7*	11*	2*
Kingfisher Lake	460	50	25	25	10	40	0
Kitchenuhmaykoosib Inninuwig	905	90	40	50	20	60	10
Lac Seul	821	65	35	30	30	30	5
McDowell	—	—	—	—	—	—	—
Mishkeegogamang	896	57	28	29	5	36	16
Muskrat Dam	252	10	5	5	5	5	0
Neskantaga	265	15	10	5	0	5	10
New Saugeen	—	—	—	—	—	—	—
Nibinamik	362	30	15	15	20	5	5
North Spirit Lake	259	10	5	5	10	0	0
Pikangikum	2100	112*	55*	57*	37*	63*	12*
Poplar Hill	457	10	7	3	0	5	5
Sachigo Lake	450	20	5	15	5	15	0
Sandy Lake	1843	110	55	55	40	55	15
Slate Falls	164	10	5	5	5	5	0
Wapekeka	350	35	15	20	15	20	0
Weagamow	700	75	40	35	25	45	5
Webequie	614	40	15	25	5	35	0
Wunnumin Lake	482	45	20	25	15	20	10
Wawakapewin	21	—	—	—	—	—	—
<b>TOTAL</b>	<b>16074</b>	<b>1045</b>	<b>513</b>	<b>532</b>	<b>343</b>	<b>584</b>	<b>118</b>
<b>PROPORTION (All communities)</b>		<b>6.5%</b>	<b>3.2%</b>	<b>3.3%</b>	<b>2.1%</b>	<b>3.6%</b>	<b>0.7%</b>

<sup>(a)</sup> Statistics Canada Community Profiles for 2006, <http://www12.statcan.ca/census-recensement/2006/>.

— No data available

\* Data has been estimated by multiplying on reserve population for the community by the proportions in each demographic category for the total population

### 4.3 POPULATION CHANGES

The on-reserve populations of seven communities for whom age group data was reported for both 2001 and 2006 were compared using Census data for these years. Table 3 compares the changes in the age group 55 years and over.

Table 4 compares the change in the age group 65 years and over. Both age groups increased by about 17% over this period.

**Table 3: Population age 55 and over for 7 Communities. 2001<sup>(a)</sup> and 2006<sup>(b)</sup>.**

Community	2001 <sup>(a)</sup>		2006 <sup>(b)</sup>		Change
	On Reserve	Age 55 and over	On Reserve	Age 55 and over	Age 55 and over
Aroland	346	30	325	45	+15
Deer Lake	755	35	680	45	+10
Fort Hope	1000	90	1144	85	-5
Lac Seul	702	55	821	75	+20
Poplar Hill	373	25	457	35	+10
Sandy Lake	1705	140	1843	155	+15
Webequie	600	50	614	60	+10
TOTAL	5481	425	5884	500	+75
PROPORTION		7.75%		8.50%	+17.6%

<sup>(a)</sup> 2001 Census Aboriginal Population Profiles,

<http://www.recensement2006.ca/english/Profil01/AP01/Index.cfm?Lang=E>

<sup>(b)</sup> Statistics Canada Community Profiles for 2006, <http://www12.statcan.ca/census-recensement/2006/>.

**Table 4: Population age 65 and over for 7 Communities. 2001<sup>(a)</sup> and 2006<sup>(b)</sup>.**

Community	2001 <sup>(a)</sup>		2006 <sup>(b)</sup>		Change
	On Reserve	Age 65 and over	On Reserve	Age 65 and over	Age 65 and over
Aroland	346	30	325	25	-5
Deer Lake	755	20	680	35	+15
Fort Hope	1000	55	1144	30	-25
Lac Seul	702	10	821	35	+25
Poplar Hill	373	10	457	5	+5
Sandy Lake	1705	55	1843	75	+20
Webequie	600	25	614	35	+10
TOTAL	5481	305	5884	240	+35
PROPORTION		3.7%		4.1%	+17.0%

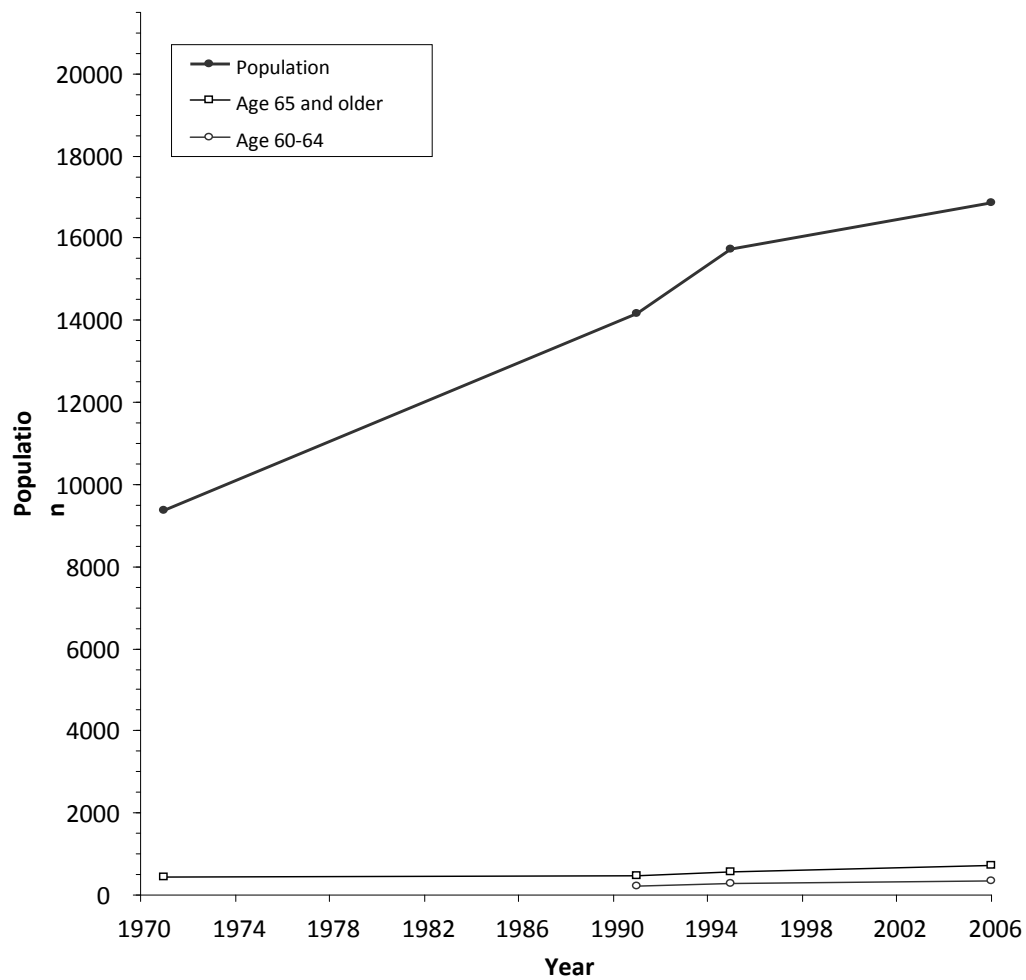
<sup>(a)</sup> 2001 Census Aboriginal Population Profiles,

<http://www.recensement2006.ca/english/Profil01/AP01/Index.cfm?Lang=E>

<sup>(b)</sup> Statistics Canada Community Profiles for 2006, <http://www12.statcan.ca/census-recensement/2006/>.

Figure 1 shows the changes in the total and Elder populations between 1971 and 2006.

**Figure 1: Total population, and number of Elders in population by age category. 1971<sup>(a)</sup>, 1991<sup>(a)</sup>, 1995<sup>(a)</sup>, 2006<sup>(b)</sup>**



<sup>(a)</sup> Sioux Lookout First Nations Health Authority, Participatory Research Project, Final Report I, Health Needs Assessment, Part II-8. Table 2.3

<sup>(b)</sup> Statistics Canada Community Profiles for 2006, <http://www12.statcan.ca/census-recensement/2006/>.



## 4.4 PROVINCIAL AND NATIONAL COMPARISONS

In Ontario, about 30% of all First Nations people live on reserve. INAC data shows the total membership of the 29 northern communities to be 24,635 persons resulting in an on-reserve population of 69% of total membership.<sup>2</sup> The proportion of people living off reserve is much lower for northern communities than for Ontario First Nations.

Between 2001 and 2006, the population of all persons of Aboriginal descent increased by 28.3%. This increase is in part a result of inclusion of all persons of Aboriginal descent - non-Status, Métis, Inuit, and First Nations - and their willingness to self-identify in 2006. The population of registered First Nations people increased by 19.5% compared to a 6.2% growth in the non-Aboriginal population.<sup>3</sup> The on-reserve population of the north, as reported in Table 3 and 4, increased by about 7.4%.<sup>4</sup>

The population aged 65 and over in the general Ontario population was estimated to be 12.5% in 2001, 13.5% in 2006 and projected to be 21.9% of the population by 2031. The on-reserve population of the northern First Nations aged 65 and over was 3.7% of the population in 2001 and 4.1% in 2006 based on figures in Table 4.<sup>5</sup>

The demographic configuration of First Nations differs significantly from that of the general population. In Ontario, an estimated 35.7% of the First Nations population is under the age of 19 compared to 25.1% in the general population.<sup>6</sup> An estimated 50% of First Nations are under the age of 25<sup>7</sup> compared to 32% of the general population.<sup>8</sup>

Using Manitoba data, comparisons between the First Nations population and the general population is illustrated in Figure 2 below.

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<sup>2</sup> Indian and Northern Affairs Canada, Search by First Nations, [www.inac.gc.ca/fnp/Main/Search/SearchFN](http://www.inac.gc.ca/fnp/Main/Search/SearchFN)

<sup>3</sup> Ministry of Finance, <http://www.fin.gov.on.ca/english/economy/demographics/projections/>

<sup>4</sup> The writers acknowledge that some of the reported increase could be a result of increased participation in the census in 2006.

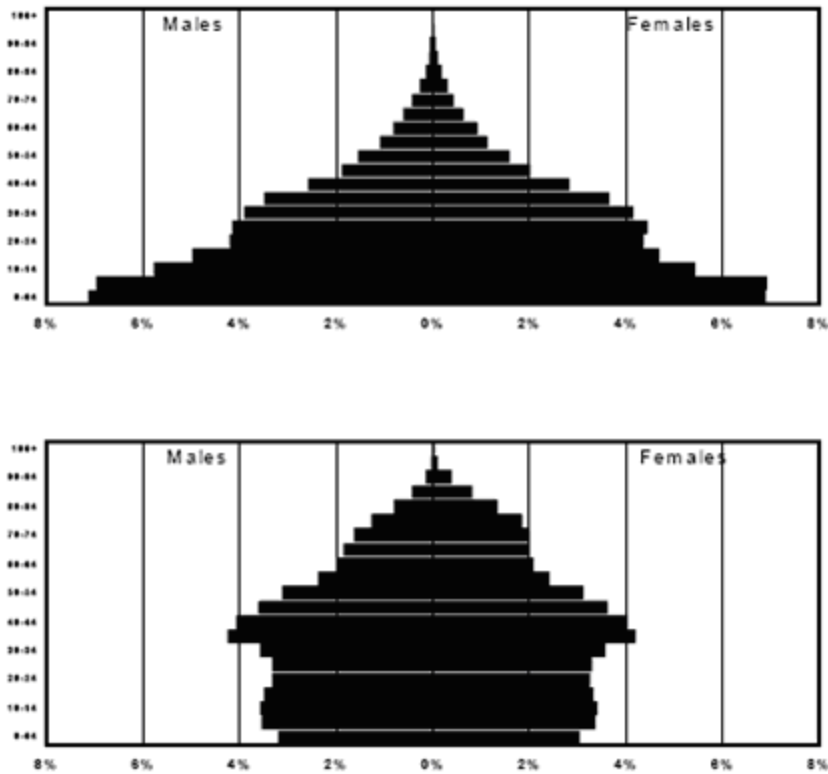
<sup>5</sup> Accurate predictions are difficult to make in the northern First Nations because of the small population.

<sup>6</sup> Ministry of Finance,

<sup>7</sup> National Aboriginal Health Organizations, Presentation to the Senate Committee on Aging, 2006, [www](http://www).

<sup>8</sup> Statistics Canada, Community Profiles for 2006, [www12.statcan/census](http://www12.statcan/census)

**Figure 2: (Top) Population profile of registered First Nations in Manitoba, December 31, 1998, population 85,959. (Bottom) Population profile of all other Manitobans, December 31, 1998, population 1,054,422.**



Source: Health and Health Care: Manitoba First Nations, University of Manitoba, Department of Community Health Services, 2003, page 38.

While the numbers of Elders still represents a smaller than expected percentage of the overall population, the above data illustrate that as the younger population ages this percentage will increase dramatically depending on health status and mortality rates. In a few decades, Elders could constitute a significant proportion of the total First Nation population. As will be discussed in the next section, the effects of chronic illnesses in the First Nations could have a significant bearing on the quality of life for this group.

## 5.0 HEALTH STATUS

### 5.1 OVERVIEW

Diseases of the circulatory and respiratory systems are by far the conditions requiring hospital care. Diabetes regularly seen as a secondary and co-morbid condition with hospital in-patients. Hospital admission data are summarized in section 5.3.

Some of the major conditions for which data has been collected by the research team from special services or persons working with the issues are summarized here.

1. A large proportion of persons over the age of 60 have Type 2 diabetes. It may be a frequent underlying cause of death. It appears to be an underlying cause of disability creating the need to move from one's home community closer to health care.
2. Possibly a third of Elders have debilitating arthritis, and an unknown number suffer from some stage of arthritis.
3. There are many Elders with latent tuberculosis that could be reactivated, although the illness may present as some other disease.
4. Renal failure requiring dialysis is the end result of many illnesses. An increase in the numbers of persons with renal failure can be predicted. With increased supports in the home community, many persons may be able to take advantage of advances in technology that will allow them to remain at home while receiving dialysis.
5. Cancer appears to be on the increase but many Elders with cancer appear to be receiving treatment in larger centres.
6. Mental health care for Elders is an unexplored area both inside and outside their communities. It cannot be overlooked in the overall health care system.
7. Dental care and possibly other conditions that are seemingly unrelated, require consideration in the health care continuum of all ages.

### 5.2 SOME GENERAL FIRST NATIONS HEALTH INDICATORS

Although quantitative mortality and morbidity data is available nationally for First Nations of all ages, data specific to Elders seems to be limited. Some comments on life expectancy and causes of mortality can be found, but little information on

health conditions specific to the age group was available.<sup>9</sup> While a comprehensive analysis of the health status of Elders in this area was beyond the scope of this study, the researchers found data that illustrates important trends that require attention in the consideration of future health care needs.

A study conducted in 2008 in Northeastern Ontario provided primarily qualitative data focusing on the participants' views of their health and long term care needs as they affected their quality of life.<sup>10</sup> A 2006 study by the Sioux Lookout First Nations Health Authority (SLFNHA) of health status in the Sioux Lookout area focused on the views of participants of all ages concerning their health and associated needs.<sup>11</sup>

Although mortality rates, causes of death and life expectancy rates specific to the area could not be determined in the time available for the study, some national and provincial information will be presented for reference. The research team focused on readily available data such as that from programs for specific illness, from professionals with specific knowledge of an illness, and from readily available admission diagnosis data from Meno Ya Win Health Care Centre.

The life expectancy of First Nations people, although increasing, is still lower than for their non-Aboriginal counterparts. First Nations people living on reserve have the lowest life expectancy of all Aboriginal people next to the Inuit. In the 1996 report of the Royal Commission on Aboriginal Peoples (RCAP), the life expectancy of First Nations on reserve was reported as 62 years for males and 69.6 for females.<sup>12</sup> In the Aboriginal People's Health Survey of 2000, life expectancy at birth for the Registered Indian population was reported as 68.9 years for males and 76.6 for females. The data reflects differences of 7.4 and 5.2 years respectively, from the Canadian population's life expectancies.<sup>13</sup> The most frequent cause of death in First Nations is disease of the circulatory system.<sup>14</sup>

There is consensus in the literature that although it is rising, the incidence of all cancers in First Nations is lower than in the general population. Some cancers, however, now surpass the general population. For example, in Ontario the rate of colo-rectal cancer in First Nations males rose sharply after 1968 such that by

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<sup>9</sup> Nancy Miller Grenier, *The Health of the Canadian Elderly*, Political and Social Affairs Division, Government of Canada, November 1993, <http://dsp-psd.pwgsc.gc.ca/Collection-R/LoPBdP/BP/bp351-e.htm#D.%20Ethnicitytxt>

<sup>10</sup> North-East Local Health Integration Network, *Aboriginal/First Nation/Matis, Elder/Senior engagement, 'Aging at Home' Final Report*, May 20, 2008.

<sup>11</sup> Sioux Lookout First Nations Health Authority (SLFNHA) *The Anishnabe Health Plan*, July 31, 2006.

<sup>12</sup> Royal Commission on Aboriginal Peoples, Volume 3, Chapter 3, Table 3.2, [www.collectionscanada.gc.ca/webarchives/20071115053257/http://www.ainc-inac.gc.ca/ch/rcap/sg/sgmm\\_e.html](http://www.collectionscanada.gc.ca/webarchives/20071115053257/http://www.ainc-inac.gc.ca/ch/rcap/sg/sgmm_e.html)

<sup>13</sup> Health Canada, *Statistical Profile on the Health of First Nations in Canada*, [http://www.hc-sc.gc.ca/fniah-spnia/pubs/aborig-autoch/stats\\_profil-eng.php](http://www.hc-sc.gc.ca/fniah-spnia/pubs/aborig-autoch/stats_profil-eng.php)

<sup>14</sup> T.Kue Young, *The Health of Native Americans: Toward a Biocultural Epidemiology*, Oxford University Press, New York, 1994.,

2001, it exceeded the rate for all Ontario males.<sup>15</sup> One group of researchers stated that First Nations cancer rates are “compatible with a population in epidemiologic transition to the Euro-American disease pattern which is dominated by chronic diseases.”<sup>16</sup>

Acute myocardial infarction rates among First Nations people are about 20% higher than the Canadian rate, and stroke rates are almost twice as high as the comparable Canadian figure<sup>17</sup>.

The National Aboriginal Health Organization (NAHO) states that 58.5 % of First Nations people over 60 live with a disability compared to 46.5% of Canadians in that age group. NAHO asserts that First Nations seniors have higher rates of arthritis, respiratory, cardiac and circulatory diseases. Thirty percent of males and 32 % of females over 65 have diabetes, compared to 14% and 11% respectively in the general population<sup>18</sup>. Health Canada estimates that Type 2 diabetes occurs three to five times as frequently than in the general population.<sup>19</sup> As will be discussed later, the number of diabetics in the northern First Nations may be much higher than in First Nations nationally.

### 5.3 HOSPITAL ADMISSIONS DATA

With the above context, readily available data for admission diagnosis data was obtained from Meno Ya Win Health Records Department, and an overview made.

A 5-year review of hospital admissions and diagnoses was made. The following information was obtained for the period 2004 to 2008:

- Number of acute care admissions of Elders to Meno Ya Win Health Centre
- Primary diagnoses upon admission
- Secondary/complicating/co-morbid diagnoses upon admission

This 5-year period was practical for the purposes of this study because the new data base program introduced about 5 years ago allowed for quick access to the admission numbers.

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<sup>15</sup> Cancer Care Ontario, The Case for Prevention and Screening in Ontario's First Nations People. 2007

<sup>16</sup> Loraine D. Marrett & Munaza Chaudhry. Cancer incidence and mortality in Ontario First Nations, 1968–1991 (Canada). *Cancer Causes and Control* 14: 259–268, 2003.

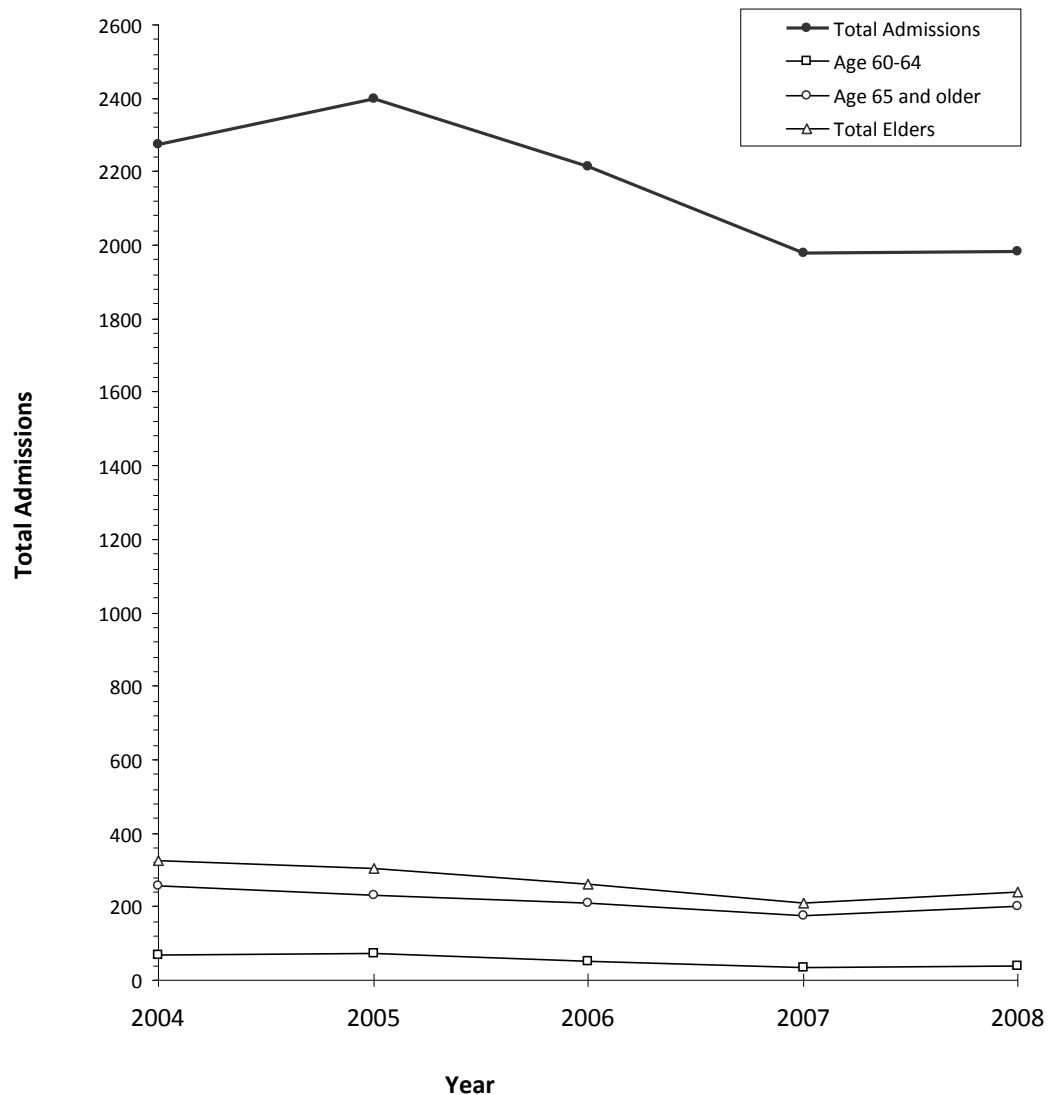
<sup>17</sup> Health Canada, First Nations Comparable Health Indicators. [www.hc-sc.gc.ca/fniah-spnia/diseases-maladies/2005-01\\_health-sante\\_indicat-eng.php#mortality](http://www.hc-sc.gc.ca/fniah-spnia/diseases-maladies/2005-01_health-sante_indicat-eng.php#mortality)

<sup>18</sup> Carol LeFontaine, Presentation to the Senate Standing Committee on Aging, November 26, 2006. [www.naho.ca/publications/agingPresentation](http://www.naho.ca/publications/agingPresentation).

<sup>19</sup> First Nations and Inuit Health Branch, <http://www.hc-sc.gc.ca/fniah-spnia/diseases-maladies/diabete/index-eng.php>

Figure 3 shows trends for the main diagnosis on admission to acute care for all ages and for 60 years and over for each year from 2004 to 2008. From the data available, it does not appear that there is any increase in the admissions of this age group over the time period.

**Figure 3: Total hospital admissions by age category. 2004 to 2008.**

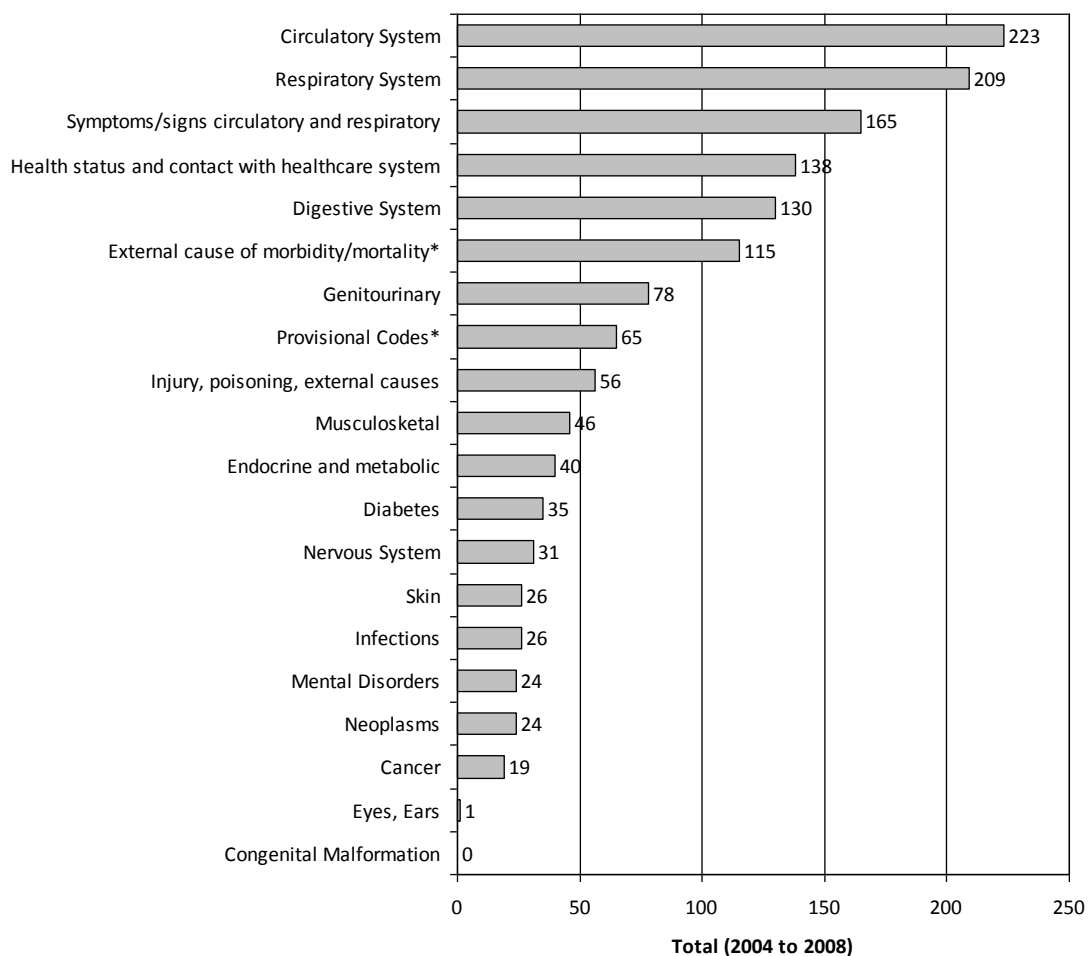


Source: Health Records Department Sioux Lookout Menoyawin Health Centre

### 5.3.1 Reasons for Admission to Hospital Acute Care

The health records department divided admission data into 19 general categories broadly based on the body system affected such as the Endocrine system or major types of illnesses such as Cancer. Because of the concern about diabetes, it was counted separately from the Endocrine category. Figure 4 illustrates the 5-year totals for main diagnosis upon admission to Meno Ya Win for acute care.

**Figure 4: Main Admission diagnoses. Five year totals by illness category. 2004 to 2008.**



\*Secondary/co-morbid diagnoses

The most common main diagnosis for acute care hospital admissions among the Elderly was a heart or lung condition or symptoms thereof. However, the “main diagnosis” does not tell the whole story. While a person may not be admitted to the hospital for Diabetes per se, diabetes might be an underlying cause of the condition that was the reason for the need for hospitalization, or at the least, might require extra care while in hospital. An examination of co-morbidity and secondary diagnoses identified in patients for all admissions, sheds more light on the prevalence of certain conditions.

The following table ranks the main diagnostic categories in descending order of frequency, and shows the total frequency of those diagnoses including their appearance as a secondary or co-morbid conditions. “Cases” refers to all instances of the diagnosis as the main, secondary or co-morbid diagnosis. Appendix 1, Table 1 shows all illnesses by category and year.

The perceptions of the people themselves are interesting: in the SLFNHA study, more than 83% of the participants (all ages) identified diabetes as the number-one health problem. Almost two thirds identified respiratory illnesses as the second major health problem, and heart disease as the fifth most common health problem.<sup>20</sup> The SLFNHA study also cites the First Nations Regional Longitudinal Health Survey that determined that arthritis was the number one self-reported illness in First Nations people of all ages.<sup>21</sup>

## 5.4 SPECIFIC ILLNESSES

For a number of medical conditions, specific programs or services attached to them provided a more detailed examination of the condition over and above what the hospital data showed and some insights for services. These illnesses - diabetes, tuberculosis, arthritis, renal failure, cancer and mental health – are discussed in more detail in this section. Data on predominant illnesses, those that are major causes of mortality such as cardiopulmonary diseases, were not available.

### 5.4.1 Diabetes<sup>22</sup>

#### *Hospital Admission Data*

Diabetes was not a common reason for admission to hospital constituting 45 main diagnoses in the 5 year period. However, it appeared in 504 cases as a main, secondary or co-morbid condition, the 3<sup>rd</sup> highest for all diseases.

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<sup>20</sup> SLFNHA 2006, page 30.

<sup>21</sup> SLFNHA 2006, page 17.

<sup>22</sup> Personal interview with Maureen Chabbert Sioux Lookout Diabetes Program, March 24<sup>th</sup>, 2009



### *Prevalence and Incidence*

There has been dramatic increase in all groups of the prevalence and incidence of diabetes, the “silent killer”.<sup>23</sup> As reflected in the hospital admission data, diabetes appears as the third most frequent secondary or co-morbid condition. It associated with a number of other chronic illnesses such as diseases of the circulatory system and even colorectal cancer, the prevalence of which is now three times higher than it was four decades ago.<sup>24</sup> Although, it is not known how many other illnesses are complications of diabetes, as stated above in, 83.3% of over 300 respondents from the North identified Diabetes as the number-one health problem in the SLFNHA study.

The increase in prevalence rates for diabetes is a result of both rigorous screening programs and an apparent increase in the occurrence of the disease. Table 5 illustrates the number of diabetics registered in the Sioux Lookout Diabetes Program (SLDP) each year from 2004 to 2008. These numbers are updated regularly to account for new cases and deaths. Overall, there has been a 44% increase for all ages, and a 70% increase in the population age 60 and over.

As of 2008, the SLDP had 1,270 persons age 60 and over registered as having Type 2 diabetes, while minimum estimate data derived from the 2006 census suggest that only 1045 are 60 years of age and over. The discrepancy could be a result of a combination of factors: data collection, potential underestimation of the Elder population (by as much as 30% as discussed earlier), movement into the 60 and over age group between 2006 and 2008, and the escalation of the disease.<sup>25</sup>

NAHO reported that 30-32% of First Nations over 65 have the disease. In one of the First Nations in this study with a population of under 1,000, there were 157 diabetics or 17.4% of the population diagnosed. In that community, 42 of the 90 persons over 65 (or 46%) were diabetic. In a second and third community, both with populations of about 500, a nurse reported the percentage of diabetics as 60% and “over half” respectively. Diabetes is thought to be increasing because of drastic diet and life style changes in the last several decades. The extent of the burgeoning problem is borne out by the fact that there are 72 children under the age of 18 registered with the diabetes program for Type 2 diabetes. Type 2 diabetes is generally a disease of older adults, not children. In the above-mentioned community of just under 1,000, there are 9 diabetics under the age of 20.

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<sup>23</sup> Prevalence is the number of existing cases of a disease in a population; incidence is the number of new cases of a disease in a population.

<sup>24</sup> Loraine D. Marrett, Carmen R. Jones, and Karen Wishart, First Nations Cancer Research and surveillance Priorities, Workshop Report, September 2003, Surveillance and Aboriginal Cancer Care Units, Division of Preventive Oncology, Cancer Care Ontario, Toronto,

<sup>25</sup> It was confirmed that SLDP updates its data base regularly including deleting the deceased from the registry

As an underlying cause for heart disease, kidney failure, blindness, and the need for amputations, support services to remain at home are direly needed for diabetics.

***Table 5: Diabetics from northern First Nations in Sioux Lookout Diabetes Program, and proportional change. 2004 and 2008***

<b>Age</b>	<b>2004</b>	<b>2008</b>	<b>Change</b>
Under 60	1,888	2,530	+34%
60-74	560	870	+55%
75-89	188	400	+113%
All Elders	748	1,270	+70%
All ages	2,636	3,800	+44%

Source: Sioux Lookout Diabetes Program. Personal interview with Maureen Chabbert.

In addition, 20% of the 325 Type 2 diabetics living in Sioux Lookout aged 60 to 89 years old are First Nations.

### *Services*

The Sioux Lookout Diabetes Program is a provincially funded program located in Sioux Lookout that serves all persons in the SLMHC catchment area. It employs two nurses and two dieticians who serve the north via videoconferencing and community visits. The program provides 60-70 consultative videoconferences per month for persons with diabetes and a 3-day visit per year to each community.

The Aboriginal Diabetes Initiative is a First Nations and Inuit Health Branch program designed to provide a more comprehensive, collaborative and integrated approach to decrease diabetes and its complications among Aboriginal peoples. Each community has a diabetes worker or nurse working in the program whose main function is to promote education, prevention and compliance with medications and diet.

### *Gaps and Challenges/Implications for Service*

Several gaps and challenges have been identified in programs for diabetics.

1. The federal government does not pay for newly diagnosed diabetics to travel to Sioux Lookout for diabetic education. Only if already in the hospital do diabetics receive in-person services. Otherwise, the program provides education by videoconferencing, even teaching Insulin injections. While there may be savings in time and money, the quality of the teaching may be compromised. This would be especially challenging if the teaching were to be done through an interpreter.
2. No funders are willing to take specific responsibility for foot care and chiropody although this is one of a range of many services covered by the Community Support Services Program. Because diabetes is an illness that affects sensation in the feet, foot care is an important consideration. Foot care nursing that requires special training does not receive dedicated funding. Chiropody for foot wounds such as ulcers is also not available. Some nurses specially trained in foot care may provide the service in the course of their other duties, or may teach PSWs to do so.
3. Some Elders appear to be compliant with their diabetes treatment, but there is a concern expressed by northern health care professionals about compliance in a significant number of others. Several health care personnel noted that non-compliance in the 45-65 year age group was common. Preoccupation with the social issues facing this age group has been suggested as one reason for this phenomenon. The implications for the future health care needs of young non-compliant diabetics are significant if a high level of compliance cannot be attained.
4. Persons with illnesses that result from complications of diabetes may require education in nutrition, for example, but only as an in-patient are they eligible for this service. Otherwise these patients are referred to the Thunder Bay Regional Hospital for service often provided through videoconferencing. The close working relationship between SLMHC and the SLDP would work to the advantage of such patients.

The data in Table 5 emphasize the rapid increase in diabetes in the north among Elders as well as those in younger age groups. The implications of this disease including its implications for other chronic illnesses and the care they require is of grave importance in any consideration of the health and status of First Nations Elders. The data suggests that the health care system for Elders may face insurmountable challenges if diabetes cannot be controlled, not only in Elders but in younger persons who will one day be Elders. It could become increasingly difficult to keep Elders living in their communities regardless of the services available to them.

## 5.4.2 Arthritis<sup>26</sup>

Arthritis has been identified as the most frequently self-reported medical condition in First Nations adults.<sup>27</sup> An estimated 15% of the general population suffers from arthritis of some form.<sup>28</sup> Two types of arthritis are common in northern communities: osteoarthritis and rheumatoid arthritis. Osteoarthritis is a frequent occurrence in the Elder population as a result of decades of heavy work and physical activity inherent in trapping and gathering one's own wood and water. Rheumatoid arthritis is a major problem in some small communities because of the small genetic pool in the north.

### *Hospital Admission Data*

Musculoskeletal Illness was not a common reason for admission to hospital constituting 46 main diagnoses in the 5 year period. However, it appeared in 321 cases as the main, secondary or co-morbid condition, the 8<sup>th</sup> highest.

### *Prevalence and Incidence*

Osteoarthritis occurs in about 20% of the general population and rheumatoid arthritis in 1% of this group. In the northern communities, a study in 1996 showed that .83% of the population had rheumatoid arthritis. However, the prevalence varied from about .2% in one of the largest communities to 4% in one of the smallest. The incidence is not declining according to a key informant who has worked as a physiotherapist in the area for several decades.

The key informant reported that in four communities she serves, in 2008 she had 42 clients of which 27 suffered from arthritis (65% of the caseload). Of this number 21 were 60 years of age and over. The combined population of the four communities was about 1,600 with about 75 people aged 60 or over indicating that 28% of those 60 and over in those communities were debilitated from arthritis severe enough to require physiotherapy services. This means that their illness had progressed to the point of inability to perform a key daily function such as bathing, showering, or climbing stairs. Of the 27 Elders with arthritis, five suffered from rheumatoid arthritis.

The overall number of persons in the communities with this disease is not known. It was speculated that numerous younger persons are living with arthritis and have not been identified because of their focus on other aspects of life such as family and work. The chronic nature of the illness may have also resulted in a higher pain tolerance. As noted earlier, arthritis was identified in the First Nations Regional Health Study as the number one self-reported illness.

### *Services*

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<sup>26</sup> Information from Barbara Lacalamita, Physiotherapist in private practice, Sioux Lookout.

<sup>27</sup> Citing the First Nations Regional Longitudinal Health Survey of 2002/03 in SLFNHA 2006, page 17.

<sup>28</sup> Canadian Arthritis Society,

There is no specific program funding for arthritis. Non-Insured Health Benefits (NIHB) has ceased covering visits to Sioux Lookout for physiotherapy services for arthritis. Some communities and tribal councils contract individual physiotherapists to visit communities and work with community based Personal Support Workers (PSW). PSWs can be trained to work with clients with some of the exercises prescribed. In the case of one tribal council, each community receives two 3-5 day visits per year. Between visits the physiotherapist is available for consultation and teaching.

#### *Gaps and Challenges/Implications for Service*

**Late diagnosis:** It is observed that many young adults delay seeking attention for early symptoms of rheumatoid arthritis. When diagnosed, the loss of many years of valuable treatment time results in increased debilitation.

**Isolation:** Patients living in the north who are on waiting lists for knee and hip replacement may wait considerably longer than others. In the event of a cancellation occurs, they are not the first to be called because of communication and travel challenges and no guarantee that the northern patient will be able to fill the spot in time. Patients who live in highway-accessible communities are generally selected first. Further, according to the Arthritis Society, the average arthritis sufferer in Canada seeks physiotherapy therapy on a weekly to monthly basis<sup>29</sup>. Northern patients, if they are lucky, may receive a visit from a physiotherapist twice a year.

**Targeting High Risk Communities:** It would appear that the hereditary component of rheumatoid arthritis exacerbates the prevalence of the disease in small communities where the genetic pool is smaller. These communities will need identification for the provision of special services.

### **5.4.3 Kidney Failure<sup>30</sup>**

Kidney failure is a result of several illnesses – glomerulonephritis, diabetes, hypertension, Lupus to name a few - with diabetes being a major precursor for many sufferers. With inadequate preventive and other health care, the chance of an Elder in the north suffering renal failure is higher. Kidney failure impacts many systems within the body.

#### *Hospital Admission Data*

In 2006, 2007, and 2008, there were 97 persons with end stage renal failure admitted to hospital. It was the main diagnosis in only 4 instances. In 71 cases the

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<sup>29</sup> The Arthritis Society Arthroscopy 1997, page 31.

<sup>30</sup> Information provided by Julia Salmon, Director TBHSRDP and Kathy Poling,

disease was associated with diabetes. It is not known why this diagnosis was not found in 2004 and 2005.

### *Services*

Thunder Bay Regional Health Sciences Centre (TBRHSC) Renal Service provides care to patients with end stage renal disease. Patients are referred by a nephrologist to the Chronic Kidney Disease (CKD) Clinic of the TBRHSC Renal Service. Ideally, patients are followed at the CKD clinic for over a year before requiring dialysis. TBRHSC has a satellite hemo-dialysis unit at the SLMHC.

TBRHSC offers in-centre hemo-dialysis, peritoneal dialysis and home hemo-dialysis. For in-centre hemo-dialysis, the patient attends the renal clinic three times/week for treatment provided by a nurse. Peritoneal dialysis is a form of dialysis in which patients in their own home are able to do their own dialysis alone or with the support of a family member. It involves instilling and draining solution through a catheter placed in the patient's abdomen. This is done manually four to five times a day or with the use of a cyclor (machine) to which the patient is connected at night. Home hemo-dialysis is also available to patients who have suitable housing, adequate water and sewer, caregiver support and are assessed as suitable by the home hemo-dialysis program. Apparently, the unit in Sioux Lookout has had its first request from a patient to attempt home hemo-dialysis.

The entire renal program serves 98 First Nations people from the north at all levels. Eleven are served by hemo-dialysis at SLMHC, two of whom are over the age of 65. At the Thunder Bay site, an estimated seven Elders over the age of 65 are on hemo-dialysis.

A total of nine Elders over 65 live outside their northern communities in order to receive dialysis, two in Sioux Lookout. One of the latter resides in Extended Care and the other in his/her own accommodation.

Although it cannot be confirmed, the TBRHSC estimates that 30 persons over 65 have re-located to larger centres to receive the various levels of services that the centre offers. The top five communities where clients originate are: Lac Seul, Kitchenuhmaykoosib Inninuwug, Fort Hope, Sandy Lake and Pikangikum.

Table 6 shows the breakdown of persons from the north and the type of renal service they are receiving.

**Table 6: Renal service provided to northern First Nations patients**

	<b>Thunder Bay</b>	<b>Sioux Lookout</b>	<b>Total</b>
Patients receiving renal service	88	10	98
65 and older	28	2	30
Hemo-dialysis	7	2	9
Peritoneal Dialysis (at home)	N/A	N/A	1
Pre-dialysis Program			20
Relocated for hemo-dialysis	7	2	
Total relocated (estimate)			30

*Gaps and Challenges/Implications for Service*

With the increased prevalence of illnesses such as diabetes and high blood pressure and the large prevalence of chronic illnesses in middle-aged persons, one can expect that renal failure will be a major problem in the north as time progresses.

For those who wish to remain at home, the option exists to have peritoneal dialysis for some. This requires a high level of motivation, diligence and competence of the patient and/or caregivers. It is hoped that as technology improves, home hemo-dialysis will be a reality as well for the north. Home hemo-dialysis requires potable water that is filtered through a reverse osmosis water system, adequate housing with room for a hemo-dialysis machine and supply storage. Home Hemo-dialysis also requires a person who is capable of learning how to provide dialysis safely and has a supportive caregiver. There would be challenges with providing home hemo-dialysis to patients in the north including transportation of equipment and supplies, timely water testing results, maintenance of equipment and accessibility. Home hemo-dialysis requires eight weeks of training as an outpatient in Thunder Bay.

Conceivably, more renal failure patients could remain at home with peritoneal dialysis if increased support were available through the health clinics for both medical and emotional issues. Some supports that would be necessary are: assistance with ordering and obtaining dialysis supplies from the airport, interpreters who understand the medical terminology, and all-round community support. It would also be necessary for renal patients to receive an augmented level of home and community support for routine needs such as obtaining wood, groceries, etc. This support could also include physiotherapy, occupational therapy, and specially trained Personal Support Workers to be sensitive to the special needs and care of renal patients. Finally, increased respite for family members who are providing the dialysis services would be essential.

For those who move from their northern communities to receive hospital hemodialysis at the Thunder Bay Regional or its SLMHC satellite, there are numerous needs. One of the most critical is transportation. In Sioux Lookout, a return taxi trip to the hospital three times a week could cost about \$50 a week. A person on a disability and full old age pension and supplement might receive \$900 per month. If fortunate, he/she would live with relatives or in a rent-geared-to-income housing unit where the rent is about one-third of a person's the income. The amount left would still be meager for the other necessities of life including nutritious food. In Thunder Bay, for those who cannot manage public transportation, costs would be higher because of greater distance from the hospital.

NIHB and the SLFNHA only cover transportation costs for persons living in the north attending the hospital. Services such as the Life Long Care Program described later provide invaluable services for many Elders including transportation, but also provide significant emotional and social support.

#### 5.4.4 Cancer<sup>31</sup>

The Oji-Cree word for cancer is 'Kitchi-Akoosowin,' meaning 'the Great Sickness,'<sup>32</sup> possibly a reflection of its newness and its seeming lethal nature for First Nations people. Cancer was rare in First Nations until 40 years ago. While overall the incidence of cancer is still lower in First Nations, incidence rates of some cancers are increasing, and are sometimes higher than in the general population. For example, colorectal cancer rates increased by more than three times between 1968 and 2001, with the incidence in First Nations' males surpassing males in the general population.<sup>33</sup>

A number of factors are contributing to rising cancer rates in First Nations including smoking and diabetes. Non-ceremonial smoking of tobacco is a more recent phenomenon. It is speculated that the high prevalence of Type 2 diabetes may result in future increases in the incidence of so-called 'western cancers' (cancers of the breast, prostate and colorectum)<sup>34</sup>. Many of the cancers in First Nations are preventable or can be caught in the early stages – prostate, colorectal, breast, cervical. However Cancer Care Ontario reports that survival rates for First Nations persons with cancer are poor, likely because of late stage detection,

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<sup>31</sup> Unless otherwise cited, information is from the Menoyawin chemotherapy Unit.

<sup>32</sup> Quote from Charles Fox, Ontario Regional Chief, in Loraine D. Marrett, Carmen R. Jones, and Karen Wishart, First Nations Cancer Research and Surveillance Priorities, Workshop Report, September 2003, Surveillance and Aboriginal Cancer Care Units, Division of Preventive Oncology, Cancer Care Ontario, Toronto

<sup>33</sup> Cancer Care Ontario, The Case for Prevention and Screening in Ontario's First Nations People. 2007

<sup>34</sup> Marrett, Jones, and Wishart,



although there is a reduction in deaths from cervical cancer because of wider spread screening through pap smears.<sup>35</sup>

### *Hospital Admission Data*

Cancer was not a common reason for admission to hospital constituting only 19 main diagnoses in the 5 year period and appeared as a main, secondary or co-morbid condition 77 times. Many persons with cancer are not admitted to hospital and treatment occurs as an out-patient.

### *Prevalence and Incidence*

Accurate Cancer data for the area could not be accessed in the time available for the study. Often cancer patients are admitted directly to 'B' ward, or receive out-patient care through the chemotherapy unit.

At the time of this writing, there was only one northern First Nations person over the age of 60 receiving chemotherapy in the Sioux Lookout unit. In a 2005 study at SLMHC, it was found that of six persons receiving chemotherapy in the unit, two were over the age of 65.<sup>36</sup> The nurse at the chemotherapy unit remarked on the notable increase in colon cancer in the 40-60 year age group, and in breast cancer in the 30-70 year age group reflecting national data on these cancers in First Nations.

### *Services*

Thunder Bay Regional Cancer Centre provides comprehensive cancer treatment for the region. A small satellite Chemotherapy Unit exists at SLMHC that can provide all levels of chemotherapy. After diagnosis, persons with cancer receive their first treatment in the Thunder Bay unit where their reactions to the medications are assessed. Patients usually stay in their home communities while receiving treatment. Chemotherapy can be administered anywhere, and its frequency ranges from once every two weeks to monthly. NIHB covers cancer care travel costs provided there are five days between appointments; otherwise patients must stay in Sioux Lookout.

The SLMHC cancer unit provides considerable 'extras' to its patients that would be unavailable in larger centres. Not only are interpreters always available, the cancer nurse is accessible by phone to patients. Also, the unit has some added touches. It keeps a supply of wigs for those who lose their hair. The local quilting guild donates patients a quilt for their use during their treatment period, which they can take home.

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<sup>35</sup> Marrett, Jones, and Wishart.

<sup>36</sup> Sioux Lookout Meno-Ya-Win Health Centre, Bii maa di zi win and Men-Ya-Win: a Study of Development of Traditional Approaches to Health Care at Sioux Lookout Meno-Ya-Win Health Centre, 2005.

In recent years, mammogram screening has become available in Sioux Lookout through the mobile van. It is well used by northern women brought out for the service. The new hospital will have mammography. Screening will result in earlier detection of the disease, increased need for treatment and associated home care. In addition, as part of their orientation, northern nurses are now trained to do pap swabs. This should result in higher survival rates.

Although data concerning the numbers of persons receiving chemotherapy in Thunder Bay from the north could not be accessed, it is conceivable that some Elders receiving care there, at least from the Sioux Lookout First Nations in the west of the district, would have a significantly more difficult time with the distance from home. On the other hand, Elders from the east side where there is more traffic between the communities and Thunder Bay may have more opportunity to stay with relatives during their treatment.

#### *Gaps and Challenges/Implications for Service*

According to Cancer Care Ontario, pap test screening for First Nations women has been lower than in the general population. However, efforts to increase screening may be the reason for a reduced incidence of cervical cancer in First Nations.<sup>37</sup> Increased efforts will be needed for cancers that can be detected early such as prostate and colorectal cancer. More effort will be necessary for prevention of lung cancer by anti-smoking campaigns, and of course in diabetes prevention and compliance. Cancer Care Ontario has made a strong case for prevention and screening for cancers that are preventable (lung) or treatable through early detection (Breast, prostate, colorectal, cervical). In a publication in 2007, Cancer Care Ontario illustrates graphically cancer rate increases and decreases as well as risk of death from these cancers showing the efficacy of early screening.<sup>38</sup>

Cancer treatment carries far fewer side effects than previously; however, fatigue is a common factor. For Elders, this would mean that extra assistance in the home would be required, including meal preparation and housekeeping.

New medical technology may one day permit patients on chemotherapy to remain at home during much of their treatment by the use of a central line, an Intravenous line put into the heart by a surgeon. However, northern nurses are not permitted to do maintenance on these lines, so home-chemo is not a possibility in the near future.

With the predicted increases in cancer rates among First Nations, there will be increased demand for services at the preventive, secondary, tertiary and palliative points in the continuum of care. Extensive and extra training for PSWs will be required, as will extra home care and extra training in palliative care for all

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<sup>37</sup> Marret, Jones and Wishart.

<sup>38</sup> Cancer Care Ontario, *The Case for Prevention and Screening in Ontario's First Nations People*, 2007

caregivers. Again, the long-term care needs of the north will be inseparable from the health needs of those in the generation that follows.

The value of cancer prevention and screening in the north cannot be overemphasized in considering the health care needs of elders.

### 5.4.5 Tuberculosis<sup>39</sup>

#### *Hospital Admission Data*

Tuberculosis as a main diagnosis occurred 3 times in the 5 year period and was present in 7 cases as a main, secondary and co-morbid condition.

#### *Prevalence and Incidence*

Over the last decade, the national tuberculosis (TB) incidence rate has declined slowly. No significant TB incidence rate change occurred in Canadian-born Aboriginal populations. However, when viewed regionally, the picture differs.<sup>40</sup> While TB rates in the Sioux Lookout District First Nations continue to fluctuate widely from year to year, the number of cases is small compared for example, to Manitoba First Nations and the immigrant population.

The incidence of TB has dropped rapidly since 1970. Between 1970 and 1974 there were 288 new cases of TB in the northern communities; from 1990 to 1993, only 87.<sup>41</sup> Between 1993 and 2008, a total of 109 new and reactivated cases of tuberculosis disease were identified. Of this number, 20, or 27% were diagnosed at the age of 65 years and over.

Although actual numbers are not available, it is known that many persons over the age of 55 have latent TB infection. Certain factors increase the risk of latent TB infection becoming active disease: aging, diabetes, immune-suppressive and cancer treating drugs, and high risk behaviours such as alcohol and drug abuse, and transience. It is the reactivation of the disease that is significant for Elders.

During the last five years, there have been seven persons over the age of 60 diagnosed with TB, three of whom had reactivated disease. There have been three persons over the age of 60 in SLMHC's acute care known to be treated for TB in the last five years, most probably presenting with COPD or pneumonia. All other cases had known latent TB infection that eventually became TB disease. As the persons diagnosed in the early 1970s reach their Elder years, the reactivation of TB may be significant and an illness to consider. Figure 5 shows the number of cases of TB diagnosed since 1998 and the age at diagnosis.

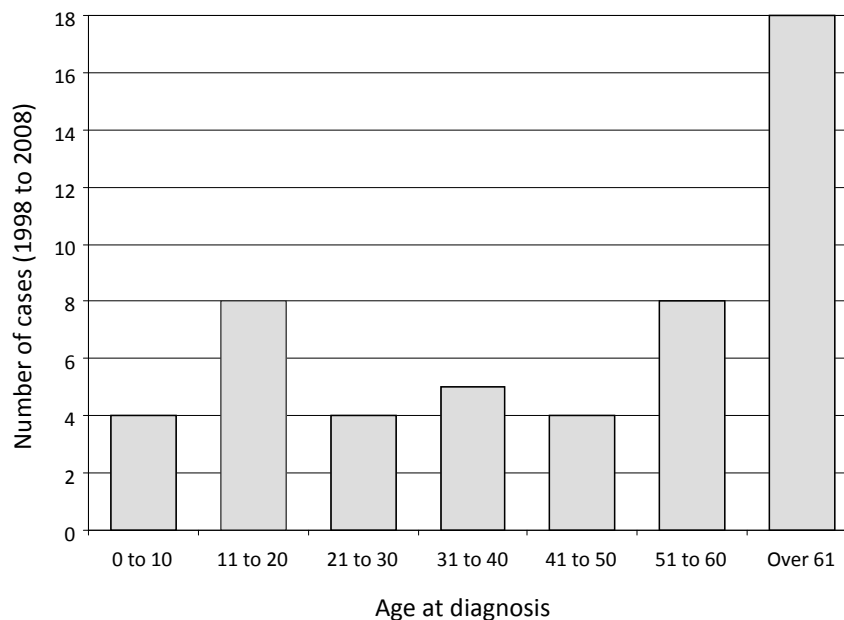
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<sup>39</sup> Information from Paddy Dasno RN, SLFNHA Tuberculosis Control Program nurse.

<sup>40</sup> Public Health Agency of Canada, Tuberculosis In Canada 2006.

<sup>41</sup> Participatory Research Project, Health Needs Assessment, II-36.

**Figure 5: Age at diagnosis. Sioux Lookout Zone tuberculosis cases. 1998 to 2008.**



Source: Sioux Lookout First Nations Health Authority, Tuberculosis Control Program

### *Services*

The SLFNHA Tuberculosis Control Program has developed a TB data base that includes persons with latent TB infection, new cases of TB disease, and those known to have had TB disease in the past.

SLMHC's Infection Control Nurse is in regular contact with the SLFNHA TB Control Program to determine if a hospitalized Elder has had TB in the past. Newly diagnosed patients with pulmonary TB may be isolated in the hospital for a period of two weeks. As the population ages, the long term effects of TB will continue as a health problem in the population. Although the prevalence and incidence is lower than elsewhere, vigilance to its possible threat is warranted.

### *Gaps and Challenges/Implications for Service*

Health care providers including home care workers need TB education. Because TB is spread through the air by persons with untreated pulmonary TB disease, others who share airspace, including home care providers, could be at risk of exposure.

Residents of long-term care facilities are vulnerable if exposed to tuberculosis. All long-term care clients are screened for TB status before admission. TB education

is required for anyone working with Elders whether in the hospital or in the community.

### 5.4.6 Mental Health

With the emphasis on youth suicide in the north, little data has been made available either in terms of prevalence or incidence, service utilization or conditions suffered by Elders. What data that could be found is presented here with some suggestions for consideration in Elder care.

#### *Hospital Admissions Data*

Mental Illness was the main reason for admission to hospital in 35 instances but appeared in 110 cases as a main, secondary or co-morbid condition. Of the latter, 11 were alcohol related, and 74 were diagnosed as mental illnesses. The remaining diagnoses were associated with an organic condition or dementia. It should be noted that the absence of a mental illness does not indicate a state of good mental health. As the study illustrated, the pervasiveness of grief in the lives of the elders was remarkable. That it does not show up in data is significant for consideration of an outreach approach.

#### *Services*

A number of mental health services are available for First Nations Elders in Sioux Lookout for the SLMHC catchment area communities:

1. Nodin Child and Family Intervention Services of SLFNHA, a First Nations Counselling services for the north that employs largely First Nations counselors. It is funded jointly by the federal First Nations and Inuit Health Branch and the Ministry of Community and Youth Services;
2. Community Counselling and Addictions Services (CCAS) that exists under the umbrella of SLMHC and employs a social worker to work with all in-patients. The social worker is a First Nations person who speaks the language;
3. Psychogeriatric consultation services through St. Joseph's Care Centre.
4. Older Adults Program funded through the Canadian Mental Health Association with provincial health care funding.

All persons in the north are eligible for mental health counselling through Nodin. Nodin receives referrals from SLMHC of patients in hospital whether or not the reason for hospitalization is related to mental health. In addition, a First Nations worker who speaks the language is located at the hospital for Elder support.

Elders who have moved to Sioux Lookout are eligible for services from SLMHC's CCAS, an outpatient service administered through the hospital. The Sioux Lookout Older Adults Mental Health Program is dedicated to clientele in the community of Sioux Lookout and provides short-term consultation and intervention.

In 2008, 22 or 3.5% of the 624 persons served by Nodin in its Sioux Lookout offices were 61 years of age and over. These were likely people already receiving other medical care at SLMHC as either inpatients or outpatients. That same year, 49 of the 1,217 people served in the communities, or 4%, were 61 and over.<sup>42</sup>

The 2006-07 Annual Report of Nodin CFI reported that 64 of 889 clients served from its Sioux Lookout service, or 7%, were 60 years of age and over. Of 123 primary and secondary presenting problems listed for these 64 persons, 31 were seen for loss and grief and 23 were medically related, such as adjustment to a medical condition.

The hospital social worker from CCAS placed at Meno Ya Win makes a routine contact with all in-patients in the hospital and visits Extended Care regularly. She works with family, helps with placements and frequently becomes involved in counseling. In 2008, there were a total of 2 Elders with a main diagnosis of Depression and 11 with depression or anxiety as a secondary/co-morbid condition. Yet, in that same year, 40 elders accessed counseling services having an average of 2.7 sessions with the social worker. This is slightly less than the number of sessions that a young person in crisis brought to the hospital would receive, according to Nodin data. The numbers illustrates how hidden and widespread mental health problems seem to be with Elders.

The social worker also worked with 10 First Nations patients of the 17 in Extended Care. The main problem dealt with at the Extended Care was the Elder's feeling of abandonment.

Table 7 shows the presenting problems and the total number of sessions for Elders admitted to the hospital acute care.<sup>43</sup>

***Table 7: SLMHC Elders receiving mental health services 2008***

<b>Identified Problem</b>	<b>Number of patients</b>
Depression	14
Loss and grief	21
Anxiety, marital, stressful situation	5
Total clientele	40
Patient contacts	109
Average contact per patient	2.7

<sup>42</sup> Sioux Lookout First Nations Health Authority Annual Reports of Nodin Child and Family Intervention Services, S2007-2008

<sup>43</sup> Chris Quequish, Community Counselling and Addictions Services, Men Ya Win Health Centre.

Although a mental illness does not present itself as a common reason for care at SLMHC, mental health problems are clearly factors in the overall health of Elders. If not an underlying reason for hospitalization, it is certainly a factor that may impede recovery. According to the CCAS social worker who works with all elders in the hospital, in most cases, the Elder had lost a child or grandchild. The effects of the grief on one's physical health and recovery cannot be underestimated.

The Older Adults Program, a provincially funded service, operates in Sioux Lookout. It provides short-term intervention services and consultation to caregivers on mental health and related issues such as dementia and Alzheimer's disease.<sup>44</sup> Although the actual numbers of clientele could not be accessed, the social worker in the program noted that the majority of clientele referred for mental health reasons suffer from depression and anxiety. The issues tend to be related not only to historical issues but also to the inability to live in the north. The social worker noted the high quality of care she observed of new clientele coming from the north, and the length of time relatives are able to manage caring for their relatives.

It is not known how many persons over the age of 60 suffer from major mental illness such as bi-polar depression or schizophrenia in the northern communities, although some are known to be in hospitals or supportive housing services outside their communities including in Sioux Lookout. With modern medications, younger persons with schizophrenia are now more able to remain in their home communities, and this mental illness will be a consideration for Elder care in the north in the future.

#### *Gaps and Challenges/Implications for Service*

The mental health of Elders has received little attention for numerous and complex reasons: the focus on youth, the age of counsellors assigned to this task, and cultural reasons resulting in Elders not coming forth with problems.

There have been approximately 350 completed suicides in the last 22 years, and long term rates of suicide amongst youth is as high as 50 times the national average in some young age groups. With some communities losing as many as 15 young people over the course of a decade, it is understandable that Elders' problems would be overshadowed. Further, most Elders would have lost a child, grandchild or extended family member to suicide. Some are known to have had multiple deaths of children from suicide, accidents or violence. Most service providers are young and unable to gain the trust of the older population, about whose life they may have no comprehension.

Additionally, persons over the age of 60 in the north will have been subject to one or more of the following stresses over the course of their lifetime:

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<sup>44</sup> Information from Alyson Martin, M.S.W., Sioux Lookout Older adults Program.

1. Attendance at a residential school and the potential abuses inherent thereof.
2. Long stays in hospitals outside of their communities for TB treatment.
3. The move from traditional lands to permanent settlements.
4. The loss of the hunting and trapping economy and the transition to the wage economy.
5. Radical changes in diet from traditional to western carbohydrate rich foods.
6. The disruption of their world view through the prosecution for sexual abuse of several previously esteemed clerics of the Christian church that served their communities.
7. The changing role of Elders as leaders with the necessity for leaders to be conversant in English and the ways of the government.
8. The early onset of potentially debilitating diseases such as diabetes, arthritis and the re-emergence of tuberculosis combined with longer life spans may result in despair in many Elders.
9. The loss of children and grandchildren, siblings in the wave of suicide and violent deaths that has plagued the northern communities.

Some Elders referred to past problems with alcohol abuse. Logic would inform us that Elders living through the multiple and complex losses described above would have a very high risk for depression. However, cultural values and norms may affect Elders' willingness to engage in formal counselling. Furthermore, the difference in age between these Elders and the counsellors would be a barrier to seeking help if so inclined. Just as teenagers might express depression as "boredom", Elders might express depression as "being lonely".

As a hidden disease in Elders, depression may need to be considered as a possibility for all Elders. Personal Support Workers trained for the north are given an entire module in mental health, much of which focuses on dealing with grief and loss, and attempts to design unique ways of addressing mental health issues of Elders.<sup>45</sup> Screening for clinical depression might be a sensible strategy to introduce to all Elder care.

While mental illness did not stand out as a major factor with Elders in the hospital data, respondents referred to it directly and indirectly. The gap in meeting the mental health needs may be partially filled using strategies such as videoconferencing visits with family for those unable to stay at home, friendly visiting, regular house checks etc. PSWs will need to be especially sensitive to the potential for mental health problems in this age group.

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<sup>45</sup> Personal knowledge of senior researcher.



### **5.4.7 Parkinson's Disease**

Hospital staff noted an increase in Parkinson's disease. Although, the hospital data did not demonstrate this observation specifically, Parkinson's was the main diagnosis for 18 admissions over the 5 years period surveyed, and a secondary or co-morbid diagnosis in 55 cases. It was the most frequently observed disease of the nervous system reported as either a main or secondary/co-morbid diagnosis.

### **5.4.8 Dental Health<sup>46</sup>**

Although not initially included as part of this study, in the course of deliberations, a dental health professional did describe how dental health is a factor in the overall continuum of health and care for Elders. The professional indicated that she had never treated an Elder who had teeth, providing denture fitting services only. Without teeth, eating meat and other traditional foods may be difficult and may be replaced by more chewable soft carbohydrates. This could aggravate diabetes, the consequences and complications of which are well known.

Although on the surface, dental health may not necessarily seem an important factor, this anecdote does illustrate how all health problems are connected to overall care and the ability to age at home.

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<sup>46</sup> Dr. Valerie Dorward

## 5.5 LIVING SITUATION

It is useful to have an understanding of the current living situations of Elders in their communities to effectively establish a continuum of care for this age group. The study team used interviews with Elders and Elder care professionals in the First Nations communities to collect this information. The team also prepared a ‘snap shot’ of First Nations Elders who have relocated from the north to Sioux Lookout for medical or other reasons as this completes a picture of their current situation.

Table 8 outlines a summary of the living arrangements of 298 Elders age 65 and over in 13 communities in the area studied.

***Table 8: Living arrangements of Elders age 65 and older in First Nations communities surveyed***

Alone	19%
With a spouse or partner	36%
With a relative (in own home or relative’s)	45%

The majority of Elders share accommodation with a family member; however, it was explained that “Elders living with a relative”, could often still be living in their own homes with an adult child or grandchild(ren).

There were numerous situations referred to where widowed Elders remained in their homes and grandchildren moved in with them, frequently in close proximity to the grandchildren’s parents, i.e. the Elder’s grown children. Another 36% (106 individuals) live together with a spouse or partner, in many cases still receiving extensive support from nearby children and grandchildren.

The category of Elders residing entirely alone was the smallest 19% or 58 Elders living alone. Some of these lived in single units of seniors’ buildings where they exist.

Of note, in several communities there were only one or two Elders living alone, and in two communities including one of the biggest in the north, no Elders reside entirely on their own. One comment explaining this situation was, “No Elders live alone (here) – it’s not part of our culture to leave people alone.”

It was noted that most Elders are more comfortable staying in their own homes so many families try to accommodate this by having a relative (often a teenager or youth) move in with them. Elder care workers in other communities referred to some independent seniors who refuse to live with other family members once their spouse or partners die. Where Elders live in a larger extended family, some

may have their own rooms in the house or some might prefer to stay in the living room.

In general, Elders interviewed expressed contentment about their living situation and would not want to live elsewhere, although one Elder stressed that, “It’s not easy living here”. One couple had an opportunity to move into nearby seniors’ accommodation but chose to stay in their home because the seniors’ building was poorly constructed. One couple noted that they, “give thanks every day” that they are able to live independently thanks to help from family and the Band. Of the four Elders currently in hospital or extended care, two were very actively trying to return home despite serious health conditions and two were adjusted and content with their arrangement.

### 5.5.1 Reasons for Elders leaving their communities

There are multiple and complex reasons why an Elder may leave his or her northern home. Some move for their own medical care. Others because of a spouse’s medical condition, and others to be close to relatives. In the latter two categories, the team encountered two individuals who were gainfully employed.

The reason given in our interviews with community health care professionals are illustrated in Table 9.

***Table 9: Reasons for Elders leaving home***

Renal dialysis	45%
Family could not provide enough care	24%
Stroke	7%
Dementia	6%
Housing issues	4%
Parkinson’s Disease	4%
Peritoneal dialysis	2%
Alcohol use	2%
Osteoporosis/fracture	2%
Cardiac	2%
Lung cancer	2%

The primary reason for Elders leaving their community was renal failure requiring dialysis. Twenty-four individuals or 45% left their home communities for this reason. 13 of the 53 Elders (or 24%) have left home because their family could not provide enough care. In some cases Elders required someone to be with them extensively, sometimes around the clock, and their families could not sustain this level of care. In others, the families themselves were dysfunctional from substance abuse or other issues and could not handle the additional care of an Elder.

Home care workers noted instances where they worked with families to develop comprehensive care plans to keep Elders home; however, they could not achieve success in all cases.

Most of the other reasons noted for Elders leaving their home communities involved various health related conditions illustrated in the table and described in this report

## 5.6 LEAVING HOME FOR MEDICAL CARE

An estimated 50-60 First Nations Elders live in Sioux Lookout to be close to medical care or to secure better living conditions.<sup>47</sup> We were unable to determine how many lived in larger centers such as Thunder Bay or Winnipeg although, we are aware of at least 28 in the renal program in Thunder Bay.

Many of these Elders are staying in a medical facility, non-profit housing or in rented units of the Aboriginal housing service. The study team was able to estimate numbers of First Nations Elders living in these facilities through interviews with the managers of these services. The team was also able to estimate numbers of Elders who moved to Sioux Lookout for medical reasons, and numbers of those on waiting lists hoping to move closer to medical facilities.

Table 10 shows where northern First Nations Elders are housed in Sioux Lookout. About 56 have moved to Sioux Lookout for medical reasons, and of this number, 28 (or half) live independently and half are in a health care facility.

There are 186 First Nations persons on waiting lists for housing or long-term care facilities. Of those waiting, 16 or 8.6% are persons over 60 from the north requiring housing in Sioux Lookout for reasons related to medical conditions. It is noteworthy that Nitawin Housing has a total wait list of 33 persons wanting housing in Sioux Lookout for medical reasons, 14 over 60 years of age and 19 under 60. The high number of persons under 60 requiring housing for medical reasons portends the demands on the system in the future.

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<sup>47</sup> Support workers Peggy Cutfeet and Sheila Beardy, Life Long Care program, Nishnawbe Gamik Friendship Centre, Sioux Lookout.

**Table 10: First Nations persons from the north housed in Sioux Lookout**

Facility	Units	On waiting list	Over 60		
			In facilities	In for medical reasons	On waiting list for medical reasons
Rent-geared-to-income seniors facilities <sup>(a)(b)</sup>	81	3	30	24	2
Nitawin <sup>(c)</sup>	45	183	7	4	14 <sup>†</sup>
All non-profit housing <sup>(b)</sup>	176	0	2	0	0
B ward <sup>(d)</sup>	15	N/A <sup>(e)</sup>	11	11	N/A
Extended care <sup>(d)</sup>	20		17	17	22 <sup>‡</sup>
<b>Total</b>	<b>337</b>	<b>186</b>	<b>67</b>	<b>56</b>	<b>38</b>

<sup>†</sup> Another 19 persons under the age of 60 are waiting for housing for medical reasons.

<sup>‡</sup> There are 3 persons in their home communities on a waiting list for extended care, 8 in other out of town facilities, and 5 persons currently in the hospital.

<sup>(a)</sup> Adrian DePorto, Housing Manager Kenora District Services Board

<sup>(b)</sup> Terry Korobanik, Housing Manager, Sioux Lookout Non-Profit Housing Corporation

<sup>(c)</sup> Che Curtis-September, Manager, Nitawin Community Development Corporation

<sup>(d)</sup> Heather Fukishima, Nurse Manager Sioux Lookout Meno Ya Win Health Centre

<sup>(e)</sup> Persons requiring chronic care in emergencies often come first to the acute care unit to await a bed on the chronic care ward, where patients are awaiting a bed in the Extended Care Facility.

According to other sources, seven persons 60 and over from the north live in Thunder Bay for dialysis treatment.

An unknown number of First Nations persons live in private housing alone or with family members. According to Statistics Canada, there were 1,450 First Nations living in Sioux Lookout during the 2006 census.<sup>48</sup> Given the limitations of the data, the 67 First Nations Elders estimated to live in Sioux Lookout would therefore constitute 4% of the total First Nations population of Sioux Lookout.

### 5.6.1 Services provided in Sioux Lookout

In Sioux Lookout, the largest group of Elders live at a seniors rent-geared-to-income facility, Patricia Plaza, operated by the Kenora District Services Board. Across the street is the new and comfortable Sioux Towers, which has only two First Nations residents. Both have been Sioux Lookout residents for many years. Often there is no waiting list at the Plaza, which has no elevator at this time. Therefore someone in urgent need from the north, can often access housing within a relatively short waiting time. Because so many First Nations persons from the north live there, it is often the first choice of housing for First Nations Elders.

<sup>48</sup> <http://www12.statcan.ca/census-recensement/2006/>

Nitawin Housing is a 45-unit housing service through the Canadian Mortgage and Housing Corporation under its Section 95 Urban Aboriginal Housing portfolio. It serves families from the north usually new to the area. There are four persons over the age of 60 listed as the primary tenant living in Nitawin. Conceivably, there could be more Elders living in the units with family who are not listed as the tenant.

Elders requiring fully assisted living may be placed in SLMHC's William B. George Extended Care facility. Currently, 17 First Nations Elders are resident there. SLMHC has 11 First Nations Elders on its chronic care ward, most waiting for placement at the extended care unit.

There is a notably long wait time for long term care in Sioux Lookout. The wait time for admission to the Extended Care facility is the second highest in our region for both First Nations and non- First Nations clients. There is also a contributing and significant lack of understanding of the assessment/application process by First Nations families and potential clients e.g. people do not understand how long the wait is, the importance of getting on the list, and the fact that, after first refusal, people are moved to the bottom of the list, etc. And there is no CCAC staff or representative in communities to assist Elders in understanding admissions process.

### **5.6.2 Support for Elders Living Outside Their Communities<sup>49</sup>**

The Life Long Care Program is an urban Aboriginal strategy funded by the Ministry of Health and Long-Term Care and administered by Ontario Friendship Centers. It has existed in Sioux Lookout for about 11 years, and has been staffed by the same trained PSWs for that time. Like most Friendships Centre programs that assist First Nations with transition to urban life, the Life Long Care Program assists those with medical and mobility challenges to adjust to urban life. It serves an estimated 50 clients, about 80% of whom are 60 years of age and over. The workers identified the challenges of the home communities to accommodate Elders with medical and physical challenges as a significant gap:

- For arthritics, the shortage of ramps and the difficulties associated in obtaining funds for the Band to build them.
- Increased numbers of persons requiring wheelchairs.
- Complications from diabetes such as renal failure and blindness reducing the ability to manage at home.
- Loneliness and depression being separated from family, difficulty grieving and few counselling services.

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<sup>49</sup> Interviews with Peggy Cutfeet and Sheila Beardy, Nishnawbe Gamik Friendship centre, Sioux Lookout, and focus group with 11 clients of the program.

There are only 12 supportive housing spaces in Sioux Lookout. There is no Handi-Transit program for local or out of community transportation. Homemaking services are available from the regular program. The Life Long Care Program attempts to fill these gaps with the following support services:

- Transportation via the program's vehicle for shopping and medical appointments, both locally and to places such as Dryden when the hospital or NIHB do not cover
- Security Checks
- Interpreter services when visiting physicians at the Hugh Allen Clinic
- Meals on Wheels
- Visiting
- Socializing – regular Friday gatherings for lunch, outings
- Securing wild food from sources such as the MNR
- Connection to services in Sioux Lookout such as the Sioux Lookout Diabetes Program

The program's long term funding is not certain.

### **SLMHC Services**

The SLMHC has developed a range of specialized care available to First Nations patients with particular emphasis on services that meet the needs of Elders. These ranges from a traditional food and medicine program, interpretive, translation and patient advocate services that are unique in the province. The Health Centre board is advised by an Elders Council whose mandate is to ensure the integration of First Nations services in the hospital.

### *Implications for Service*

The service provided by the Friendship Centre was applauded by its participants even though most of those interviewed indicated their preference to live in their home communities. However, they noted that life in town had some advantages over life on the reserve:

- Warm housing, no need to get wood
- Less costly - wood varies but many Elders have to purchase, food is less expensive in town
- Proximity to relatives who left their communities for employment

With increasing numbers of people moving from the north for employment, Elder parents experiencing difficulty in caring for themselves are certain to follow. Conceivably, services and housing in Sioux Lookout may be unable to house and care for these individuals.

With increasing prevalence of chronic illness in all ages, home care and home support services for Elders in the north will be of critical importance.



## **6.0 INVENTORY OF CURRENTLY AVAILABLE SERVICES FOR ELDERS**

### **6.1 OVERVIEW**

Table 11 provides an overview of the three main government programs providing home-based services to Elders in the northern First Nations. These programs are:

- The provincially funded Home and Community Support Services (HCSS) from which the communities use the element called Community Support Services (CSS).
- The joint Homemaking and Nurses Services program, 80% provincially funded and 20% federally funded through INAC's Assisted Living Program. (Note that nursing services are not covered under this program).
- The federally funded (Health Canada) Home and Community Care (HCC) service.

The first two programs are used mainly to provide environmental assistance to Elders in the north including indoor housecleaning and outside maintenance, often involving wood and water services. These services are often referred to as "home support". The third program is used primarily to provide personal care to Elders in their homes, including nursing support; however, some housework is done under this program as well. In most communities, this program is referred to as "home care".

There is no formal coordination between the agencies that fund these programs. The people in the communities are the only ones who know exactly how the three programs are being used locally, and service implementation, priorities and administration differ significantly from one community to the next. Within communities, a lack of coordination is cited as a limiting factor for the best and most efficient services.

**Table 11: Elder care directory of services in the north**

	<b>Community Support Services</b> <i>CSS, Long Term Care</i>	<b>Homemaking and Nurses Services Act</b> <i>HNSA, Homemakers</i>	<b>Home and Community Care</b> <i>HCC, Home Care</i>
Funding	<ul style="list-style-type: none"> <li>▪ 100% provincial from Health and Long Term-Care through LHINs</li> <li>▪ Since 2001 – \$6M to 40 northern FNs to augment H&amp;NSA</li> <li>▪ Since late 80's/early 90's with federal contribution</li> </ul>	<ul style="list-style-type: none"> <li>▪ 80% provincial, 20% INAC (Assisted Living Program)</li> <li>▪ Federal/Provincial Social Services agreement, 1965</li> </ul>	<ul style="list-style-type: none"> <li>▪ 100% federal from Health Canada</li> <li>▪ Piloted In 1999</li> </ul>
Services	<ul style="list-style-type: none"> <li>▪ Main services provided in FNs: <ul style="list-style-type: none"> <li>▪ Transportation</li> <li>▪ Home Help</li> <li>▪ Home Maintenance &amp; Repair</li> <li>▪ Case Management</li> <li>▪ Meal services – Congregate Dining (in a few communities only)</li> </ul> </li> <li>▪ LHIN Elder Services not often provided in FN communities: <ul style="list-style-type: none"> <li>▪ Security</li> <li>▪ Wheels-to-Meals</li> <li>▪ Caregiver Respite</li> <li>▪ Caregiver Support Groups &amp; Counselling</li> <li>▪ Volunteer Hospice</li> <li>▪ Social &amp; Recreational Services</li> <li>▪ Foot Care</li> <li>▪ Supportive Housing</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>▪ Housekeeping (child care, meal planning and preparation, cleaning, laundry, personal care, simple bedside care, training and instruction)</li> <li>▪ No nursing care</li> </ul>	<ul style="list-style-type: none"> <li>▪ Management and support</li> <li>▪ Nursing</li> <li>▪ Case assessment</li> <li>▪ Equipment</li> <li>▪ Client assessment</li> <li>▪ Personal care</li> <li>▪ Respite care</li> <li>▪ Information and data collection</li> </ul>

...continued

**Table 11: Elder care directory of services in the north (continued)**

	<b>Community Support Services</b>	<b>Homemaking and Nurses Services Act</b>	<b>Home and Community Care</b>
	<i>CSS, Long Term Care</i>	<i>HNSA, Homemakers</i>	<i>HCC, Home Care</i>
Administ- ration	<ul style="list-style-type: none"> <li>▪ Band administered</li> <li>▪ KO administers for their communities</li> <li>▪ One Community has Long Term Care Coordinator – manages Community Support Coordinator (CSC) and Homemakers</li> </ul>	<ul style="list-style-type: none"> <li>▪ Band administered</li> <li>▪ One community has Long Term Care Coordinator – manages CSC and Homemakers</li> </ul>	<ul style="list-style-type: none"> <li>▪ Tribal council</li> <li>▪ Individual band</li> <li>▪ Health authority</li> </ul>
Manage- ment	<ul style="list-style-type: none"> <li>▪ Band</li> <li>▪ Health Director</li> <li>▪ Welfare administrator</li> <li>▪ Social Services (community)</li> <li>▪ Long Term Care Coordinator</li> </ul>	<ul style="list-style-type: none"> <li>▪ Band</li> <li>▪ Health Director</li> <li>▪ Welfare administrator</li> <li>▪ Social Services (community)</li> <li>▪ Long Term Care Coordinator</li> </ul>	<ul style="list-style-type: none"> <li>▪ Nurse Manager (Tribal Council level program management)</li> <li>▪ Home and Community Care Coordinator (community level – coordinator may be a nurse, in most cases a PSW)</li> <li>▪ Some communities act alone, manage own programs and contract own nurses for monthly visits</li> </ul>
Eligibility	<ul style="list-style-type: none"> <li>▪ Economic needs assessment</li> <li>▪ Age 60</li> <li>▪ Retired/pensioned</li> <li>▪ Medical certificate from Dr./age 60</li> </ul>	<ul style="list-style-type: none"> <li>▪ Economic needs assessment</li> <li>▪ Functional limitations/disability</li> <li>▪ Mostly seniors but not exclusively</li> <li>▪ Medical certificate from doctor</li> </ul>	<ul style="list-style-type: none"> <li>▪ Medical/functional needs assessment</li> <li>▪ Mostly Elders but not exclusively</li> </ul>

## 6.2 PROVINCIAL PROGRAMMING

Table 12 outlines the provincial programs for the aged funded by Ontario. This overview demonstrates the range of programming provided in Ontario as a whole, of which presently only a small number of the services possible are actually being delivered in the north, namely those under Community Support Services (CSS), element #4 of the Home and Community Support Services Program.

The main provincial program accessed by northern First Nations is the Community Support Service (CSS) This is the one of the four elements of the Home and Community Support Services Program which is part of the provincial Programs for the Aged of the Ministry of Health and Long Term care. This program incorporates funding from a 2001 agreement with Chiefs of Ontario that provided \$6M for Aboriginal on reserve services allocated to 40 First Nations across the north. This funding augments the existing Homemakers and Nursing Services Act funding (Ontario/Canada).

Services delivered vary from community to community. In most cases provincial funding goes directly to the Band Councils and the main services provided are:

1. Homemaking – most of the programs administered on reserve are picked up in this category;
2. Home maintenance and repair;
3. Transportation;
4. Congregate dining – very sporadic in communities, but where it does exist it could move into a meals on wheels program; and,
5. Case Management – including making arrangements for a client who needs to leave the reserve for a referral

**Table 12: Overview of provincial programs for the aged. Ministry of Health & Long Term Care.**

<b>Home and Community Support Services</b>	<p>Helps clients manage their own care while living at home. Services can be obtained individually or in combination. Four main categories:</p> <ol style="list-style-type: none"> <li>1. <b>Visiting Health Professional Services</b> Provides health care in client's home including visits to assess needs, plan and/or provide care. Supplies &amp; equipment relating to these services may be available.</li> <li>2. <b>Personal Care and Support</b> Helps clients with a variety of daily living activities e.g. bathing, dressing, toileting, eating, etc.</li> <li>3. <b>Homemaking</b> Assists with routine household activities e.g. menu planning and meal preparation, shopping, light housekeeping, etc.</li> <li>4. <b>Community Support Services (CSS)</b> Includes a wide variety of services: <ul style="list-style-type: none"> <li>▪ Security Check including volunteer friendly visits</li> <li>▪ Transportation to medical appointments or programs (consumer fee involved)</li> <li>▪ Meal Services (home delivered to client home up to once a day by volunteers depending on eligibility)</li> <li>▪ Meals to Wheels, Diner's Club, Congregate Dining (volunteers take clients to a dining hall to join others – consumer fee involved)</li> <li>▪ Caregiver Respite (includes in-home respite, adult day programs – fee involved, &amp; short-stay respite in a long term care home – fee involved) Caregiver Support Groups and Counselling (individual counseling – fee involved)</li> <li>▪ Caregiver training, information &amp; education and caregiver education groups)</li> <li>▪ Volunteer Hospice (volunteer social support for palliative patient in home)</li> <li>▪ Foot Care (a fee may be involved);</li> <li>▪ Home Help (assistance with routine household activities including meal prep, shopping, laundry, paying bills or banking)</li> <li>▪ Social and Recreational Services (learning and recreational activities for seniors that encourage community involvement and intergenerational contact)</li> <li>▪ Home Maintenance and Repair (heavy home maintenance tasks – fee involved)</li> <li>▪ Supportive Housing (on-site personal care and support services within particular apartment buildings)</li> </ul> </li> </ol> <p>...continued</p>
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**Table 12: Overview of provincial programs for the aged. Ministry of Health & Long Term Care. (continued)**

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<b>Residential Care</b>	<p>Enables people to move to a place that provides accommodations with the level of support they need. In Ontario, there are three main types of residential care:</p> <ol style="list-style-type: none"><li><b>1. Supportive Housing</b> Accommodations for seniors who require minimal to moderate levels of personal care and support to live independently. Many locations have rent-g geared-to-income subsidies available.</li><li><b>2. Retirement Homes</b> Privately owned rental accommodations for seniors who require minimal to moderate levels of personal care and support to live independently. Funded entirely by the revenues from resident fees.</li><li><b>3. Long Term Care Homes</b> Designed for people who need the availability of 24-hour nursing care, supervision or higher levels of personal care. These government regulated homes are also known as nursing homes, municipal homes for the aged, or charitable homes. Residents pay for accommodation charges and the care is funded by the Ministry of Health and Long-Term Care.</li></ol>
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Table 13 summarizes federal programs geared to status Elders the most significant of which for in-home support are the Home and Community Care Program and the 20% contribution to the Homemakers Program.

***Table 13: Overview of federal programs for the aged***

Health Canada	<ol style="list-style-type: none"> <li>1. <b>Aboriginal Diabetes Initiative</b> (all population)</li> <li>2. <b>National Native Alcohol &amp; Drug Abuse Program</b> (all population)</li> <li>3. <b>Community Primary Care</b> Provided to remote and/or isolated First Nations (FNs) where such services are not provided by provincial or regional health authorities. Program clients: FNs on-reserve.</li> <li>4. <b>First Nations and Inuit Home and Community Care</b> Includes home and community care services that enable FNs of all ages with disabilities, chronic or acute illnesses and the Elderly to receive care in their homes and communities.</li> <li>5. <b>Non-Insured Health Benefits Program</b> Provides eligible FNs with a limited range of medically necessary health-related goods &amp; services not provided through private insurance plans, prov/territorial health or social programs or other publicly funded programs. Includes some of the following: prescription drugs, over-the-counter medication, medical supplies and equipment, short-term crisis counselling, dental care, vision care, and medical transportation</li> </ol>
Human Resources and Social Development Canada (HRSDC)	<ol style="list-style-type: none"> <li>1. <b>Guaranteed Income Supplement (GIS)</b> Provides a monthly non-taxable benefit to low-income Old Age Security (OAS) recipients living in Canada.</li> <li>2. <b>Old Age Security Pension (OAS)</b> A monthly benefit available to most Canadians 65 years of age or older who have lived in Canada for at least 10 years</li> <li>3. <b>Allowance Program</b> A monthly benefit for low-income seniors (aged 60-64) whose spouse or common-law partner is eligible for, or currently receiving, the OAS pension and the GIS</li> <li>4. <b>Allowance for the Survivor Program</b> Provides a monthly non-taxable benefit to low-income widowed spouses who are not yet eligible for the Old Age Security (OAS) pension.</li> </ol>
<b>...continued</b>	

**Table 13: Overview of federal programs for the aged (continued)**

Indian and Northern Affairs Canada (INAC)	<p>Assisted Living Program - 20% Federal contribution to Homemakers Program (compliments HCC and NIHB):</p> <ul style="list-style-type: none"> <li>▪ No nursing care paid for by INAC.</li> <li>▪ Helps FN's with functional limitations to maintain independence, maximize their level of functioning, and live in conditions of health and safety</li> <li>▪ Three components: in-home care - homemaker services; foster care - supervision &amp; care in a family setting; and institutional care - services in Type I and II institutions.<sup>50</sup></li> <li>▪ Provided to registered FN's people living on-reserve who have functional limitations because of age, health problems or disability and who require care.</li> <li>▪ Part of federal government's general policy to provide First Nations people on-reserve with access to services which are comparable to those provided by the provinces to other Canadians</li> <li>▪ 1984 Memorandum of Understanding between INAC and Health Canada sets out respective areas of responsibility</li> <li>▪ Although INAC is mandated to provide funding for institutional care, in 1988 a moratorium was placed upon the construction of new on-reserve personal care homes, placing greater emphasis on in-home care</li> </ul>
Canadian Mortgage and Housing Corporation (CMHC)	<p>Residential Rehabilitation Assistance Program (RRAP)</p> <ul style="list-style-type: none"> <li>▪ Provides funding to FN councils and individuals to repair on-reserve housing that does not meet minimum federal health and safety standards</li> <li>▪ Dwellings must be at least five years old, lack basic facilities or require repairs to their structure or electrical, plumbing, heating or fire safety systems</li> <li>▪ Household income must be below an established limit based on household size and location</li> </ul>

<sup>50</sup> Type I is residential care for individuals requiring only limited supervision and assistance with daily living activities for short periods of time each day. Type II is extended care for individuals requiring some personal care on a 24 hour basis, under medical and nursing supervision. Individuals requiring more intensive levels of medical care (i.e. Types III, IV and V) are considered the responsibility of "health authorities".



## 7.0 UTILIZATION OF SERVICES

### 7.1 OVERVIEW

There was general agreement among northern health care providers and Elders interviewed that the Home and Community Care Program provides the most useful home-based services to assist Elders and their families in the north, with the Community Support Services program (known as Home Support or Long Term Care) also a key service for Elders in their homes. An overview of these programs was described in Table 11, *Elder Care Directory of Services in the North*.

The home-based support provided by these programs is thought to work best when there are close working relationships between the community nursing staff, the Home Care staff and the Home Support staff. Several nurses indicated they feel that HCC does reduce the number of Elders seen at clinics thus freeing up nurse resources to deal with more critical clients. It was generally agreed that the HCC program may now be considered an essential resource in all communities. It took time for Elders to accept the program, but they now know, accept and appreciate the program and the staff. It is estimated that Elders comprise from two thirds to eighty percent of the clients of home support programs.

The Home and Community Care Program was described as being most effective when it supports family care rather than replacing it. There are still a significant number of families in the north who are caring for their parents and grandparents and respondents felt that all efforts should be made to support these caregivers at critical times so that they can continue to do so.

Some of the strengths of the HCC Program highlighted as most effective include:

- The role of the Personal Support Worker (PSW) in personal care for clients extends their ability to stay at home, particularly given the PSW role as monitors of overall health of Elders and of communicating urgent problems to medical personnel within the community thus identifying problems in a more timely fashion
- PSWs who are trained and certified are the most effective in their positions and are now providing important continuity for Elder health care, given the often very high turn-over in nursing staff
- Case management is often done by professionals and the role of Home Care Nurse is effective in client assessment and re-assessment, care plan creation and oversight, supervision of care and PSW training and upgrading

- Effective referral and client management system because it is possible for anyone (individual, family member, nurse, PSW) to refer a client to HCC services
- Takes active role or lead in coordinating after-hospital care which, in turn, is more effective when there is discharge planning from hospital (discharge planning is considered to work best, at present, with patients discharged from the Sioux Lookout Menoyawin Health Centre)
- Medication distribution to Elders after hours if they do not wish to have it in their homes, requiring after-hours work by PSWs (done infrequently but very much valued as a service)

## 7.2 PRIORITIZED SERVICES

In this section is outlined specific services provided to Elders in the community and singled out for inclusion and discussion by respondents. The findings reveal the extent to which the service appears to be effective and highlights gaps and problems perceived by the health care professionals and leaders interviewed. Many of these services are provided through funding to Home and Community Care or Home Support programs.

### 7.2.1 Palliative and Respite Care

Although this service (as a paid service) does exist in some communities and is useful where it does, there are significant gaps in the provision of it in almost all communities. In communities where it is provided, HCC or other staff may coordinate volunteers and family members to give 24/7 care, often with the support of the Band Office. Team work and coordination are necessary in order to involve doctors and nursing staff in pain management. There is also a considerable discrepancy from community to community in the amount of palliative support able to be provided by family. In some instances the family and volunteers are very active but in others there is significantly less support from the family which places additional strain on home care staff (usually PSWs). A few communities are able to designate resources for respite care staff, but they are often not properly trained and so are not able to deliver effective coordination and care services in this area. It is strongly felt that staff, if they are tasked with respite care, require additional and specialized training in end-of-life care

In many communities HCC staff (both the HCC Nurses and PSWs) are limited in service provision to Monday- Friday during the days. This means they are not able to be extensively involved in palliative or terminal care after hours although some staff use their work time to assist in the coordination of volunteers and family members. Sometimes staff will cut back on regular service if there is a

high need or a palliative client. Although volunteers are used to assist families, this can be stressful if the need is long term.

There is no doubt that when someone is critically or chronically ill, this quite frequently results in them being medevaced out and they frequently end up staying out for longer periods because the community feels unable to look after them. “Zone Hospital becomes respite care”, as one respondent put it. There is also a need for increased counselling for staff, family and volunteers involved in critical and end-of-life care. It was generally agreed that respite for staff and caregivers might help families cope better with Elders.

“There is very little community respite available. It’s very stressful for the family caregivers” said one respondent. Many times we need a rest. I needed counselling when my in-laws died after 12 years of supporting them in our home with only two one-week breaks. My wife and I needed counselling when they passed. We used traditional counselling with two local Elders. We were deeply exhausted. I was depressed and didn’t recognize it. The Elders stayed with us for 2 weeks, and helped us recover.”

Another operational problem was raised regarding the timely acquisition of equipment for palliative patients. With Health Canada’s Non-Insured Health Benefits approval process, it usually takes 3-4 weeks to get approval and delivery of something like a special mattress to prevent ulcers, but this is not appropriate timeline in palliative care.

The management of medication for Elders was mentioned frequently as a related issue. Most Elders do not wish or are not allowed to have medication in their homes. In some communities, HCC staff may pick up medication for Elders but in others this is not allowed by policy. The issue of medication administration to Elders in all conditions is perceived to be causing an increasing burden on family members, particularly in many palliative situations where medication is required daily.

There is general agreement that enhanced funding to provide after-hours support, skilled respite workers and emotional support for all involved would assist in raising the quality of care for critical Elders and keep Elders at home longer.

### **7.2.2 Physical and Occupational Therapy**

All communities stress the importance of on-site physiotherapy and occupational therapy/rehabilitation care in the provision of successful Elder care at home. There is, however, considerable discrepancy in the physical and occupational therapy programs provided community to community. Some communities are able to provide two-three visits to each community a year by occupational and/or physiotherapists. In one community the HCC program provides 6 weeks of OT/PT on-site visits a year. Some communities are piloting use of video cameras

in patient rehab after surgery or injury. (Please see description below of Tele-rehab)

In some instances, PSWs are trained to assist clients to do the required exercises and when a client returns home from the hospital, the PSWs assist clients to follow the program given to them by the PT. Many communities have no on-site physiotherapy or occupational therapy programs.

Even when there is a program involving on-site visits of physical and/or occupational therapists, the strong opinion of northern health care professional is that these services should be expanded, with a particular emphasis on the need for a whole range of physiotherapy services – visits of professionals, training of staff, rehabilitation care and planning, arthritis management, etc. The lack of physical and rehabilitation therapy were repeatedly stressed as a significant missing link in recovery, rehabilitation and successful living of Elders in their communities.

#### *Assistive Devices Loans*

“Loan cupboards” is a service provided under Home and Community Care and is seen as an essential service in many of the communities. Most “cupboards” have canes, walkers, commode chairs and wheel chairs (not all) for loan to anyone who needs them after surgery or until their own equipment arrives. This service is particularly useful because it may take up to six months to obtain equipment after it is ordered. Gaps described in this service include the need for more and newer equipment.

### **7.2.3 Telemedicine**

Almost all respondents mentioned Telemedicine as performing a valuable tool for Elder support and care in the community. Many indicated that the monthly Telemedicine- originated multi-site Elders gatherings coordinated by Keewaytinook Okimakanak Telemedicine (KOTM) provide effective social and cultural support in that many Elders enjoy them, look forward to them and attend them regularly. These events involve food (at each site), story-telling and exchanges and often the presentation of a health promotion topic. Approximately 50 Elders in up to 10 different communities participate. The most popular of these gatherings is the Christmas telegathering which hosted 26 sites and over 100 Elders in 2008. This kind of innovative event is described as being an ideal way to alleviate the growing isolation and loneliness of some Elders.

The use of video conferencing for individual Elders visits between communities is also seen as a good service, assisting Elders to communicate in their own language with Elders in other communities or when they are in hospital. It was pointed out that the community to hospital video conferenced visits occur less frequently than community to community Elder visits.

Telemedicine was also cited as being useful in some communities to support HCC staff, provide PSW training, do case management review and meet with Health Directors. The KO Home and Community Care Program has been able to certify 13 PSWs since 2005 using a blended video-conferenced/ftf mode of instruction. Of the 300 hours required in a PSW certification course, 99 hours need to be provided face to face. KO provides all 201 other hours by video conferencing.

Telehomecare is being piloted in two homes in two communities. One camera was placed in a palliative Elder's home for over 18 months being used for support and education of staff and family involved. The client was able to visit with relatives in other communities two days before her death. These are pilot projects which are being evaluated by KO Telemedicine.

Four video conference cameras have been purchased by a Tribal Council and have been moved to four communities where a stroke victim lives. Community Telemedicine Coordinators and HCC staff from these four communities have received training about use of the technology from the Stroke Network and others will be trained once there is a client in their community and the equipment is moved to their location. Using this technology, the Stroke Network provides services through video conferencing to patients when they return home to these communities from hospital for six weeks and then in 3- month follow up visits.

#### **7.2.4 Seniors Infrastructure**

Five of the 13 communities interviewed have seniors homes although most of these reported upkeep and maintenance problems with them and a lack of funding to do proper maintenance and repair.

In most facilities of this kind, a small number of the units is occupied by families with no Elder present. This is attributed to the critical housing shortage in all communities as well as Elder integration and infrastructure issues. In one community a six-unit complex was built several years ago but now has no Elders living in it. Problems with building upkeep and maintenance (water supply, heating problems, safety issues, consistent funds for maintenance and repair) led to Elders moving back to their previous homes or to the home of a family member.

Another community built 2 buildings with 4 units each for Elders in 2005, but the Elders were reluctant to move in for awhile considering it "too fancy", unfamiliar and with prohibitively high rent. Some preferred to remain in their own homes even without running water. The community administration needed the income so they finally rented the units to families, some of whom have Elders living with them and some of whom do not. There are about 9-10 Elders in the complex now.

At least one designated seniors facility has now been closed because of lack of funding and underuse and one community is in the process of developing a proposal for such a facility.

In general, however, Health Care professionals and leaders interviewed feel that a seniors facility does or would benefit services for Elders. They consider that homes with 24-hours support are a desirable service goal. Several respondents indicated that another advantage to a seniors home is having a central safe place for Elders to gather, something which is now not available in many communities.

The maintenance of existing seniors homes was cited as a constant problem. Despite problems in maintaining and operating seniors homes, most communities agree that they are required if Elders are to stay at home. “The ideal would be a seniors home with independent units providing a case manager, a full time nurse and a full complement of workers with a well equipped centralized unit where Elders can socialize,” said one respondent.

### *Accessibility*

There remain a significant number of challenges in most communities to try and adapt Elders’ own homes appropriately for their physical and motor needs. Some clients were reported as waiting for ramps for a year or more, for example. In many communities it is the band housing fund that is left to deal with these additions and several respondents pointed out how stretched the band housing budget is already. The band does hire carpenters to build ramps for Elders but sometimes the ramps are not built to specification – they could be slanted or too steep, etc. One respondent said there are not sufficient resources in his program or from band funds to do adequate repairs of other kinds on the houses of Elder clients. Sometimes, for example, there are bedbugs or house mould that they cannot address because of shortage of resources.

There is reportedly a new component within LHINs that supplements funding for housing for adaptability. One Coordinator reported that Elder clients and staff find it impossible to complete the new online forms provided.

## **7.2.5 Mental Health Support**

Although a few communities studied provide counselling services geared to Elders, in general, this was seen as an area where there are few designated services. In one community only, the Home and Community Care Program has engaged an Elders Mental Health Advisor. Nodin Child and Family Services does offer counselling services and support for community mental health staff in the communities but it was strongly felt that the almost exclusive focus of this service is on younger and more critical clients.

There was general agreement that depression, loneliness and even angst are not uncommon among Elders despite their overall strength and resilience and their characteristic resolve to maintain independence which may lead to resistance to admitting a need for help. Elders today are dealing with unprecedented problems with their children and grandchildren and many are called on to be caregivers to grandchildren when parents are not able to do so. Many are grieving over the loss of life of grandchildren and or other younger relatives. One Elder pointed out that all her sons were “still alive” indicating the frequency with which this is not the case.

Repeated mention was made of the new and emerging issue of prescription and other drug abuse in communities and its toll on existing resources and on all segments of society including Elders. This problem is now seen as affecting the ability of families to cope with aging relatives and it is having a pronounced effect on volunteerism, criminal justice, service providers, leadership and many other sectors of the community. Some Elders are seen as being consumed with worry about their families and many of them cannot even speak to their grandchildren because many of the younger ones don't speak the language.

Abuse of Elders was raised several times and is seen as a potentially growing problem should current prescription drug abuse continue to increase. There was little mention made of physical abuse, but there were a significant number of instances reported where Elder relatives are harassed for money, access to debit cards and where stealing is occurring.

Many Elders insist of keeping their independence and refuse help sometime to their detriment. They are also wary of the services when they are presented to them, preferring to keep to their usual customs and rely on family. Similarly Elders may refuse to leave the community to obtain treatment unless accompanied by an escort which, at times, can be problematic given Non-Insured Health regulations and protocols.

## **7.2.6 Diabetes Support and Prevention**

Some communities have been more successful than others in supporting diabetes control and awareness among Elders. For example, in a few communities HCC and other Health workers are teaching Elders to monitor their sugar levels, promoting diabetes prevention awareness and maintaining a relationship with the Sioux lookout Diabetes program (through CHRs). Nutritionist visits to communities to work with Elders are seen to be very effective provided there is good interpretation. (For further data on the gaps and services for Elder diabetes see Section 5.4.1).

As with other much other health promotion and treatment support in the communities, however, much of the focus of both local and visiting diabetes staff is on younger patients. Few communities, even those with well developed

diabetes programs, have diabetes education and prevention programs geared specifically at Elders. For example, there are walking/exercise programs in a number of communities but none of these is geared specifically to Elders. Lack of exercise was mentioned a number of times as a growing problem with all ages of Elders.

There is general agreement that not giving Elders priority for nutrition and lifestyle education when they have diabetes in turn is responsible for the number of complications arising from the disease among Elders. One community studied has received regular visits from a pharmacist to visit elder and other diabetes clients to explain their medication, need for regular use, side effect ,etc, which has been described as useful for those Elders who often forget to take their medication.

#### *Meals on Wheels/Nutrition*

Although many Elders continue to consume traditional foods, it is felt that there are many others who do not have access to these foods regularly, who eat poorly, who have limited access to nutrition education and little money to afford a range of fresh and nutritious foods. No communities studied have any kind of organized Meals on Wheels programs for the sick and Elderly although a few have informal congregate dining programs and all have periodic feasts and meals geared specifically to Elders.

A majority of health care professionals interviewed felt that a Meals on Wheels program would fill an important service gap, particularly on a temporary basis when family caregivers are away or ill or during recovery and rehab, etc, but also to ensure a minimum standard of regular nutritious food daily. It would be especially effective if such a program could include traditional foods. Some of the reasons cited for the lack of development of these program included inability to meet provincial standards for food preparation and congregate dining, no facilities to prepare and serve meals that would meet provincial standards and lack of enough resources to fund this service along with others that are more pressing priorities.

#### *Foot Care*

Foot care screening, assessment and treatment is now offered or partially offered in approximately half of the communities studied. It is thought to be an increasingly important service for Elders but as one respondent said “no one wants to fund it”. It is an allowable service under the Community Support Services program, but it is felt that there e are too many other demands of the resources in this program to fund this service. Home and Community Care programs allocate funds to training PSWs in this area who then may offer the services provided they are supervised by a nurse. However, the level of services able to be provided at present falls far short of what is needed given the prevalence of diabetes and the necessity for foot care for this condition.



### **7.2.7 Transportation**

Some home care/support programs have vehicles for transportation of staff and clients but most do not. Almost everyone agreed that transportation of Elders is a critical service issue that is often not able to be filled except by family members and friends. As well, staff feel they would be more effective if they had a program vehicle to take them from house to house. In communities that are spread out or in separate locations, Elders find it difficult to find transportation to do essential shopping, like for groceries and other necessities. It is incumbent on staff to drive clients in their own vehicle for which there is no insurance.

Some health programs have access to the medical transportation vehicles to transport Elders to events or to do groceries, etc, but this is difficult because the medical vehicles are required for appointments and other related transportation. Sometimes HCC programs used band-vehicles but this too is problematic in that band activities supersede. If they are using another program's vehicle and lose it, home support workers may phone the client instead of visiting resulting in a reduction of service.

### **7.2.8 Communications Services**

The need for appropriate communications services came up numerous times as an issue when Elders interface with care givers who do not speak their language. This is an issue when dealing with physicians or nurses who are not fluent in the language of the community, but interpretation services are usually provided for clinical interventions. Because of language barriers in the evenings, however, Elders are reluctant to call the Nursing Station afterhours and this delay can lead to more serious problems and complications. There is a barrier between the Elder and the worker when they do not speak the same language, a situation which can have a deleterious impact on the services provided.

Several respondents indicated that amount of forms and paper work Elders may be required to fill out most often impossible unless family members are available to do so. Because many Elders are not fluent in writing or reading in English this can be a huge challenge. Some Home Care staff attempt to fill this role but this is not cost effective and is a tax on valuable time and most claim they do not have the time to provide this service.

### **7.2.9 Recreation and Social**

Almost all respondents said the Elder-specific events geared to health promotion, socializing and feasting were very popular with Elders and an important supportive service for Elders and their families. Examples given were teas, feasts, craft and woodworking sessions and the monthly inter-community Telemedicine

gatherings described above (7.2.9) . Christmas feasting for Elders is the practice in some communities.

There was mention made several times, as well, about craft production as an important income source for some Elders. Those communities which organize the selling of the crafts contribute significantly to Elder income in this way.

Almost all health care personnel stressed the need for more such activities for Elders, many of whom experience increasing loneliness and isolation as their families are working more and lifestyles and norms change in the north. More activities in the common rooms of seniors complexes would be beneficial, as an example, regular organized sewing sessions. One respondent said that when the Elders first moved into the seniors complex in their community, they mainly slept all day because there was nothing for them to do. There is strong opinion that Elders require more and more organized social, recreational and nutritional activities but that there is not time to coordinate this type of activity by staff in the existing home care and support programs.

#### *Home visits*

Some respondents felt that staff should be assigned to visit all Elders on a frequent and regular basis, particularly those who are alone or in couples, alone. This should apply to all Elders in the community whether or not they are HCC or Home Support clients. Changing work and lifestyles in the community mean that not all families have time to monitor and take care of their Elder relatives. Often both members of a couple are working. Community nursing staff still make home visits a priority but tend to have the time to visit chronic or seriously ill patients only.

## 7.3 SERVICE ISSUES

Training, resource limitations and coordination of services are thematic areas raised during the interviews with community health care professionals. These three were raised the most often as issues affecting the quality of service for Elders in the communities. The findings from interviews are presented below.

### 7.3.1 Training

There are notable instances of communities where all or most home care and support staff are certified. In general, more workers are certified as PSWs or are in training for certification in the Home and Community Care Program than in the Home Support Program where very few staff are certified as PSWs although many have First Aid and CPR training. One Tribal Council which coordinates Home and Community Care for five communities has accomplished the training of PSWs by video conferencing, a cost-effective method of providing a critical mass of trained workers and also used in in-service training, orientation and team-

building. (Further described in 7.2.3) By comparison, another Tribal Council HCC Unit does all their training in person and has organized five 2-week sessions in Sioux Lookout for a recent course.

In other communities training of PSWs has been provided in a larger community by the HCC Nurse (on contract) using the curriculum, test materials and certificates from the Ontario Community Support Association (OCSA). A number of PSWs and CHRs have now received foot care training.

One Home and Community Care Coordinator stressed the importance of certification and training to achieve quality of service. She herself is a graduate of a college PSW program and felt that the five-day placement she had in a Nursing Home in Thunder Bay while on placement with the program was “the best preparation and training” she has ever had for her job.

The lack of PSW certification and specific (palliative, respite, dialysis, client lifting) skills acquisition were cited many times as a critical gap in the capacity to provide more effective services to Elders. When communities hire new staff with no training, they aren't able to do hands-on work with clients until they have been trained. This means significant delays in service provision thus leaving families without needed support and sometimes delaying the return of clients from the hospital.

College programs do not always work because many of the PSWs do not have Grade 12 and may not be able to leave the community. Some PSWs have done the first part of the PSW training (Personal Attendant training) by Distance Ed with Confederation College.

There is no funding specifically identified for PSW and other specialized training. In one community funds may be able to be designated for this purpose; in another the money has to go to other pressing priorities. One program reported being able to do training only if there was a year-end surplus. While many key informants stressed the importance of providing PSW and other training, they also indicated that providing this training uses limited program resources (See Resource Limitations below, 7.3.2). Palliative/respite care training is seen as an essential need for workers although there aren't enough of these workers in place and they don't work after-hours in order to really fill that need. Concerns were also expressed about the ongoing and critical need for First Aid, First Response and other kinds of safety training, e.g. proper preparing of firewood

### **7.3.2 Resource Limitations**

A significant number of respondents spoke about the limited resources available to provide the programs/staff needed for the number of clients serviced in the communities, particularly in the Home and Community Care Program. Some of the resource limitation problems raised were cramped and inadequate office

space; office space that is not accessible; need for more staff and staff training; more Home Care Nurse time in the communities; waiting lists to receive service; inability to provide after hour service, additional trained respite staff; inadequate housing for Home Care Nurses; inability to do all required house repairs and accessibility construction in Elders' own homes. There may be additional program dollars to assist with some of these gaps but it is difficult for coordinators to find time to complete all the proposals and often the time frame in which to submit these proposals is considered too short.

Getting and dealing with wood was raised numerous times as a problem Elders in some communities. Certain communities are able to cover the costs of getting and processing wood while in other communities this is not done. This gap may occur primarily where Elders are living with family who are considered physically able to provide wood and so Home Support does not provide that service. Several incidents where Elders injured themselves bringing in wood were noted. There may be additional programs to assist with services but it is difficult to find time to complete the proposals and often the time frame in which to submit these is far too short.

Almost all Elders are on a fixed income (\$600-\$900 a month) which often presents personal shortfalls particularly toward the end of the month. Some HCC programs set aside contingency funds to use when emergency supplies are required which Elders cannot afford including dressing supplies or other necessities. Several respondents mentioned that Elders can run out of food before the end of the month. Some staff try to help from their own pockets.

There is no doubt that Elders do "fall through the cracks" because of service gaps. One community staff person spoke about an Elder in a wheelchair who burned himself with boiling water and it took this incident for him to get on as a HCC client where there was a waiting list.

### **7.3.3 Coordination of Services**

Issues related to the coordination of services on the ground and in funding protocols were repeatedly raised during the study.

Some communities combine funding from the two home support and one home care programs and coordinate them through their local health authority. Others separate the home support funding and administer those services through the Band, often through the welfare office, and administer the federal HCC program through their local health authority. In still other cases, tribal councils have some involvement in the coordination, training and implementation of the programs.

Communities where there is coordinated programming (e.g. Home and Community Care and Community Support/Homemaking operating together) are seen to work better because "people have less change of falling through the

cracks”. There is a strong body of opinion among providers that centralization (Tribal Council level) and/or coordination at the community level does contribute to improved services and doing more for the money allocated. It is better for the Elder client if there is one call to be made for help instead of two or three. In fact, most Elders call the same number for help no matter what the need and they do not usually distinguish between the programs. Joint Case management is done in a few communities and this is judged a more effective approach to service provision and an important means of preventing overlapping.

Some services are housed in different locations in the community. In one community, Home and Community Care operates from an office in the seniors complex, the Health Services office is in another building and there are some staff who provide services to Elders -like the Diabetes Coordinator and the CHR - in the Nursing Station.

Even when home-based programs operate independently of each other, coordination among the programs and caregivers is essential given limited resources and a high demand for services.

Table 14 illustrates two tribal council- based coordinated models of home care delivery. The table compares Windigo Tribal Council and Keewaytinook Okimakanak’s approach to service coordination in their communities. In Windigo’s case HCC services to four FN communities are coordinated out of the tribal council in Sioux Lookout with home support services remaining a band responsibility. In KO’s case, both the provincial Community Support Service program and the federal HCC program are coordinated for five communities through the tribal council office in Balmertown.

**Table 14: Two tribal council based home care models**

	<b>Windigo Tribal Council</b>	<b>Keewaytinook-Okimakanak</b>
	<i>Home &amp; Community Care Program</i>	<i>Home &amp; Community Care and Home &amp; Community Support Services</i>
Administration & Operation	<ul style="list-style-type: none"> <li>▪ TC employs a Nurse Manager to manage programs in 4 (of 5) communities; 2 trained PSWs in each community. PSWs are TC staff who report to Nurse Mgr.</li> <li>▪ Nurse manager organizes PSW training through Ontario Community Support Association (OCSA) – open to district.</li> <li>▪ 1 community takes its share of funding and provides its own services.</li> </ul>	<ul style="list-style-type: none"> <li>▪ HCC Nurse Supervisor in TC supervises staff in 5 communities: skills, training, education. HDs supervise day-to-day.</li> <li>▪ Each of 4 communities have a full time (F-T) coordinator/PSW plus a P-T PSW; 1 community has F-T coordinator, F-T PSW plus P-T respite worker all under HCC.</li> <li>▪ 4 of a total staff of 11 are trained PSWs.</li> </ul>
Nursing Services	<ul style="list-style-type: none"> <li>▪ 2 Home Care Registered Nurses on contract provide support to PSWs; report to Nurse Manager. They do detailed patient assessment &amp; case management 3 days/month, 10 months/yr.</li> </ul>	<ul style="list-style-type: none"> <li>▪ 3 nurses: a supervisor, an RN &amp; an RPN (P-T funded by LHIN)</li> <li>▪ Nurses travel north once a month for 2-4 days depending on need</li> </ul>
Additional Services	<ul style="list-style-type: none"> <li>▪ Physio – 1 trip/yr per community</li> <li>▪ Loans Cupboard – equipment on loan to clients until their own arrives</li> <li>▪ Some congregate dining from different funding source (LHIN)</li> </ul>	
Funding	<ul style="list-style-type: none"> <li>▪ Federally funded with some congregate dining funding from LHIN (provincial)</li> </ul>	<ul style="list-style-type: none"> <li>▪ HCC funding from Health Canada and LHIN funding for HCSS goes through TC; Homemakers (HNSA) funding goes to communities</li> </ul>

...continued

**Table 14: Two tribal council based home care models (continued)**

	<b>Windigo Tribal Council</b>	<b>Keewatinook-Okimakanak</b>
	<i>Home &amp; Community Care Program</i>	<i>Home &amp; Community Care and Home &amp; Community Support Services</i>
Advantages	<ul style="list-style-type: none"> <li>▪ Centralized coordinated programming for Elders in terms of personal care and support</li> <li>▪ Band Councils may prefer to control home support services (HCSS &amp; HNSA services). This model keeps that support within Band</li> </ul>	<ul style="list-style-type: none"> <li>▪ Communities delegate coordination through TC.</li> <li>▪ In 2 communities HCC Coordinator supervises HCSS and HNSA, i.e. coordinates all client services (requires BCR to include homemakers). Better scheduling; client gets full benefit of services available</li> <li>▪ Extensive cost sharing possible with 2 programs for 5 communities managed through TC office</li> <li>▪ Government would like HCC Nurse to do case management for all 3 programs.</li> </ul>
Drawbacks	<ul style="list-style-type: none"> <li>▪ Services may overlap with Home Support (HCSS).</li> <li>▪ No service coordination or formal connection between HCC &amp; Band.</li> <li>▪ Health Office usually houses the HCSS programs apart from Nursing Station. Best if close or in same building.</li> </ul>	

## 7.4 ELDERS' FEEDBACK

### 7.4.1 Overview

All Elders interviewed individually in the course of this research indicated an awareness of home-based services available to them in their communities. Many indicated a parallel desire not to rely on community services, preferring to be independent for as long as possible. These individuals noted they don't require many services because of family support or because they are still strong themselves.

The majority of Elders interviewed receive home care and home support services in their communities and most were satisfied with the frequency and range of

services provided. A minority felt they required more home support than they received including one Elder who stated they have to “beg for services”, claiming he and his wife have to phone “maybe 10 times” before they get someone to help them.

All of the recipients getting home care or support receive help with wood although this may or may not be free. One Elder who lives with his two sons receives house cleaning daily Monday to Friday, but most Elders receive home support once or twice a week only. One Elderly couple appreciated the house cleaning and outdoor work they receive, including wood chopping and stacking indoors (for which they do not have to pay). They also receive weekly assistance with grocery shopping transportation (for which they pay), but expressed that it would be helpful to have support with their laundry. One Elder responded, “I’m happy with the type of support I get.” She noted she had no complaints about the service but it would be good if there could be overnight and weekend coverage. This individual received weekly help with bathing and personal care and expressed that it was good for her spirits.

About one-quarter of Elders do not use any home support or home care services in their communities and are content with that situation. One Elder and several Elder care workers noted that there are some “stubborn people” (the Elder’s words) who refuse assistance even though they may need it.

All but two of the Elder respondents reported relatively easy access to transportation for nursing station appointments. A few Elders are still able to drive themselves by skidoo or car (not always with a license), some are transported by family members if they have a vehicle, but most who require transportation are able to access a nursing station van and driver. Not all nursing stations have the capacity to transport HCC clients however. In some cases, the home support or home care service provides transportation but the study team frequently heard of vehicle shortages. In the case of the two Elders, a couple, who don’t have easy access to transportation, they responded, “we are on our own in this small community.”

### *Challenges*

Elders interviewed were generally coping and many are vital and in charge of their lives. They were able to articulate their health and life challenges, however, and had a keen sense of present and future obstacles facing them and their families.

Many Elders described their health challenges: one woman in hospital noted her main concern is to get well and go home. Another Elder described his determination to walk again after his lower leg was amputated. He expressed the need to be very single minded and positive. He refused to return home until he could walk off the plane himself – which he did successfully four months after



surgery. Some caregivers spoke about Elders reaching a point when they had to leave their communities stressing the pain for everyone involved.

Numerous Elders mentioned loneliness and grieving. Several mentioned the death of a spouse, siblings or children, one noting that she sleeps a lot more now. One couple is suffering the loss of five children, two due to suicide. The woman noted that she seeks comfort in the bush – if she stays home, she “cries all the time”. This couple has sought counselling from a mental health worker, a medicine man, sweat lodges, and church leaders and noted these have all helped somewhat. Another mother who had several sons suffer from sexual abuse has not found easy access to counselling. Another Elder confided that the most difficult thing is feeling helpless and discouraged when seeing children and grandchildren do negative things or become involved with alcohol and drugs. One spoke of a decreased sense of family unity leading to poor mental and spiritual health for Elders.

Some Elders noted that when they are sad, depressed, or feeling isolated, there is no counselling system for them. They do not consider it acceptable to be counselling young non-Native doctors who don't know the language and don't understand their background and may tend to prescribe anti-depressants inappropriately. One couple in their early 60's noted that dealing with Elders is a specialized field and should be treated as such.

One Elder noted that she worries when her groceries or wood start to run out. Shopping was noted several times by Elders as a challenge.

Many Elders referred to financial challenges and the fact that it's tight covering expenses on their pensions, especially if they pay for wood (almost \$700/month for one couple). One Elder lamented not being able to give money to her grandchildren. At 79 years of age, she has 32 grandchildren and 40 great-grandchildren. It's also expensive for Elders to feed themselves. Some of the Elders who used to fish and trap mentioned that the price of gas is prohibitive these days.

One Elder expressed regret that a speech difficulty has meant that grandchildren don't come to visit like they used to – they get frustrated and it is upsetting for both parties when they can't communicate.

Heating with wood is a necessity in most homes in the north. Paying for that service from a modest pension is cost prohibitive. For Elders who do not have substantial family support, the process of buying wood and paying for it to be split and brought into the home is significant. Even just the task of keeping the woodstove filled can be a demanding task for a senior. The study team spoke with several Elders who had burned themselves while stoking the woodstove and one who was hospitalized for breaking a leg while bringing wood indoors in the middle of the night.

Some communities totally support Elders in supplying wood at no charge ready to burn in the home interior; other communities deliver wood unchopped to the seniors' door; while still others, a significant number, charge seniors for wood. Many Elders referred to the difficulty of making ends meet in the winter. Some noted that Elders purchase green wood because it is less expensive even if it does not burn well. Elders and their caregivers recommended that wood be a free service

### *Elders' Advice*

Elders, in general, are content with and grateful for the services they receive in their communities; however, many Elders and their caregivers and relatives gave suggestions for improvement to community-based services. Below are some of their suggestions and advice.

### *Home Support and Home Care*

Some suggested that a supplementary source of heating would keep Elders in their homes longer and there is a growing need to assist Elders more with the entire process of heating their homes.

Ramps, railings, panic bars in bathrooms, etc. all need upgrading in Elders' individual homes. One Elder described a home with no ramp, steep steps and no railings leading into her home and her husband has poor eyesight. She herself has had a hip replacement and numerous other health problems leading to mobility issues.

There is a need for more home-maker services and more trained workers. It is important to provide proper orientation for all workers who work with Elders, especially for relief staff. Home care and support staff should be evaluated regularly and clients should be involved in their evaluation.

Elders like to eat traditional food and some of them are not eating properly. It would be good to have a central place where they could live and eat communally or even just a place for them to go for one meal a day. Meals on wheels or some food preparation by home support workers would be helpful especially when family members are away or busy. Few Elders reported that they receive help with meals.

One couple reported they needed "more training regarding our diabetes". They suggested diabetic Elders seem to be forgotten. Training, orientation around exercise and eating and support for depression are all needed. This sentiment was echoed by numerous others. Another couple noted there is not nearly enough education for Elders available in the community for healthy living and lifestyle particularly around food, exercise and spirituality, especially healing. One woman explained that the most helpful thing when she was caring for her two aged

parents was a training session that demonstrated how to move them and how to deal with dementia.

Elders need to spend time in the bush – it raises their spirits and helps them heal. “Some people think healing is down here (in Sioux Lookout), but healing is right here where we are. It’s how you approach it,” noted one Elder.

In one community, a boil water order is in effect. This adds an extra workload on Elders of water purchase or water hauling a substantial distance. In these communities, water should be provided to Elders. Several Elders mentioned a preference for lake water but stressed the difficulty of hauling it home. One woman called the tap water, “Javex water”.

There is a need for respite care, especially in the evenings and weekends to give caregivers a break. It needs to be someone Elders can trust. Some relief workers don’t know what they are supposed to do - this is stressful for senior clients.

Elder support and preparation for appointments is sometimes a service gap particularly for Elders who live alone or in couples, alone. Often no one is telling them when to go, what to expect, what questions to ask, etc.

In one community, a band employee delivers medications to Elders under the nurses’ supervision but it is not safe for them to have medication in their homes. One Elder noted that young people come looking for drugs. Some Elders have had their medication stolen. Others don’t take the medications they should.

PSWs need to be fluent in the language. Communication is a key element in good care and is often overlooked.

Foot care is very good in some communities and sporadic in others. The daughter of one diabetic Elder recounted an injury her mother recently received cutting her foot while trying to trim her toenails. Foot care is not a regular service in her community. It should be given a high priority for service.

Some Elders responded that staff need to advocate for Elders, explain their needs to nurses and doctors, etc., think of the clients as their “boss”. One Elder stated that no one is explaining to health care professionals what Elders need and why they say what they say. In some communities, Elders need protection from family members. They need an option to live on their own in a seniors home, away from those relatives.

There is no physiotherapy available for some Elders who need help with exercises which are difficult to do with circulation problems and disabilities.

### *Mental Health*

Elder counsellors, advisers designated for Elders, are required. Elders require support for their emotional and mental health needs and these are not available. Generally, they will relate to older counselors.

Elders expressed an interest in being involved as community leaders and helping pass on to young people their important values and traditions. When Elders have this passion, it helps them to live well and stay healthy - they must feel as if their values, experiences and skills count.

There needs to be forgiveness for old wrongs and problems and real efforts made to blend Christian and traditional systems.

### *Infrastructure*

Increased and enhanced Elders housing on reserve was a frequently repeated suggestion by Elders and caregivers. However, some Elders expressed concern that separate Elder accommodation might divide Elders from family members too much and relatives might not help them anymore.

A suggestion recounted repeatedly by Elders and northern health care professionals was for nursing homes to be built in the north with dedicated nursing and PSW services. It was suggested that there are many Elders who could remain in their communities with this extra service. In many cases, families would stay involved but would be relieved of the 24/7 responsibilities, which are sometimes unsustainable. Community volunteers would find it easier, too, to support Elders who were centrally located.

## 8.0 KEY ISSUES AND NEXT STEPS

### 8.1 FURTHER STUDY

There is little data available concerning First Nations Elders' health in general and even less in the Sioux Lookout District communities and the scope of this report did not allow for the collection of accurate community by community demographic, health status and services data. This report presents a "snap shot", but it is first stage information only, hopefully leading the way to further study to provide detailed and accurate information about this population, their health status and service issues. This report does raise a number of questions that could be pursued further to better understand and plan for the health and care requirements of Elders.

### 8.2 HEALTH CHALLENGES OF ELDERS

It is evident that there is a marked increase in chronic disease in the north, the result of which will be that Elders in the future will require much more care than their predecessors, particularly if they are going to stay in their home communities. While the number of Elders still represents a smaller than expected percentage of the overall population, as the younger population ages, this percentage will increase dramatically, meaning that in coming decades Elders could constitute a significant proportion of the total population. Further in-depth analysis of how the health care system continuum will be able to respond to the needs of Elders both now and in the future is a critical next step.

Arthritis, diabetes cancer and mental health illness are illnesses that present a high risk for all persons in the north. All are potentially debilitating if not treated, and treated early. The data suggest, for example, that the health care system for Elders may face insurmountable challenges if diabetes cannot be controlled not only in Elders but also in young people who will one day be Elders. It could become increasingly difficult to keep Elders living in their communities regardless of the services available to them.

As another example, the pervasiveness of grief and perhaps depression in the lives of Elders was noted in the interviews. Repeated mention was also made of the new and emerging issue of prescription and other drugs abuse in the communities and its toll on existing resources and on all segments of society including Elders. Some Elders are consumed with worry about their families. and experience helplessness in the face of these new and troubling issues. Elder abuse is seen as potentially growing problem related to drug abuse.

Because of the high proportion of younger people on reserve and the seriousness of their health and related problems, Elders may be overlooked in treatment and

program protocols. This was repeatedly mentioned with regard to issues such as diabetes management and prevention education and with mental health issues.

### 8.3 ELDER'S HOUSING

It is recommended to do further analysis of housing needs for Elders in the north. Less than half of the communities have seniors housing and those that do struggle with operational, maintenance and programming challenges. Elders and their families do use the housing for the most part when it exists, but lack of resources plagues the operation of these facilities. There are some communities (e.g. Lac Seul and Wunnumin Lake) where seniors' complexes appear to be working well and these should be examined in more depth for the lessons to be learned for other similar communities in the district.

Evidence of the increasing problem of Elder accommodation in home community is the waiting list for extended care services at Meno Ya Win Health Centre in Sioux Lookout. The waiting list for admission to the extended care facility is the longest in the region. There are also problems with northern Elders and families understanding the application process and dealing with a number of form-filling requirements. PSW's and nursing in the north do not have the time or mandate to assist clients with the application process and there is no designated staff in communities to work with families and Elders on these issues.

### 8.4 SERVICE STANDARDS AND COORDINATION

While there is a reasonable range of services provided to Elders in the north, these are funded by three separate provincial and federal programs with no formal coordination among funding agencies and delivery mechanisms. Problems of integration are significant and include disparity in funding and salary levels, complex and different reporting mechanisms, duplication of mandates, lack of sharing of client information, etc. Many examples emerged of discrepancies from community to community, for example, palliative care and support; provision of physical and occupational therapy; foot care, and seniorshousing facilities.

It would be beneficial to look more closely at those models of service delivery that are coordinated at a Tribal Council level to investigate scalability. This should suggest ways in which the funding programs for Elders could be better coordinated to offer more consistent services and programs. Communities where there are coordinated programs are seen to work better because 'people have less change of falling through the cracks' and Elders are given "one-stop" service. There is also value in examining working partnerships (Windigo and KO Tribal Council) which purchase services collectively such as physiotherapy and foot care. Examples of unique solutions emerged during the study which could be further examined, for example, Weagamow Lake First Nation has developed their

own facility and service protocol for palliative care making good use of volunteers to support staff.

## 8.5 GAPS AND RESOURCES

Gaps and inconsistencies in services to Elders emerged as a theme in this Scan. While there is general satisfaction and support for programs, particularly Home and Community Care, Elders and Caregivers did repeatedly cite certain key deficits in the areas of: staff certification and training, physiotherapy and occupation therapy, and the development, operations and, maintenance of Elders housing. Elders appear to be most concerned about adequate wood supply and survival on limited fixed incomes given the high cost of food and fuel in the north. The failure of the health care system to address problems such as travel costs for those requiring physiotherapy for arthritis, education for newly diagnosed diabetes and adequate respite and palliative care were pointed out during this study. As mentioned above, it appears as if some communities/Tribal Council areas have made progress toward meeting these gaps and it is recommended that these be looked at more closely, but the overall issue of the seeming inadequate resourcing of some of these services needs to be taken into consideration.

Elders repeatedly stressed their desire to be in their home community (or at least close to it in Sioux Lookout). This is problematic and may become increasingly difficult given the inconsistent and sometimes insufficient services required to keep Elders at home. The consensus is that home support programs do help Elders to stay at home and Elders generally praised the services they do receive, but concerns were raised such as inadequate office space, Home and Community Nurse time in communities, need for after hours and respite services, and accessibility of Elders' own homes, as well as others mentioned. Many services are eligible within federal or provincial program guidelines but are not affordable given amount of resources and dispersed nature of the communities and populations. The ability of the communities to provide the services necessary to keep Elders at home will be more problematic in the future.

## 8.6 STAFF CERTIFICATION

There is a considerable difference in the educational levels of staff involved in Elder care and support in the communities. The lack of PSW certification and specific skills acquisition (palliative care, dialysis, language skills, patient advocacy, quality control and excellence) were cited as a critical factor in the capacity to provide more effective services to Elders. Approaches to training of Personal Support Workers are fragmented and there is no designated funding provided to train existing staff. It would make sense to look at models adapted by communities or groups of communities that have made the most progress in this area, in particular, the use made of distance/video training by the KO Tribal Council.

## 9.0 APPENDIX

### 9.1 ADDITIONAL TABLES

*Appendix Table 1: Frequency of main admission diagnosis for patients 60 years and over at Meno Ya Win by illness category 2004-2008*

Illness Category	2004	2005	2006	2007	2008	Total
Infections	7	6	4	3	6	26
Cancer	7	3	2	4	3	19
Neoplasms, Diseases of blood, Immune system Spleen	8	6	5	3	2	24
Endocrine and metabolic (excluding diabetes)	12	9	8	4	7	40
Diabetes	5	7	9	12	2	35
Mental Disorders	7	2	4	6	5	24
Nervous System	8	12	8	1	2	31
Eyes, Ears	0	0	0	0	1	1
Circulatory System	55	51	44	33	40	223
Respiratory System	44	53	33	38	41	209
Digestive System	36	29	29	14	22	130
Skin	6	9	4	4	3	26
Musculoskeletal	12	11	4	10	9	46



<b>Illness Category</b>	<b>2004</b>	<b>2005</b>	<b>2006</b>	<b>2007</b>	<b>2008</b>	<b>Total</b>
Genitourinary	16	15	20	7	20	78
Congenital Malformation						
Symptoms and signs involving circulatory and respiratory system	44	33	43	24	21	165
Injury, poisoning, consequence of external causes	12	15	8	13	8	56
Provisional Codes (research/temp assignment)						61*
External Cause of morbidity and mortality						115*
Factors influencing health status and contact with H/s investigations etc		42	30	33	33	138

\*These categories did not appear as Main Diagnosis. Total secondary/co-morbid diagnosis is noted here.

## 9.2 RESEARCH INSTRUMENTS

The following research instruments are attached in this appendix for reference:

- Letter to Chiefs
- Description of study for Chiefs
- Elders' Questionnaire
- Elders' Council Questionnaire
- Interview Guide for Community Health Professionals

## **Florence Woolner and Associates**

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March 9, 2009

Dear Chief:

I am writing to introduce you to the research team of Florence Woolner and Associates and to request your support for the study that we have been asked to complete for the Sioux Lookout Meno Ya Win Health Centre. Florence Woolner, Joyce Timpson, Lois Mombourquette and I will be carrying out an *Elder Care Continuum Scan* for the First Nations of the Sioux Lookout District. The purpose of the scan is to gather information about Elders, and their care needs. The study will identify gaps in care that make it difficult for some Elders to remain living in their communities and make recommendations for filling these gaps.

The Study should be completed by the end of April and the results and data will be made available to Chiefs and Councils of the First Nations of the Sioux Lookout District. The study will also be reviewed and input received by the Meno Ya Win Elders Council.

Please do not hesitate to get in touch with Florence or any of the research team if you have any questions or concerns or if you would like us to interview anyone in particular in your community about this study. We hope to interview you or the Councillor responsible for health and/or social services as well as the Health Director and the home support staff in the course of the research for the study. We will be speaking with Tribal Council staff as well.

You will find attached, a description of our study and an outline of how we plan to conduct it. Contact information for the research team is found below.

Sincerely

Laurel Wood, Research Associate

### **Florence Woolner and Associates Research Team:**

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## **Meno Ya Win Elder Care Review**

**March 2009**

Because 65% of inpatients at the Sioux Lookout Meno Ya Win Health Centre are Elders, the hospital is trying to understand what community level services can help Elders live at home longer. This is part of a provincial “Aging at Home Strategy” for which the Health Centre would like to develop an Elder Care Continuum that applies to First Nations in the North.

Little information is available about First Nations Elders in the Sioux Lookout District. In order to get a clear picture, Meno Ya Win is conducting a study of Elders in the District First Nations to gain answers to questions such as:

- How many Elders live in the northern communities and what is their health status?
- What level of dependence or independence do the Elders have?
- What services exist now for Elders in communities and how much do the Elders or their family members use these services?
- What services are not available in the north or need improvement?
- What challenges do Elders and their families face?

The study will also propose partnerships and strategies to address these challenges.

Meno Ya Win has hired Florence Woolner and Associates consisting of Florence Woolner, Laurel Wood, Lois Mombourquette and Joyce Timpson to undertake this research. With the communities’ permission, Florence and her team hope to interview key stakeholders at the tribal council and community level such as political leaders, health care personnel, service providers, Elders and their families. The research team will employ a variety of approaches including telephone and face-to-face interviews, videoconferencing and statistical research.

## **ELDERS' QUESTIONNAIRE**

Introduction and explanation

May I know your date of birth?

Where Interviewed: (home, 'A' ward, etc)

Community:

Health problem:

### **LEVEL OF INDEPENDENCE**

1. Are you living in:
  - your own house in the community?
  - A Senior's Apartment?
  - A relative's house?
  - Other – state (hospital etc)
2. Would you prefer to live somewhere else?
3. If so, where would you prefer to be?
4. What extra help would be needed for you to live there?

### **SERVICES AND UPTAKE**

5. Are you aware of services that are for Elders only in your community?
6. What services that are only for elders do you use ?
7. In each case, is this service provided enough times per week/month etc? How often should it be provided?
8. Is there a transportation service to get people to the Health clinic? Do you use it? If not, why not and how do you get to the Health Clinic for appointments?

### **IMPROVEMENTS AND OTHER SERVICES NEEDED**

9. How else can the services that you are receiving be improved?
10. What services are not available that you think should be available?
11. If you live with relatives, what extra help do you think they need?

### **CHALLENGES**

12. What is the most difficult thing that elders face today?
13. If you were in charge of services for Elders, what would you require happen?

## **ELDERS' QUESTIONNAIRE for ELDERS COUNCIL MEMBERS**

May I know your date of birth?

Where Interviewed: (home, 'A' ward, etc)

Community:

Health problem?:

### **LEVEL OF INDEPENDENCE**

1. Are you living in:
  - your own house in the community?
  - A Senior's Apartment?
  - A relative's house?
  - Other – state (hospital etc)
2. Would you prefer to live somewhere else?
3. If so, where would you prefer to be?
4. What extra help would be needed for you to live there?

### **SERVICES AND UPTAKE**

5. Are you aware of services that are for Elders only in your community?
6. What services that are only for elders do you use?
7. In each case, is this service provided enough times per week/month etc? How often should it be provided?
8. Is there a transportation service to get people to the Health clinic? Is it used? If not, why not and how do elders get to the Health Clinic for appointments?

### **IMPROVEMENTS AND OTHER SERVICES NEEDED**

9. How else can the services that elders are receiving be improved?
10. What services are not available that you think should be available?
11. For elders who live with relatives, what extra help do you think the relatives need?

### **CHALLENGES**

12. What is the most difficult thing that elders face today?
13. If you were in charge of services for Elders, what would you require happen?

## INTERVIEW GUIDE FOR COMMUNITY HEALTH PROFESSIONALS

(Health Directors, Home Care Coordinators and staff, Nurses, CHR's)

My name is \_\_\_\_\_. I am a part of a research team hired by Menoyawin Health Centre to find out about Elders and their health care status and needs in the First Nations in the Sioux Lookout District. We have informed the Chief and Council about this study and have indicated to the Chief and Council that the information we gather will be shared with them, Health Directors and with the Menoyawin Elders Council. Menoyawin is interested in learning more about Elders' needs because more than half of their patients are Elders. Menoyawin plans to work with other stakeholders in the area of Elder care in the District and province to improve services for Elders in the communities and the District. This is part of an *Aging At Home Strategy* that Menoyawin is involved in.

1. We know there are services and programs available to assist Elders and their care-givers in your community(ies). When you think about those services, which ones work best for the Elders in your community(ies)? Why do they work well?
2. Are there problems with Elders using certain services or programs and if so what are the problems?
3. What programs or services are not available or used in your community that would be helpful for Elders or their care givers?
4. Could you give us your suggestions for improving services or programs in your community?

We have found that there is not much up-to-date information available about Elders and their health status in the communities. We are wondering if you can help us find out this information yourself or by telling us how we might find it out in your community (ies).

5. Optional: How many persons are in your community who are age 65 and over?
6. Optional: How many persons over the age of 80 are in your community (ies)?
7. How many person 65 and older are -
  - a. Living alone (Living without a spouse)
  - b. Living with a spouse/partner
  - c. Living with a relative (s)
8. How can we determine how many persons 65 or over are able to walk without a walker or wheelchair in your community (ies)? For those Elders who are not mobile, can you say how many of their homes are fitted with ramps, handle bars etc to make getting around easier?

9. How many Elders (age 65 and over) suffer from the following illnesses:
  - Diabetes and complications
  - Tuberculosis and complications
  - Mental illness such as depression, schizophrenia
  - Cancer
10. Can you indicate what other chronic illnesses Elders suffer from that require a lot of attention?
11. How many any Elders, if any, are forced to live away from the community (ies) because of any of the above illnesses? Where are they?
  - a. With relatives in Sioux Lookout or other town
  - b. In another town living on their own
  - c. In a hospital
  - d. In a Long Term Care facility
12. What services would have been needed in the community to have kept those people in their home community (ies)?

HCC Coordinator (if appropriate)

13. How many Home Support workers are there? How many clients in total?
14. How many Home Care workers are there? What do they do? How many clients?
15. How many Home Care and Home Support workers are trained as PSWs?
16. How many of the Elders receive
  - Home care? For what medical problems?
  - Home Support?
  - What services are lacking?

### 9.3 COLLECTED RESPONSES

A document containing the combined raw interview data from the **Elders' Questionnaire** and the **Interview Guide for Community Health Professionals** is available from the authors upon request.



