ASSEMBLY OF FIRST NATIONS

Submission to
Senate Committees Directorate
Social Affairs, Science and Technology

On the Increasing Incidence of Dementia in First Nations Communities: causes, consequences moving forward

April 20, 2016
ABOUT THE ASSEMBLY OF FIRST NATIONS

The Assembly of First Nations (AFN) is the national, political representative of First Nations governments and their citizens in Canada, including those living on reserve and in urban and rural areas. Every Chief in Canada is entitled to be a member of the Assembly. The National Chief is elected by the Chiefs in Canada, who in turn are elected by their citizens.

The role and function of the AFN is to serve as a national delegated forum for determining and harmonizing effective collective and co-operative measures on any subject matter that the First Nations delegate for review, study, response or action and for advancing the aspirations of First Nations.

For more information, please contact us at:

55 Metcalfe Street, Suite 1600
Ottawa, ON K1P 6L5

Telephone: 613-241-6789
Toll-Free: 1-866-869-6789
Fax: 613-241-5808

or visit the AFN Web site: www.afn.ca
SPEAKING NOTES

• To begin, I would like to thank the Algonquin people, on whose territory we are meeting.

• It is my honour to appear before you to speak to the increasing incidence of dementia in Canada: the causes, consequences, and the way forward for First Nations.

• The AFN considers engagement with government on First Nations senior’s issues and the increasing incidence of dementia in Canada from a First Nations perspective to be a top priority.

• Prior to our full presentation, I first wish to outline our key recommendations:

• We require increased research that is respectful of First Nations governance and processes and OCAP to fully understand dementia and its impact on First Nations.

• We require the federal government to commit to the full implementation of the First Nations Mental Wellness Continuum Framework. The Framework recognizes that culture plays a central role in improving the mental wellness of First Nations, while also seeing the importance of evidence-based best practices.

• We call upon the federal government to use population statistics from current population figures when allocating funding for the Home and Community Care Program.

• First Nations require supports and caregiver training and preparedness to meet the complex challenges in caring for someone diagnosed with dementia.

• Support is required for urgent respite care and a structured day program funded as a preventative measure to provide families with enough support to be able to keep Seniors home as long as possible. Currently seniors may be sent to a Long Term Care facility far from their community and this is traumatizing for them and may result in re-victimizing a residential school survivor.

• Interested First Nations communities in remote and isolated regions may meaningfully benefit from key government supports and investments in e-health.

• Finally, we welcome continued engagement and encourage continued collaborative efforts to address the increasing incidence of dementia in Canada; the root causes, the consequences of inaction and apathy, and the way forward in a manner whereby First Nations communities can adapt, reform and realign wellness programs and services according to First Nations priorities.
• **First**, I would like to speak to the United Nations Declaration on the Rights of Indigenous Peoples, Article 23: “Where Indigenous Peoples have the right to determine and develop priorities and strategies for exercising their right to development, in particular, Indigenous peoples have the right to be actively involved in developing and determining health, housing and other economic and social programmes affecting them and, as far as possible, to administer such programmes through their own institutions.”

• **Article 24(2)** of the Declaration states that “Indigenous individuals have an equal right to the enjoyment of the highest attainable standard of physical and mental health. States shall take the necessary steps with a view to achieving progressively the full realization of this right.”

• **Second**, it has long been the goal of the Assembly of First Nations to close the gap in health outcomes between First Nations and the general Canadian population.

• While we clearly share similar objectives, the fact remains that First Nations people continue to suffer disproportionately with poor health, both mentally and physically.

• **Third**, the government’s role in examining and reporting on the increasing incidence and deficits in care of those with dementia needs to include First Nations and our history— with an understanding of the history of our cultures and impacts to our cultures (colonialism, residential schools, its effects on First Nations and our interactions with government). There is a growing awareness on the health crisis faced among our communities — and this crisis implicates our senior populations.

• Furthermore, when discussing the health and wellbeing of First Nations peoples, it is critical to acknowledge and understand the important connection between the Social Determinants of Health (SDoH) such as physical, social, and environmental conditions as they relate specifically to racism, discrimination, colonization, oppression and marginalization.

• When considering seniors, then, we must look not only at the social determinants that seniors are experiencing in the present, but also the determinants they have been exposed to from birth (or even conception) onwards, which have all acted to shape the person’s life and health; according to researchers (*Lopie-Reading & Wein, 2009*).
SNAPSHOT OF FIRST NATIONS SENIORS

- Following, is a brief snapshot of First Nations seniors. In 2007 the Assembly of First Nations shared with the Special Senate Committee on Aging a comprehensive report “Sustaining the Caregiving Cycle: First Nations People and Aging” regarding the status of seniors including key data and recommendations\(^1\). Subsequently, the Special Senate Committee in its report outlined key points and direction for further work as it regards First Nations and seniors\(^2\).

- Researchers note that population projections show the number of First Nations people in Canada is expected to increase by 40% between 2006 and 2031 (Malenfant & Morency, 2011\(^3\)), and a disproportionate amount of the growth will be among those aged 60 and older, who are expected to more than triple in number to 184,334 in 2031.

- Ten to twenty years ago, dementia was not a significant concern in most communities. Emerging research is demonstrating that the rates of dementia in indigenous populations are higher than those in the non-indigenous population and communities are struggling to deal with this crisis. According to Dr. Kristen Jacklin, associate professor at the Northern Ontario School of Medicine, this increase in prevalence can likely be contributed to an aging population and the fact that aboriginal people are living longer than ever, along with higher rates of related illnesses such as high blood pressure, heart disease and diabetes.

- Many researchers are making the connection that people with diabetes, especially with type 2 diabetes may be at a higher risk of developing dementia. However, more research is required to better understand this link.

- There are many more reasons why this population is seeing an increase in dementia. First Nations peoples are already dealing with the lasting effects of colonization and residential schools, and suffers from what is often described as a form of post-traumatic stress disorder or (PTSD); as many seniors suffer from the legacy of residential school, compounded by grief associated with aging including loss of independence, and the desperate state of First Nations communities, families and youth in crisis, including suicides.

- Added to this, many seniors find themselves socially isolated and families are less able to care for seniors because of their own challenges including mental health issues, addictions, poverty and family violence. First Nations communities often see their children and youth migrating to cities and urban centres for education and jobs and often do not return to their communities. This lack of family support means that more families are relying on the community to step in.

\(^1\) Assembly of Fist Nations www.ahrni-rras.ca/index.php?

\(^2\) Special Senate Committee Study, 2007 linked at:
http://www.parl.gc.ca/Content/SEN/Committee/391/oaei/rep/repintfeb07-e.pdf

\(^3\)Population Projections by Aboriginal Identity in Canada, 2006 to 2031 http://www.statcan.gc.ca/pub/91-552-x/91-552-x2011001-eng.htm
The First Nations and Inuit Home and Community Care (FNIHCC) Program is intended to enable people with disabilities, chronic or acute illnesses and the elderly to receive the care they need in their home communities. Care provided in these familiar settings allows First Nations people to be close to their loved ones for as long as possible and to keep their independence.

Home and Community Care may include nursing care, personal care such as bathing and foot care, home support such as meal preparation, and in-home respite care, that is, caring for someone while family members have a rest.

Unfortunately, the Home and Community Care program still administers funding that is based on population statistics from 1997. Home Care nurses are seeing firsthand the growing number of clients, and the growing rates of dementia, with no additional funding, or supports to assist them in addressing this growing epidemic. Some communities decline to administer the program because it is simply not enough funding. Some provinces will not assist with Home Care on reserve, citing federal jurisdiction.

RISK FACTORS

There are many modifiable risk factors of dementia; these include Type 2 diabetes, head injury, strokes and mini strokes, high cholesterol, high blood pressure, mild cognitive impairment (MCI), chronic inflammatory conditions, a history of clinical depression, lack of cognitive stimulation and obesity (Alzheimer Society, 2010). Other factors that have been linked to a possible increased risk for developing dementia include a lack of formal education, low socio-economic status, smoking and alcohol abuse (Alzheimer Society, 2010).

Once again, important considerations must be given to First Nations peoples and the long-term effects of colonization and intergenerational trauma and how the compounded layers of historical trauma may have detrimental impacts on First Nations people when attempting to understand the full spectrum and symptoms of dementia.

CONSEQUENCES

We cannot state this any clearer, every year that Home and Community Care funding uses population figures from 1997, it results in increased pressure on the HCC nurses, the clients, and the community budgets. As a result, there is no additional funding to meet the growing demands of clients with dementia - and this must change. Where traditionally family step in to care for Seniors, in too many circumstances we are seeing families struggling with poverty and addictions and they are unable to do so, leaving the care of Seniors with much uncertainty.
THE WAY FORWARD

- While researchers note that dementia is a condition of the brain and is not a mental illness or disease; we recognize the strong links between dementia and mental wellness and wish to note our wellness plan, called The First Nations Mental Wellness Continuum Framework.

- This Framework may serve as a model to guide and support conversations with major healthcare providers, other service providers, and jurisdictional partners to enhance collaboration and build partnerships to ensure the needs of First Nations people are met on dementia. Our link to the framework can be found at www.afn.ca

- The First Nations Information Governance Centre’s Regional Health Survey (RHS) is currently in the field asking key questions on dementia; the RHS report will assist in supporting necessary evidence from a First Nations perspective. The RHS final report is due in 2018.

- The World Health Organization (WHO) is currently developing iSupport, which is an e-health solution that provides evidence-based education, skill training and social support for caregivers of people living with dementia. First Nations communities in remote and isolated regions may meaningfully benefit from investments in e-health.

- A vital component of any effort to improve health outcomes for older First Nations people and to plan for the future is the use of high quality, relevant and accessible research and data.

- First Nations also require culturally appropriate diagnosis, assessment, and treatment for dementia, in their home communities.

Thank you for this opportunity to present before the Committee.

Miigwetch!