

“WE JUST TOOK CARE OF EACH OTHER”: EXPLORING CULTURAL  
UNDERSTANDINGS OF NEUROLOGICAL CONDITIONS

by

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## List of Acronyms

CAHR - Centre for Aboriginal Health Research  
CCDSS - Canadian Chronic Disease Surveillance System  
CCHS - Canadian Community Health Survey  
CCNA – Canadian Consortium on Neurodegeneration in Aging  
CIHI - Canadian Institute for Health Information  
CIHR - Canadian Institutes of Health Research  
CRGBA - Culturally Relevant Gender Based Analysis  
CR-GAP - Culturally Relevant Gender Application Protocol  
FAS(D) - Fetal Alcohol Spectrum (Disorder)  
FNIH – First Nations Inuit Health  
HICPS - Health Information and Claims Processing Services  
IRM – Indigenous Research Methodology  
KICA – Kimberly Indigenous Cognitive Assessment  
NAO - National Aboriginal Organizations  
NHCC - Neurological Health Charities of Canada  
NIHB – Non-Insured Health Benefits  
NNADAP - National Native Alcohol and Drug Abuse Program  
NPHSNC - National Population Health Study on Neurological Conditions  
NWAC – Native Women’s Association of Canada  
PHAC - Public Health Agency of Canada  
PTMA - Provincial and Territorial Member Associations  
RCAP – Royal Commission on Aboriginal Peoples (final report released in 1996)  
SLNCC - Survey on Living with Neurological Conditions in Canada  
SNCIC – Survey of Neurological Conditions in Institutions in Canada  
TRC – Truth and Reconciliation Commission (final report released in 2015)  
UFW – Understanding from within project  
WHO – World Health Organization



## Abstract

In 2009, the Government of Canada announced a four year national population health study on neurological conditions. The aim of the study was divided into four focus areas: incidence and prevalence of neurological conditions (scope of problem); risk factors for developing neurological conditions; health services, including gaps in services; and the impacts of neurological conditions. The Native Women's Association of Canada (NWAC), with Dr. Carrie Bourassa, First Nations University of Canada, as the principal investigator, submitted a proposal to look at three out of the four focus areas, risk factors, health services / health gaps, and impacts, among Indigenous women. Out of the 13 research projects that were funded, this was the only project that focused specifically on Indigenous people, gathering much needed baseline information on how Indigenous people think about neurological conditions, how it impacts their lives, their families, and communities, and what they see as needed to support neurological health and wellbeing.

Individual interviews and research circles were conducted with people who live with a neurological condition and caregivers of people with a neurological condition. Key informant interviews were also conducted with traditional knowledge keepers, health care professionals and practitioners. The open ended questions encouraged participants to share as much or as little information as they wanted to. The stories shared contained a wealth of information, far exceeding the study's focus areas. Unfortunately, due to external deadlines and budgetary constraints, the research team only had time to focus the research report on the three key areas outlined in the proposal – risk factors, health gaps, and impacts. A lot of the information shared was not fully explored. In this dissertation, a secondary analysis of the data is conducted to explore role of culture, as well as cultural understandings of neurological conditions, and interactions with the health care system. The theoretical framework will utilize Indigenous ways of knowing and Critical Medical Anthropology as part of a “two-eyed seeing” approach. Mi'kmaw Elder Albert Marshall suggested the phrase “two eyed seeing” as a guiding principle for health research, where one eye looks at the issue through the strengths of Indigenous knowledges and ways of knowing, while the other eye looks at the issue from the strengths of Western knowledges and ways of knowing. By using both eyes together to fully analyse the material, the strengths of both Indigenous and Western knowledges are brought together. Through using these different frameworks to explore the narratives, the research fills a gap in the literature regarding how Indigenous cultural understandings of neurological conditions can influence how Indigenous people access care.

## Chapter 1: Introduction

My interest in cultural understandings about neurological conditions stems from my time in the health department at the Native Women's Association of Canada (NWAC). From 2011 to 2013, I was a health research coordinator for the project, "Understanding from Within: Developing community driven and culturally relevant models for understanding and responding to neurological conditions among Aboriginal peoples"<sup>1</sup>. This project was part of a large National Population Health Study on Neurological Conditions (NPHSNC)<sup>2</sup> that looked at incidence and prevalence of neurological conditions in Canada, along with risk factors, impacts, and gaps in health services. The NPHSNC funded 13 research projects with the "Understanding from Within" (UFW) project being the only project to look at neurological conditions in Indigenous people in Canada.

The UFW project collected information on the impacts, risk factors and gaps in the health care system from Indigenous people living with neurological conditions and providing care for loved ones with neurological conditions. Key informant interviews were conducted with health care providers and traditional knowledge keepers to learn more about the risk factors, health services, and cultural understandings of neurological conditions. The stories shared touched on many themes outside of the key areas of impacts, risks, and health gaps.

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<sup>1</sup> This was the formal title that was submitted to the Public Health Agency of Canada and in the National Population Health Study on Neurological Conditions. Within the recruitment flyers, the title was modified to "Understanding from Within: Exploring the impacts of neurological conditions on Aboriginal women, their families, and communities".

<sup>2</sup> A full listing of the projects under the National Population Health Study on Neurological Conditions, funded by the Public Health Agency of Canada can be found at <http://www.phac-aspc.gc.ca/cd-mc/nc-mn/fnd-fin-eng.php#pjcts>

A small team managed all aspects of the research project including recruiting, planning and conducting interviews, research circles, and key informant interviews. All staff were also involved with analyzing the data and writing up the results. The research team was able to learn about the different conditions, including the symptoms associated with the conditions, the general progression of the disease, and how difficult navigating the health care system could be. More importantly, they were able to talk with Indigenous people across Canada who live with a neurological condition or who care for a loved one with a neurological condition. These participants shared their stories of what it was like to live with a neurological condition or care for someone with a neurological condition, including their journey from first experiencing or seeing symptoms, to navigating the health care system, and the physical, mental, emotional, spiritual, and financial impacts they experienced along the way.

Being a part of this project was humbling and awe-inspiring in many different ways. The interviews were open-ended, allowing the participants to share as much or as little information as they wanted.<sup>3</sup> Some individuals expressed this was the first time they were able to fully talk about their experiences. Participants were able to share their thoughts about health care in Canada; including the challenges they faced in accessing care, jurisdictional issues, along with their vision of what they would like to see to increase health and wellbeing amongst Indigenous people. Many of the participants shared their understandings of neurological conditions, including their cultural beliefs around neurological conditions. Many of these participants also shared that it was their culture and cultural beliefs and practices that helped them understand the role

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<sup>3</sup> The data collection and analysis process is fully explained in Chapter 3.

neurological conditions played in their life, as well as cope with the impacts of living with a neurological condition or caring a person with a neurological condition.

The UFW project is important in that it asked Indigenous people across Canada about their experiences with neurological conditions. It gathered much needed baseline information and encouraged many Indigenous people to share their stories.

Unfortunately, due to time and funding constraints the research team was only able to focus the analysis on the three key areas as outlined in the contribution agreement: impacts of neurological conditions, risk factors, and gaps in health services. In this dissertation, a secondary analysis of the data is conducted to gain more insight on the role of culture in understanding neurological conditions.

## Key Terms

Throughout this dissertation, the First Peoples now living in Canada are referred to using different terms. Whenever possible, the name of the nation the person comes from is used. For example, Cree, Anishinaabe, Métis, Mi'kmaq, or any other tribal affiliations listed. When tribal affiliation is not listed or I am referring to a collective group, I will try to use the term Indigenous.

I have included the following terms that may be used throughout my dissertation, along with a short description of these are used in the Canadian context,

- Indian – legally defined by the Indian Act of 1876
- Aboriginal – Under Sect 35 of the Canadian Constitution to include Indian, Inuit and Métis people
- First Nation – can refer to a band or reserve based community (for example, Gordon's First Nation); can also refer to Indigenous people who are neither Inuit nor Métis, but may include status and non-status Indians.

- Métis – a person who self identifies, is distinct from other Aboriginal peoples, is of historic Métis Nation ancestry, and is accepted by the Métis Nation
- Inuit – distinct people typically from parts of northern Canada, Greenland, Alaska.
- Native – similar to Aboriginal, but not commonly used anymore.

The terms American Indian, Native American, and Native Hawaiian will be used when referring to Indigenous peoples from the United States, as well as the terms Aboriginal and Torres Strait Islander people when referring to Indigenous people of Australia and Maori when referring to Indigenous people from New Zealand. The word wholistic will be used to refer to the mind, body, spirit connection.

## Secondary Analysis of the Data

Permission was obtained from Dr. Carrie Bourassa, Principal Investigator for the UFW project, to use these data for my dissertation study. Secondary data analysis uses existing data to answer new research questions. The data from the UFW project contains in depth interviews and research circles from 80 participants across four provinces and one territory. Following steps outlined by Heaton (1998, 2008) the details of the original study are included in chapters 1 and 3 to give the context of the data collection process. The methods used in the secondary analysis outline the new questions and framework applied to the three data sets. The benefits of reusing existing data include “efficiencies in time, money, and other resources, and the maximisation of the use of potentially important data that might otherwise lie dormant” (Whiteside et al 2012). One of the challenges is determining if the data can sufficiently answer these new questions.

## Research Questions

The secondary analysis focuses on the role of culture, including cultural understandings of neurological conditions and interactions with the health care system.

My research questions for each data set are listed below:

### Health Care providers

- What are the experiences of HCP in caring for Indigenous people who either live with a neurological condition or care for a loved one with a neurological condition?
- Do they know if their patients are using cultural ceremonies / or traditional practices as part of the care routine?

### Traditional Knowledge Keepers

- Are neurological conditions fairly new or have Indigenous people always experienced these types of conditions?
- How were people with neurological conditions traditionally cared for?

### Individual interviews and research circles

- How are neurological conditions culturally understood?
- Does this understanding influence how people access care?

Each dataset was recoded to look at the role of culture in understanding neurological conditions and how this understanding influences how people access care. The key informant interviews with health care providers contain a wealth of information on working with Indigenous people, along with their understanding of how culture can influence how people access health care services. The interviews with Traditional Knowledge Keepers touch on if neurological conditions always existed. They also speak to how communities cared for Indigenous people living with a neurological condition. The interviews and research circles with people who live with a neurological condition or care for a loved one with a neurological condition includes stories related to cultural

understanding of neurological conditions, along with how these understandings shape how they access care.

Dr. Bourassa agreed to the data being used in this manner and felt that this secondary analysis would provide more insight around the role of culture in understanding neurological conditions and in accessing care.

The term “culture” in this dissertation is used to look at the beliefs, practices, and worldviews of a people belonging to a specific ethnic group. Cultures adopt and adapt certain elements from other cultural groupings, while retaining the core of their uniqueness, their worldviews, and their narratives. For the definition of culture is drawn from cultural anthropology using Bates and Plog (1990) and Holm’s (2005) peoplehood matrix. The Indigenous population in Canada is very diverse, with more than 1.4 million people identifying as Aboriginal, which includes people who self-identify as First Nation, Inuit, and Metis in the 2011 National Household Survey (<http://www.statcan.gc.ca/daily-quotidien/130508/dq130508a-eng.htm>). While looking at the role of culture in understanding neurological conditions on a national scale is daunting, there are too many stories of Indigenous people experiencing inequitable care. Where possible, I will include how the participant self-identified and name their tribal affiliation.

## **Dissertation Roadmap**

This dissertation is organized into seven chapters. The first chapter provides an overview of neurological conditions in Canada and the UFW project. Chapter 2 reviews the general health and wellbeing of Indigenous people in Canada, providing a snapshot of the colonial impacts on Indigenous health before looking at the literature on neurological conditions and Indigenous people. Special attention will be on the conditions identified

by the participants in the Understanding From Within Project. Chapter 3 returns to the UFW project with a discussion of the methods used in collecting the initial data. This will be followed by a discussion of the methods and theoretical framework used to reanalyze the data sets. Mi'kmaw Elder Albert Marshall's "two-eyed seeing" approach is used as a guiding principle, bringing together Indigenous ways of knowing and Critical Medical Anthropology as the main framework. The following three chapters outline the themes identified in the key informant interviews with Health Care Professionals, Traditional Knowledge Keepers, individuals, and from research circles with Indigenous people who live with a neurological condition or care for a loved one with a neurological condition. These chapters examine closely the cultural understanding of neurological conditions and interactions with the health care system acknowledged by the participants. Chapter 7 presents the conclusions, recommendations, and implications of findings for future research.

### **Understanding the Scope of Neurological Conditions in Canada**

Within the last 10 years neurological conditions and their impact on the Canadian population, in terms of families, communities, the health care system and the general economy, has been garnering more attention. In 2007, the Canadian Institute for Health Information (CIHI) released their report on *The Burden of Neurological Disorders and Injuries in Canada*, which looked at the economic costs of neurological conditions. *The Burden of Neurological Disorders and Injuries in Canada* (2007). The authors identified 11 neurological conditions that affected Canadians most and its costs on the Canadian health system. The conditions included in the report were Alzheimer's disease, ALS, brain tumours, cerebral palsy, epilepsy, head injury, headaches, multiple sclerosis,



Parkinson's disease, spinal injuries and stroke. According to the report the total cost of all illnesses in Canada were estimated by Public Health Agency of Canada (PHAC) to be \$176.4 billion dollars, with \$97.9 billion in direct costs<sup>4</sup> and \$78.5 billion in indirect costs.<sup>5</sup> Meanwhile the total costs of the 11 neurological conditions highlighted in the report were estimated "to be \$8.8 billion, representing 6.7% of the total attributable cost of illness to Canadians in 2000-2001" (CIHI 2007: 9). Strokes "accounted for \$665 million in direct costs and \$2.1 billion in indirect costs in Canada in 2000-2001" (Ibid. 107); this was the greatest generator of financial costs out of all the neurological conditions, followed by Alzheimer's disease and dementia, and then debilitating headaches.

The CIHI report is important in that it provides baseline information on the economic burden of neurological conditions that impact Canadians most. The report touches on the direct and indirect costs, while admitting that they do not include transportation costs, medical devices, as well as time lost from work or leisure activities. The report includes recommendations for future research centred around pathways of care, including timely access to care, availability of services, quality of care; gaps in services and data and the impacts of neurological conditions on quality of life. The limitations outlined in the report signaled the need for more research in all areas of neurological conditions.

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<sup>4</sup> Direct costs include public and private sector spending for hospital care, physician care, health care professional fees, medication and any additional fees for research, long term care facilities or other resources.

<sup>5</sup> Indirect costs include the mortality costs as looked at by years of life lost due to early death caused by the neurological condition and morbidity costs which look at activity days lost due to long term disability resulting from the neurological condition.

## **A National Population Health Study on Neurological Conditions**

In 2009, the Public Health Agency of Canada (PHAC) partnered with the Neurological Health Charities of Canada (NHCC), Health Canada, and the Canadian Institutes of Health Research (CIHR) to coordinate and support a National Population Health Study on Neurological Conditions (NPHSNC). In order to conduct this study, the Government of Canada invested \$15 million over four years. The overall goal of the study was designed to fill gaps in knowledge about neurological conditions in Canada and their impacts on individuals, families, and the health care system. Another goal of the study was to gain a better understanding what programs and services were needed in order to reduce the burden of neurological conditions in Canada.

For the purposes of the study, neurological conditions were classified as any condition that affects the brain, spinal cord, or peripheral nerves that are caused by infection, inflammation, injury, tumour, or an inherited genetic mutation. According to the Neurological Health Charities of Canada (NHCC) there are over “1,000 different types of brain disorders – neurological, developmental and psychiatric – affecting people at every age and stage of life” (<http://mybrainmatters.ca/education/>). Some of the symptoms associated with different neurological conditions may be managed with certain treatment options, but many of the conditions do not have effective treatment protocols..

Advisory groups, made up of over 50 experts from the Canadian neurological research community, were formed to define the scope and objectives of the study. For the purposes of the study, 14 understudied conditions were selected based on the lack of knowledge and potential population disease burden. These included Alzheimer’s disease and related dementias; Amyotrophic Lateral Sclerosis (Lou Gehrig’s disease); Brain Tumours; Cerebral Palsy; Dystonia; Epilepsy; Huntington disease; Hydrocephalus;

Multiple Sclerosis; Muscular Dystrophy; Neurotrauma (including brain and spinal cord injuries); Parkinson's disease; Spina Bifida; and Tourette Syndrome. The objectives were to address these conditions in four key areas:

1. The **scope** of neurological condition in Canada, including prevalence, incidence, and comorbidities.
2. The **risk factors** for development and progression of these conditions
3. The **impacts** of neurological conditions on people living with these conditions, their families, caregivers, and communities; and
4. The effectiveness of existing **health services**, including the identification of any gaps in services and recommendations for improvements.

Organizations and individuals with expertise in neurological health were given two opportunities to submit specific proposals, with the first proposals being accepted in January of 2010 and the second call for proposals extended in November 2010. A total of 14 contribution agreements were signed with different organizations. Thirteen projects took place and a synthesis committee brought all the findings together in a final report called: *Mapping Connections: An Understanding of Neurological Conditions in Canada* (2014).

The NPHSNC call for proposals encouraged applicants to extend their research activities to cut across the different key areas. While each project may have included multiple objectives in their proposals, these were not reflected on PHAC's website. Instead, PHAC listed the projects by their primary area of focus: scope; impacts; risk factors; health services; and multiple focal points. In this listing, five projects looked at the scope of neurological conditions in Canada; two projects looked at impacts; two projects looked at risk factors; one project looked at health services; and three projects

used multiple focal points to look at incidence, prevalence, impacts, risk factors, and health services.<sup>6</sup>

The NPHSNC and PHAC supported the use of quantitative survey designs and microsimulation modeling to gain a better understanding of the incidence, prevalence, and the health and economic impacts of neurological conditions. Three national surveys were conducted to collect vital information about neurological conditions in Canada. The Canadian Community Health Survey (CCHS) was one of the surveys that was updated to include modified questions and additional modules related to neurological conditions, loss of productivity due to health issues, and immunization. The CCHS is a national survey that collects data from 117 health regions covering all provinces and territories in Canada, excluding individuals from reserves and other Aboriginal settlements, institutional residents, full-time members of the Canadian Forces and residents from certain remote regions. The survey collects information related to “health status, health care utilization and health determinants for the Canadian population” and does ask if the respondent is Aboriginal, North American Indian, Metis or Inuit. The identifier question is critical when trying to decipher the incidence and prevalence of neurological conditions within the Aboriginal population. Unfortunately, Aboriginal identifier questions are not applied consistently across all aspects of health surveillance, including primary and secondary health care records.

The CCHS has undergone various redesigns from when it first started collecting data in 2001. These redesigns address data collection periods, sample size, optional content, where health regions have the opportunity to ask specific questions that address

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<sup>6</sup> For a full listing of the 13 funded projects, see <http://www.phac-aspc.gc.ca/cd-mc/nc-mn/fnd-fin-eng.php>

provincial or regional health priorities, and rapid response content, where organizations can put forth specific questions related to the health of the population. Any content in the rapid response segment are collected on a cost recovery basis, takes two minutes or less of the interview time and only appear in the survey for a single collection period. The module on neurological conditions was added to the CCHS for the 2010 and 2011 collection periods. The CCHS underwent another major redesign in 2012 and it is not clear if the module on neurological conditions will be included in the 2015 cycle.

Individuals who identified as living with a neurological condition in the CCHS 2010 and 2011 cycles were invited to participate in the follow up questionnaire, Survey on Living with Neurological Conditions in Canada (SLNCC). This survey was developed specifically for the NPHSNC by Statistics Canada in collaboration with the PHAC and members of the neurological advisory group. Data collection took place from September 9, 2011 to March 31, 2012, with 8,200 people included in the raw sample size. With the sample being derived from the CCHS respondents, households with at least one person with a neurological condition was selected across 10 provinces. The same exclusions that were used in the CCHS were also used in the SLNCC. Statistics Canada cautioned users against using the SLNCC to produce prevalence estimates for neurological conditions due to the high number of out-of-scope cases

(<http://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SDDS=5182&lang=en&db=imdb&adm=8&dis=2>). Instead, they suggested that any prevalence estimates should come from the CCHS files.

The third survey designed to collect information on neurological conditions was the Survey of Neurological Conditions in Institutions in Canada (SNCIC). This survey

collected data on the prevalence of neurological conditions in long term residential care facilities. Residents with neurological conditions in these facilities are excluded from the CCHS. This survey was designed to address this important gap in the existing data by recording the number of people with neurological conditions. In order to be included in the survey, the facility must provide 24 hour care and include: “homes for the aged, persons with physical disabilities, persons who are developmentally delayed, persons with psychiatric disabilities, and emotionally disturbed children”

(<http://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SDDS=5187&lang=en&db=imdb&adm=8&dis=2>). Drug and alcohol rehabilitation centres, independent living facilities and temporary shelters for the homeless were not surveyed. From October 2011 to February 2012, 7210 institutions were contacted to take part in the survey. Of these, 530 were determined to be out of scope. Only 4245 institutions completed the survey. Survey respondents were asked about the age and sex of residents in their facility as well as the number of male and female residents in the facility diagnosed with a neurological condition at the time of reporting. This survey did not ask about ethnicity of residents in the facilities or ethnicity of people diagnosed with a neurological condition.

Data examining incidence, prevalence, impacts, and risk factors also came from microsimulation models and the expansion of the Canadian Chronic Disease Surveillance System. One project within the Study worked with Statistics Canada to develop seven microsimulation models to project health outcomes and costs for select neurological conditions. The models were based on data from the research findings from the overall Study, national surveys, and administrative health data. According to Statistics Canada, these models help “project incidence and prevalence of neurological conditions, the

impact on mortality, life expectancy, disability-adjusted life years and health-adjusted life expectancy (HALE) and the direct costs of treatment and indirect costs (lost wages and tax revenue) (<http://www.statcan.gc.ca/eng/microsimulation/health/health>). In addition to looking at all these factors, the models also looked at the costs of informal care.

One project expanded the Canadian Chronic Disease Surveillance System (CCDSS) to collect information on neurological conditions using provincial and territorial administrative health data (NHCC et al. 2014). According to PHAC, the CCDSS

uses linked administrative data sources from every province and territory to estimate the incidence and prevalence of chronic conditions, as well as related risk factors, use of health services and health outcomes. Its aim is to foster the collection of surveillance data in a consistent and comparable way across jurisdictions. (<http://www.phac-aspc.gc.ca/surveillance-eng.php>)

Four neurological conditions were added to the CCDSS (Alzheimer's disease and other dementias, epilepsy, multiple sclerosis, and parkinsonism) as part of a pilot project where "all the provinces and territories test the case definitions in their jurisdiction" (NHCC et al. 2014). Stroke is already included in the CCDSS. Since health care is under provincial jurisdiction, the case definitions for each condition are not standardized on a national scale. The data from the pilot project was analyzed to see if selected case definitions could be applied across all provinces and territories (NHCC et al. 2014). Standardized case definitions across all the provinces and territories would allow the data to be compared across the country and see if the incidence and prevalence of certain neurological conditions are higher in some areas of the country than others. Some of the challenges with standardizing the case definitions is making sure that the definition takes into account the health inequities in different cultural groups, and rural or remote

populations. At the time of publication, the case definitions were not standardized on a national scale, but the authors stated that the CCDSS would continue to work towards do this.

The projects within the NPHSNC are important in that they contributed to further understanding the incidence and prevalence of neurological conditions, along with the risk factors, impacts, and gaps in health services within a general Canadian context. While the NPHSNC expanded the knowledge base that exists for neurological conditions, many knowledge gaps still exist. Some of these challenges were outlined in the synthesis report, including the lack of data from specific populations, such as First Nations, Metis and Inuit (NHCC et al. 2014). This can be seen as more of a systemic issue in that First Nations and Metis people who live on reserves or settlements are excluded from all national surveys. Another limitation is that the final report did not account for culture or gender or outline the social determinants of health that often contribute to health inequities. Understanding these factors, along with the colonial history is important in understanding the health discrepancies that exist in Canada.

### **Background on the UFW Project: A Look at Neurological Conditions in Indigenous People**

The UFW project differed from the other NPHSNC projects in that it was the only one that focused solely on Indigenous people. It was also the first time that Indigenous people were included in a national population health study. The Native Women's Association of Canada (NWAC)<sup>7</sup> in a collaborative partnership with Dr. Carrie Bourassa,

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<sup>7</sup> The Native Women's Association of Canada is one of the five officially recognized National Aboriginal Organizations (NAOs) and was incorporated in 1974. NWAC was founded on the "collective goal to enhance, promote, and foster the social, economic, cultural and political well-being of First Nations and Métis women within First Nation, Métis and Canadian societies" (<http://nwac.ca/nwac-profile>). Much of the work they do is to advance the well-being of First Nations and Métis women and children, "their



an Indigenous community based researcher,<sup>8</sup> conducted the research. Dr. Bourassa has worked with and supported many Indigenous communities in conducting research and viewed the relationship with NWAC as a community partnership. She wanted to support their goal to conduct quality research on par with academic institutions.

A Letter of Intent was submitted to PHAC in January 2010, and the full proposal in April 2010. The reviewers for the grant competition requested a number of revisions to be made and Bourassa resubmitted the revised proposal in July 2010. The contribution agreement was signed at a later date, with funding becoming available in January 2011. This delay in funding effectively cut the time allotted for the research from 36 months down to 27 months, which caused further delays in terms of hiring staff, engaging with the advisory committee and community partners, submitting applications, and getting out into the communities to conduct the interviews and research circles.

The NWAC, much like the other NAOs, has a small core operating budget and is dependent on project based funding to support its goals in advancing the wellbeing of Indigenous women and girls in Canada. The Health Department within NWAC relied entirely on proposals being funded by outside agencies. The same was the case for the Understanding from Within project. This meant that the health department did not feel comfortable in hiring any outside staff until the funding was released to NWAC. This was different from many of the other projects that were a part of the NPHSNC and had

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families and communities through activism, policy analysis, and advocacy” (<http://nwac.ca/about-nwac>). The other NAO’s include The Assembly of First Nations (AFN), Congress of Aboriginal People (CAP), Métis National Council (MNC), and Inuit Tapiriit Kanatami (ITK).

<sup>8</sup> Dr. Carrie Bourassa is a Professor at First Nations University of Canada, in the department of Indigenous Education, Health and Social Work. She was is the nominated Principal Investigator on a Canada Foundation for Innovation Grant that funded Indigenous community based health research labs at First Nations University. Dr. Bourassa was also recently inaugurated into the Royal Society of Canada’s College of New Scholars, Artists and Scientists. For more information see <http://www.fnuniv.ca/campuses/regina-campus/regina-campus-ihs/108-carriebourassa-bios/healthstudies/carriebourassa/401-carriebourassa>.

large scale institutional supports in place to help cover the project start-up costs, including hiring staff and conducting preliminary research to support the overall project.

The research team included two co-PIs<sup>9</sup>, a research coordinator, a research assistant, administrative assistance for finance and reporting, an advisory committee, and later on a project manager and data analyst. The advisory committee included two Elders and two youth, as well as six Indigenous and non-Indigenous experts in Indigenous health research in Canada. The author was hired by NWAC as a health research coordinator for the “Understanding from Within” project in April of 2011 and worked closely with the co-PIs, and research assistant to ensure the project was successful in meeting its deliverables.

The UFW project concentrated on Indigenous women (although Indigenous men who wished to participate were invited to do so). Indigenous women were the focus of the study for a number of reasons: on average, they have a longer lifespan than Indigenous men (Stats Canada 2011), and they represent the majority of caregivers in Indigenous communities, regardless of whether they are paid or unpaid (Korn et al. 2009; Hennessy and John, 1995, 1996). In addition, they “are more likely than [Indigenous] men to experience difficulties with: long waiting lists; the availability of a doctor or nurse in their area; seeking approval for NIHB covered services; arranging for and costs of transportation; and the costs of childcare” ([http://fnigc.ca/sites/default/files/ENpdf/RHS\\_2002/FN\\_Womens\\_Forum\\_Fact\\_Sheet.pdf](http://fnigc.ca/sites/default/files/ENpdf/RHS_2002/FN_Womens_Forum_Fact_Sheet.pdf)).

The research team undertook a culturally relevant gender based analysis (CRGBA) to address the inequities faced by Indigenous women, as well as to highlight

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<sup>9</sup> The co PI for NWAC resigned in May of 2012.

and explore the needs and challenges they face in accessing care. Undertaking a CRGBA acknowledges that:

women have unique health needs and concerns that are different from those of men, and that women have also experienced differential treatment in health research, policy, programming and practices. For Aboriginal women, this differential treatment has been compounded by the effects of colonization, which denigrated Aboriginal peoples as a whole, but also deeply damaged the roles and respect of Aboriginal women who were traditionally held in high regard. (NWAC: Culturally Relevant Gender Analysis. <http://www.nwac.ca/programs/culturally-relevant-gender-analysis>)

NWAC wanted to ensure that the funders and the rest of the teams that were a part of the NPHSNC understood that there are many systemic and structural factors that impact Indigenous peoples health and wellbeing, with the greatest one being colonization and the lasting legacy of colonial policies that are experienced today. They particularly wanted to bring attention to the fact that Indigenous women face different circumstances than Indigenous men and that women need to be included in any decisions that may affect them. NWAC created a culturally relevant gender application protocol (CR-GAP) to advance the use of CRGBA and help funders, policy and decision makers identify gaps in the processes that shape and effect health and well-being and ensure that Indigenous women are included in the conversations (NWAC, A Culturally Relevant Gender Application Protocol. <http://www.nwac.ca/sites/default/files/imce/CR-GAP%20Context%20AUG2010.pdf>). The research team used this analysis in putting forth the final recommendations and hoped that it would also be used by the NPHSNC steering committee during the in the synthesis process.

The research team recognized that there is a huge knowledge gap in regards to neurological conditions among Indigenous people and did not limit the scope of the study

to the prescribed fourteen conditions. This was supported by one of the key informants, who stated:

*The education piece I think is also a very big piece as well to know about what is a neurological condition and what would be the signs and symptoms and are there things that I can do about that? That type of thing, for sure, yeah. I keep thinking going back to Diabetes and coronary artery disease because there's so many neurological conditions that come from there but there's the head injury piece too from trauma because trauma's such a big area of common injury. There's just even the substance abuse and things that goes on and that causes brain damage and such as well too. And then, there's the epilepsy piece and there's the hereditary piece of different things. So, there's just so much and people don't really know or understand what it is. So, I think there's a lot of education that needs to go on as well and that's kind of more health promotional side of things. (KI 11)*

The research team expanded the scope to include any conditions that impact the brain, the spine, or the nervous system. The only conditions that were excluded were Fetal Alcohol Spectrum (FAS) and Fetal Alcohol Spectrum Disorder (FASD), as these conditions are not classified as neurological conditions, even though they may impact cognitive function. Conditions that were brought forward throughout the project include: Acquired Brain Injury, traumatic brain injury, and head injury; Alzheimer's Disease, Dementia, and HIV Related Dementia; Ataxia; Cerebral Palsy; Diabetes Related Neuralgia; Epilepsy; Migraines; Minamata Disease (mercury poisoning); Multiple Sclerosis; Rett Syndrome; severe PTSD; Shingles; Stroke; and Trigeminal Neuralgia. The differences between the conditions listed in the NPHSNC and the ones brought forward by the UFW participants can be seen in figure 1. Definitions for each condition can be found in Appendix A.

**Table 1. Neurological conditions studied and brought forth by participants**

<i>Conditions identified by the NPHSNC</i>	<i>Conditions identified by “Understanding from Within” participants</i>
Alzheimer’s disease and related dementias	Alzheimer’s Disease; dementia; HIV related dementia
Amyotrophic Lateral Sclerosis (Lou Gehrig’s disease)	
Brain Tumours	
Cerebral Palsy	Cerebral Palsy
Dystonia	
Epilepsy	Epilepsy
Huntington Disease	
Hydrocephalus	
Multiple Sclerosis	Multiple Sclerosis
Muscular Dystrophy	
Neurotrauma (including brain and spinal cord injuries)	Acquired brain injury; traumatic brain injury; head injury
Parkinson’s Disease	
Spina Bifida	
Tourette Syndrome	
	Ataxia
	Diabetes related neuralgia
	Migraines
	Minamata Disease (mercury poisoning)
	Rett Syndrome
	Severe PTSD
	Shingles
	Stroke
	Trigeminal Neuralgia

Through opening up the definition to include any condition that impacts the brain, the spine or the nervous system, the UFW project was able to connect with individuals who may have never come forward if we had limited participation to the 14 listed conditions. In addition to reaching a wider audience, the UFW project was able to

highlight additional conditions that are of importance to Indigenous people. Out of the nine additional conditions we put forward in the final report, the synthesis team for the NPHSNC acknowledged migraine, Rett syndrome and stroke, outlining that there are data limitations and that it was not “always possible to provide uniform coverage of each neurological condition under study in this report” (NHCC et al. 2014:11).

### **Indigenous Social Determinants of Health and Neurological Conditions**

The research team understood that Indigenous people may be at greater risk for neurological conditions based on disparities in health, connections to poverty, violence, and systemic racism. Many of the participants have multiple morbidities and spoke about the challenges of living with the conditions, addressing chronic pain associated with these conditions, and knowing that living with multiple morbidities often put them at increased risk for other neurological conditions. For example, many people spoke about diabetes in the context of diabetes related neuralgia and the pain they experienced due to nerve damage; many participants understood that living with diabetes also put them at additional risk for stroke and other conditions, such as vascular dementia.

In addition to discussing neurological conditions, many of our participants provided stories of racism, Indian Residential Schools or other colonial policies directed at Indigenous people and that these experiences may have a direct impact on their health and well-being. A couple of participants spoke about the systemic racism they and their families faced in accessing health care. For example, one participant shared that their uncle was turned away from the health clinic because the staff thought he was intoxicated, when the man was actually having a stroke. Other participants spoke about the impacts of Residential Schools on their families and the physical, mental, emotional, spiritual, and sexual abuse that was experienced. Participants, whose parents and

grandparents attended the residential schools, spoke about how some of these traumas were passed down to them, resulting in intergenerational trauma, and loss of culture. Some participants believed that their neurological condition or their loved one's neurological condition stemmed from the resulting trauma and intergenerational trauma. Understanding the impacts of colonization is important in that these policies can have lasting impacts on the individual, the families, and larger community. It is also one of the reasons why we kept the interview from the participant who was diagnosed with severe PTSD, even though the synthesis committee felt that it should be excluded, labeling it as a mental health issue.

### **Challenges and Limitations of the UFW Study**

The UFW project was ground breaking in a number of ways, including the fact that this was the first time that NWAC was able to contribute to a national population health study. While there were a number of successes that resulted from this research, there were also a number of challenges encountered along the way. These included delays with funding; delays with ethics approvals; staff turnover; research capacity; recognition of Indigenous research methodologies within a western scientific study. The general time constraints imposed on the overall project greatly contributed to many of the challenges along the way.

Under the original proposal, the research team was to utilize a mixed methods approach, using both quantitative and qualitative data collection and analysis techniques. In-depth qualitative data from interviews and research circles would inform the creation of a community based survey. These surveys were to be administered to 1000 Indigenous participants living with a neurological condition or caring for a person with a neurological condition. This was a lofty goal considering the project timelines and

limited staff available to conduct a national survey on a series of conditions that were not very well known, understood, or discussed in Indigenous communities.

The project scope and goals were changed in early 2012 to omit the community-based surveys and expand the interviews and research circles. Through restructuring the project to focus solely on the qualitative data, the research team were able to reach out and listen to more stories from Indigenous people who either lived with a neurological condition or provided care for someone with a neurological condition. The research team finished the data collection in September 2012. A total of 80 participants took part in interviews, research circles, or key informant interviews. Participants identified themselves as First Nations, Métis, and non-Aboriginal. Unfortunately, no Inuit participants offered to participate. There are a number of reasons why this may have happened, including the lack of Inuit representation on the Advisory Committee; lack of interest in the study or that the Inuit organizations contacted had more pressing issues to deal with at the time.<sup>10</sup> Cultural and organizational protocols also limited NWAC from advertising or traveling to Nunavut, without having some sort of partnership in place or a formal invitation from the National Inuit Organizations.

Adhering to the strict timelines set out by PHAC and the NHCC was challenging, but the research team managed to complete all tasks outlined within the contribution agreement, including completing the NPHSNC report template, producing a community research report, knowledge translation materials, and drafting an article which was later submitted for publication. In addition to completing these tasks, the research team was

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<sup>10</sup> Pauktuutit Inuit Women of Canada were contacted and asked if they would be able to help us in reaching out to Inuit women who live with a neurological condition or care for a loved one with a neurological conditions. Unfortunately, they also faced a number of funding cuts in 2012, and had more pressing issues to contend with.



asked near the end of the project to align our research activities and findings to the other qualitative research projects to allow for greater comparability by the NPHSNC Scientific Advisory Committee and the synthesis committee.

The Scientific Advisory Committee was unsure of how the UFW findings would fit into the final report and thought that aligning the activities and findings with the other projects would give a clearer picture of how neurological conditions impact Indigenous people and how this might be different from the rest of Canada's population. After much discussion between the UFW research team and members of the Advisory Committee, we reiterated to the Scientific Advisory Committee that this project differed from the other projects in that we used Indigenous Research Methods, and followed participatory research approaches. We were also the only project that focused specifically on Indigenous people and for many of them, this was the first time that they had been asked to share their stories, let alone share their life experiences for a national study. We wanted to ensure that the Scientific Advisory Committee would be able to understand and acknowledge that many of the impacts, risk factors, and experiences with inadequate health care can be attributed to the colonial legacy Indigenous people face, along with Institutional Racism, and Indigenous Social Determinants of Health. Unfortunately, since the formatting of the final report was not decided on at that time, the Scientific Advisory Committee could not commit to including this very importance background information. The research team decided at that point to focus on our own findings, as opposed to focusing on how to make the findings comparable with the other projects.

While there were many challenges and limitations encountered, there were also many lessons learned along the way. One of the biggest lessons for me was that there is

still a lot of work left to be done to ensure that Indigenous voices are included within large national projects. Indigenous and non Indigenous researchers who are undertaking Indigenous health research need to continue to advocate for funding and services, as well as educate others, including the general population on why Indigenous perspectives, including the colonial history, and Indigenous social determinants of health need to be included.

### **Significance of the UFW Study and the Secondary Analysis**

The UFW project is important in that it asked Indigenous people across Canada about their experiences with neurological conditions. It gathered much needed baseline information and encouraged many Indigenous people to share their stories of what it was like to live with a neurological condition or care for someone with a neurological condition. Many of these stories outlined participants' journeys from first experiencing or seeing symptoms, to navigating the health care system, and the physical, mental, emotional, spiritual, and financial impacts they experienced along the way. Participants were able to share their thoughts about health care in Canada identifying the challenges they faced in accessing care, jurisdictional issues, along with their vision of what they would like to see to increase health and wellbeing amongst Indigenous people.

In conducting secondary analysis on the data, this dissertation will focus on cultural understandings of neurological conditions. This will fill a gap in the literature by including Indigenous thoughts and understandings of what living with a neurological condition or caring for someone with a neurological condition entails and means. This is important on many levels, especially within American Indian Studies (AIS) and within Indigenous communities.

AIS programs emerged out of the civil rights movements of the 1960s and 70s. AIS programs sought to not only deconstruct stereotypes, but include Indigenous voices, and encourage community involvement in academia through the use of elders, activists, and political leaders. AIS programs in the last fifty years have worked towards deconstructing stereotypes and myths, and incorporating Indigenous voice, language, and paradigms within its scholarship, while fostering Indigenous identity (Kidwell and Velie 2005). These stories of cultural understandings of neurological conditions can fill a gap in the literature, while upholding Indigenous ways of knowing.

For Indigenous communities, this research can help foster further discussions to enhance historical understandings of neurological conditions, including whether these conditions existed historically, how neurological conditions were conceptualized, how people with neurological conditions were cared for, and whether or not treatment was sought for a neurological condition. This research could hopefully encourage other Indigenous people who live with a neurological condition or care for someone with a neurological condition feel more comfortable in talking about their beliefs and experiences with neurological conditions.

The second research question seeks to understand how cultural understandings of neurological conditions influence how people access care. Indigenous people have higher rates of multiple morbidities and often times seek care for the most pressing concerns. For example, if a person is living with diabetes, high blood pressure, or heart disease and is having trouble with their memory, they may be more concerned and seek care for their diabetes and not ask about their memory loss. In this case, the memory loss becomes normalized and the person or caregiver may not seek help for this problem until much later on. Additional factors such as access to care, previous experiences with health care

providers, and jurisdictional complications could further impact how Indigenous people seek care. According to one movement specialist, obtaining a diagnosis for Ataxia can take approximately 7-10 years. For Indigenous people, the path to diagnosis can take even longer depending on access to health care, access to specialists, jurisdictional complications, along with experiences of discrimination and racism at the different levels within the health care system.

This situation is particularly important when looking at the different experiences in accessing health care. Browne et al. (2011) in their article, “Access to Primary Care from the Perspective of Aboriginal Patients at an Urban Emergency Department,” documents and categorizes the inequities faced by Aboriginal people trying to access health services. Preceding the 2011 article, Tang and Browne (2008) interviewed Indigenous and non-Indigenous people on their experiences using the emergency department in an urban setting near a large core area. The interviewees spoke of the discrimination they felt within the various emergency departments they went to. When the researchers presented this back to the health care providers they believed that they treated all patients the same regardless of ethnicity.

Understanding the challenges that Indigenous people face when dealing with the health care system may help explain why many researchers and physicians historically thought that Indigenous people were genetically protected against neurological conditions. Bringing Indigenous peoples’ stories forward of how their interactions with the health care system could also help strengthen and support the need for culturally safe and integrated care.

## Chapter 2: Literature Review

The NPHSNC brought much needed attention to the incidence and prevalence, the impacts, and risk factors associated with neurological conditions. It also highlighted the gaps in health care services and set out a number of recommendations in terms of moving forward. The synthesis report for the project, *Mapping connections: an understanding of neurological conditions in Canada* (2014), used the information from the 13 different projects to outline some of the challenges of accessing care when living with a neurological condition or providing care for someone living with a neurological condition.

The findings from the Understanding from Within project were minimally covered, with little analysis or discussion around why the health disparities exist between Indigenous and non-Indigenous people in Canada exist. This chapter will outline the general health of Indigenous people in Canada, and examine the existing literature on the neurological conditions brought forward by the participants.

### General Health of Indigenous People in Canada

The Indigenous population in Canada is the fastest growing segment of the Canadian population making up 4.3 percent of the total population (<http://www12.statcan.gc.ca/nhs-enm/2011/as-sa/99-011-x/99-011-x2011001-eng.pdf>). Despite having a median age 13 years younger than the general Canadian population, the number of Indigenous seniors doubled between 1996 and 2006 (<http://www12.statcan.ca/census-recensement/2006/as-sa/97-558/p4-eng.cfm>). While this

increase may seem significant, in 2011 the number of Indigenous seniors aged 65 and over accounted for 5.9% of the total Indigenous population, while non-Indigenous seniors accounted for 14.2% of the population (<http://www12.statcan.gc.ca/nhs-enm/2011/as-sa/99-011-x/99-011-x2011001-eng.pdf>). Even though the health and wellbeing of Indigenous people has increased over the last 50 years, Indigenous people still experience higher rates of ill health than non-Indigenous people.

The health status of Indigenous people is far below the national average. Indigenous people have a lower life expectancy than non-Indigenous people and are plagued by higher rates of chronic diseases, cancers, and mental illnesses (Reading 2009). It is important to note that, due to health disparities between Indigenous and non-Indigenous people in Canada, Indigenous seniors are defined as 55 years and older, as opposed to 65 years and older for the general population (Health Council of Canada 2013). Available health surveillance data suggests that Indigenous people experience much higher rates of co-morbidities compared to the non-Indigenous population. For example, the number of First Nations people aged 55-64 reporting three or more chronic conditions is 3.5 times higher than non-First Nations people and 45% of the 65+ First Nations population report fair/poor health with 69% having activity limitations (Wilson et al. 2011). It is generally accepted that poorer levels of health in the Indigenous population are deeply rooted in inequity, social exclusion, historical injustice, and the social determinants of health (Loppie-Reading and Wein 2009).

There are many factors that put Indigenous people more at risk for ill health than their non-Indigenous counterparts, some of these risks include: poverty, housing, access to health care, food security, education, violence, incarceration, as well as environmental

factors, such as air and water quality. When looking at the issue of socio economic status alone, Indigenous women tend to be worse off than their male counterparts. According to the Health Council of Canada's 2005 report on the Health Status of First Nations, Inuit and Métis Peoples,

Aboriginal women are even poorer than their male counterparts. In 1996, 43% of women aged 15 years and over had an income level that was below the low income cutoff compared to 35% of Aboriginal men and 20% for non-Aboriginal women. For lone Aboriginal mothers, the situation was worse as 73% of them lived below the low income cutoff. (2005, 28)

Living in poverty can impact a person's ability to access healthy foods, quality housing and/or health care. This in turn can impact the physical and cognitive development of children and youth, as well as impair cognitive abilities in adults. According to the National Collaborating Centre for Aboriginal Health, "poverty has been associated with an increased risk of chronic disease, injury, poor infant development, a range of mental health issues (stress, anxiety, depression, and lack of self-esteem), and premature death" ([http://www.nccah-ccnsa.ca/docs/fact%20sheets/social%20determinates/NCCAH\\_fs\\_poverty\\_EN.pdf](http://www.nccah-ccnsa.ca/docs/fact%20sheets/social%20determinates/NCCAH_fs_poverty_EN.pdf)).

Research conducted by NWAC, further highlights the inequities that exist for Indigenous women. They found that Indigenous women in Canada have higher rates of chronic illnesses, mental health issues and spousal abuse than non-Indigenous women. They also found that:

They have higher rates of unemployment, poverty, incarceration, and victimization compared to any other sector of the Canadian population. Aboriginal women are five times more likely than other Canadian women to die as a result of violence (CR-GAP Context Aug 2010).

## Snapshot of Colonial Impacts on Indigenous Health

While the health status of Indigenous people is far below the national average, it is important to remember that it has not always been this dismal. Traditionally Indigenous people were in good health. The Royal Commission on Aboriginal Peoples (RCAP) state:

Skeletal remains of unquestionably precolumbian date...are, barring a few exceptions, remarkably free from disease. Whole important scourges [affecting Europeans during the colonial period] were wholly unknown....There was no plague, cholera, typhus, smallpox or measles. Cancer was rare, and even fractures were infrequent....There were, apparently, no nevi [skin tumours]. There were no troubles with the feet, such as fallen arches. And judging from later acquired knowledge, there was a much greater scarcity than in the white population of...most mental disorders, and of other serious conditions. (1996, 5)

The introduction of infectious diseases such as measles, polio, diphtheria, smallpox, among other diseases, decimated many Indigenous communities during the eighteenth and nineteenth centuries. Health epidemics continued to plague many Indigenous people and communities throughout the twentieth century and were characterized through the high levels of influenza, tuberculosis and other diseases. Today, in the twenty first century, we are still seeing a disproportionate rate of ill health amongst Indigenous people, especially when looking at the rates of diabetes, heart disease and HIV/AIDS among the Indigenous population in comparison to the general Canadian public.

The physical ailments that afflicted and continue to affect Indigenous people can be tied to the colonial history. Since contact, many Indigenous peoples have suffered assaults on their culture, beliefs and physical persons because of colonization. During the last century and a half, Indigenous people in Canada were forced onto reserves, placed under the Indian Act and subject to policies directed at assimilating Indigenous people. Examples of assimilation include the banning of ceremonial practices, compulsory attendance at residential schools, forced relocation, and the removal of children through



the 60s scoop. Wesley-Esquimaux and Smolewski state, “Aboriginal people never had enough time, between various sequences of new world epidemics, genocide, trauma and forced assimilation to develop tools for passing through the periodic social and cultural disintegration of their nations” (2004; 77). Any traumas that were not dealt with were often passed on to future generations. Intergenerational / multi-generational trauma happens when the effects of trauma are not resolved in one generation. “When trauma is ignored and there is no support for dealing with it, the trauma will be passed from one generation to the next. What we learn to see as ‘normal’, when we are children, we pass on to our own children” (Ibid. 2). These unresolved traumas contribute to the challenges facing the health and wellbeing of many Indigenous communities today (CCMHI 2006; Krieg 2009; Haskell & Randall 2009; Browne et al 2011).

Within Indigenous communities, health and wellbeing encompass the physical, emotional, mental, and spiritual aspects of our being. When one aspect is out of balance, it can affect all other areas. An example repeatedly referred to in the literature is the multigenerational impacts of residential schools. The impact of the schools on individuals, families and entire communities can be seen throughout all four aspects of health and wellbeing (CIHI 2009; CCMHI 2006). The intergenerational impacts of the residential schools can be seen in the disproportionate levels of abuse, including but not limited to substance abuse, addictions, violence, self-inflicted injuries, as well as poverty and high rates of incarceration that Indigenous people are faced with today. (Haskell and Randall 2009). All of these areas can have serious neurological impacts on Indigenous people and their families. For example, in looking at the impacts of abuse and trauma on Indigenous people Haskell and Randall look at abuse and trauma in childhood and brain

development, stating “studies have shown that children who are abused and neglected tend to have impaired cognitive functioning” (2009, 61). Traumatic experiences in one’s childhood can elevate stress levels and affect how we deal with stress later on in life (events that may not be particularly stressful can evoke strong fight or flight responses), which can lead to heart disease, cancer and stroke, as well as vascular dementias.

The coping mechanisms used to deal with unresolved trauma can further impact personal health and wellness. According to a 2003 study on the Saskatchewan Mental Health Sector, 35-60% of Indigenous people with substance abuse problems are afflicted with mental disorders (Conway 2003). Conway suggests that at some point in our lives everyone suffers from mental health problems, specifically distress, anxiety or depression, which can impact our work, families, and overall health (2003). A more recent study on Chronic Disease Risk Factors in Indigenous Peoples in Canada, suggests that mental disorders can delay individuals from seeking help or diagnosis for other health concerns, including neurological conditions (Centre for Aboriginal Health Research, 2009).

## Literature

The majority of the research dealing with neurological conditions and Indigenous people focuses on Alzheimer’s disease and dementia studies, followed by MS and Parkinson’s disease. Much of this literature tends to focus on the incidence and prevalence of the disease and more of the biological markers of a condition. More recent studies on Alzheimer’s disease and dementia are focusing on impacts and culturally appropriate assessment tools. With many of the conditions researched, it was thought that Indigenous people were less susceptible of being diagnosed with a neurological

condition because of their genetics. This line of thinking has since changed and the rates of neurological conditions among Indigenous people are increasing. Part of this increase can be attributed to a number of reasons including: socioeconomic reasons, intergenerational trauma, access to health care, disproportionate levels of chronic health conditions, as well as other social determinants of health; all of which can lead to increased risk factors.

There is little published information on how Indigenous people think about neurological conditions. This includes how Indigenous people culturally understand neurological conditions, how living with a neurological condition or caring for a loved one with a neurological conditions impacts the individual, the family, and wider community, as well as how these beliefs and impacts influence how people access formal and informal health care.

An extensive review of both peer reviewed and grey literature highlights the need for more research to be conducted on Indigenous peoples' cultural understandings of neurological conditions. Since the literature looking at Canadian Indigenous people was so small, I expanded the search to look at peer reviewed literature focusing on Indigenous people and neurological conditions from the following countries: Canada, United States, Australia, and New Zealand. Indigenous peoples from each of these lands have faced similar colonial policies and practices that have greatly impacted and continue to impact their health and wellbeing. The following databases and sites were reviewed: ProQuest Sociological abstracts, Pubmed, Native Health Database, Embase, and Academic Search Complete. The search terms included: Alzheimer's disease OR dementia OR Brain Injury OR Traumatic Brain Injury OR Acquired Brain Injury OR Trigeminal neuralgia OR

Parkinson's disease OR Cerebral Palsy OR Multiple Sclerosis OR Migraine OR Epilepsy OR Rett Syndrome OR Ataxia OR Stroke OR Minamata Disease OR Shingles AND Aboriginal OR First Nations OR Inuit OR Métis OR Indigenous. These terms were brought forward by the participants in the individual interviews and the research circles.

Within the EMBASE database, which includes medline and embase, the search initially resulted in 12, 595 peer reviewed articles. After limiting the findings to English only journals with abstracts and dealing with human subjects, this resulted in 5,579 articles. The listing was further reduced by study type to 938 with a focus on case reports, cohort analysis, comparative studies, interviews, methodology, prospective studies, questionnaires, or retrospective studies. From there, the listing was paired down to look at Indigenous people in the US, Canada, New Zealand and Australia. Only 22 were selected from the listing.

The Academic Search Complete database was also searched using the same terms and found over 800,000 listings. The findings were limited to scholarly peer reviewed articles from the four countries, with the following subject areas – psychological aspects, societies, economic aspects, physiological aspects, case studies, social aspects, interviews, social conditions, health aspects, questions and answers, bringing the number of articles down to 298; seven articles were relevant.

I repeated the search terms for the grey literature, focusing on websites, reports, and presentations. For these sites, I limited my search to Canadian specific sites. In searching through dissertations and theses, I expanded the search to include Canada and the US from 2000 to 2014. Dissertations between 2000 and 2014 were looked at and

fifteen were downloaded. This listing was further scrutinized based on whether it dealt with the following areas of relevancy:

- cultural understandings
- cultural importance
- perspectives
- stories
- Medicine wheel / holistic – spiritual, emotional, physical, and mental

Only a small number of sources looked at Indigenous cultural understandings of neurological conditions.

### **Limitations within Existing Literature**

Working on a project of this magnitude opened my eyes in many aspects, particularly with regards to the lack of literature on Indigenous people and neurological conditions. Much of the literature that was available focused on dementia among Indigenous people, but there was not much information on the other conditions. If literature was found, it tended to focus on genetics and not on the personal thoughts, beliefs, and impacts it had on the individual, the caregivers, or the family and community.

Please note that there is not a lot of published information on some of the additional conditions brought forward by the participants. For example, there is no literature related to Indigenous people and Ataxia, Rett Syndrome or Trigeminal Neuralgia. There are also no data or literature on incidence or prevalence of shingles or migraines among Indigenous people in Canada.

### **Alzheimer's Disease and Other Dementias**

Research surrounding Alzheimer's disease and dementia make up most of the literature on Aboriginal people and neurological conditions. Alzheimer's disease (AD) is the most common form of dementia, accounting for 64% of all cases in Canada (CIHI

2007). AD is a “progressive degenerative disease characterized by a general decline in mental abilities involving memory, language and logical thinking” (CIHI, 2007, 27).

With AD, certain regions of the brain will have “numerous tiny dense deposits scattered throughout the brain which become toxic to brain cells at excessive levels [called “plaques”] and “tangles” which interfere with vital processes eventually “choking” off the living cells” (<http://www.alzheimer.ca/english/disease/whatisit-intro.htm>). The brain cells essentially wither and die, causing the brain to shrink in some regions. Over time, this shrinkage will drastically affect different areas of the brain and how the person functions. At present, there is no cure for AD but there are medications available that may delay progression and ease symptoms.

Dementia, unlike AD, is a syndrome that can be caused by other conditions aside from Alzheimer’s. For example, dementia may occur in the case of strokes, Parkinson’s disease, HIV/AIDS and alcohol related cognitive decline. Some of the symptoms associated with dementia “include loss of memory, judgment and reasoning, and changes in mood and behaviour” (<http://www.alzheimer.ca/english/disease/dementias-intro.htm>). In cases where dementia occurs because of depression, thyroid disease, infections or drug interactions, the symptoms may be stopped or even reversed with the proper treatment if caught in time.

Research on Alzheimer’s disease and dementia in Indigenous populations is a relatively new area of study (Pollitt 1997). Initially it was thought that Indigenous people were more resilient to contracting AD due to their genetic makeup (Griffen-Pierce et al 2008). This research was first supported by Hendrie et al (1993), who found that Alzheimer’s disease was quite rare among the group of Cree seniors in Northern

Manitoba as compared to a group of seniors from Winnipeg who were a part of the sample study (0.5% compared to 3.5%). Similar research focusing on degree of Indigenous blood as a resilient factor was done by Rosenberg et al. (1996), who studied the relationship between degree of Cherokee ancestry and the development of Alzheimer's disease. They found that the greater degree of Cherokee ancestry (blood) reduces the risk of developing AD. For Cherokee people over the age of 80 years old, the chances of developing AD start to increase. Weiner et al. (2007) looked at the National Alzheimer's Coordinating Center database and found that the number of American Indians, who were seen and evaluated for possible and probable Alzheimer's disease, was a significantly lower amount than White and African Americans who were seen and evaluated. Additionally, survival rates were found to be the same for American Indians / Alaska Natives compared to Caucasians (Mehta et al 2008).

The differences between the amount of Indigenous people who were seen and evaluated for possible and probable Alzheimer's disease or dementia may have to deal with cultural understanding of the disease. One of the challenges may be the lack of understanding and knowledge surrounding dementia and Alzheimer's disease. Garvey et al (2011) surveyed 174 Indigenous Australians at a sports cultural festival and found that participants could not differentiate between Alzheimer's disease and dementia. This may be due to the fact that the word 'dementia' has no meaning in the Indigenous language. Tools such as the CSI 'D', as used by Hendrie et al (1993; Hall et al 1993) with the Northern Cree of Manitoba, translated the evaluation into Cree then back translated it into English, while useful, may not fully incorporate the cultural nuances needed to fully assess cognition.

Cultural concepts and use of language are important in understanding how communities historically dealt with disease and sickness. Henderson & Traphagan's (2005) study attempts to demedicalize dementia by looking at the cultural understanding of senility between Japanese and American Indian populations. Within many Indigenous cultures, confusion and forgetfulness that are associated with early stages of Alzheimer's disease and dementia are seen as a normal, natural, and accepted part of the aging process (Jacklin et al 2015; Cammer, 2006; Hulko et al., 2010; Jacklin & Warry, 2012; Henderson & Henderson 2002; Pollitt 1997). The hallucinations that come with dementia are seen as communication with the other side / the spirit world. The authors note that this is not seen as a stigma, but as a sign of esteem. In looking at dementia and Alzheimer's disease, health care providers need to look at the cultural aspect of senility and how caregivers perceive and interact with their loved ones who may exhibit signs of dementia or Alzheimer's disease.

Lanting et al. (2011) conducted group interviews with Indigenous grandmothers in Saskatchewan, who had experience in providing care to Indigenous seniors in rural and remote conditions. The study was aimed at addressing the gaps in understanding the "cultural perceptions of normal aging and dementia in an Aboriginal population and to explore issues related to the development of culturally appropriate assessment techniques" (104). They found that culturally appropriate assessments should be developed for each region, as Indigenous groups are very diverse throughout the country. Similar techniques have been developed and used to assess cognitive function among Aboriginal and Torres Strait Islander people living in the Kimberley region of Australia,



called the Kimberly Indigenous Cognitive Assessment (KICA) (Smith et al 2008; Smith et al 2010).

By addressing the cultural aspect of aging and forgetfulness or confusion, along with the signs and symptoms of dementia or Alzheimer's disease, clinicians can work with Indigenous patients and communities to better assess cognitive function (Cattarinich et al 2001; Finke 2003; Lindeman & Smith 2010; Smith et al. 2011; Martin et al. 2012). Within the studies the authors found that more acculturated tribal people did better on the standard cognitive tests than those who had less education, were dependent on a supplemental security income (fixed income) or involved in risky health behaviours. Verney et al (2008) found that depressed American Indians / Alaska Natives performed the same in regards to education levels, but also found that depressed individuals performed indistinguishably from non-depressed individuals which is problematic due to depression being an aggravating factor in the development of Alzheimer's and dementia. Jervis and Manson (2002) state that some of the problems may lie with issues in measurement and how the current assessment tools may not be culturally relevant to Native Tribes, by not addressing language, cultural translation or educational biases. This was found in their studies which examined the performance of older American Indians on the Mini Mental State Examination (MMSE) and the Mattis Dementia Rating Scale (MDRS) (2007 and 2010).

Based on the research, the projections and growing awareness for culturally appropriate assessments, we can expect the rates of Alzheimer's disease and dementia will increase with the growing number of aging Indigenous people (McCole Phillips 2003). Within Australia it is suggested that the prevalence of dementia among remote and

rural Indigenous people could be four to five times higher than the general population (Alzheimer's Australia 2007; Bennett 2008; LoGiudice et al. 2010). Smith et al. (2010) look at the demographic, lifestyle and clinical factors associated with dementia in Aboriginal Australians living in the Kimberley region. The researchers identified 400 people over the age of 45 who lived in the region for at least 6 months who were eligible to take part. The KICA was used by trained Indigenous men and women in the area to assess cognitive function. In addition to measuring cognitive function, the authors also analysed demographic features including age, sex and education; lifestyle factors such as smoking, alcohol and chewing tobacco; and clinical factors which includes head injury, heart disease, hypertension, diabetes, previous stroke, epilepsy, falls, mobility, incontinence, urinary problems, vision and hearing. They found that individuals most at risk for dementia were males of an older age, who had little to no formal education and currently smoked, had previous stroke, epilepsy, or head injuries. Demographic, lifestyle, environmental, and clinical factors, especially in terms of having quality access to education, health care, nutrition and employment need to be considered in dementia research and preventative measures for Indigenous people (Osuntokun et al 1992; Weiner et al 2008).

In Canada, while the dementia rates between Indigenous and non-Indigenous population have not been quantified on a national scale, there are some data to suggest the rates are increasing. Jacklin, Walker, and Shawande (2013) looked at population health databases in Alberta and found that the prevalence of dementia was higher for First Nations (registered status Indians) than non-First Nations people. They found that First Nations people who were being diagnosed were diagnosed at an earlier age than non-First

Nations people, with the rates to be 34% higher, and with First Nations men having a “disproportionately higher risk of dementia than non-First Nations males” (Jacklin et al. 2013:42). The Manitoba Metis health status and health care use report looked at the prevalence of dementia among Metis and non-Metis adults aged 55 years and older living in Manitoba from 2002-2006. The prevalence rate “of dementia for Métis in Manitoba aged 55 years and older was 12.4%, higher than the prevalence rate of dementia for the rest of Manitoba, which was 10.6%.” (Smylie & Kooshesh 2013; <http://www.mmf.mb.ca/images/pdf/health/full.pdf>).

In 2014, the Government of Canada, through CIHR and 14 partner organizations announced the launch of a national initiative to research age related neurodegenerative diseases. The Canadian Consortium on Neurodegeneration in Aging (CCNA) is a five-year initiative and consists of 20 teams and over 350 clinicians and researchers working the areas of prevention, treatment, and quality of life (<http://ccna-ccnv.ca/en/about-us/>). Team 20 is the only team within the CCNA that investigates dementia in Indigenous populations. Team 20 is composed of two distinct research streams, rural and Indigenous. Dr. Kristen Jacklin and Dr. Carrie Bourassa lead the Indigenous stream with community partners in Ontario and Saskatchewan (<http://ccna-ccnv.ca/en/about-us/>). The objectives for Team 20 includes,

- examining pathways of dementia care and identifying effective cultural approaches to care for Indigenous people;
- developing and piloting a cognitive assessment protocol that is culturally appropriate to use in Indigenous communities in Canada;
- building capacity and awareness concerning Indigenous dementia research, and
- establishing the incidence and prevalence of dementia in Indigenous and rural populations (<http://www.i-caare.com/>)

Team 20 has adapted the KICA to use with Anishinaabe people on Manitoulin Island in Ontario and will pilot the tool in February 2017. Adapting a culturally appropriate assessment tool to use with Indigenous people in Canada may lead to an earlier and more accurate diagnosis. It may also help improve health outcomes by identifying supports and services for the person with dementia, their caregivers, family and community (Pitawanakwat et al. 2016). The work within Team 20 will lead to further information being published about dementia within Indigenous peoples.

### Multiple Sclerosis

The prevalence of Multiple Sclerosis (MS) in Canada is among the highest in the world, with the rates being at least 100 per 100,000 and much likely higher in more rural or remote areas where official diagnoses are not always available (Pope et al. 2008). In Rosati's 2001 study on "The Prevalence of Multiple Sclerosis in the World; an update" found MS to be quite rare among "Samis, Turkmen, Uzbeks, Kazakhs, Kyrgyzis, native Siberians, North and South Amerindians, Chinese, Japanese, African blacks and New Zealand Maoris, as well as the high risk among Sardinians, Parsis and Palestinians" (117). As more studies are conducted, especially in the Americas, the prevalence of MS seems to be increasing.

Rosati's research suggested that Canadian Natives are at low risk for MS, except when they had Caucasian ancestors, and then their chances increased. This research was initially supported by Warren et al (1996), which looked at the parental ancestry in Albertan MS patients and controls. The authors used the data from the Alberta Health Care insurance plan from April 1984 to March 31, 1989, and found that virtually all patients and controls were Caucasian and had primarily resided in Canada prior to onset age. The authors found that the higher reporting of Indigenous ancestry, the lower

prevalence of MS was reported for both men and women. The authors then went on to disclose that there were no MS patients or controls with Indigenous ancestry in their study and stated that "... our study's observation of a negative correlation between aboriginal ancestry and MS risk is consistent with the observation that MS is virtually non-existent among native North Americans and Inuit, and rarely seen in Métis"(8). The study did not state whether or not they screen for Indigenous people who may have had co morbidities, which is something that Mirsattari et al (2001) found.

Mirsattari et al (2001) conducted the "first population based analysis of MS in aboriginals" by looking at all the registered Indigenous people diagnosed with MS in Manitoba between Jan 1, 1970 and Dec 31, 1996. They found a prevalence of MS among the selected group to be 40 per 100,000, which was significantly lower than the general population in the prairies, which was estimated at a rate of 340 per 100,000 in the Prairie Provinces. This however was still significant compared to worldwide standards, which are classified as low risk if the rates are less than 4 per 100,000 and considered high risk if the prevalence is 30 or higher per 100,000. What Mirsattari et al did find though, was that the disease took an aggressive course with the predominance of neuromyelitis optica (NMO) associated signs and symptoms, which was resistant to conventional MS treatments, and resulted in the rapid development of a secondary progressive disease (2001, 320). This may suggest that patients with co-morbidities are not necessarily being diagnosed with MS.

Two articles by Warren et al (2007) and Svenson et al. (2007) looked at the prevalence of MS among First Nations people in Alberta compared to the rest of the general population. They gathered information from the government health database

between 1994 and 2002 where a diagnosis of MS was mentioned. Svenson et al (2007) look at Mirsattari et al's study (2001) on rates of MS in Indigenous people living in Manitoba, from 1970-1996, which is looked at above. The Alberta study found that the prevalence for MS amongst Indigenous people increased from 56.3 per 100,000 in 1994 to 99.9 per 100,000 in 2002. The prevalence for MS in Alberta's general population during that same time was 262.6 per 100,000 in 1994 and 335.0 per 100,000 in 2002. The difference in rates according to Svenson et al (2007) may be attributable to "lower exposure to an environmental risk factor, greater exposure to a protective environmental risk factor or lesser genetic preIndigenous disposition despite increasing admixture" (180). Warren et al (2007) suggest that:

The lower MS incidence rates among First Nations people than among the general population of Alberta might result from some combination of a younger age of exposure to a causal infection due to differing socio- economic conditions and a lesser genetic predisposition to the disease. (Warren et al 2007, 27)

These statements imply that due to the gross disparities between Indigenous and non Indigenous health, Indigenous people may be more prone to early ill health, but less likely to have MS. This speaks to the larger issues that are evident throughout Indigenous communities. The authors called on more research to be conducted on the prevalence of MS in First Nations across the country, along with an investigation into the adequacy of MS services available to First Nations people.

The lack of research addressing the prevalence of MS in Indigenous people was also brought up by Poppe et al (2008), who reviewed the literature on the prevalence of MS in Canada. The literature review looked at MS studies conducted in each region / province and found more studies were conducted in the west and the Maritimes, than in central Canada. They also focused on studies that were inclusive and therefore excluded

any literature that focused on studies that looked specifically at First Nations or Hutterites in their findings. In their search however, they mentioned that not many studies have addressed MS prevalence in Indigenous people.

One of the main challenges facing researchers in the field includes lack of funding. McFarland (2011) stresses the need for more funding to support lab studies to better understand MS, along with the underlying cause of the disease. In addition, more funding for research is needed to understand the cause of the disease, as to whether genetics (Ramagopalan 2009) or environment play more of a role in someone being more susceptible to MS. More research is also needed to assess the impact of MS on the social, mental or emotional wellbeing of patients or caregivers. Researchers also need to be sensitive to the cultural differences that do exist, especially when working with Indigenous populations.

### **Parkinson's Disease**

It is estimated that nearly 100,000 Canadians have Parkinson's disease, affecting 1% of the population over the age of 65 and increasing to 2% with those aged 70 and over (CIHI 2007). According to the CIHI report on *The Burden of neurological diseases, disorders and injuries in Canada* (2007), the direct and indirect costs of Parkinson's disease in Canada was estimated in 2000-2001 to be \$446.8 million (83). Parkinson's, like many other neurological conditions listed, does not have a known cure however, medications and surgery can help manage the disease.

Most of the research surrounding Parkinson's disease and Indigenous people focus on environmental factors and prevalence rates among Indigenous people living in the north. Beuter et al. (1999) compared Cree subjects exposed to methylmercury to people who have Parkinson's disease, along with a control group and found that

methylmercury affects a different part of the brain and motor function than Parkinson's disease. Methylmercury however has been linked to other conditions that may have Parkinson like symptoms.

Wermuth et al. (2004) evaluated the prevalence of Parkinson's disease among Inuit in Greenland. They found a total of 40 patients, 15 women and 25 men, with a mean age of 68 years had Parkinson's disease. This information was deciphered through the collection of data on LD containing drugs, patients registered with suspected Parkinson's disease seen by the neurologist, and information gathered on patients with possible Parkinson's disease from all hospitals, nursing homes and general practitioners. The authors made note of the low number of Inuit people over the age of 50 years and hypothesized that as the population ages the rates of Parkinson's disease will also increase.

In a separate study, Wermuth et al. (2004) compared the clinical characteristics of Parkinson's disease among the Inuit in Greenland and patients of the Faroe Islands and Als (Denmark). They found that the patients with Parkinson's disease were younger in Greenland than in the Faroe Islands and Als. They also had a higher proportion of cognitive decline than the patients in the other areas. Part of this may stem from the fact that there are no neurologists in Greenland, but rather they have a visiting neurologist that goes two weeks a year as a consultant. This would delay any testing for Parkinson's disease or any other neurological conditions until a neurologist was available. The Faroe Islands have a part time neurologist and Als have five neurologists as well as private neurologists. The higher prevalence may also be due to environmental factors in that the



Inuit have a higher intake of seafood, which has higher concentrations of organochlorine compounds.

Parkinson's studies involving Indigenous people in Canada have been rather limited. Lix et al (2009) looked at the "association between socioeconomic status and prevalence and incidence of Parkinson's disease" using data from the province of Manitoba, which has a high Indigenous population throughout the northern part of the province (Lix, 2009: 335). The researchers found a greater burden of Parkinson's disease in low income rural and urban areas (Ibid.). The findings of this study suggest that further research should be conducted on the correlation between Parkinson's disease and environmental factors, as individuals in rural areas, especially in the Prairie Provinces, may have "greater exposure to environmental contaminants, such as pesticides" (Lix, 2009: 339).

The linkages between socioeconomic status, environmental factors, and access to health care and prevalence rates of Parkinson's disease is alarming when looking at the health and wellbeing of the Indigenous population compared to the non Indigenous population. Indigenous people on average are more afflicted with poor health compared to non Indigenous people (HCC 2005; Shah 2005; Rosenberg et al 2009; Loppie Reading & Wien 2009). Indigenous people in Canada also have lower levels of education and higher rates of unemployment than non Indigenous Canadians, which can impact the health and wellbeing of an individual. For Indigenous people who live in rural or remote areas, health care and access to specialists such as a neurologist may be harder to come by. Inadequate access may mean that individuals will not be able to get the treatment or medication needed to help control or alleviate symptoms.

## Cerebral Palsy

There are many different types of Cerebral Palsy with the classification being by number of limbs involved or type of movement disorder. Cerebral Palsy occurs when the brain is damaged, “whether caused by genetic or developmental disorders, injury or disease” in fetal development, during birth or in early childhood.

(<http://www.cerebralpalsy.mb.ca/about.htm>). The condition is not progressive, but the effects of cerebral palsy may change over time. According to the CIHI, “common symptoms include muscle tightness or spasm, difficulty with gross and fine motor skills and abnormal perception and sensation” (CIHI 2007, 51). The report also suggests that

Individuals with CP may also develop seizures, learning difficulties, behavioural problems and difficulties in communicating, swallowing and breathing. CP varies widely in its severity. In its mildest form, it manifests in a slight awkwardness of movement or hand control; in its most severe form, there may be virtually no muscle control and profoundly compromised movement and speech. (CIHI 2007, 51)

Cerebral Palsy is not hereditary, nor is it contagious or life threatening and it cannot be cured. People living with Cerebral Palsy have a normal life expectancy. The direct and indirect costs in 2000-2001 were estimated to be \$381.8 million (CIHI 2007).

Rates of cerebral palsy in Indigenous people in Canada, are not documented, nor are the impacts on the families or communities caring for individuals with cerebral palsy. The literature that does exist is related to the exposure of methylmercury in pregnant and nursing women. There are many factors during pregnancy that may cause cerebral palsy including,

multiple births; a damaged placenta which may interfere with fetal growth; infections; poor nutrition; exposure to toxic substances, including nicotine and alcohol; maternal diabetes, hyperthyroidism or high blood pressure; premature dilation of the cervix leading to premature delivery; biochemical genetic disorder; chance malformations of the developing  
(<http://www.cerebralpalsy.mb.ca/about.htm>).

Rivera et al (2003) and Walker et al (2006) looked at the impacts of methylmercury on high risk groups such as pregnant women and children. Rivera et al state “Methyl mercury has been noted to be one of the most potent neurotoxic compounds known to man, which easily crosses the placental barriers in pregnant women and into the fetus’ blood-brain barrier resulting in “infantile cerebral palsy like syndrome” (2006; 1141). In areas where traditional foods may be the cheapest and healthiest option for pregnant and nursing women, the risk of foods being contaminated is very scary.

Further research needs to be conducted on the prevalence rate of cerebral palsy among Aboriginal people especially when looking at the environmental factors, combined with diet and nutrition as well as the other factors that may occur during pregnancy. Additional research could focus on longitudinal studies to document the impacts of methylmercury on neurological function. Of course, research on the impacts of raising children with cerebral palsy, especially in more remote regions, would greatly add to the literature.

## **Epilepsy**

There are many different causes and types of epilepsy, in which “the incidence is highest during childhood and among the elderly” (CIHI 2007, 59). Seizures are not always indicative of epilepsy, as there may be other reasons associated with an individual having seizures, such as a high fever or adverse reaction to medication or other drugs. According to Epilepsy Canada, approximately 0.6% or 175,000 Canadians are affected by epilepsy with close to 15,500 additional people being diagnosed each year (<http://www.epilepsy.ca/en-CA/Facts/Epilepsy-Facts.html>). Epilepsy may occur as a result of a brain tumour, stroke, head trauma, injury or infection, poisoning or substance

abuse, but in “50 to 60% of cases, the cause of epilepsy are unknown”

(<http://www.epilepsy.ca/en-CA/Facts/Epilepsy-Facts.html>). Treatments may include medication or surgery if only part of the brain is affected, nerve stimulation and a ketogenic diet

([http://www.bcepilepsy.com/publications\\_and\\_resources/FAQs.aspx#howis](http://www.bcepilepsy.com/publications_and_resources/FAQs.aspx#howis)). The direct and indirect costs associated with Epilepsy in 2000-2001 were estimated at \$797.7 million (CIHI 2007, 60).

Jette et al (2007) looked at how epilepsy patients utilize health resources in the Calgary Health Region. In one of the studies that the authors looked at showed that “epilepsy patients in Ontario had more frequent visits to physicians, more hospitalizations, and greater use of psychology, and/or social work services compared to individuals without epilepsy” (587). While conducting the research the authors found that “Aboriginals were more than twice as likely than non aboriginal to see a GP, visit the ER, or be hospitalized, yet were a third less likely to see a neurologist” (Jette et al, 2007, 591). They speculated that this may be due to “poor communication due to language differences, geographic remoteness, poverty, and cultural differences” (Ibid.). While this study looks primarily at the costs of health resource utilization, it raises an interesting point in that Indigenous people are less likely to see a neurologist than non Indigenous people. The rationale behind why this may happen does not seem to consider institutional racism or if Indigenous people are even being referred to neurologists at the same rates of non Indigenous people. This needs to be taken into account, especially when looking at Indigenous children in care and how they may slip through the cracks and not be referred to a neurologist if they are moved around a lot. A study conducted with the Tewa Pueblos

in New Mexico, found that parents were very forthcoming in seeking health care for their children with epilepsy symptoms (Debruyn 1990), but that culturally inappropriate care, social isolation, and lack of access to care resulted in barriers that deterred many from seeking care.

Wilson et al (2012) found that Indigenous Australians reporting to the emergency department of hospitals for treatment of epilepsy-related seizures have suboptimal adherence to anti-epilepsy drug treatment. Approximately 50 percent of those admitting to inpatient services under-utilize their anti-epilepsy drug treatment. Indigenous Australians are overrepresented in emergency department treatment of epilepsy seizures. The authors note that alcohol abuse and traumatic brain injury, both associated with seizures, are more prevalent among this population. The under-utilization of medication is complex, and not unique to Indigenous people suffering from epilepsy. Regular follow-up and improved access to information may contribute to a decline in lack of adherence and emergency department visits.

Schiariti et al (2009) looked at the prevalence of epilepsy in children in British Columbia with data obtained between January 1, 2002 and December 31, 2003. They found that there was a higher prevalence of epilepsy “among those with low socioeconomic status” as well as “a higher prevalence of epilepsy was observed in those health regions with a higher proportion of First Nations” (Schiariti et al, 2009, 36). No exact cause has been identified to explain why this may be the case. The authors also note that there have been no studies that have focused specifically on the prevalence of epilepsy in First Nations people in Canada. Treatment outcomes and surgery success rates often do not collect demographic information, which presents another challenge to

assessing targeted programming (Szaflarski et al. 2006). More research in this area would help identify why these gaps exist and describe how Indigenous people cope with the challenges of caring for individuals with epilepsy, as well as treatment-seeking behaviours across cultures.

### **Head Injury (including Traumatic Brain Injury and Acquired Brain Injury)**

Head injuries in Canada in 2000-2001 accounted for \$151.7 million in direct costs (CIHI, 2007, 68). The indirect costs were not available as the exact prevalence for head injuries is unknown, but estimated at 11.4 per 100,000 for severe traumatic brain injuries (TBI) and 600 per 100,000 for mild TBI, also known as concussions (CIHI, 2007). According to The Brain Injury Association of Canada, “brain injury is two times greater in men” than it is in women (<http://biac-aclc.ca/en/what-is-it/>). This can result from motor vehicle accidents, falls, or blows to the head. Colantonio et al (2009) found that hospitalization in Ontario for TBI was highest amongst the oldest segment of the population. This study however, did not have any specific information in regards to Indigenous people and TBIs.

The rates for acquired brain injuries, both traumatic and non traumatic, for Indigenous people in Canada are much higher than the general population. According to Karmali et al, “Aboriginal Canadians had nearly a 4-fold greater risk of severe trauma than the non-Aboriginal population.” (2005: 1010). Severe trauma in this case includes motor vehicle accidents, assaults, and self injury including suicide. Karmali et al also found that “Aboriginal Canadians had a 10-fold greater risk of injury secondary to assault and a 3-fold greater risk of traumatic suicide” (2005, p. 1010). Cameron et al (2005; 2008) looked at injury outcomes following a TBI over 10 years in the province of Manitoba. Part of their findings addressed the fact that TBI in Manitoba impacts younger

people, mostly males from lower socio-economic groups with poor education levels and Indigenous people (2008, 437). Blackmer and Marshall (1999) found that Indigenous people in the province of Saskatchewan were more likely to suffer from a head injury where alcohol is involved and are less likely to obtain resources for rehabilitation after a TBI than non Indigenous people. These findings are consistent with US research that reports that American Indians / Alaska Natives suffer mild TBI at much higher rates than the rest of the population, but males and those under five years of age are at a higher risk even within this group (Bazarian et al 2005).

## Stroke

A stroke is caused by an interruption of blood flow to the brain, which results in a sudden loss of brain function. This can cause the brain cells in the affected area to die. Depending on where the brain was injured and how much damage occurred during the stroke, an individual's ability to "move, see, remember, speak, reason and read and write" will be affected

([http://www.heartandstroke.com/site/c.ikIQLcMWJtE/b.3483935/k.736A/Stroke\\_What\\_is\\_Stroke.htm](http://www.heartandstroke.com/site/c.ikIQLcMWJtE/b.3483935/k.736A/Stroke_What_is_Stroke.htm)). According to the Heart and Stroke Foundation of Canada, there are over 50,000 strokes each year in Canada and 14,000 deaths from stroke. Also reported, more women than men die each year from stroke even though men are often at higher risk than women to have a stroke. (<http://www.heartandstroke.com/>). This may result from a combination of factors including stress, diet/nutrition, lack of physical activity, and high blood pressure. For Women who smoke or have diabetes, their risk of stroke increases. According to CIHI (2007) the total costs associated with stroke in Canada in 2000-2001 was \$2.8 billion.

In Canada there is insufficient information relating directly to Indigenous people and stroke. Most of the literature looks at the links between diabetes, cardiovascular disease and strokes. The University of Manitoba, along with the Manitoba Metis Federation looked at the rate of stroke among Metis people in the province. They found that the rate of stroke among Manitoba Metis is nearly 25% higher than for other Manitobans. Yiannakoulis et al (2009) looked at how cerebrovascular disease is diagnosed between differing facilities / geographic areas in Alberta. In more remote and rural areas, where a large portion of Alberta's Indigenous people live, differences in diagnostic practice style may exist, leaving remote and rural patients with unequal access to treatment and survival. Unequal health care for Indigenous populations living in remote or rural locations is consistent throughout most of the literature, so this observation is not surprising.

The literature throughout Canada, the United States, Australia, and New Zealand speaks to the discrepancies between the Indigenous and non Indigenous populations when it comes to strokes and health care matters, including prevalence, prevention and rehabilitative measures. Zhang et al (2008) looked at the incidence of strokes among American Indians and found that American Indians have a higher incidence of stroke compared with US white and black populations. They also found that "the case-fatality rate for first stroke is also higher in American Indians than in the US white or black population in the same age range" (1577). Feigin et al (2007) stated that "Maori and Pacific peoples are at a two to three times greater risk of ischemic stroke and intracerebral haemorrhage," then New Zealanders of European descent (209). The authors also found that the incidence of strokes in Maori and Pacific peoples is occurring



at a younger age than non Maori and Pacific peoples. This in itself can be a problem due to

funding for and access to rehabilitation services in New Zealand is much more restricted for patients under 65 years of age than those 65 years of age or greater [which] means that there is institutionalised bias against Maori and Pacific Island stroke patients in our public health system. (209)

Lack of proper access to services can add even more stress to families and communities dealing with a difficult situation. In Australia, Faux et al (2009) consider the differences in care, rehabilitation and cultural understanding between urban and rural and Aboriginal and non Aboriginal people. Cardiovascular risk factors (CRF) and history of an individual contribute to the likelihood of stroke, as well as developing Alzheimer's disease. Choctaw Indians were found to have more and more severe CRF than the white population. Modifiable risk factors, such as diabetes, elevated cholesterol, smoking, and obesity were found to be more influential than non-modifiable risk factors such as genetic predisposition. Due to the presentation of more, and more intensified, modifiable CRF in Choctaw Indians, Weiner et al (2010) argue that these risks could be mitigated through preventative interventions. Some of the discrepancies between cultures exist due to language barriers, cultural understandings of stroke and rehabilitation, poor infrastructure, and remote access of the communities.

The co-morbidities that exist between diabetes, heart disease and stroke greatly impact Indigenous people. Indigenous people are at greater risk of developing type 2 diabetes, with 1 in 5 Indigenous people over the age of 18 being diagnosed with diabetes compared to 1 in 19 in the general Canadian population ages 20 and older. The prevalence of smoking, obesity, and high blood pressure is also higher among Indigenous people than the general population

(<http://www.heartandstroke.com/site/c.ikIQLcMWJtE/b.3483991/k.34A8/Statistics.htm>).

Given these risk factors, more research should be conducted on the impacts of stroke on Indigenous people and their families. In terms of public awareness, the Heart and Stroke Foundation is trying to make people aware of the warning signs through public service announcements, pamphlets, posters and videos geared specifically towards Indigenous people.

([http://www.heartandstroke.com/site/c.ikIQLcMWJtE/b.3479041/k.FFD0/First\\_Nations\\_Inuit\\_M233tis\\_Resources.htm](http://www.heartandstroke.com/site/c.ikIQLcMWJtE/b.3479041/k.FFD0/First_Nations_Inuit_M233tis_Resources.htm)). In addition to the PSAs and additional resources, the Canadian Stroke Network also published a report with a series of recommendations for the public, care providers and policymakers (2011). Research in areas such as prevalence of stroke in Indigenous people, access to health care, health professionals, and rehabilitation could add to the literature.

There is a need for more information concerning Indigenous people and neurological conditions. Within the literature review, most of the research and publications pertaining to Indigenous people and neurological conditions are on Alzheimer's disease and dementia. This area also includes the most literature on cultural understandings of dementia and Alzheimer's disease. The findings within this dissertation look at some of the gaps in the literature when it comes to cultural understandings of neurological conditions and how this understanding influences how people access care.

### **Chapter 3: Methodology and Theoretical Lens**

The UFW project gathered a wide array of stories from people who lived with a neurological condition, caregivers who looked after loved ones with a neurological conditions, as well as health care providers, and Traditional Knowledge Keepers. This chapter discusses the background and methodology of the original project, and the theoretical lens used to conduct the secondary analysis. The secondary analysis of this data set brings forth stories related to cultural understandings of neurological conditions and interactions with the health care system. The theoretical framework used in the secondary analysis draws on both Indigenous ways of knowing and Critical Medical Anthropology. Mi'kmaw Elder, Albert Marshall, best describes this framework as “two eyed seeing”, where one eye looks at the issue through the strengths of Indigenous knowledges and ways of knowing, while the other eye looks at the issue from the strengths of Western knowledges and ways of knowing (C. Bartlett, 2011; Bartlett, CM et al. 2007, 2008, 2012; Iwama et al 2009).

The stories gathered during the UFW project shed a light on what it means to be an Indigenous person living with a neurological condition or caring for a loved one with a neurological condition. For many participants this was the first time they were ever asked to share their stories. This dissertation aims to honour the spirit of the stories and the participants who shared them through providing a more thorough analysis on the role of culture in living with a neurological condition or being a caregiver for someone living with a neurological condition. It will also look more closely at the interactions with the health care system.

## **Background and Methodology of Original Project**

The UFW project wanted to get a better understanding of how neurological conditions affects Indigenous people who live with a condition and people who care for those with a condition, including the impacts on their families and communities. The UFW study initially proposed a mixed methods study, where qualitative data would be collected through key informant interviews and research circles, and quantitative data would be collected through surveys. The anticipated sample size for the study was 50 participants for the qualitative section and 1000 participants for the survey. Under the proposed activities and work plan, the co-PI's called for an emergent design, to incorporate the contributions from the Advisory Committee members. This approach requires flexibility to adapt the work plan as needed. Outlining this approach helped when the Advisory committee and research team realized that there is no baseline information on incidence and prevalence rates and that designing and administering a survey without this information would prove to be incredibly challenging. The research team was also faced with funding delays, time constraints, and limited staff to conduct a project of this magnitude. The project was scaled back to a qualitative study, to focus on the lived experiences of Indigenous women living with a neurological condition or caring for a loved one with a neurological condition.

## **Indigenous Research Methods**

The research team utilized Indigenous Research Methodologies (IRM) into the design of the questions, collection of data, and the analysis of the findings. In the context of the UFW project Indigenous Research Methodologies includes Indigenous ways of

knowing, Indigenous protocols, along with the 4R's of research involving Indigenous peoples – Respect, Reciprocity, Relevance, and Responsibility (Kirkness and Barnhardt; 1991). The Centre for Aboriginal Health Research (CAHR) based out of the University of Victoria provides the following outline of the 4R's:

***Respect***

*Respect toward Aboriginal Peoples is demonstrated through research partnerships that value the contribution of diverse indigenous knowledge. Respectful research acknowledges that expertise comes from local traditions and cultures, which are embodied within community members. This approach addresses the power imbalances between community members and researchers by not privileging “expert” knowledge from the academy over community expertise.*

***Relevance***

*Relevance of research partnerships requires not only the respectful integration of indigenous perspectives into research methodology, but also requires that the research is relevant to the experiences of Aboriginal peoples. In particular, research projects should be developed in partnership with community members to ensure that the research is taking up issues that are important to the community.*

***Reciprocity***

*Reciprocity requires that researchers and communities are engaged in a two-way process of learning and knowledge exchange. Community-based research needs to ensure that communities directly benefit from their participation in the research. The presentation of results need to be accessible and understandable to community members, and should be delivered through community-based processes of knowledge exchange (presentations at community dinners and storytelling).*

***Responsibility***

*Responsibility requires that researchers are actively engaged in rigorous self-reflection, and take cues from ongoing engagement and consultation with the community. In particular, responsibility requires that researchers follow ethical research guidelines of their own institutions, as well as any community-based protocol. Preparation of research agreements that outline the community's rights to ownership, control, access and possession (OCAP principles) of the research, represents that commitment to be a responsible and respectful partner in community-based research.*

<http://www.uvic.ca/research/centres/cahr/research/current/community/index.php>)

The research team used this framework to engage with Indigenous men and women, and their communities in a culturally appropriate and safe manner.

In reaching out to potential participants, the research team relied heavily on the Advisory Committee, NWAC's provincial and territorial member associations (PTMAs), existing networks, and various forms of media, including Facebook, radio announcements, and a local television interview. We knew that we would have a better chance of recruiting Indigenous people to come forward to share their stories if they had a better idea of who they were sharing their stories with and why it was important. The research team was very aware that some people may be leery of another study "targeting Indigenous people" and wanted to be as open, inviting and transparent as possible. The Advisory Committee helped guide the research, assist with the recruitment process, and data analysis.

In order to engage Indigenous women across Canada and fulfill the mandate of the NPHSNC, the research team took a four directional approach in recruiting participants. The research team, with the help of the Advisory Committee, went to great lengths to engage Indigenous people and communities in all four regions of the country. The divisions are classified in the following ways: the eastern quadrant includes Ontario and all provinces east of there, the southern part of the country was listed as Saskatchewan and Manitoba, the western quadrant includes Alberta and British Columbia, and the north includes the territories of Nunavut, North West Territories, and the Yukon.



The research team worked with Advisory Committee members from the different areas to ensure that the proper protocols of each region were followed. This included having a community person, where community members could approach and give feedback on the research project, as well as creating a safe environment for Indigenous people to share their stories and experiences. These methods are consistent with Indigenous Research Methodologies in terms of ensuring accountability based on the relationships between the community members, the community contact person and the research team (Wilson 2008; Kovach 2009; Tuhiwai Smith 2012).

The research team wanted to ensure that the participants were able to share their story and used two methods to collect information: in-depth interviews and research circles. The research coordinator set up the interviews and research circles, as well as

conducted or took part in the majority of interviews and research circles. The research coordinator's role was to collect and take care of the stories. This included setting up the process for participants to feel at ease and trust that the coordinator would treat their stories with respect. In order to facilitate this process, coordinator would start with introducing herself, stating who she was, where she was from, how she came to be a part of the project, and share some of her own experiences with neurological conditions. This process of situating oneself within the research is consistent with Indigenous Research Methodologies (Kovach 2009, Wilson, 2008). This method is also described by Absolon, who states: "Indigenous worldview seeks that you identify yourself to the Spirit, the people and the Spirit of the work you intend on doing and this act establishes the beginning of respectful practice" (2010: 75). For many of the participants, knowing that the coordinator was of Cree and Ukrainian descent, a member of Gordon's First Nation, in Saskatchewan, and had personal experiences with neurological conditions helped in making them feel more at ease. Being an Indigenous researcher, also means being responsible to the people we are working with, along with the communities, while proving to the funders that this work is needed and that the research is valid. This concept of insider and outsider research is discussed by Innes:

...although insider researchers have had to face certain research challenges, they have also had to address the issue of the validity of their research. Insider researchers reject notions that research can be objective and bias-free, that they have to distance themselves from the research groups, and that the perspectives they bring to the research agenda do not have scholarly merit. They acknowledge that being insiders has not meant automatic access to research participants. Because most insiders for a variety of reasons are to some extent also outsiders, they also have to negotiate their research relationships. Their relationships with the research group are different from those of outsiders, for insiders may have to contend with protocols and community expectations. Their insider status, however, gives them a deeper contextual insight into the community. (2009:446)



The research team, along with the Advisory Committee acknowledged that all of us had a responsibility to ensure that the research conducted was “sympathetic, respectful, and ethical from an Indigenous perspective” (Louis, 2007: 139). This responsibility also carried over into fighting for the participants’ stories to be included in the national synthesis report. To explain how living with a neurological condition or caring for a loved one with a neurological condition is different for Indigenous people and account for the colonial history and Indigenous determinants of health.

### **Collecting the Stories**

In-depth interviews and research circles were used to collect the stories. In-depth interviews were conducted with three distinct groups of people: key informants (KI) (18), made up of health care professionals; traditional knowledge keepers (TKH) (4), including traditional Elders and healers; and individuals (ID) (18), who are Indigenous people living with a neurological condition or caring for someone with a neurological condition. The interviews followed a conversational style where open ended semi-structured interview questions were used to prompt the discussion.

Research circles were used to share and gather knowledge. The research circles were conducted similar to a sharing circle, but with the understanding that the information shared will be used for research purposes. Each participant was invited to share their story and then pass the floor to the next participant when they were finished. There were six research circles in three provinces and one territory, for a total of 40 participants. The research team worked closely with a community contact person to ensure the research circles were culturally appropriate for the region and provided a safe space for participants to share their stories. Depending on the region and cultural traditions practiced, Elders were presented with tobacco, cloth, and an honorarium and

asked to open and close the circle with a prayer. Within some Indigenous cultures, tobacco is one of the four sacred medicines and is used as an offering to ask for guidance as well as give thanks. In presenting the Elders with cloth and tobacco, we were asking them and the spirit world to help us with our research; to help ensure that our bodies, minds and hearts were open to receiving the information that was being shared, and that the participants felt comfortable in sharing their stories with us. The Elders who were involved in the research circles were trusted members of the communities they served and were able to provide additional support to the participants, if needed, after the circle ended.

All participants were offered food, refreshments, and an honorarium for their time. Transportation and childcare were also provided for individuals who would otherwise not be able to participate. All interviews started with the interviewer introducing their self and explaining how they became involved in the research project. All the participants were asked to share their own story. For people who lived with a neurological condition or cared for a loved one with a neurological condition, this often included information about the neurological condition, the signs and symptoms exhibited, the path to getting a diagnosis (if one was sought out), and their life after the diagnosis. The key informant participants often shared how they became interested in their profession and the path they took to get there. The traditional knowledge keepers shared information about their own lives, including where they were from, their family, as well as their path through life.

In addition to asking the participants to share their own stories, the researchers also had a set of open-ended questions for each group. The following questions were asked to the participants in the individual interviews and the research circles:

- Prior to your experience with a neurological condition, what did you know or think about neurological health? How has your understanding of neurological health changed since diagnosis?
- What kind of impacts has the condition have on you / family – for example emotionally, spiritually, mentally, physically?
- In trying to develop a vision that comes from Aboriginal women themselves to help guide ongoing and future efforts to foster neurological and overall health and well-being of Aboriginal women, their families and communities, we would like to ask you what you feel is needed, what you think would help to promote and support neurological health and well-being for Aboriginal peoples and communities across Canada.

Key informant participants and Traditional Knowledge Keepers were asked a slightly modified set of questions. Key informant participants included Indigenous and non-Indigenous health care professionals, who work in primary, secondary, and tertiary care settings, research institutions, and community care settings. The key informant participants were asked the following questions:

- Could you tell me about your knowledge and experience relating to neurological health? (Potential probe/clarifying question: This might include your personal or work experience, traditional Indigenous teachings or western education...)
- We are particularly interested in the impact of neurological conditions on Aboriginal women, their families and communities, including access to neurological health care.
  - o From your perspective, what information would be helpful for Aboriginal women to know in accessing neurological healthcare?
  - o From your perspective, what information would be helpful for service providers to know in responding to Aboriginal women accessing neurological healthcare?

- As part of our project, we are exploring Aboriginal cultural perspectives on neurological health. Could you talk about how you have seen issues of culture (Aboriginal or otherwise) addressed in neurological health care?
- Our project seeks to contribute towards improving neurological health for Aboriginal women, their families and communities. Based on your experience, what issues or information do you think are important in promoting the health and well-being of Aboriginal women living with a neurological condition or care-giving for someone living with a neurological condition?

The questions posed to the Traditional Knowledge Keepers and Elders looked more at traditional understandings of neurological conditions.

- Western medicine has defined neurological conditions as conditions effecting the brain, spine and nerves. This does not easily relate to more holistic views of health that are typical to many Indigenous traditions. Could you speak about how you think neurological health issues could be understood and addressed through the lens of the traditional teachings that you carry?
- Our project aims to contribute towards improving neurological health for Aboriginal women, their families and communities. Based on your experience and knowledge, what issues or information do you think are important in promoting the health and well-being of Aboriginal women living with a neurological condition or care-giving for someone living with a neurological condition?
- What knowledge do you think service providers working in neurological healthcare should know in providing care for Aboriginal women? What knowledge do you think health policy makers should know to better respond to the needs of Aboriginal women, their families and communities?

Even though the questions were geared towards each group of participants, the researchers wanted the questions to be open enough to allow the participants to share their thoughts, experiences, and hopes for the future.

In explaining the project and going through the letter of information and consent, participants were able to choose to have their interview audio recorded or for the interviewer to take notes. The interviews and research circles were transcribed with a

copy of the transcription being sent back to each participant for review and editing. Once the transcripts were approved, all identifying information was taken out of the transcripts and the data was coded using NVivo 10.

Grounded theory was used in the initial analysis of the data. During the first look at the data, concepts were identified using a line by line analysis (open coding) (Moghaddam, 2006). These concepts were broken down into significant events, actions, objects, or phenomena. These events were given names that were grounded in the words of the participants. During the second stage of coding (axial), categories were compared to subcategories and several categories were collapsed together to form a new category based on similarities during the analysis. In some cases new categories were completely renamed. A third level of coding (selective coding), was applied and the categories were analyzed to see if the categories were related and interconnected (Understanding from Within report 2013).

The advisory committee were invited to participate in the second phase of the analysis using an adapted Collective Consensual Data Analytic Procedure (CCDAP) as described by Bartlett et al. (2007). This collective process allowed the research team to draw off the expertise of the Advisory Committee to ensure that the research findings remained relevant and that respectful inclusion of the Indigenous voice occurred. The process is described below:

A CCDAP normally follows a process during which all interviews and research circles are transcribed, coded, and printed onto cards. On one side of the card is a word or small sentence summarizing what is contained on the other side of the card. The other side of the card is typically a piece of coded data or in other words, a quote from the interviews or research circles. The team then collectively clusters the cards under symbols (symbols are used to avoid pre-naming the columns) based on similarity or association. Discussion may be required among

the group to come to consensus on where to place a given piece of data. Consensus, for the purposes of this process, does not mean everyone has to agree fully with every decision; rather, the group needs to find the middle ground or what decision can be lived with. Once all the cards are placed on the —walll in columns, the clusters are rechecked for accuracy and then given names that typically become the main themes of the study. (NWAC 2013. Final Report: “Understanding from Within”: Exploring the impacts of neurological conditions on Aboriginal women, their families and communities. p.48)

The research team connected with members of the Advisory Committee remotely using GoToMeeting, where an eight hour virtual meeting took place. Major themes and sub themes<sup>11</sup> emerged in the research, along with a series of recommendations intended to improve relations between the medical community and Indigenous peoples, and to promote the importance of Indigenous control of health care services (NWAC 2013).

### Secondary Analysis of the Data

Conducting secondary data analysis has certain benefits, while also posing certain challenges. The original project was national in scope, with recruitment efforts taking a four directional approach – North, East, South, and West. Interviews and research circles were conducted across four provinces and one territory with a total of 80 participants. Replicating the data collection for a dissertation would not be feasible for a number of reasons, including the time and budget needed to travel to each province and territory to engage community members and recruit participants (Long-Sutehall et al. 2010). During the original study the questions asked of the data were sufficiently answered and data saturation was achieved. In the secondary analysis, new questions are posed to gain a better understanding of the role culture plays in thinking about and accessing care for neurological conditions. Permission was obtained from Dr. Carrie Bourassa, Principal

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<sup>11</sup> A summary of the analytic categories outlining the themes and subthemes are listed in appendix A.

Investigator for the “Understanding from Within” project, to use the data for my dissertation study.

### **Understanding the Use of Culture**

Culture within the context of this thesis will draw from cultural anthropology and Holm’s “peoplehood model” (Holm 2005). Bates and Plog define culture as “a system of shared beliefs, values, customs, behaviors, and artifacts that the members of a society use to cope with their world and with one another, and that are transmitted from generation to generation through social learning” (1990: 7). The collective and cumulative knowledge surrounding these beliefs, values, and experiences help make sense of the world. The peoplehood model consists of a distinct language, ceremonial cycle, territory, and sacred history. The peoplehood matrix is interconnected in that language gives meaning to the sacred history and place of a tribe, while place gives meaning to the ceremonial life that are in turn connected to environment (Holm 2005). The four factors of the peoplehood model, language, sacred history, ceremonial cycle, and land, are interwoven and dependent on one another (Holm, Pearson & Chavis; 2003: 12). No one factor is more important than the other, nor can any one factor exist without the other. The knowledge stemming from the peoplehood model comes from within the culture. It helps explain how a group of people see themselves and want to be represented. Internally the peoplehood model embodies kinship roles and sovereignty.

Cultural understandings and beliefs play a large role in how a person lives life, cares for a loved one, and interacts with the outside world. Culture needs to be taken into consideration when looking at how a person views their own health and interacts with the health care system. Failure to consider culture in relation to health and health care

services contributes to the continuation of inequitable care, which results in the health disparities among Indigenous people that are seen today. Over the last 20-30 years, the importance of including culture in health care can be seen with the development of cultural awareness, cultural sensitivity, cultural competency, and cultural safety courses. Through acknowledging that culture matters in discussing how Indigenous people think about neurological conditions and in turn access care, including health care services, we can learn more about what is needed to ensure that the services rendered are culturally safe for the people who access them.

### **Theoretical Framework for Secondary Analysis**

The “two-eyed seeing” theoretical framework encompasses Indigenous knowledge and Critical Medical Anthropology. Indigenous knowledge, while drawing on cultural knowledge, encompasses knowledge of Indigenous peoples, practices, languages, histories, and relationships. Indigenous knowledge is something that has been experienced, thought about, passed down, reworked and improved upon by succeeding generations. Indigenous knowledge is tied to land, and includes the stories pertaining to the land, the place names, ceremonies, and medicines gathered. Indigenous knowledge is also linked to a sacred history; in Canada and parts of the US, this can be seen through the treaties and treaty rights. In the US, this can also be linked to treaties, removal, termination, and tribal self-governance. According to an Indigenous and Northern Affairs Canada (INAC) report titled “Indigenous Knowledge and Pedagogy in First Nations Education: A Literature Review with Recommendations:”

Indigenous knowledge thus embodies a web of relationships within a specific ecological context; contains linguistic categories, rules, and relationships unique to each knowledge system; has localized content and meaning; has established customs with respect to acquiring and sharing of knowledge (not all Indigenous



peoples equally recognize their responsibilities); and implies responsibilities for possessing various kinds of knowledge. (Battiste, 2002, p. 14)

Under this definition, Indigenous knowledge is understood as a living process. The core information remains relatively stable, while the details may shift depending on who the information is being told to.

In using Indigenous ways of knowing, along with a critical interpretative medical anthropological framework, I will contextualize the stories to help explain the micro and macro social situations, the political systems and local cultural patterns in shaping health.

Critical anthropology underlines the significance of how politics and economic powers take part in the influence of welfare and sickness, and the human experiences of health and illness. Critical medical anthropology takes it a step further and recognizes the value of the holistic causes of illness and the discriminatory qualities that biological and physiological principles act as a predominant influence over others. It also looks toward the relationship between medical providers with political structures, and the challenges that are faced between individuals and their medical providers. (Walker 1998)

Neurological conditions do not exist in a vacuum. There are many factors that surround health and wellbeing, including colonial policies that continue to impact how people think about health and in turn how they access health care services.

### **Secondary Analysis Using a Narrative Approach**

The secondary analysis was conducted using NVivo 10 to help organise the data. The transcripts of the individual interviews and the research circles were recoded using the two research questions: 1) How are neurological conditions culturally understood? 2) Does this understanding influence how people access care? In rereading through the interviews, nodes were used to capture key themes and ideas related to culture, supports, health care, and treatment. These nodes show all the related material in one place. After each transcript was coded, a memo link was created, outlining key details and themes that

stood out including, whether the participants lived with a neurological condition or was a caregiver, what the condition was, and whether culture came up, as well as treatments accessed. Multiple nodes were created to capture the different aspects of culture that arose throughout the transcripts. These included the condition being seen as a gift, cultural practices, cultural understanding, cultural and normalization, culture and taboos, resilience, and role of culture..

In looking at the second part of the question around how people access care, participants spoke about health care services, the differences between traditional and western medicine, as well as supports they either had or needed to have in order to improve care. A couple of participants spoke about the stigma and institutional racism they faced in accessing health services. Participants also brought forward stories of discrimination in trying to access services related to care, such as medical, social, or disability assistance or services. This was particularly true for participants who lived with hidden or invisible disabilities, such as brain injuries, epilepsy, severe PTSD, trigeminal neuralgia, among other conditions.

The secondary analysis of the key informant transcripts followed a similar method, with slightly different questions guiding the analysis. The research questions for this data set are: 1) What are the experiences of HCP in caring for Indigenous people who either live with a neurological condition or care for a loved one with a neurological condition? 2) Do they know if their patients are using cultural ceremonies / or traditional practices as part of the care routine? The key informant interviews were conducted with Indigenous and non-Indigenous health care professionals, including nurses, general

practitioners, physician specialists, health directors, Indigenous patient advocates, navigators, and directors, counselors, as well as Indigenous health researchers.

The key informant transcripts were coded using nodes to capture key themes and ideas. After the transcript was coded, a memo was created outlining the participant's position, key ideas and notes pertaining to culture. Many of the themes brought forward from the key informant interviews highlight the existing cultural supports that hospitals and clinics utilize. They also make specific reference to the gaps in the health care system and how mandatory cultural safety training for all health care workers can help address some issues, but more is needed in terms of changing the policies that govern the health care system and Indigenous health care services. This includes addressing the social determinants of health; two-thirds of the key informant participants brought up issues related to poverty, housing, food insecurity, transportation, and unresolved trauma as being key reasons why Indigenous people may not be seeking care for neurological conditions.

The traditional knowledge keepers transcripts were relooked at using the following questions to guide in the analysis: 1) Are neurological conditions fairly new or have Indigenous people always experienced these types of conditions? 2) How were people with neurological conditions traditionally cared for? Nodes were used to capture key themes and memos were linked to each transcript outlining the key ideas and notes pertaining to cultural understandings and practices related to neurological conditions. While the number of traditional knowledge keepers interviewed is quite small, the interviews are very rich in terms of cultural understandings and normalization of conditions. Additional themes that arose throughout the Traditional Knowledge Keeper

data include differences between western and traditional medicine; impacts of colonization; programs and services; recommendations; policy; social determinants of health; and racism. The Traditional Knowledge Keepers stressed that people with neurological conditions were simply taken care of by their families and communities.

The secondary analysis uses new questions to look at the role culture plays in thinking about and accessing care for neurological conditions. Similar to the initial analysis, each data set was analyzed using a different set of questions. There was sufficient data to answer each of these new questions. The analysis of each data set is outlined in the following three findings chapters. The first findings chapter looks at the key informant data and the themes pulled during the secondary analysis. This is followed by the analysis of the Traditional Knowledge Keeper data, with the last findings chapter focusing on the individual interviews and research circle data.

## **Chapter 4 Key Informant Interviews: Health Care Providers Experiences Working with Indigenous People**

The key informant interviews took place at the same time as the individual interviews. Key experts involved in health care, through either practice, research, or advocate roles shared their experiences and knowledge of working with Indigenous people who live with a neurological condition or their caregivers. Data collection consists of two focus groups with four key informants in one group and two key informants in the other group, as well as 12 key informant interviews for a total of 18 participants in this category. The key informant interviews and focus groups took place in four provinces and one territory over the course of nine months. More than two thirds of the key informants identified as First Nation or Metis and one third of the key informants identified as non-Indigenous, but did have experience working with Indigenous people.

The first focus group included health care professionals from a First Nation Health Program at one of the major hospitals we visited. The First Nation Health Program supports First Nations, Metis and Inuit patients at the hospital. The team consists of liaison workers, social workers, traditional coordinators, and advocates to help patients and their families understand the care they are receiving, provide support to the patient and their families, and help with any discharge planning. The First Nation Health Program also has a traditional coordinator that can arrange for traditional foods, ceremonies, and plant based medicines for patients who wish to use these.

The second group interview was with two people who work for an Aboriginal Patient Navigator Program. This program is unique in that the navigators help Aboriginal clients regardless of where they live, on or off reserve, in rural and urban locations. The

relationship between the navigators and clients extend beyond an emergency crisis or hospital stay to make sure the client is able to get the services they need.

*So we provide all kinds of services from medical relocations to employment and income assistances issues that connect with the medical relocation and housing and medical equipment for example, dental, vision, all that stuff. (KIFG02)*

This type of service is invaluable for many Indigenous people who may not know what services they can access or how to advocate for services or funding through insurance or NIHB.

Other key informants include a director of an Aboriginal Health Access Centre, a counsellor for a National Native Alcohol and Drug Abuse Program (NNADAP), six physicians, many of whom are also involved in teaching, research, and are working to address the health inequities that exist within many Indigenous communities. We also interviewed a nurse, a nurse practitioner, a health researcher and a movement disorder specialist.

The health care professionals interviewed did have varying degrees of experience working with Indigenous people living with a neurological condition or their caregivers. The conditions the key informants brought up included: Cerebral Palsy, Multiple Sclerosis (MS), Alzheimer's disease, Acquired Brain Injuries (ABI) and Traumatic Brain Injuries (TBI), Parkinson's Disease, Huntington's Disease, Dystonia, Epilepsy, Diabetic Neuropathy, Strokes, as well as Alcohol related Seizures. A few key informants brought forward their experience with patients and clients who lived with the effects of FASD. At the time of the study, PHAC did not acknowledge FASD as a neurological condition and asked the UFW team not to include it in the questions asked or in the findings. A couple of key informants were asked about HIV related dementia, due to the increasing rates of

HIV amongst Indigenous people, but felt that it was not prevalent at this time. One key informant felt that the population in his practice is much too young (18-30 years old) to have the signs or symptoms of HIV related dementia.

The data from these interviews uncovered a wealth of information on what health care providers see within their practices, research, and the health care system in general. In looking at the key informants experiences of working with Indigenous people who live with a neurological condition or their caregivers, underlying themes relating to access to care, including social determinants of health, location, systemic issues related to care, and jurisdictional issues were brought forward. Almost all of the key informants spoke about the need for more education, prevention, and support services to help Indigenous people understand neurological conditions, signs and symptoms, as well as treatment options better.

Special attention was paid to the understandings of culture or traditional practices being used as part of the care routine. Many of the key informants discussed their openness to patients using cultural practices or traditional based medicines as long as they were aware of what their patient was using. Some key informants shared their experiences of working with patients who practiced cultural ceremonies or used traditional plant based medicines as part of their treatment plan. In sharing their stories, several of the key informants expressed the need for more culturally safe care and recalled stories of where the health care system failed Indigenous patients, their families, and communities. The recommendations brought forward from the stories highlight the need for cultural safety to be embedded throughout the health care system, from the

education of health care professionals and staff, to the policies and procedures at the regional, provincial and national level.

### **Experiences of Health Care Professionals Working with Indigenous People Who Live with a Neurological Condition or is a Caregiver to Someone Living with a Neurological Condition.**

The recruitment for the key informant interviews included purposive and snowball sampling. We wanted to speak with Indigenous and non-Indigenous health care providers, scientists, and researchers who either worked largely with the Indigenous population, were familiar with Indigenous health, or specialized in neurological conditions. For every key informant that was interviewed, we asked if they could suggest other people, we should speak with. This process allowed us to speak with many different individuals and hear about their thoughts, experiences, and recommendations in moving forward.

In going back through the data, only a few of the key informants spoke specifically about what they saw in terms of Indigenous people with neurological conditions. The movement disorder specialist did see a large number of Indigenous patients with dystonia and found that the condition was just as common to Indigenous people as it is to non-Indigenous people (KI04). This specialist also commented on the low rates of Parkinson's disease in the northern parts of one province, which also has a large Indigenous population. He was curious to see if the rates were low because Indigenous people are less likely to get Parkinson's or if it was low because people do not have access to health care services. Both of these factors are extremely important in understanding the health inequities that exist. A lack of incidence and prevalence rates may mean less resources are put towards Parkinson's research and related health care



needs. Fewer resources may translate into fewer specialists in the area, which could translate into higher wait times to see a specialist to get a diagnosis.

A few of the key informants recalled seeing head injuries as some of the more common neurological conditions that they see, but more often the key informants reflected on the high rates of diabetes within the Indigenous population and the complications that arise from living with type 2 diabetes. One family physician shared that a many of his patients live with type 2 diabetes, so most of the neurological conditions he sees are related to complications of living with diabetes and diabetes related neuralgia:

*It can lead to conditions where we got into some of the neurological pieces of that in relationship to what we called diabetic neuropathy which is a neurological condition causing a lot of pain. (KI06b)*

The rates of type 2 diabetes in Indigenous populations are three to five times higher than in non-Indigenous populations and occur at an earlier age (Canadian Diabetes

Association <http://www.diabetes.ca/getmedia/513a0f6c-b1c9-4e56-a77c-6a492bf7350f/diabetes-charter-backgrounder-national-english.pdf>). First Nations adults with type 2 diabetes have a higher prevalence of other chronic health conditions. Access to treatment to manage the disease may not always be readily available or sought out. This could result in further complications related to diabetes such as cardiovascular disease, stroke, blindness, kidney disease, and amputations (<http://www.phac-aspc.gc.ca/cd-mc/publications/diabetes-diabete/facts-figures-faits-chiffres-2011/highlights-saillants-eng.php#chp6>).

Another physician commented that his clinic tends to see more women than men. The men do not go for regular checkups and often do not come in until the late stages.

While he did not see a lot of people with neurological conditions, he did notice that people will often come in with other conditions or problems that they feel are more urgent. Many of the key informants shared similar stories where patients may be experiencing multiple symptoms, such as pain, dizziness, or numbness in their extremities, and will focus on dealing with the pain first, before discussing the other symptoms they are experiencing. These stories speak to the larger themes brought forward in the interviews in terms of access to care and what does this mean for people who live in urban or rural or remote areas, for people who have competing social issues to deal with, or for Indigenous people who may not trust the health care system.

### Access to Care

Many of the key informants spoke at length about the challenges Indigenous people have in accessing care, getting a diagnosis and managing treatment. Accessing health care services extends beyond being able to see a physician, nurse practitioner, or health care professional. For many individuals it may mean taking time away from work, or other responsibilities, making an appointment, or finding time to get to a walk in clinic or hospital, as well as access to transportation to get to the clinic or hospital. This process may be more complicated if the person has caregiving responsibilities and needs to make alternate arrangements to ensure these responsibilities are met. When considering these factors, it is easy to understand how some people may delay seeking care until their symptoms are much worse. For example, one physician stated that some people learn to adapt to the signs and symptoms they are experiencing and therefore may not seek out treatment until much later on.

These factors speak to the difficulties in accessing primary health care, let alone all the steps it takes to get an actual diagnosis. The key informants recalled stories of how

people may access care where they can receive it the fastest. This generally means that people are not setting up appointments with a family physician, assuming people have a family physician in the first place. The Health Council of Canada 2013 progress report on Health Care Renewal in Canada found that “only 47% of Canadian primary care physicians are able to provide patients with a same-day or next day appointment” (Progress Report 2013, 19). This may result in people going to walk in clinics or visiting the emergency department, where wait times are on average four hours or more.

For physicians who have a long line of patients waiting to see them, they may limit their time with each patient or cut some exams, such as a neurologic exam short. One physician shared the following:

*And then if there're 20 people in the room, you might cut your neurologic exam short. And I think even for primary care practitioners, like the quality of our neurologic exams in terms of identifying early signs of – like more subtle presentation of neurologic disease are probably not very good. (KI07)*

When accessing walk in clinics or emergency departments, a copy of the medical visit record is supposed to go to the patient's family physician, assuming they have a family physician. This is not always the case though, as poor communication between clinics, hospitals, specialists and physicians can complicate the coordination and integration of health care services. Some people go to the same walk in clinic under the belief that at least their medical records are all at the same place. This unfortunately is not always the case, especially if the clinic does not keep electronic medical records (EMR), as many of the offices may not have the physical space to keep individual records for each person that accesses the clinic. This can all lead to the health of the person being compromised because of sporadic care and incomplete medical records.

Focus group 2 shared that many people end up falling through the cracks, especially when you consider the long wait times to see a specialist. According the Health Council of Canada, patients can wait two or more months to see a specialist (Progress Report 2013). After a patient sees a specialist, they may have to wait even longer for diagnostic testing, especially if they need diagnostic imaging, such as MRI and CT scans. One key informant explains the difficulties of getting a diagnosis:

*Getting people the differential diagnosis is hard too because you would have to refer people a lot of times to figure out more subtle neurologic signs. It means invasive testing that you have to wait a long time for. People have to show up on time and get needles stuck into your skin and stuff, so that's not probably high on people's priority list that are dealing with everyday kind of concerns around just adequate food and shelter and child care. (KI07)*

Getting a referral, testing, and diagnosis takes a tremendous amount of time and energy that many people may not have, especially if they are dealing with competing issues such as ensuring the basic necessities of life are covered. Even if a person is trying to juggle their basic household needs with their health care needs, they still may fall through the cracks, especially if they are late to an appointment or accidentally miss an appointment.

One physician shared what she sees with some of her patients:

*I find the access is very- long duration, limited and if a person misses their appointment then, people don't want to book them again or people are even refusing to see them again and- And sometimes, the reason they've missed the appointment is because they ran out of food so they had to wait in line at the food bank and that took longer and they- It's a day to day situation for a lot of people and I keep coming back to the whole Maslow's hierarchy of needs, if you don't have food and shelter, I mean, you can't worry about other things and so, again, thinking about these- often these single-moms who are often the ones that are dealing with everything or even- or even if it's the grandmother or whatever; they're also often involved too. So, it's really difficult, the wait is very heavy on people but, there's no accommodation in the system, it's just kind of like "Well, you missed your appointment, you're really not that interested in healthcare, OK see ya, goodbye!" (KI11)*

If a patient is late to an appointment or misses it entirely, they may be charged a fee for the missed appointment, resulting in the patient having to pay out of pocket; or be moved back to the waiting list, which can result in another long delay for services. In some cases, the specialist's office may refuse to rebook the appointment and send the patient back to the physician that made the initial referral, starting the whole process over again.

In discussing some of the challenges in accessing health care services with the key informants, I was struck by the sheer amount of referrals, testing, and follow up appointments it takes to get a diagnosis. When we asked the movement disorder specialist how long it typically takes to get a diagnosis, he gave an example of someone getting a diagnosis of dystonia and stated:

*It takes an average of three years for the provinces to find a doctor who knows what's wrong with them. It takes a lot longer if you're Aboriginal, but if you're an Aboriginal female, I guess it would... but I don't know. Take six years and go back ten if you have to still go and find a doctor who knows what's wrong with you. (KI04)*

Finding a doctor that recognizes the signs and symptoms associated with certain neurological conditions, can take a long time. General practitioners may not be fully aware of all the different neurological conditions and may not have time to attend continuing medical education (CME's) sessions on the signs and symptoms associated with the different conditions. Physicians may not know what tests to order or even who to make a referral to. In some cases, physicians may not even order any tests and view the person as drug seeking or exaggerating their symptoms. This type of interaction could greatly affect how a person interacts with the health care system. If a patient does not feel like the physicians will listen to their concerns or will not send them for further testing, they may delay seeking care until much later on.

Focus group 1 shared a story of a young Indigenous woman going to the emergency room because she could not use her legs and had no feeling in them. The doctor at first thought the woman wanted drugs and that it was all in her head and did not order tests until later on. The focus group shared that the woman was a young mom with three children and came from a community a couple of hours away. The whole interaction of not being listened to and accused of making the symptoms up caused a great deal of stress and frustration for the patient and their family who traveled to be with them. Once it was evident that the young woman was not drug seeking or exaggerating her symptoms, she was transferred to a larger hospital in a different province that had the specialists available to diagnose and treat her. Unfortunately, not all health regions or even provinces have the resources to have all the personnel needed to effectively treat a person living with a neurological condition in one place.

### **Access to Care in Rural and Remote Areas**

For the purposes of this dissertation, I will be using the Statistic's Canada definition of the term rural whereby "rural is the population outside settlements with 1,000 or more population with a population density of 400 or more inhabitants per square kilometre" (<http://www.statcan.gc.ca/pub/21-006-x/2008008/section/s2-eng.htm>). Remote communities are accessible only by air year round, or by ice road in the winter. Health Canada provides funding for the delivery of health services to remote First Nations communities as "access to provincial health care services is either non-existent or severely limited" (Office of the Auditor General of Canada Spring 2015 Reports of the Auditor General of Canada, report 4: Access to Health Services for Remote First Nations Communities. Found at [http://www.oag-bvg.gc.ca/internet/English/parl\\_oag\\_201504\\_04\\_e\\_40350.html](http://www.oag-bvg.gc.ca/internet/English/parl_oag_201504_04_e_40350.html)). According the 2015

Auditor General report, First Nations people living in remote locations are serviced by 85 health facilities, led by approximately 400 nurses who serve approximately 95,000 First Nations individuals. Health Canada also provides medical transportation benefits when health services are not available within the community. Medical transportation for non-emergency situations must be approved in advance by the Health Canada regional office.

Focus group 1 spoke of the difficulties of accessing specialised services in the three Canadian territories. Due to the low population and limited health infrastructure within the territories, residents often have to travel outside of the territory to access a range of hospital and specialist services. The territorial government provides medical travel benefits for residents. For First Nations (status Indians) and Inuit residents, medical transportation benefits are covered through non-insured health benefits (NIHB), which is a federal program. The medical transportation benefits covers the travel to the nearest appropriate health facility, assistance with meals and accommodations, medical escort, such as a physician or registered nurse when needed, and a non-medical escort if the patient has a physical or mental disability and cannot travel without help, is medically incapacitated, or is a minor. NIHB will cover the “most efficient and economical mode of transportation consistent with the urgency of the situation and the medical condition of the client” ([http://www.hc-sc.gc.ca/fniah-spnia/pubs/nihb-ssna/medtransp/2005\\_medtransp-frame-cadre/index-eng.php](http://www.hc-sc.gc.ca/fniah-spnia/pubs/nihb-ssna/medtransp/2005_medtransp-frame-cadre/index-eng.php)). Modes of transportation include ground, water, and air travel. NIHB does not cover compassionate travel, so any person who wishes to accompany the patient to an appointment must be preapproved as a non-medical escort or pay out of their own pocket (<http://www.hc-sc.gc.ca/fniah-spnia/nihb-ssna/benefit-prestatiion/medtransport/index-eng.php>).

A few key informants spoke about the challenges in serving patients and dealing with NIHB in remote communities. One physician who worked with remote communities in northern Manitoba and Ontario recommended that visiting physicians should have a referral template with a list of providers that they can send their patient to receive care.

*In the isolated communities the service provider should have a template of where they would have to go or access or have a list of consultants that would deal with these issues and that is primarily the visiting physician that goes into the communities that sees the Aboriginal women that are requiring access to the specialized treatment for neurological issues. Need to know what their consulting lines are ... for example I wasn't particularly familiar with who I could send the referral to ... they wanted me to send the referral to Sioux Lookout and then the hospital would deal with it but that was inefficient ... people would get to the hospital and often get sent back to community without being referred to a neurologist in Winnipeg or Thunder Bay. I established a referral system to Thunder Bay or Winnipeg and I would call the doctor that I wanted the patient to see directly. I made the arrangements ... then NIHB would chastise me but I made the referral where the patient would get the best service possible. This depends on the tenacity of the service provider on whether s/he would buck that system. (KI10)*

Having a direct referral line bypasses the two-step system of having patients travel to Sioux Lookout and then travel further for more specialized care. Sioux Lookout Health Authority serves approximately 30,000 people (33 First Nations communities). The Sioux Lookout Meno Ya Win Health Centre has 40 active physicians and approximately 50 locums, where health care professionals fly into a community for a set amount of time. The Centre provides a broad range of basic and specialized services, including orthopedics, ear, nose and throat, and psychiatry. They are also seeking specialists in internal medicine and paediatrics (<http://www.slmhc.on.ca/additional-services>). Under the two-step system if the patient required more specialized care, they would need to



either wait in Sioux Lookout or be sent back to their community until a referral is made. This process would take a considerable amount of time and money in needless travel.

Another key informant discussed the difficulties patients may experience in traveling to a see specialist. For many people living in remote areas, traveling to large urban areas to see a specialist may cause a lot of anxiety, especially if they have to travel by themselves or if they need an interpreter. In certain cases, a physician may understand what is going on with a patient, but may recognize that a referral to a specialist may not be very helpful.

*I think sometimes too they realize that by the time you get in to see somebody and there's not really much they can do, you know like so people are feeling that they're not getting the access to specialist sometimes that they would. I know one of the concerns that one of our physician's brought up too was even having access to surgeries and things. So, if they needed a surgery for something, like say a back injury or something like that, they have to wait to get in to see the- you know, the patient with the doctor then they have to wait for the referral for down south and it's a big issue for a lot of people to go down south too because it costs so they might- They don't always get their costs covered unless they're First Nations and the cost is only covered one-way, it's not covered for the return trip back and there's often not enough money like for the food stuff down there and then there's the language issue so they often bring a family member to try to help them. And also to navigate because to drive in the city is like huge compared to up north so, I mean there's all kinds of different things and there's horror stories that way too. (KI11)*

Traveling from rural or remote communities to an urban centre can be quite stressful for many people. If a person is required to stay close to the hospital or treatment facility for an extended period of time, NIHB will cover the cost of meals, accommodations, in-city transportation to the hospital or treatment facility up to a three month period. After that, the patient needs to access provincial or territorial services, such as subsidized housing, employment, and income assistance.

Most urban hospitals have an Aboriginal patient navigator program, where patients can ask the navigator to help them in accessing services, and filling out paperwork. The key informants in focus group 2 spoke at length about their advocacy services and navigation services to First Nations living on and off reserve throughout the province and not just in city. They also spoke of some of the difficulties their clients face in trying to follow a treatment plan, especially if they move back to their home community.

*We go to case conferences, where the doctor makes a treatment plan for the -- especially young people that have acquired brain injuries. But it's not carried out up north because there's really nothing up there. And they just exist like that. And their parents get frustrated. You don't know where to go. (KIFG02)*

Other key informants also brought up the lack of services in rural and remote communities. The lack of rehabilitative services can affect treatment plans and the ability for a patient to improve.

*so, people in First Nation communities and Metis communities, they don't have access to rehabilitative services, for example. Ok. Because it is a Non-Insured Health benefit but people could gain access to it if they lived in Winnipeg, you could just go to a hospital, they could just do that for you. But, in the country and in First Nations communities there's no access to provide services to rehabilitate people to a level that's better than the first injury that's occurred. (KI03)*

NIHB will pay for rehabilitative, supportive, and palliative / end of life care, but these services are not in every community. Patients, who need specialized care, may have to leave their communities in order to access treatment. Even when a patient wants to return to their home and community, they may run into difficulty when considering the infrastructure in the community. For example, housing within many First Nations communities may not be accessible or even adaptable to accommodate a person with

special needs. Lack of home care services, or even clean running water, can limit a patient's ability to come back to the community.

### **Access to Medication**

Another barrier that was brought forward by the key informants was price of medications. Non Status Indians, along with Metis people are not eligible for NIHB and must find coverage elsewhere. In these cases it is important that patients are upfront with their health care providers and tell them if they have coverage or not. One key informant spoke of the importance of health care providers talking to their patients and asking them about medical coverage and whether or not they can afford the medication that is being prescribed. She goes on to state that many of the medications that are used to treat high-blood pressure and diabetes are expensive and not all patients have coverage or can afford to take the medications prescribed.

First Nations people, who are Status Indians under the Indian Act, are covered through Non Insured Health Benefits (NIHB). According to Health Canada:

The Non-Insured Health Benefits Program is Health Canada's national, medically necessary health benefit program that provides coverage for benefit claims for a specified range of drugs, dental care, vision care, medical supplies and equipment, short-term crisis intervention mental health counselling and medical transportation for eligible First Nations people and Inuit. <http://www.hc-sc.gc.ca/fniah-spnia/nihb-ssna/index-eng.php>

The drug benefit list for NIHB is updated on a quarterly basis. This means that certain drugs may be taken off the approved benefit list with little warning. NIHB is the payer of last resort and typically only covers the generic brand of a medication. If a physician wants to prescribe a drug that is not on the list or a brand name (not generic drug), they often need to write a letter explaining why a particular drug is needed and why it should be approved for the person to use.

One specialist shared his experience in dealing with NIHB and how difficult it could be to get medications approved for coverage, even though they have been approved by Health Canada for the general population.

*I find that the pharmaceutical support system for Aboriginal population to be archaic and really irritating, because it's... I assume, out there, because it's supposed to help them. I assume that money going into it is huge, but it's backwards, because I have to go through more steps to get certain medications approved to treat someone with cervical dystonia, even though it's an approved medication for... well, since 1992. And I still have to fill out these extra forms, while all I have to do for anybody else is just write out prescriptions. And that's not just that drug, it's for all sorts of drugs. (KI04)*

Health Canada uses Express Scripts Canada to administer “the Health Information and Claims Processing Services (HICPS) system on behalf of the NIHB program”

(<http://provider.express-scripts.ca/>). Physicians and specialists prescribing medications that are not on the drug benefit list need to fill out prior authorization forms for their patients. The form asks physicians to list the medication needed, the patient’s medical condition, the stage / severity of the condition, any additional information relevant to the patient’s medical condition and treatment, drug dosage and administration, concurrent therapy or therapies for the same treating condition, any previous tried therapies, as well as any additional comments or notes the physician may have. If the request is denied, the patient can appeal the decision or ask the physician to appeal on their behalf. There are three levels of appeal available.

Physicians can write an appeal to the regional office and ask that the brand name medication be used instead of a generic version. While the generic medications have the same active ingredient as the brand name medication, the inactive or non-medicinal ingredients may be different. Physicians can also request a prior authorization form for

medications listed on the limited use benefit, and to drugs not added to the NIHB drug benefit list. The limited use benefits include medications “that have been found to be effective in specific circumstances or have quantity and frequency limitations”

(<http://www.healthycanadians.gc.ca/publications/health-system-systeme-sante/drug-benefit-list-winter-2016-hiver-liste-medicaments/index-eng.php>). The medications that

are not added to the formulary or not listed on the NIHB drug benefit list include medications that may be deemed as being too expensive compared to existing therapies. Physicians need to complete an “exception drugs request form”, which is reviewed on a case-by-case basis. The first focus group shared a story where one physician went all the way to the head office in Ottawa to advocate for certain medications to be approved for his patient:

*we had a patient here that got medi-vac to Victoria because he had a stint put in him and the medication that Non-Insured gave him, they didn't have the medication here and so he had a massive heart attack. And, they sent him to Victoria and depending on what doctor they have...the doctor that he had in Victoria really advocated for him. They wanted to put him on the lowest medication that- the less money but, if he was to go on that medication he would have to take his blood every week to make sure that he doesn't get blood clots in his heart and coming from a small community, by the time we draw blood from here and it goes to Whitehorse, he'd have about 3 or 4 blood clots. So, the doctors in Victoria got really mad and upset, and it went straight to Ottawa and reamed them out and they approved him on the highest medication so he doesn't need to check his blood every week, it will do it, that medication will do it for him.*

(KIFG01)

The focus groups, along with other key informants spoke of the importance of having a doctor that is willing to advocate for you and get the proper medications needed to treat the condition.

NIHB also covers certain medical supplies and equipment to assist with bathing and toileting, feeding, dressing, lifts and transfer aids, mobility aids, urinary supplies and

equipment, wound dressing supplies, and low vision aids. NIHB also covers certain supplies and equipment related to audiology, orthotics and custom footwear, oxygen supplies and equipment, pressure garments and pressure orthotics, prosthetics, and respiratory supplies. In most cases, medical supplies and equipment need to be prescribed by a physician or nurse practitioner. Prior approval is needed for many of the medical supplies and equipment benefits, including oxygen. Key informants in focus group 1, shared a situation where a First Nations woman needed oxygen 24/7 and had to stay in the hospital for several weeks until the prior approval process was authorized by NIHB head office. The focus group participants expressed frustration that the current policies often result in unnecessary hospital stays, and health care resources being needlessly spent.

NIHB also provides coverage for dental care, vision care, and mental health counselling benefits. Basic dental procedures such as diagnostic services, preventative services, restorative services, limited root canals can be billed directly to NIHB without having to fill out forms for predetermination. Vision care coverage includes eye examinations and prescription eyeglasses, once every 24 months for people over the age of 18. The mental health counselling benefit requires that the mental health provider must meet the eligibility requirements and enroll with the NIHB program. Providers must be registered with a legislated professional regulatory body in their province / territory where the services are being provided. Traditional Elders who may provide guidance to community members, but do not belong to a formal regulatory provincial or territorial body are not eligible to be paid through NIHB. The mental health benefits are also only designed for short term crisis intervention and must be preapproved (<http://www.hc->

sc.gc.ca/fniah-spnia/nihb-ssna/benefit-prestation/crisis-urgence/guide-eng.php#a31).

None of the key informants spoke about their interactions with these other benefit programs.

### **Social Determinants of Health and Impacts on Accessing Care**

*There are at least 20 different obstacles to care for Aboriginal people....poverty to social isolation to...mistrust of institutions to mistrust of staff to past experiences with those institutions that are perceived as racist...sometimes it just is. Aboriginal people are not treated to the guidelines because...“there’s no point of giving them the medication, they’re not going to take them anyway”. So, all these obstacles are there...with this expectation you can write a report...social determinants of health, lack of access to care, lack of data, poor quality; we need better data, we need better...without consideration of Aboriginal population...here are our recommendations... (KI05)*

Almost all of the key informants talked about the social determinants of health playing a huge role in how Indigenous people interact with the health care system. In Canada, Mikkonen and Raphael state that the social determinants of health includes the following factors: income and income distribution, education, unemployment and job security, employment and working conditions, early childhood development, food insecurity, housing, social exclusion, social safety network, health services, aboriginal status, gender, race, and disability (2010). Mikkonen and Raphael argue that all of these factors have an impact on our health and wellbeing, but do not fully explain why having Aboriginal status, results in Indigenous people having poorer health outcomes. The colonial history and policies are glossed over, unlike Loppie Reading and Wien’s report, *Health Inequities and Social Determinants of Aboriginal Peoples’ Health* (2009). Loppie Reading and Wien look at the social determinants across the life course and link the determinants of health to proximal, intermediate, and distal levels. They also look at the

colonial history, policies and experiences of racism, discrimination and social exclusion (2009).

The approach taken by Reading Loppie and Wien looks at various factors related to the health and wellbeing of Indigenous peoples. The proximal factors are the direct impact on a person's physical, mental, emotional, or spiritual health. Access to housing, education, food, employment and income, and a reliable support system all play a role in the health and wellbeing of a person and their dependents. The intermediate determinants are the policies, procedures and systems in place that influence the proximal determinants. For example, educational systems, health care policies, community infrastructure and resources affect how people are able to access services. The distal determinants are the underlying factors that affect the health and wellbeing of Indigenous people. These include colonialism, racism and exclusion, and self-determination. Colonial policies, such as the Indian Act, sought to assimilate and acculturate people into the dominant society. Indigenous people were dispossessed of their land and moved onto reserves; cultural ceremonies and practices were banned and replaced with Christian patriarchal practices, and children were removed from their homes and placed into residential schools (Leslie & Macguire 1979). Unfortunately, the impacts of colonial policies can still be seen today in terms of racist policies and practices that are entrenched in established organizations and institutions, as well as policies that require First Nations people to request permission to travel to access specialized care.

Many of the key informants spoke about Maslow's hierarchy of needs and how many of the people they see are struggling to attain adequate food, water, shelter, and clothing for themselves or their dependents. If people cannot get their basic needs met,



health concerns, especially those that are not immediately life threatening, will often be pushed aside.

*People who are hungry and do not have a place to sleep are going to be consumed by those basic needs before they can even address their neurological health. People will naturally think about only those primary needs and only when those are met will they come forward. (KI09)*

The social determinants of health, and especially poverty, were brought forward as competing factors to accessing care regardless of where people live.

In looking at the demographics for rural and urban areas, I had to go back to the 2006 census, as the mandatory long form census was cut in 2010 by the Conservative government. The Liberal government reinstated the long form census in 2015 with information being collected in 2016. The long form census collects information on demographics, social, and economic subjects. According to the 2006 census, approximately 60 percent of First Nations people lived off reserve, with approximately 34% living in large cities, such as Winnipeg, Edmonton, Vancouver, Calgary and Toronto (<https://www12.statcan.gc.ca/census-recensement/2006/as-sa/97-558/p16-eng.cfm>). Indigenous people counted for at least 10 percent of the population in smaller urban areas, such as Prince Albert, SK, Prince Rupert, BC, Thomson, MB, and La Tuque, QC. Off reserve Indigenous people were more likely to live in houses that need repairs, have a lower income, and experience food insecurity at higher rates than non-Indigenous people ( Aboriginal People`s Survey, Social Determinants of Health for the off reserve First Nations Population, 15 years of age and older. Found at <http://www.statcan.gc.ca/pub/89-653-x/89-653-x2016010-eng.htm>). Indigenous women living off reserve are more likely than Indigenous men to be lone parent households with

children living with them. The report does not state if there are multiple generations living in the same off reserve home, as many Indigenous women may have their children and other family members living with them (<https://www.aadnc-aandc.gc.ca/eng/1100100014298/1100100014302>). A report released by the *Canadian Centre for Policy Alternatives* states that child poverty rates are as high as 60% for Status First Nations children living on reserve, 41% for Status First Nations off reserve and between 23-29% for non-Status, Inuit and Metis children (MacDonald & Wilson 2016, *Shameful Neglect: Indigenous child poverty in Canada*. Found at [https://www.policyalternatives.ca/sites/default/files/uploads/publications/National%20Office/2016/05/Indigenous\\_Child%20\\_Poverty.pdf](https://www.policyalternatives.ca/sites/default/files/uploads/publications/National%20Office/2016/05/Indigenous_Child%20_Poverty.pdf)).

In order to have a better understanding of poverty, the definition that is most commonly used in Canada was reviewed. It was surprising to discover that the Government of Canada does not have an official poverty line, or an official measurement of poverty. Instead, policy analysts, organizations and advocacy groups look at other measures that typically fall within two very broad frameworks, measuring absolute poverty and relative poverty. Absolute poverty is seen as the lowest amount of money needed to sustain life, whereas relative poverty looks at other factors in terms of location and cost of living. The main measures that are used in Canada include: Statistics Canada's Low Income Cut-Offs and Low Income Measures; the Fraser Institute's "Basic Needs", and the Human Resources and Social Development Canada's (HRSDC) "Market Basket Measure" (Collin, 2008 "Measuring Poverty: A Challenge for Canada. Parliament of Canada PRB 08-65E <http://www.lop.parl.gc.ca/content/lop/researchpublications/prb0865-e.htm>). According to

Statistics Canada, “the low income cut-offs are income thresholds below which a family will likely devote a larger share of its income on the necessities of food, shelter and clothing than the average family” by upwards of 20 percentage points more (<http://www.statcan.gc.ca/pub/75f0002m/2012002/lico-sfr-eng.htm>). The “basic needs approach” by the Fraser Institute looks at cost of basic necessities to maintain “long term physical well-being and [is] regarded as a minimum acceptable standard within the community which that person resides” (<http://www.lop.parl.gc.ca/content/lop/researchpublications/prb0865-e.htm>). The necessities included in this list are food, shelter, clothing, health care, personal care, essential furnishings, transportation and communication, laundry, home insurance, and miscellaneous items. HRSDC uses the “market basic measure” to look at the cost of a specified basket of goods and services representing a modest, basic standard of living for different regions across Canada.

Each of these measures have a different baseline of what a single person and a family of four would need to survive. For example, the Fraser Institute’s basic needs poverty line for a single person living in an urban Ontario community in 2013 is \$13,055, while a family of four is \$26,109. Stats Canada income cut-off rates are calculated to be \$16,723 for a single person and \$31,618 for a family of four, and the HRSDC market basket measure is \$17,463 and \$34,926 respectively (Lammam and MacIntyre 2016, An Introduction to the State of Poverty in Canada. Fraser Institute, found at <https://www.fraserinstitute.org/sites/default/files/an-introduction-to-the-state-of-poverty-in-canada.pdf>). Depending on which measure is used, the rates of poverty may be calculated to be as low as 4.5% or as high as 14.9%. While having a clear definition

would be helpful for analysts and policy makers, it may not be helpful for the people who are struggling to put food on the table or a roof over their head. The cost of living can differ significantly between provinces, and even within the same province. The cost of living may be very different for a person living in a large urban area in the southern part of the province, then for someone who lives in the far north. A few of the key informants thought urban poverty was under estimated, due to migration patterns and lack of data to accurately capture the demographic, social and economic changes.

One family physician stressed the need to talk to patients about other factors besides health. He stated that many of his patients want to know where they could access services, money or income to access housing, food, and other basic needs. They also want to know where they can access information for addictions, and what general resources are available if they do need extra help. In this case, we need to look at where the patient / client lives in relation to where the services are offered and whether or not they can get to these services. He stressed that we should also be asking the client about their family situation, do they have support, whether that is emotional, financial, or even the physical support of having someone that could help with household chores. If they have kids, do they have family to help out, while they seek medical treatment? Do they have access to affordable and accessible housing? Are there other issues that they are dealing with, whether that is mental health issues, addictions, or homelessness?

*In neurological conditions along with any other medical conditions, those patients live within a very real social context, and those social determinants of health need to be addressed. If a woman has a neurological condition, she's also still at-risk for other issues that any Aboriginal is at-risk for. So, those need to be dealt with. And, so some of our sickest clients like end-stage persons with HIV; their lives are dominated by the social determinants of health. It's really all about housing, opportunity and the chance for meaningful work. Those kinds of ideas,*

*and it would be the same for women with neurological conditions. And, that's really hard for them in the medical community to understand. They want to talk to us about intervention, medicine and medication. And about where our doctors- where can they access primary healthcare, where are the specialists? And, we have to say to them: Well, the answer for our clients is not going to be in a million-dollar imaging machine, you know, because that's what they go to, it's not going to lie in getting blood samples or tissue samples from them so that they can understand better the origins of the disease. It's really going to be in the low-cost, low-tech, simple things like: Does she have a place to sleep? Can she eat properly? Can she rest? You know, because she's not well. (KI05)*

All of these factors and more need to be taken into consideration when we look at Indigenous peoples' health and wellbeing and whether or not they are accessing health care services.

In terms of the intermediate determinants, the key informants spoke about the policies, procedures, and systems surrounding the health care services and how they are accessed. Focus group 2 talked about their experiences in helping First Nations people navigate through the health system. They stressed the need for individuals to have proper identification in order to access health services or other services such as subsidized housing, homecare, employment and income assistance. Individuals who do not have a valid health card or an Indian status card, issued by Indigenous and Northern Affairs Canada, could be charged a fee before they are allowed to see a physician or nurse practitioner.

Policies relating to discharge practices were also brought forward. Focus group 2 works with Indigenous people who are homeless, as well as Indigenous people who are from rural and remote communities and are in the hospital. They shared that when these individuals are discharged from the hospital, they are often released to the Salvation Army if they have no other place to go or no immediate way to return to their

community. The Salvation Army is for emergency shelter on a first come first serve basis. Individuals can only stay one night at time, and not book in advance or stay multiple nights. Not having a safe place to stay can greatly compromise the health and wellbeing of an individual.

Additional policies issues that were brought forward deal with the lack of services for people who are dealing concurrently with mental health issues and addictions. Focus group 2 stated that many of these individuals cannot access mental health care until they are clean and sober. Ironically, they are also limited in accessing services to deal with their addictions until they deal with their mental health issues. Mental health issues and addictions are not independent of each other. Policy makers need to understand that addictions may be a symptom of a larger issue affecting the person. If a more wholistic approach was taken, then more people would be able to get the help they are searching for.

In looking at health care services, policy makers need to look beyond who is accessing services to gain a better understanding of who is not accessing services. Many of the key informants spoke about location of services how services need to be placed where people can easily access them.

*But we have a certain street that is a barrier to going across. Because it's beyond the barrier, they ... it's hard to walk to another location as opposed to taking ... you know, they don't have money for a taxi or for a bus, so they'll walk to a certain point. And so if you can put resources within that certain geographic area then they ... you might have a better chance of being able to go there and ... and do some good work. (KI06b)*

Placing services in the heart of a community, where community members can see and interact with the health care providers can improve uptake of health services. One of the

nurse practitioners spoke about her and her colleagues walking through the neighbourhood they served to interact with residents and tell them about the services they offered at the health clinic. This clinic also included traditional Elders who often held workshops for young parents once a month. By going out into the community, they were able to draw more people in and make them aware of the services they offered, including the health promotion workshops and informational sessions. Through promoting these services and interacting with the community, these health care providers were stepping outside of the status quo and encouraging people to be active participants in their health and wellbeing.

A couple of key informants spoke about the innovative work that health care providers and certain organizations are doing to promote health and wellness within their practices and communities. The example above outlines the steps that one clinic took to build awareness and foster relationships. Unfortunately, this is not always possible especially when individuals, clinics, or organizations rely on government or outside funding and need to produce measurable outcomes in a timely manner.

*I think that there is lots of great people doing good things. I feel passionate about the health inequities that are experienced by Indigenous peoples. And I guess a lot of what I see is ineffective health services because health services have been mostly created in – and though there’s some talk otherwise, I still see them mostly being programmed and evaluated at least in a way that marginalizes indigenous ways of knowing and doing. (KI07)*

Health programs and services need to be adapted for community use. This means that program developers need to engage in meaningful dialogue to understand the needs of the community, including the objectives the community wants to achieve, and what outcomes they would consider successful. Any evaluation measures should be developed with the communities that are being served.

Unfortunately, this is not always the case. One key informant spoke about the colonial and patriarchal attitude within the regional and provincial health care systems that he works in. He shared a couple of examples of how much more work is needed to get bureaucrats to understand that they need to include Indigenous people from the beginning.

*Another thing that we have to do, besides social determinants of health is to remind healthcare workers that these- Aboriginal people are worthy of care. It's really hard to get them to understand that our opening conversations with every agency, every bureaucrat, with every health institution starts with them telling us what we should do for our clients. Telling Aboriginal people how to take care of Aboriginal people or how Aboriginal people should take care of themselves.*

*What can we do together or what can your agency do to help us out? So, if you were visiting with a neurological ward, I'm sure that the staff there would say to you: "Well, why don't Aboriginal people do this and that and this?" And then, you'll say: "Ok, now what can we say or do to actually help the people here who are actually Aboriginal and have neurological disorders." And, that would be a new question...they'll say: "I never thought about that!" That's neglect and I mean neglect, it's actually part of history of neglect where institutions and policies are set-up without consideration of us. So, they have to be reminded but, that's actually part of our colonial experience. And, it must not continue, and if they continue to do that then we will stop and come back when they are ready to talk or, we will work against their current lack of policy, which is a form of violence and racist. It's a colonial, racist, thing for them to not consider us because we are an important part of the population. That's a really tough- like that's the first-year of meetings. (KI05)*

Systemic and institutional racism perpetuates the health inequities that Indigenous people face. Failing to listen to the needs of Indigenous people further marginalizes Indigenous ways of knowing and doing speaks to the distal determinants of health, where the root causes of the health disparities are tied to colonial policies and persistent racist stereotypes. These distal determinants of health have a profound influence on the health of populations because they represent political, economic, and social contexts that



construct both intermediate and proximal determinants” (Loppie Reading and Wien, 2009, 25).

Colonial assumptions and racist stereotypes can greatly affect how Indigenous people access health care services. It can lead to delayed treatment or lack of treatment, especially if Indigenous people feel judged by health care providers and staff within the admitting process. A prominent example of systemic racism can be seen through the story of Brian Sinclair’s unnecessary and tragic death in 2008. A community physician referred Brian Sinclair, a 45-year-old Indigenous man and double amputee, to the emergency department at the Winnipeg Health Sciences Centre to treat a blocked catheter and prescribe antibiotic treatment for a bladder infection. Sinclair was pronounced dead after waiting 34 hours in the emergency department waiting room without ever receiving treatment, even though other ER visitors asked nurses and security guards to attend to him. A provincial inquest was held to look into the death. Several staff testified that they assumed Sinclair was homeless and was simply in the ER to warm up, watch TV, or sleep off intoxication, while some staff said they never saw him in the waiting room. The hospital staff and the Chief Medical Officer of Manitoba denied the role of racism in Sinclair’s death, suggesting that it was human error that his name was not recorded on the triage list, even though the triage aide was seen on tape speaking with Sinclair. The Provincial Inquest Report failed to examine or address the role of systemic racism in his death or how Indigenous people are treated within the health care system (Brian Sinclair Inquest 2014, found at [http://www.manitobacourts.mb.ca/site/assets/files/1051/brian\\_sinclair\\_inquest\\_-\\_dec\\_14.pdf](http://www.manitobacourts.mb.ca/site/assets/files/1051/brian_sinclair_inquest_-_dec_14.pdf)). A couple of the key informants, including focus group 2, talked about

Brian Sinclair and what happens when institutions fail to address colonial assumptions and racist stereotypes.

*So not only is that a form of – an ongoing form of colonization and I guess genocide is a strong term but if you continue to marginalize people's ways of being, it is a form of genocide in my mind. Then it's also very ineffective because people aren't going to use and benefit from health services if they're designed by outsiders who have different values and skills and knowledge sets. They just aren't going to come or feel comfortable when they do come or follow whatever guidance they're given lots of times. (KI07)*

Over the last 20-30 years, Indigenous people, communities and organizations have been trying to address the inequities within the health care system, by taking control of their health services and programs on reserves through the Indian health Transfer Policy in 1989. In other jurisdictions, Indigenous people have been developing their own programs, health centres, and health authorities, with the First Nations Health Authority in BC being a great example of a tripartite agreement between BC First Nations, and the Federal and Provincial governments (Allan and Smylie 2015). Indigenous people and organizations have also been working with regional and provincial health organizations to offer programs, services and supports within mainstream institutions, such as Aboriginal patient navigators or liaisons to help support and advocate for Indigenous patients. The second focus group spoke about the amount of time it has taken to build relationships with the different health care providers and services. They also stated that they still have a ways to go with some people in terms of them just not understanding First Nations culture or colonial history.

## Key Informant Understandings or Knowledge of Cultural or Traditional Practices as Part of the Care Routine

Within the original study the key informants were asked to share any stories they have heard or seen in regards to culture being addressed in neurological health care. This line of questioning left the conversation open enough for key informants to discuss what they have seen in their practices along with areas where culture needs to be taken into consideration within the health care system. In discussing the role of culture, one of the key informants shared that health care providers need to acknowledge that many Indigenous people still follow traditional cultural practices and may not look at a neurological condition from a deficit model. Instead, they may look at how the condition fits within their worldview: *“how does this fit into the mind-body-spirit connection or the four elements”* (KI05). Unfortunately, Western medicine does not always acknowledge the connection between the mind, body, and spirit and tends to view health conditions from a deficit model as opposed to a gift that can impart many teachings to the person and those around them.

Most of the key informants were open to their patients using traditional plant based medicines or cultural practices as part of their care routine. The movement disorder specialist shared that one of his Indigenous patient’s with Parkinson’s disease goes into the bush and fasts when she is not feeling well. He stated that for her, that was her therapy. While he would not recommend it for any of his other patients, he was aware that this is what worked best for her. He did not know if his other Indigenous patients took part in cultural ceremonies and practices or used traditional plant based medicines as part of their treatment plan. When asked if patients readily share this type of information with their health care provider or health care teams, many of the key informants

acknowledged that there is still a lot of fear that stops patients from sharing this information.

*Yes, a little bit. I haven't seen too many people that would share that they are doing cultural or traditional things. People are reluctant to tell me that they are using traditional medicines because there's that barrier and that perception that traditional medicines and culture isn't being taken too seriously. (KI09)*

First Nations cultural practices and ceremonies were banned under the Indian Act up until 1951. Indigenous people who were caught taking part in ceremonies could be fined or incarcerated, which forced many of the cultural practices underground (Boyer, 2014). Even with the ban lifted in 1951, individuals and families who used plant based medicines or took part in cultural practices and ceremonies may have faced social repercussions from others. For example, if a person was known to use certain ceremonies or traditional medicines as part of a healing practice, more Christianized members of the community may accuse them of using witchcraft or being pagans. Any fear or uncertainty around sharing cultural information with outsiders would be passed on to younger generations.

Over the last 50 years, there has been a lot of changes within the health care system to address the inequities Indigenous people face, including the need for culturally safe care. Many of the key informants shared details on how their work place included Indigenous health services, such as Elders, healers, traditional coordinators, Indigenous social workers, liaisons and patient navigators and advocates. Many of them also knew if the hospitals and clinics they worked with had designated areas or rooms where people could go and pray and hold ceremonies. One physician that works closely with Indigenous patients shared that he tries to encourage his patients to get the best of both

wolds in terms of medicines and cultural practices that will help diabetes and perhaps reduce the risk of diabetic neuropathies.

*I think that what we've tried to do with that condition is to, sort of, combine the best of both worlds. You know, is there ... between getting information the patients get from the elders or getting it from medicine men, getting it from different types of healing circles and that combined with, sort of, medical medications, right, and medical sort of approaches, whether it's exercise or whether it's weight loss, whether it's medications that can help control the diabetes. (KI06b)*

Patients that are using traditional plant based medicines are encouraged to share this information with their health care team. This would reduce the risk of any adverse reactions or complications between the traditional plant based medicines and the western medications. This physician also has access to Elders, traditional coordinators, and Indigenous patient liaison staff that he could direct patients to, as well as ask any questions that he may have about offering wholistic health care.

Many of the health regions that we went into had an Indigenous health strategy that focused on patient care, workplace diversity, as well as educational workshops and courses offered to health care providers and staff to increase cultural awareness and understanding. Focus group 1 discussed the Indigenous health services team within their small urban hospital. When the Indigenous liaison unit was first put in place, they had two workers to help Indigenous patients navigate through the health care system. Over the last 17 years, the program has grown to employ 16 workers. The liaison unit includes social workers, translators, ER liaison worker, a discharge planner, child worker, along with a traditional coordinator and coordinator helpers that are knowledgeable about traditional plant based medicines. The traditional coordinator helps patients' access traditional medicines, teachings and traditional foods. The coordinator also works with

the nurses and doctors to ensure there are no adverse reactions to using both traditional plant based medicines and western medications.

*And then, with traditional medicines, she'll come up and she'll assess what the need is, what they're [the patient] looking for then, she'll discuss it with the doctor and the nurses in regards to what they worked out and then they'll go make it or she'll make it and provide it. (KIFG01)*

Members of the team will also provide support to the patient and family members in whatever way they can, whether it is through accessing healers or if the patient prefers clergy members in the community to come and provide prayers or conduct ceremonies. The hospital has a healing room where patients and their family can go and smudge, sing, drum, eat traditional foods, have traditional medicines, along with a one-bedroom room, that family members could use while their loved one is being cared for in the hospital. The Indigenous liaison unit does its best to offer culturally safe patient centred care.

The importance of providing patient centred care came up quite a bit during the interviews. Many of the key informants spoke about needing to take the time to build a relationship with the patient and listen to what they are saying. One key informant shared that she does not believe in scheduling patients every 10 minutes and that if she needs to spend an hour with a patient in order to build trust she will take that time. Providing a wholistic approach to care includes looking at all components of the person and working together to find a solution. In providing patient centred care, a couple of key informants stressed the importance of empowering patients to take control of their health. This means taking the time to explain the different treatment options and asking them what it is they are able or willing to do. One key informant stressed the importance of starting with small manageable goals; *“incrementally provide success indicators rather than focusing on disease indicators”* (KI12). Another key informant stressed that physicians

should also be asking their patients if they have insurance to cover medications and if they do not, can they afford the medications that are being prescribed; do they need another option that is more affordable? Unfortunately, not every health care provider has the time or patience to make sure that each patient feels listened to or empowered to make decisions in their care plan. One key informant talked about the power imbalance between patients and providers and how patronizing and paternalistic attitudes can undermine patient safety.

*I just still see today that we're still doing a lot of that colonization by not giving people options. We're not explaining things to people because we're in a hurry and such, which I think is a poor excuse because the reality is that if people actually understand what's going on then they're able to make those choices and they're able to look after themselves in a better way. (KI11)*

This key informant shared number of stories where patient safety was not prioritized. One example included an older First Nations woman, who did not speak English, being emergency air evacuated from her remote community to a large urban hospital to be investigated for signs of stroke. The woman did not have any family members with her to support her or act as a translator. The hospital did not have interpreter on site that could tell her what tests were being conducted or why. The patient was in a vulnerable position with no family members or support person to help her understand what was going on. The lack of communication between the patient and health care providers meant that the patient was not able to communicate their needs, which further added to their vulnerability. When the hospital did release her, it was late at night and she had no way of getting home and nowhere to go. The woman was eventually taken to a women's shelter where she found someone that spoke her language and was able to help her. This type of practice of releasing patients without a care plan or even a safe place to go is

negligent. At present, there is no standard discharge process across Canadian hospitals, as each province and / or health region has their own protocols in place. The key informant rhetorically asked, what were the odds of the older woman going back to the health clinic the next time she felt ill? Sadly, this story is not unique or rare and highlights the need for culturally safe care, for departments to share information with Indigenous patient navigators and liaisons to better coordinate care and services, and for discharge protocols to be put in place to ensure patients have safe place to go when they are released.

Irihapeti Ramsden, a Maori nurse, in New Zealand in the late 1980s, developed the term cultural safety in response to Maori people's discontent with nursing care. Cultural safety "moves beyond the concept of cultural sensitivity to analyzing power imbalances, institutional discrimination, colonization and relationships with colonizers, as they apply to health care" (NAHO 2006 Fact Sheet: Cultural Safety). Culturally safe care involves building trust with Indigenous patients, communicating respect for a patient's beliefs, behaviours, and values, empowering patients to be willing and informed participants in their health care plan, and understanding the social determinants of health and the role this has on health. Cultural safety requires self-reflection in order to understand our own attitudes, beliefs, and assumptions (Health Council of Canada, 2012). One key informant stressed the importance of the patient and health care provider building a relationship together. This cannot be done if the health care providers do not take the time to recognize their own biases and how that can impact the relationship.

*I think a lot of our healthcare providers come from their perspective. Even though they don't mean to and they don't recognize that the reality is we all have biases so, I think we have to start to be acknowledging that we have our biases and that's OK, we've learned them and I have biases too, well all do! But, it's just trying to acknowledge them and try to be more cognisant of them and also being cognisant that we're in a relationship which means two people because I find in healthcare,*



*it's almost like we're viewing people like a zoo, like you know, we're kind of there to observe and do all these things but, the reality is that we're actually part of that relationship. (KI11)*

Critical self-reflection is an important component of cultural safety. Providers need to look at their own biases, values, and assumptions and understand how these beliefs influence their encounters with their patients.

A majority of the key informants felt that health care professionals and staff needed to have a better understanding of Indigenous people and their histories, including the treaties, residential schools, along with the Indian Act and other policies that affected Indigenous people. They felt that students would retain this information better than providers that have been in the system for a number of years. One key informant, who is a director of an Aboriginal residency program, insisted that her students take a hands on approach and immerse themselves in community and take part in any community activities, events and teachings. This type of immersion is slowly becoming more prevalent in medical schools and nursing programs.

One key informant did not entirely agree with cultural safety training being aimed at service providers unless they make long-term commitments to staying in the community. This person also expressed doubt that cultural safety workshops could make health care providers change their behaviours.

*And then just going to a workshop and being told be nicer to aboriginal people. Like people think it's useful but they don't change their behaviours right? Like some of that's set. I guess I used to say I think by the time we're 6 we start having our basic values and stuff. (KI07)*

Unfortunately, a onetime workshop will most likely not change the behaviours of a health care provider. If the health care provider works in an institution where policies and procedures are in place to promote cultural competency and safety, then change may

occur over time. Any courses or workshops aimed at the providers and staff needs to be ongoing and mandated at an institutional / organizational level.

## **Commentary and Recommendations on Promoting Health and Wellbeing**

### **Need for Advocates**

A couple of the key informants offered advice in terms of what Indigenous patients should know when accessing health care. One key informant spoke about the importance of bringing a friend or advocate with you to appointments to ensure that any questions or concerns are heard. In cases where a person does not have a friend, family member or advocate that could accompany them to their appointment, the key informant suggested recording the conversation or bringing a notepad and writing the information down. This is an important skill to learn especially if the person is seeing multiple specialists or care providers and the medical records are not transferred or updated across all clinics.

### **Need for Professional Interpreters**

Another comment that was made by a couple of key informants was the need for qualified interpreters to accompany patients who do not speak English as a first language. One specialist expressed frustration over patients using family members as interpreters and not being able to get at the broader health issues. A trained interpreter working within the health care system will be able to communicate any questions the provider may have in terms that the patient will understand. Unfortunately, there are no national standards in Canada for language interpreters in the health care system and hospitals are not legally required to provide professional interpreters for patients (Bowen, 2001; Health Interpretation Network 2010; Bascaramurty 2012). Some health regions do have policies

in place regarding medical interpreters. For example, the Winnipeg Regional Health Authority (WRHA) has trained health interpreters to provide face-to-face interpreter services in 30 languages and over the phone services for approximately 200 languages. The WRHA Indigenous Health Services have trained medical interpreters that speak Cree, Ojibway, and Oji-Cree. As part of the policy staff at WRHA facilities and WRHA funded facilities needs to ask patients their preferred language and if they need an interpreter during intake and registration. When interpreter services are requested or deemed as required by health care staff, all reasonable efforts need to be made to obtain the services of an interpreter regardless of time. (WRHA Policy: 10.40.210, Interpreter Services – Language Access. July 2013). Protocols and policies regarding trained medical interpreter services can help ensure equitable access to health care.

### Health Promotion

A vast majority of the key informants stressed the need for patients to learn more about their health. This includes what they need to do to remain healthy and stay in their homes longer. One key informant felt that women needed to be provided with more information on risk factors particularly around food, as women generally buy the groceries and prepare the meals for their families. A couple of the key informants felt this information would be better geared towards children and youth as opposed to adults or seniors who may be set in their ways. One key informant made the comment that more needs to be done to make healthy foods and activities more accessible to all people.

*We have a lot of policies and we have a lot of public health policies. And everyone knows what you should be eating and everyone knows that you should be exercising, everyone knows this stuff and to keep directing money and resources at that kind of information, being ... just bombarding people with information, I kind of think it's not helping. (KI8)*

This key informant felt that for many people, eating a balanced diet, exercising, or even practicing mindfulness to protect the body, mind and spirit balance, are out of reach due to high costs of healthy food, fresh fruits and vegetables gym memberships. Many people may also need access to transportation and / or childcare to participate in certain activities, go to appointments or get groceries. She recommended more funds to support community liaisons that could help people in the community access services, arrange transportation and childcare, as well as offer classes that teach people how to eat healthy on a budget.

## Conclusion

The key informant interviews raised a number of issues around caring for Indigenous people who have chronic health conditions, including neurological conditions. In discussing their experiences in working with Indigenous people in the health care setting, they shared some of the difficulties around accessing health care services, especially if there are competing factors not limited to geographic location, poverty, and negative past experiences within the health care system. Most of the physicians, specialists, and nurse practitioners were open to their patients using traditional medicines, as long as they told their care providers what they were using. The openness and acceptance of traditional plant based medicines and cultural practices as valid and recognized part of a treatment plan was encouraging. It would be interesting to see if this attitude would be present in a much larger sample of health care providers.

A major issue that kept coming up in the key informant interviews is the need for culturally safe care at all levels of the health care system. Systemic and institutional racism still very much exist within the Canadian Health Care system. Health care services

aimed at Indigenous people need to include meaningful consultation with Indigenous people from the very beginning. Health care providers and staff need recognize the biases they carry and how this can influence how they treat others. Colonial assumptions and racist stereotypes have no place in the health care system, yet stories of discrimination and racism continue to be seen in urban, rural, and remote health centres. More education is needed around Indigenous cultures, ways of knowing, and the impacts of colonialism on health and wellbeing.

The recommendations brought forward by the key informants speak to patient centred care practices. Many of the key informants encouraged their patients to bring a loved one or a friend to their appointment to help support the patient and hear what the physician is saying or ask any additional questions. Key informants also encouraged their patients to ask for professional interpreters if they felt more comfortable speaking in their own language. Most of the health regions that the health care providers worked at did have interpreter services for their patients. In order to access these services, the patient would need to request an interpreter when they booked their appointment. Unfortunately, not all patients know what health care services they can access or what their rights are in accessing these services. This speaks to the need for more education about patient rights and responsibilities. Many of the key informants shared that this type of information, along with health promotion, and identification of risk factors should be embedded in primary and secondary education curriculums.

## **Chapter 5 The Role of Traditional Knowledge Keepers in Understanding Neurological Conditions**

Many Traditional Knowledge Keepers and Elders guided the UFW project. Two project Elders helped guide the overall vision of the project. In addition to the two project Elders, the UFW team worked closely with Traditional Knowledge Keepers and Elders from different First Nations and Metis backgrounds across the country, four of whom agreed to be interviewed for the project. This chapter differs from the other two findings chapters in that both the stories and knowledge shared throughout the life of the story will be included along with the secondary analysis of the four interviews. The stories and knowledge shared has continued to unfold over the years.

The terms Traditional Knowledge Keeper and Elder is used to acknowledge the knowledge and teachings carried by First Nations, Inuit and Metis people that have been passed through the generations (Medicine, 1983; Stiegelbauer, 1996; Wilson, 2003; Stonechild, 2016). Elders and Traditional Knowledge Keepers are not defined by age but are recognized by their community for the gifts, teachings, and knowledge they carry.<sup>12</sup> While this definition is rather simplified, each of the Elders and Traditional Knowledge Keepers for this section were recognized and greatly respected within their communities and within NWAC as an organization. They each played a very important role in helping research team understand the stories that were being told to us by the participants. In certain cases, they were able to provide context and history behind the personal accounts that were shared. They also led smudge ceremonies and prayers, as well as shared healing

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<sup>12</sup> There is no standard definition of who is an Elder or Traditional Knowledge Keeper. This may differ by communities and cultures.

songs to the participants and researchers. The inclusion of ceremonies and prayers helped the research team to spiritually ground the work we were doing. Flicker et al. (2015) summarizes this role in stating: “Elders often provide the wisdom, knowledge, and ceremonial guidance to assist with research processes that respect Indigenous worldviews” (1149).

Each of the Traditional Knowledge Keepers played a role in how we thought about the objectives of the project, the development of the methods, the opening and closing of research circles, and the understanding of the stories that were being told to us. In following traditional protocols, each of the Traditional Knowledge Keepers were given tobacco and cloth and asked for their guidance in conducting this research “in a good way”. Flicker et al. (2015) state:

“In a good way” is an expression used by many Aboriginal communities to denote participation that honors tradition and spirit. Among the Anishinaabe people, this is embodied through the Seven Grandfathers Teachings of wisdom, love, respect, bravery, honesty, humility, and truth. From an Indigenous worldview, research done “in a good way” is a sacred endeavor that illuminates the connections between the spiritual and the physical world. (Flicker et al 2015: 1149)

The research team strived to incorporate these teachings throughout all aspects of the project and were guided by two project Elders, Sister Veronica Matthews and *Kookum*<sup>13</sup> Betty McKenna<sup>14</sup>.

The Principle Investigators each asked an Elder that they worked closely with to help guide the research process. Sister Veronica Matthews is a Mi’kmaq woman from Eskasoni Mi’kmaq Nation. She was asked to sit as a project Elder by the co-PI, who had

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<sup>13</sup> *Kookum* is Cree for grandmother. The team members called her *Kookum* or Elder Betty as a sign of respect for the teachings she carried.

<sup>14</sup> The project Elders and Advisory Committee Members are all listed in the “Understanding from Within” research report 2013. <https://nwac.ca/wp-content/uploads/2015/05/2013-NWAC-Neurological-Disorders-Report.pdf>

developed a close relationship with her through previous Indigenous health projects. Sister Veronica is a registered nurse who has a tremendous amount of experience in community health and is a founding member of the Aboriginal Nurses Association of Canada. When the co-PI resigned from the project, Sister Veronica continued to help guide the research and share her wisdom and expertise with team.

The other project Elder is *Kookum* Betty McKenna; an Anishinaabe woman from Shoal River First Nation. *Kookum* Betty carries many traditional teachings that she learned from her Grandmother and many other Elders. Dr. Bourassa has worked with *Kookum* Betty over a number of years and has sought her guidance throughout a number of research projects on health, wellness, addictions, healing and end of life care. *Kookum* Betty also works within the public school boards in Saskatchewan as a resident Elder. The research team regularly consulted with the project Elders to ask for advice pertaining to staffing, research methods, project delays, as well as data collection and analysis.

In addition to guiding the project, *Kookum* Betty McKenna worked with an Anishinaabe artist, Mike McKenna, to develop the logo used for the “Understanding from Within” project (figure 3).



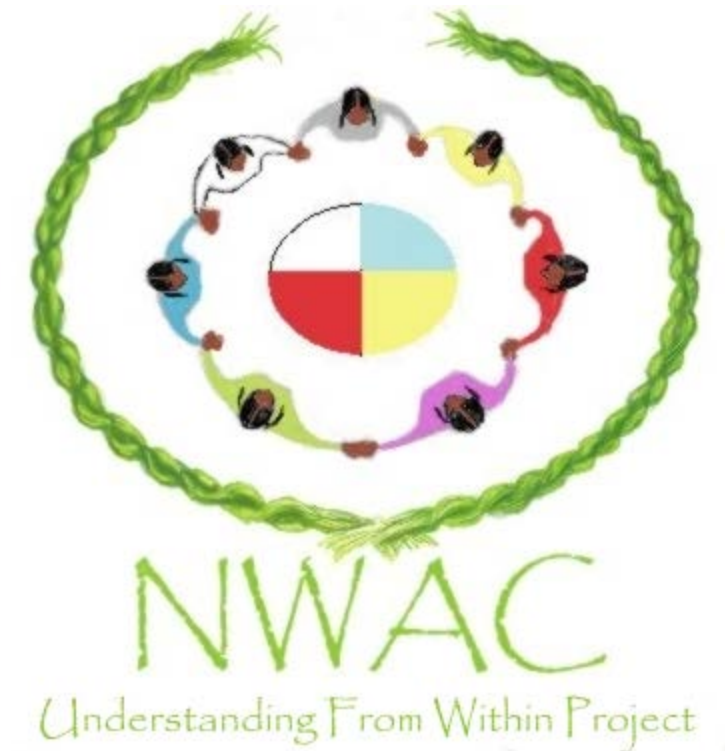


Figure 3.

The logo includes seven grandmothers around a medicine wheel with a braid of sweet grass with the opening at the top of the circle surrounding the grandmothers. The logo depicts key teachings and helps support us in learning about and living with a neurological condition or caring for someone living with a neurological condition. The colors used in the logo are red, blue, green, purple, yellow, white and grey. *Kookum Betty* gave the following explanation for each of the colors:

- Red is the color of passion and is the catalyst that is driving us forward to learn about the conditions;
- Blue represents calm and serene and corresponds to people need to accept how things will be;
- Green is the color of growth. It is between blue and purple and signifies that everyone will be touched by the condition. Growth and understanding are needed in learning how to live with a neurological condition;

- Purple represents confidence and how we need to be confident in the decisions we make in regards to our care;
- Yellow represents new beginnings;
- White represents the eagle's power and being at one with the Creator;
- Grey is happiness and changes throughout the stages of life.

She also named each of the Grandmothers and gave a brief explanation of what the names represent. The seven Grandmother names are Growth, Order, Adequacy, Love, Social Approval, Security, and Self-Esteem. These concepts are important teachings that are typically given to youth to help them navigate through early adulthood, but are very relevant to people who are experiencing symptoms associated with a neurological condition or caring for someone that lives with a neurological condition. The circle in middle represents the medicine wheel and the physical, mental, emotional and spiritual components. These seven Grandmothers help to root us in Mother Earth. *Kookum* Betty shared that the Grandmothers are the ones that bring healing. She stated that healing starts with the individual, from the inside out. The braid of sweet grass with the opening at the top represents strength and protection. The opening reminds us that when we burn sweet grass we need that opening to allow the smoke and happiness to come in.

The logo helped frame the project and remind the research team of our role in supporting the participants that would be coming forward to share their story. It was used on recruitment posters and canvas reusable bags that were given to participants. The teachings embodied in the logo were brought forward in many of the interviews and research circles with people who lived with a neurological condition or cared for someone with a neurological condition. The Traditional Knowledge Keepers also discussed these teachings and expanded on their own experiences working with people who have a neurological condition, and in one case living with a neurological condition.

In addition to the two project Elders, we also reached out to a number of other Elders and Traditional Knowledge Keepers to help us gain a better understanding of how people who lived with a neurological condition were traditionally cared for. We kept in close contact with four Traditional Knowledge Keepers who shared their thoughts and understandings and agreed to be formally interviewed. Traditional Knowledge Keepers 1 and 2 are both Ojibway and are a married couple from the prairies. They both worked in the federal public service sector for over 25 years. These two Traditional Knowledge Keepers are fluent in their language, and serve the community through sitting on various boards, including Elder Advisory boards in public education. In addition to the interview, they led two research circles and on one occasion travelled with the research team to provide support to participants and help the research team debrief. Their presence helped everyone feel safe in sharing their experiences. The Elders also provided prayers, healing songs, counseling stories, and used plenty of humor and teasing when needed. They were able to help the research team understand that we would be hearing some heartbreaking stories that would be emotionally and spiritually draining, but we could not hang on to the pain or grief shared. Our role was to listen and hear the stories that were being shared and relay their messages and recommendations on a more national scope. Both Elders attended the last advisory committee meeting to give their perspectives on the project and what steps should be taken in terms of writing a final report.

Traditional Knowledge Keeper 3, is Cree Metis and from the prairies. She also is very active in the community and sits on several community Elder advisory boards. In addition to the interview, this Traditional Knowledge Keeper acted as an advisory member on several of NWAC's other projects. She also counseled the research team from

time to time and asked us to think about what we could reasonably do that could potentially help the participants in sharing their story. She stated that sometimes this would simply include listening and hearing the stories that were being shared, other times this included sending educational materials on the different conditions and what to expect as the condition progressed. She reminded us that caring for the people sharing their stories and fighting for these stories to be heard on a national scale to effect change were two separate things. This was helpful in thinking about the immediate needs of people sharing their stories, and the long term goals of the project in terms of providing baseline information on the needs of Indigenous people living with a neurological condition or caring for a loved one with a neurological condition. This Elder also attended the last advisory committee meeting to give her perspective on the project and a number of recommendations for policy makers.

Traditional Knowledge Keeper 4, is Cree from northern Ontario. She is a traditional counsellor and works within urban Indigenous communities and sits on numerous advisory committees. In addition to the interview this Traditional Knowledge Keeper, was contracted by the research team to help team members debrief and work through any grief or pain the researchers held on to in listening and learning from the stories. This was important in that it was not our pain to carry, and we could not effectively listen to other participants if we were carrying around the pain and grief from all the stories we were hearing.

The relationships built over the course of the project play a large role in how I think about stories shared and the teachings passed on to me through these interactions. The secondary analysis of the interviews also made me think more about the beliefs and

values shared and how this helps shape our own understanding and worldview. This is where Two-Eyed Seeing is so important in seeing and understanding the cultural nuances with one eye and using the other eye to critically look at the colonial impacts on health and wellbeing and what this means in understanding health inequities at each the individual, local, regional and federal levels.

The interviews from the Traditional Knowledge Keepers contain a tremendous amount of information regarding cultural understandings of neurological conditions, the impacts of colonization, as well as the differences between Western and Indigenous perceptions of health and wellbeing. The transcripts were reanalyzed with special attention being paid to cultural understandings of neurological conditions in terms of answering the two following questions: 1) Are neurological conditions fairly new or have Indigenous people always experienced these types of conditions? 2) How were people with neurological conditions traditionally cared for? How is this different today?

### **Cultural Understandings of Neurological Conditions**

The Traditional Knowledge Keepers were asked to share their thoughts on neurological health issues and how they could be understood and addressed through the lens of the traditional teachings they carry. This question was purposively left open to allow the Traditional Knowledge Keepers to share as much or as little information as they wanted. Many of them talked about their upbringing, where they were from, their family and how they were raised. They also spoke about their experiences in relation to the roles they have in their communities, in their families, and in their work life. This background information lays the framework for how their worldview shapes how they think about and understand neurological conditions.

In relooking at the transcripts, a few key themes stood out in relation to cultural understandings of neurological conditions. These included neurological conditions being normalized, people living with a neurological condition and their families being treated with respect, as well as people living with a condition being seen as a gift. There was a general consensus that traditionally, people who were born with a neurological condition or acquired a neurological condition later on in life, were simply taken care of by their families and community. They also spoke about the differences between Western and Traditional medicine and the impacts of colonization and Christianity on traditional beliefs and cultural understanding of neurological conditions.

### Existence of Neurological Conditions

The Traditional Knowledge Keepers were given examples of the different types of neurological conditions that were included in the NPHSNC and asked if they knew whether these types of conditions have always been in existence, or if they were a relatively new phenomenon. All of the Knowledge Keepers stated that certain conditions most likely did exist a hundred or more years ago. When asked if certain conditions existed prior to contact, they were not quite sure. One Traditional Knowledge Keeper questioned whether a person with a severe neurological condition would survive during times of famine or hardship.

*And then on the other hand, and we're going to go just right in the 'let's take the rose coloured glasses off' and let's look at the real Traditional-traditional, we were nomadic, we moved around, and in the winter time if food was scarce, there wasn't a good harvest, there wasn't a good hunting season, if food was scarce the old ones didn't eat and the young ones weren't fed, and that may have included sick people. They may have chosen not to eat because you have to keep your hunters and gatherers alive to keep the rest of the family, the rest of the community alive. You can't lose the vital youth in there so, I don't know if there's been any real archaeological-anthropological study on what they've found. I know I've heard, haven't actually seen it but, it makes sense. (TKK04)*

This Traditional Knowledge Keeper drove home the point that we need to really think about what we mean when we say “traditionally” or “back then”; do we mean 100 years ago, 300 years ago, or 1000 or more years ago. She also cautioned against romanticizing the past and think about some of the realities that people faced in times of extreme weather, hunger, migration, and even war. A summary check through the literature did not return any hits on archaeological evidence of pre-contact neurological conditions.

Two of the Traditional Knowledge Keepers believed that certain neurological conditions existed long ago, but did not put a timeframe on it. Instead, they talked about how the conditions were described in the language and stated that there were words in the Ojibway language that described what was happening to the person and to their body. For example, they brought up the condition of epilepsy and how it described in the Ojibway language. In English it translated into not having control and being in this space and you floated around here. They also talked about rheumatoid arthritis and how it was described in the language as an ailment of the bone, almost like a spider disease, where the pain and inflammation just spreads and it is not contained. The Traditional Knowledge Keepers did not know of any medicines that would cure epilepsy or rheumatoid arthritis, but were aware of medicines that would help lessen the effects.

The other two Traditional Knowledge Keeper felt that certain neurological conditions might be a relatively new phenomena. The third and fourth Traditional Knowledge Keepers talked about the impact stress has on our physical, emotional, mental, and spiritual wellbeing. When these components are out of balance, we may react differently to certain stressors. Prolonged or chronic stress can result in cognitive,

emotional, physical, and behavioural symptoms (Maté 2016; Bourassa et al. 2015; Wesley-Esquimaux & Smolewski, 2004).

*Stress can cause a lot of the neurological to react and I think that the medicinal teachings is what I follow to keep me calm and to... like just so that I don't take small things and make them larger. I try to stay very calm and lots of rest, which is part of the physical direction, and I think that if you follow the medicinal teachings holistically for all around, including your physical, that it would really impact the neurological disorders; so I think that's the best teaching to do.*  
(TKK03)

For this Traditional Knowledge Keeper, following the cultural teachings help keep her mind, body, and spirit in balance. All of the Traditional Knowledge Keepers spoke about the importance of listening to one's body and trying to find out what we were missing in order to live life more in balance.

The Traditional Knowledge Keepers also discussed how some neurological conditions may be the result of motor vehicle accidents, trauma and abuse. A few of the Traditional Knowledge Keepers talked about traumatic brain injuries (TBI) and how this may be underreported in Indigenous populations. A couple of examples were given in terms of assaults and intimate partner violence where people are hit in the head, and or face, and do not seek treatment. Repeated brain injuries can lead to increased cognitive, physical, and emotional dysfunction over time (Avner, 2010; Car, 2000).

Environmental factors were also brought forward by the Traditional Knowledge Keepers who felt that certain factors may put Indigenous people at increased risk for neurological conditions. For example, techniques associated with resource extraction may result in lands and waterways being polluted. Traditional Knowledge Keeper 3, made specific mention of the Alberta tar sands and how many of the fish in Athabasca River are deformed and how this impacts animals that drink from the water and eat the fish, as



well as the humans who hunt, fish, and gather any medicines or foods from the land and water in those areas. Elevated levels of arsenic, cadmium, mercury, selenium, and polycyclic aromatic hydrocarbons (PAHs) has been found in moose, muskrats, ducks, beavers, and fish, all which are traditional foods to the First Nations communities living the Athabasca region (Masuda et al. 2008; Timoney & Lee 2009 found at <http://cahr.uvic.ca/nearbc/documents/2009/Alberta-Tar-Sands-Industry-Pollute.pdf>; <http://america.aljazeera.com/articles/2014/7/8/canada-oil-cancer.html>; <http://business.financialpost.com/news/oil-sands-pollution-linked-to-higher-cancer-rates-in-fort-chipewyan-study-finds>).

Over exposure to these toxins can increase the risk of certain types of cancer, damage to the heart, lungs, and gut, as well as nervous system. For example, overexposure to mercury in adults can lead to tremors, loss of muscle coordination and sensation, memory loss, intellectual impairment and death (<http://www.hc-sc.gc.ca/hl-vs/iyh-vsv/environ/merc-eng.php#he>). Mercury poisoning in children can lead to cognitive delays, lack of coordination, delays with walking and talking, along with blindness and seizures (Ibid.). Health Canada has guidelines on the acceptable levels of exposure for arsenic, cadmium, mercury, and selenium and how to minimize risk, by reducing consumption and finding alternate water sources. Unfortunately, finding alternate water sources or decreasing consumption of traditional foods such as fish and other wildlife may not be viable solutions for individuals and communities experiencing high levels of poverty, or food insecurity in terms of location to the nearest grocery store.

## Caring for People Who Live with a Neurological Condition and Their Families

The conversations and transcripts revealed a couple of key concepts in terms of neurological conditions being normalized and that people living with a neurological condition were simply taken care of. The Elders and Traditional Knowledge Keepers also spoke of the gifts that come with these types of conditions and needing to recognize that there are lessons learned from every experience. *Kookum* Betty further expanded on this the same day she talked about the logo and what it represented. She explained that we are all spiritual beings having a human experience. We choose our path in life, including our parents, long before we are even born. *Kookum* Betty shared that everyone has a purpose in life and our spirit knows what this purpose is and embeds this along, with other teachings, experiences, and gifts deep within our memory. When babies first cry after they are born, it is because they forget all those memories. As we go through life, we will encounter certain helpers, experiences, and challenges that we will learn and grow from. These experiences are all part of our plan. When we accomplish what we set out to do, we start our journey back to the spirit world.<sup>15</sup>

Thinking about the concept “we are all spiritual beings having a human experience” implies that our spirit has chosen a certain path in order to expand our understanding of the world and learn from the experiences encountered. This teaching is present in other Indigenous cultures and is written in Blair Stonechild’s (2016) *The Knowledge Seeker: Embracing Indigenous Spirituality*. Stonechild (2016) writes about Indigenous spirituality, drawing on the wisdom and teachings of many Indigenous Elders

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<sup>15</sup> Phone conversation with Elder Betty McKenna, June 22, 2012.

he has worked with and interviewed throughout his life. He explains, “Key to understanding Aboriginal spirituality is the notion that “spirit” actually exists. The purpose of the physical life for spirit beings, [...], is to experience choices and learn from them” (Stonechild, 2016:51). He goes on further to state,

In fact, all things, plant animal and inanimate, have spirit essences and all things interact in a web of interrelationships. However, humans yearn to reconnect with their spirit origins. That is why in pre-contact societies so much effort was devoted to communication with the incorporeal. (Stonechild, 2016: 52)

This segment is part of a much larger Creation narrative that explains the relationship between the spiritual and physical world and the teachings that are needed to live a good life. Within our physical life, we will encounter different experiences, challenges, and teachings on our journey. Prayers, meditation, and ceremonies help reinforce the connection to spirit and can guide us through the difficult times and understand our purpose in life.

The Traditional Knowledge Keepers talked about the role of spirit in thinking about and understanding neurological conditions. They shared that people who lived with a neurological condition or any condition would be seen as being a gift, to help people see things from a different perspective.

*They were seen as people with a gift...For others to see... You know and to learn from and that's how they were viewed... You know that they were special people... (TK01-02)*

*Things would have been perceived as the person being unique. If there was a problem, or an issue, quote on quote a white man's word, they would have been seen as gifts, because this person had a different perspective. (TKK04)*

For people that were not born with a neurological condition but were diagnosed later on in life, they need to think of the gifts or the teachings that come with their condition.

There will be losses, but there are also tremendous lessons to learn from these experiences.

*And so, whatever information comes to a person, it is a gift, it is a gift even if it's hard to take. It is a gift because now you know what's what and then, you can go from there. I think it's really important to deal with the feelings, the intense feelings of betrayal, loss, whatever it is, grief and then, focus on how I'm gonna make the best out of this. What do I need to do to make the best out of this for me!? And then, go about doing that. (TKK04)*

The Traditional Knowledge Keepers stressed the need for people to see the gifts in everything they do and encounter. They also talked about the importance of learning about the condition and educating family members on signs and symptoms, as well as how to care for the person.

*You know just make sure she's comfortable and looked after and her needs are met. So we always had to be conscious of that, but I think it has to be a concerted effort by family members to educate other...*

*You know other family members saying this person has this illness and to be able to have that awareness...(TK01-02)*

One Traditional Knowledge Keeper emphasized the need for people learning how to live with a neurological condition, as well as people caring for others with a neurological condition, to practice patience and understand that some days will be better than others and some daily activities may need to be altered.

*attend to the emotional, spiritual, encourage the grieving, encourage the talking about that and encourage it about, you know, what are the gifts from it? There's still losses but, what are the gifts? That's one of the things that we do; we look for the gift in it. (TK04)*

All of the Traditional Knowledge Keepers commented that most people, who did have a health condition or were ill, were treated with respect and were taken care of by the community. They did not think a lot of attention was placed on trying to understand

why a certain condition came about, but more attention was placed on how to care for the individual and their family.

*So, there would have been ways to help ease the kind of side effects or suffering but, I have never come across any real documentation or recording of how people would have dealt with neurological damage and, to me that says that it was kind of normalized. There wasn't any particular attention paid to it then, it would've been normal. They would've treated it as something that they would just have to deal with. (TKK04)*

These Traditional Knowledge Keepers also shared that everyone in the community knew if a person lived with an illness or a health condition that limited their ability to take part in daily life activities. This type of community awareness ensured that the person would be protected and redirected if they were found doing something out of the ordinary.

One Traditional Knowledge Keeper shared an example of how the women within the community would take care of those that could not always take care of themselves.

*I remember one community member was an epileptic and when that would happen, people would you know give him that medicine, everybody knew what the medicine was and because he was... He was not married, he was a bachelor and when people knew that he had that... He had a seizure, people would make an effort to go and... Cause that's what used to happen a long time ago with our women, it was our women that kind of watched everything...(TKK01)*

This short example provides so much information in terms of relationships, caregiving, recognizing signs and symptoms of different illnesses and the need for treatment, as well as modelling behaviours in terms of everyone knowing what was needed to take care of this person. This can also be looked at in terms of worldview and the responsibility women have as lifegivers. Within many Indigenous cultures, including Ojibway and Cree, a woman's ability to produce and nurture life is seen as sacred and powerful. The ability to create life also comes with great responsibility in terms of nurturing all life.

Kim Anderson writes about Indigenous women's strength, power, and beauty in her book *A Recognition of Being* (2000), where she interviews 40 Indigenous women across

Canada. One participant, Ivy Chaske (Dakota), talked about how she understood women's responsibility to all people, not just their own children.

We have a responsibility to all of the people. We have to. We are the lifegivers. We are the life force of the nation. Our responsibility is to everyone; male and female, young or old, because we are that place from which life itself emanates. And there is nothing greater than that. (Anderson 2000: 169).

The example above also mentions the administering of medicines to help treat the symptoms. All of the Traditional Knowledge Keepers talked about traditional plant based medicines that can help alleviate certain symptoms associated with neurological conditions.

*Cause traditionally there was no medicine as such to cure that, but we did have medicines that would help in the recovery process...(TK02)*

*I'm sure that there were very advanced in their own traditional healing to have something to help, so... And like you said, they might not have been able to cure some of them, but they knew how to take care of them. (TK03)*

*I've worked with some elders who dealt with spinal injuries for people who had been paraplegic...we had some paraplegics come in, and dealing with pain management and teaching them how to do that, and teaching them how to tend to their emotions, tend to their spirit, to bring balance. (TK04)*

All of the Traditional Knowledge Keepers felt that treatment in the form plant-based medicines, would help with the symptoms, but not necessarily cure the individual.

Keeping a wholistic view of health and attending to a person's mental, emotional, and spiritual state was just as important as attending to a person's physical ailments. Bringing a sense of balance to the body, mind, and spirit, could bring the person the strength needed to manage their symptoms. This could be done with meditation, prayers, and ceremonies, with or without the assistance of Elders, healers, and other helpers.

*I think that they were taken care of through the healers and prayed upon and... and they must have had ceremonies just... The Sweat Lodge... there's a lot of healing sweat lodges, so they must have gone into the sweat lodge and got healed, you know, or doctored. I see some people with neurological disorders at the sun dances in wheelchairs and they go for the healing, and they take them up to the tree of life and they take them to the healers, you know, to be doctored. So I think they knew; I think they could have been around. (TKK03)*

Ceremonies have been used by different Indigenous groups from time immemorial to help with illnesses, receive messages from the spirit world, to give thanks, to help with harvest or to find game, to see into the future, along with various other requests (Stonechild, 2016; Deloria Jr., 2006; Preston, 2002; Wolfart & Ahenakew, 2000) .

One Traditional Knowledge Keeper shared her own experience of being afflicted with a neurological condition later on in life. The pain and symptoms associated with dystonia<sup>16</sup> would leave her with severe muscle spasms, and loss of mobility. She spent a lot of time going to various physicians and specialists to manage her symptoms, but was allergic to certain medications. She was also alcohol and drug free and did not want to be prescribed narcotics for pain relief. She found many of the health care providers were not willing to work with her to find alternate medications or practices that could help with managing her symptoms. That's when she started to turn more towards traditional healing practices and plant based medicines. She also took part in ceremonies and found that she was able to able to manage her symptoms and improve her mobility through ceremony. When asked if there were specific plant based medicines that could be used for certain neurological conditions, she did not know of specific medicines. She did comment that there may have been knowledge of different plants and healing ceremonies long time ago, but a lot of this may have been lost as a result of colonial practices and policies.

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<sup>16</sup> Dystonia is a movement disorder, where the muscles contract uncontrollably.

*We lost a lot of our medicines knowledge when everything else was hidden, and there's medicines for a lot of different cures out there. I don't know how much there is for neurological, but I know they cured me, so...(TKK03)*

## **Colonial Impacts and the Influence of Christianity**

All the Traditional Knowledge Keepers talked about the impacts of colonialism and influence of Christianity on Indigenous communities, ceremonial cycles, cultures, and traditions. Parts of the conversation focused on the Indian Act and the policies that aimed to regulate and control every aspect of Indigenous peoples life. The Indian Act was put in place in 1876 and amalgamated all previous legislation managing Indigenous people in Canada. The Indian Act defined who was an Indian and traced lineage through the male line. Indigenous women who married a non-Indian would lose their status and any children from the union would not be considered Indians under the Act (Jamieson, 1985). A couple of the Traditional Knowledge Keepers commented that many of the tribes were matrilineal and followed a clan system. The clan system outlines the responsibilities and kinship relations. People were not to marry someone from the same clan, as they would be considered related. They felt that some communities are forgetting about the clan system and are following patrilineal lines imposed by the government. They are worried that this may affect future generations, especially if people are not aware that they are related and end up having children together.

*Our societies are not patriarchal, they're matriarchal, because right now the way they're going, it's patriarchal ...They believe it's patriarchal, because that's what Europeans brought, you know so... That's why ...(TK01-02)*

Since contact, missionaries have tried to convert Indigenous people to Christianity and follow a patriarchal structure. This structure put men as heads of households, communities, and governments. Women were seen as dependent on men for all their



needs. This greatly contrasted with many Indigenous cultures where women held a lot of power and influence in their communities.

Early Indian policy sought to introduce Christianity to all Indigenous people. The federal government assigned Indian Agents to each reserve to help with the civilization and assimilation of Indigenous people. The Indian Agents were to encourage Indigenous people to abandon their traditional ways of life, including their beliefs and practices and take up Christianity and agriculture. Anyone who continued to practice their traditional ways were seen as pagans and deterrents to assimilation and eventual civilization. The Indian Agents controlled administration of the band and its finances, issued rations, enforced attendance at residential schools, controlled social, political, religious, and cultural practices, as well as movement off reserve, and sale of any goods. Policies sought to eradicate Indigenous culture and traditions through banning ceremonies starting with the Potlatch in 1884, followed by the piercing aspect in the Sun dance in 1895, and all off reserve dancing in 1914 (Leslie & Macguire 1979; Pettipas, 1994). Indian Agents on each reserve were instructed to discourage participation in all ceremonies and dances and could use other regulations such as the pass system<sup>17</sup> and trespass laws to limit Indigenous peoples' movements off reserve. The Indian Agent also had the power to remove Indigenous Chiefs and Councillors from office if they were found to be acting immorally. Threats of being arrested or having rations withheld contributed to many ceremonies, practices and traditional knowledge of medicines to be hidden and practiced underground.

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<sup>17</sup> The pass system was introduced in 1885 during the North West Uprising to prevent Indigenous people from leaving their reserves. The pass system was also used to limit off reserve visiting and participation in ceremonies and dances.

The biggest push to indoctrinate Indigenous people can be seen with the Indian Residential Schools. The Indian Residential Schools were church run institutions, funded by the federal government. The schools were established to assimilate Indigenous children into Euro-Canadian society through taking the Indian thoughts, beliefs, and practices out of Indian children (Truth and Reconciliation Commission of Canada, 2015; Milloy, 2008, 1999; Miller, 1996). Through segregating the children from their parents at a young impressionable age, the missionaries and the government officials felt that they could ‘civilize’ them and produce “children who would be interchangeable with white children except for colour” (Nock, 188: 79). The children were enrolled in a denominational residential school from the ages of six or seven until they were sixteen<sup>18</sup>. In most schools, the children were not allowed to speak their Indigenous language, nor take part in any cultural ceremonies or practices, as these were seen as pagan and uncivilized. With the Indian Residential Schools being in existence for well over 100 years, many generations of Indigenous people lost their language, were taught that their cultural beliefs, ceremonies, and practices were pagan, and people who did not follow the teachings of the church would go to hell.

The Traditional Knowledge Keepers spoke about the legacy of the schools and the influence of Christianity and how some people may see a diagnosis of a neurological condition as a punishment. Similarly, if a child was born with a neurological condition some people may think the child was being punished for the sins of their family.

*Some people were afraid as they are in any culture, they're afraid of it, don't know if it's catchy or what's going on, is it a crime and punishment thing because a lot of the people were Christianized. Christianity talks about crime and punishment; the good are rewarded, the bad are punished. There was so much*

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<sup>18</sup> In some cases children were as young as 4 years old.

*psychological-emotional-spiritual stuff that needed to be attended to. A lot of people felt that if they went the Traditional way, took the Traditional medicines they were being disloyal to their Christian teachings. So, when you look at Aboriginal people dealing with any kind of mainstream issue, it's far more complicated than those people 'who cut it off at the heads' can imagine. (TKK04)*

*A lot of people don't even know as much... you know, they've never seen a smudge bowl and there are people, that they're so Christianised... but if they can at least get a beginning of something, then maybe they won't be so fearful of it. Because they've been told that it's paganism for so many years, you know; the Catholic church always did, which is one of our biggest religions that really made sure that they were fearful of this way. (TK03)*

It was acknowledged that some people might feel conflicted when it comes to trying plant based medicines or Traditional healing practices. These attitudes are changing and more cultural aspects and rituals are being adapted and incorporated into Christian sermons.

### **Using Western and Traditional Medicines.**

All of the Traditional Knowledge Keepers stressed the importance of keeping an open mind concerning Western and Traditional medicines. One Knowledge Keeper shared that “*there was a belief that the Creator gave medicines and teachings to all races*” (TKK04). Her and another Traditional Knowledge Keeper encouraged people to reach out to Elders and Healers when dealing with neurological conditions or other illnesses.

*I think you should see elders or healers and they have some really good medicines. They don't... as I said before too, they don't ever tell you don't go to the Western doctor, don't take their medicine; they just try to help so you don't have to take as much, or it wouldn't be as hard, especially with side effects, because the medication from the Western world has a lot of side-effects that we don't know about. (TK03)*

The Knowledge Keepers stressed the need for open communication with Elders, Healers and Western practitioners. They also emphasized the importance of taking an active role in one's health and asking for a second opinion if you do not feel you are being heard or

being helped. They also spoke about the importance of talking to others and learning from them, especially if they need to access services.

*It's always best to talk to people when you're in a situation like the hospitals or social assistance. You talk to the person beside you, because you find out a lot more information than you would from anybody working in that system. (TTK03)*

Finding someone who is going through a similar situation as you are and accessing services that you need to access can be very helpful.

Another difference that was brought forward was the disconnect between the mind, body, and spirit. The Knowledge Keepers talked about the importance of tending to the whole body and not just focusing on one particular area. Within Western medicine, we go to see specialists that focus on one area, but often do not see what is happening to the rest of the body or even the impacts on our emotional and spiritual selves.

*mainstream western teachings silence the symptoms. Traditional medicine looks at the symptoms as the teachers for what's going on; they're not trying to silence them, they're trying to heal them, right!?! (TKK04)*

This Traditional Knowledge Keeper viewed Western medicine as a “sterile silo-approach” (TKK04), where the “problem” is looked at in isolation as opposed to being communicated with other professionals dealing with the whole body, mind, and spirit. She felt part of this silo approach is due to education, training, and specialization of health services, where the physicians and specialists are viewed as the experts. She commented that this process takes a lot of power away from people who are ill or experiencing symptoms associated with a certain condition and gives it to the physician or specialist. This can greatly affect how people deal with illness and interacting with the health care system.

### **Need for Culturally Safe Care**

The Knowledge Keepers wanted health care providers to focus more on a patient first strategy that empowers the patient. To take the time to listen to their patient and ensure that they understand everything that is being discussed, including treatment plans, medications, and to ask if they foresee any barriers to following the treatment plan. In certain cases, these barriers may include location and access to rehabilitative services. They also want health care providers to be aware that some people need to travel great distances to access care, especially if they live in rural or remote locations. For people in remote locations, accessing specialist services often requires a referral from a nurse practitioner or general practitioner, who may not have the experience or training to recognize the severity of certain symptoms. One of the Traditional Knowledge Keepers commented on her interactions with some of the nursing stations in the north and how prevalent racism is, especially for people who are having a stroke or exhibiting other symptoms and are assumed to be hungover and told to go home. If the patient believes that they will not be listened to or will not be treated well, they may try to suffer through their pain, instead of seeking care.

### **Jurisdictional Issues**

It is hard to look at health and wellbeing without looking at the jurisdictional issues that exist. A couple of the Traditional Knowledge Keepers talked about the impacts of policy on the health and wellbeing. They pointed out that First Nations and Inuit Health and Indigenous and Northern Affairs Canada are separate entities with separate funding and programming. They found it foolish for health to be looked at separately from education, environment, economic development, infrastructure and

housing, and social programming. They felt that greater communication is needed between both entities in order to address health inequities.

*You know and not just Health Canada, but everybody else, INAC and... You know because then if you're looking at the community and if you're doing the community health plan sort of thing, what do we need to do? Well we need to address these issues sort of thing. Well from Health Canada it's just health issues...(TKK01)*

*It's got nothing to do with education or housing or what... Well yeah education, housing and everything else that happens to the community...*

*You know it directly goes back to health, let's make sure that they have potable water...*

*Let's make sure that they have decent housing...(TKK02)*

*Let's make sure that they're properly educated. You know because then... Yeah it's not... Those decisions are not going to take effect right away, it's going to take 10/15/20 years... (TKK01)*

Both of these Traditional Knowledge Keepers spoke about the conditions on many of the reserves, including the lack of infrastructure and housing, access to clean water, and waste management, and how this contributes to poor health. They know that changes to these structures will not result in positive health outcomes overnight, but will help in the long run.

## **Recommendations**

In looking at the list of the neurological conditions outlined by the NPHSNC, the Knowledge Keepers did have a number of recommendations for people who live with a condition, their families, and communities. They wanted more education on “invisible” chronic conditions, such as migraines, epilepsy, rheumatoid arthritis, along with other conditions. Just because someone does not have a condition or illness that you can easily see, does not mean that they are not in pain, or they do not suffer. They wanted everyone to learn more about their rights in dealing with the health care system. They want to make

sure people have the right tools to ask the questions that they need to know in order to get the best treatment possible. They strongly recommended that First Nations communities develop guidelines on how to care for people with neurological conditions and other chronic health conditions. For example, if someone is diagnosed with a brain injury, the guideline could outline what is needed to support that person and his or her family, what programs they can apply for through Health Canada and through Indigenous and Northern Affairs Canada. They felt that a written policy or guideline could help the family respond to “those needs as identified by the medical profession and to support the community to look after that person” (TKK01).

Other recommendations were directed at the health system and health care professionals. These included education and cultural safety training for health care providers and staff. One Traditional Knowledge Keeper wanted the Aboriginal Liaison units in hospitals to have a basic understanding of the different types of ceremonies used by Indigenous people to help with healing. She stressed that if hospitals and health regions are going to implement an Indigenous or Aboriginal strategy, they should be working with Traditional Knowledge Keepers so people can understand why people smudge or would ask for a specific ceremony. Another Traditional Knowledge Keeper, who works closely with non Indigenous health care providers, wants providers to understand the role of spirit in Indigenous cultures and that seeing deceased people or hearing voices does not mean the person is hallucinating.

*when this psychiatrist was coming and they were going to do their internship, my job was to sit with them and explain to them that just because someone is talking about hearing voices in Native culture doesn't mean that they're schizophrenic. It means that they are talking to spirit. And, you have to differentiate between that, you have to get time to get to know this person and understand whether they are*

*having psychotic episodes or whether they're having spiritual episodes, which in the mainstream are psychotic episodes but to us they're not. (TK04)*

Having a basic understanding of Indigenous worldview and kinship structures could go a long way in helping health care providers care for their Indigenous patients.



## Chapter 6 Individual Interviews and Research Circles

The UFW project sought to gather stories and raise awareness about how Indigenous women think about and understand neurological health. For the project, neurological conditions were defined as any condition that involves the brain, the spine, or the nervous system. Part of the objectives was to look at the impacts, the risk factors, and gaps in health care services Indigenous women faced. The recruitment strategy relied on snowball sampling techniques where letters and flyers were sent to NWAC's 12 Provincial and Territorial Member Associations (PTMA). The project drew heavily on our Advisory Committee to assist in our recruitment efforts by asking them to forward information to their contacts. Letters were emailed and faxed to surrounding First Nations Community Health Directors, Chief and Council, Tribal Councils, and provincial First Nations organizations. Posters were emailed, faxed and later mailed to Aboriginal health centres, friendship centres, college and university Indigenous student associations, and Aboriginal liaison / patient navigators at the Regional Health Authorities were contacted and send posters as well as information to practicing neurologists to pass on to their patients. In addition to these efforts, information was posted on community calendars through the different local TV stations and radio stations.

Indigenous women who live with a neurological condition or are a caregiver to a person with a neurological condition were encouraged to contact the research team for more information. Potential participants were given the option to participate in an individual interview or a research circle with other women. The same questions were used for both the individual interviews and research circles, with the interviews taking approximately one to one and a half hours and the research circles lasting approximately

two to two and a half hours. When possible, individual interviews were conducted in person. Participants were also welcome to participate in an interview by telephone or videoconferencing. The research circles typically took place at a central location in the community and were guided by local Elders or Knowledge Keepers. Arrangements would be made for participants who wanted to debrief with a local Elder.

The individual interviews and research circles took place between February and August 2012. The interviews took place across four provinces and one territory with 18 people. Within the individual interviews, eight people lived with a neurological condition and 10 people were caregivers to someone who lived with a neurological condition. Six research circles took place across three provinces, two of which were on reserve and four were in urban areas. Each of the research circles were led by an Elder, in two of the research circles there were two Elders that supported the participants and research team. There were 40 participants that took part in the research circles, not including the Elders. Ten people lived with a neurological condition and 30 people identified as caregivers. The project was aimed at women, but we did not want to exclude any men who wanted to share their stories, as such, we had two men that came forward and the rest were women.

Given the large number of participants in the individual interviews and research circles, a simplified table with the participant code, role, and memo link of the condition and key notes are included at the end of the chapter. General information was collected relating to age range, how a person identified as an Indigenous person, the role they played in regards to living with a condition or being a caregiver to someone with a condition, as well as what the condition is and who it afflicts. This information will provide context in analyzing the data. The participants ranged in age with the youngest

participant in her early 20s and the oldest in her late 70s. In the individual interviews and research circles five people identified as Métis and the other 53 identified as First Nations. The conditions that were brought forward in the interviews and research circles include: Acquired Brain Injury (ABI) and Traumatic Brain Injury (TBI); Alzheimer's Disease and Dementia; Ataxia; Cerebral Palsy; Diabetes related neuralgia; Epilepsy; Fibromyalgia; HIV related dementia; Kennedy's Disease; mercury poisoning; Migraines; Multiple Sclerosis; Rett Syndrome; Rheumatoid Arthritis; severe PTSD; Shingles; Stroke; and Trigeminal Neuralgia.

The data was recoded with the following two questions being used to help guide the analysis: 1) How are neurological conditions culturally understood? 2) Does this understanding influence how people access care? Under the heading of culture, the following subthemes are included: condition as being a gift; cultural practices; cultural understanding; culture and normalization; culture and taboos; resilience, and role of culture. The nodes under health care includes: differences between western and traditional medicines; information about the condition; diagnosis; signs and symptoms; treatment, including traditional and western treatments and medication; health care providers; recommendations for culturally safe care; and stigma within the health system. The existing and needed supports will be touched on briefly as it relates to accessing formal and informal care.

## **Cultural Understandings of Neurological Conditions**

The research team started the interviews and research circles by introducing themselves and how they became involved in the project and any experiences they had with neurological conditions. The participants were asked tell the research team about

themselves, where they come from, how they think about and understand neurological conditions. Participants were encouraged to share as much or as little as they were comfortable speaking about how they understood and made sense of the idea of neurological health. The opening question was framed broad enough to allow participants to reflect on any information, experiences and teachings they have gathered along their journey. Reanalyzing the data to look at the cultural understandings of neurological conditions uncovered a wealth of information similar to the findings in the Traditional Knowledge Keepers interviews. The participants in the individual interviews and research circles talked about neurological conditions as a gift, as a normal part of life, and provided context from their own cultural practices and understandings. They also touched on resilience and the role of culture in their life journey.

### **Gifts and Normalization**

A few caregivers commented on the gifts that came with being able to care for their loved one. A couple of adult children caring for their mothers, talked about the importance of being able to return the love, care, and support given to them when they were younger. One caregiver whose mother had Alzheimer's disease, talked about how grateful he was to be able to move back in with his mother and help take care of her near the end of her life. Another caregiver who helped look after her niece talked about how the diagnosis of epilepsy brought her whole family closer and made them realize how precious life is. Kinship roles and family responsibilities were not talked about as being burden; instead, it was just something that families did.

Another gift that was brought forward by some caregivers was the ability to amplify their perspective of a situation. Some of the mothers that were interviewed talked about their experiences in caring for their children who live with a neurological

condition. One mom, whose daughter has Rett Syndrome, said that that her daughter has given her the gift of being able to see both the best and worst of people and how they treat others who have a disability.

*One thing that I find for myself like the experience as a whole is like- I have this incredible view of- like, this perspective about life. It almost seems like, S----- in so many ways has given me this incredible gift to be able to see the most- the smallest but, the most amazing things about life but, at the same, there's this other side too that there's a lot that I see and experience, it's like the worst- it's almost seeing the best and the worst. (ID06a)*

Teachings of patience, understanding was brought forward in all the caregiver interviews. Many of the caregivers also talked about love and that there is beauty all around, it just may not be what you were expecting. For these participants, taking caring for their loved one, whether it was their child, elderly parent, or extended family member, becomes part of their daily routine, normalizing the condition.

*It just seems that we accept an illness as part of life and deal with it individually or a part of the equation. (ID02)*

Acceptance, normalization, and adapting for a new normal continually came up in the interviews and research circles. One participant who was recovering from the effects of a stroke talked about the progress she has made in regards to her mobility and how hard she continues to work on maintaining her independence in spite the limitations she has faced. A couple other participants who live with a neurological condition talked about embracing the good days and knowing that some days may be harder than others. This level of acceptance speaks to the normalization of the different neurological conditions that were discussed. The majority of the people who live with a neurological condition in both the individual interviews and research circles talked about needing to find a new

normal. They acknowledged that the neurological condition was a part of their life and they need to find a way to live with the symptoms and interact with the outside world.

For many participants the best way to live with their symptoms and interact with the outside world was to look on the bright side or to recognize the humor in a situation.

*We are always making silly jokes, always, constantly; constantly, and it keeps the mood up all the time. You can't get too far into depression because that is just how they've always been, and my grandparents were like that. I know that you don't dwell on those negative emotions; they're always looking for the bright side and I think that's because of the adversity we've always faced as a people; it's that humor that's really important. And you know, I never would have appreciated that unless we hadn't been going through all this. (RC03)*

Telling a joke or making fun of a situation can lighten the mood. It can also be a way of acknowledging the situation, whether someone is mad or in pain, and then moving on.

### **Role of Culture, Cultural Practices, and Significance**

The role of culture, cultural practices and cultural significance came up a number of times throughout the interviews and the research circles. Some of the participants talked at length about the role culture plays in helping them live with or care for someone who lives with a neurological condition, where as other participants talked more about impacts of colonization on culture and how that is impacting their life, their families, and communities. Many of the participants discussed their connection to culture and spirit and how this has helped them understand their own journey in life. For this section, two interviews are drawn from to discuss the connection between mind, body, and spirit. The first story is from a caregiver's perspective and relates to some of the teachings shared by Kookum Betty in the previous chapter. The second story is from an individual who lives with a neurological condition and her understanding of culture. This person took a life cycle approach to the interview by sharing events that happened in her childhood, her

experiences with western medicine and practitioners, all the way through to working with different healers.

The first story is from a Cree Ojibway woman whose son was born at 25 weeks gestation and lives with cerebral palsy and cognitive impairment. She shared that her son was born while she was at a conference out east. She was rooming with an Elder who predicted that the baby would be born much sooner than the March due date. The baby was born the next day and was only 1lbs. 10 oz. During the first two weeks, the baby's blood pressure did not regulate and the doctors wanted to take him off life support. The birth father called an Elder who was about to go into ceremony and asked him to pray for his son.

*So, he phones this elder, it's quarter to 1 and the doctors and nurses already told us "Say goodbye to your son because we can't keep him on this life support; it's not helping him." And then so, I was OK, we were ready but, his dad says "No!" So then, phoned this elder, it was a quarter to 1 and he said "Oh, we're just going into a sweat right now, we'll pray for your boy first." So, at 1 o'clock his blood pressure regulated and until this day- as soon as they went into that lodge, they- you know everything just came together and they gave him life. The spirit said "Yup, he wants to live!" And you know, so he lived and we were out of town so they were already finished the sweat when we got there. We got our cloth and tobacco and they said "Oh, the spirits already showed us him running around," you know, how he's going to be. And then we said "Oh, OK." And we went back to the hospital and the doctors and the nurses were relentless in asking "What happened? What did you do? Tell us, what did you do? What did you do?" And just said, "Well, we didn't, we just asked for help; it's spiritual, it's a spiritual healing." They were just amazed so, that's when he decided that he was going to walk this journey, my son did, he decided he was going to walk and he is, and he did so, it's very powerful, very powerful. And he's been in a sweat lodge ever since he was 11 months old and he just loves it in there and elders make an example out of him "Look at that baby, he can be in a sweat because he missed his time in the womb." (ID13)*

Within this short segment, the caregiver talks about the power of prayer and ceremonies.

Many of the participants in the individual interviews and research circles bring up the power of prayer and how it is used ask for guidance, as a way to give thanks and

gratitude, as well as ask for strength, healing, health, and wellbeing. Ceremonies are used to connect with the spirit world. Reflecting on spirituality and ceremonies, Stonechild states “So central are ceremonies to our societies that whenever any major development occurs in our individual or collective life, be it health-related or political, a ceremony is conducted in order that matters will evolve in a ‘good way’” (2016: 47). The ceremony that the Elder was going into was a sweat lodge, which is used to communicate with the spirit world. The sweat lodge is also used for purification, spiritual cleansing and regeneration and is seen as a symbol of a mother’s womb or the womb of Mother Earth (Anderson 2000; Stonechild 2016).

The connection between “G” and the spiritual world was discussed at length. The caregiver’s cultural background helped her to understand her role in nurturing and guiding her son.

*Well, I'll tell you something. G chose this, he chose to be- to come live like this, this time and you know, like he chose his father, he chose his mother and he knew, you know that- that we would both do whatever we could because he never seemed particularly- he never seems particularly bothered about anything no matter what, like he's treated....one part of it is first of all, that G wanted this life, said I need to take this on because I want to gain these principles of life and this is the way I'm going to do it and so that's why he came this time, why he chose us.* (ID13)

Drawing from the previous chapter, *Kookum* Betty shared in that we are all spiritual beings having a human experience, and that we each have a purpose and choose our path, including our parents before we are born. Once our purpose is fulfilled we make our way back to the spirit world. This would count as one cycle in an “infinitely long journey of spiritual development” (Stonechild 2016: 50).

This caregiver recognizes and understands that her son has chosen this path to learn more on his own spiritual journey. In helping guide him, she shared that her and her



husband, “G”’s stepfather, have learned so much from him. Her husband is a traditional healer and “G”. is his helper and will often assist with ceremonies. “G”. is also hard of hearing and does not like to wear his hearing aids, so her husband had to learn how to sing the ceremonial songs really loud so that “G”. could hear them.

*So then that's what he taught us too like about how he is, the simpleness of his mind sometimes is just beautiful...he's a very strong spirit. So, he's a very, very good teacher but, like I said so as he gets older it's hard.... So, on a spiritual level he's probably very high, you know that he has to- that he would even attempt to come back like this, you know. That he wants to learn this way so and you know me knowing that really helps, you know sometimes if it's a difficult day or whatever and I just say "Hey man, it's your trip!" I'm never- I never organized it so I guess on that level and then we're very blessed...like he's become you know such a strong helper, you know like he'll- we had a sweat there on Sunday and he was standing outside there most of the time and then he'd come "You ok mom? You ok?" You know, he comes in and says "What about you dad, you hot?" [Laughing] So, he knows- he knows lots but, it's just trying to figure out what does he know? Where can I help him to grow? (ID13)*

While she talked about the many gifts and teachings her son brought to them, she also brought up some of the challenges of raising a son with cerebral palsy. Most of the frustration seems to come from interactions where other people try to stifle “G”’s ability to learn and grow as a person. She felt that the current western education and medical system were too quick to diagnose people and situations without fully looking at the person in front of them. She stressed the need for all people regardless of what condition they have to be treated with respect and encouraged to keep learning and living life to the fullest.

The other narrative draws from an Indigenous woman from the St’át’imc Nation who was diagnosed with multiple sclerosis (MS) in 1990. This interview was conducted over the phone and lasted approximately two hours. The woman started the interview by talking about her family and life growing up, including being sexually abused by a man

that her dad sponsored through AA when she was eight. She said that growing up, she was always very active and running everywhere, as well as constantly falling and getting hurt, but for the most part very healthy and happy. She got married a couple of years after graduating high school and worked as a dental assistant. She told us that her symptoms started in 1983. She lost feeling in her legs and feet and ended up burning her foot on a heater. She went to the hospital and was told by the physician on call that her symptoms were all in her head and she needed to see a psychologist. A day later, she went to a different hospital and the physician realized that she could not feel anything and started running tests. After a number of tests and a spinal tap, the doctors could not give her a diagnosis. She was finally diagnosed seven years later. The neurologist was drawn to her because of her symptoms and the fact that she is an Indigenous person. At the time, not many Indigenous people were diagnosed with MS.

In addition to talking about her path to get a diagnosis, the participant shared a lot about her cultural understanding of why certain things were happening to her body. Early in the conversation, she mentioned that a spirit visited her about a month before the symptoms started in 1983.

*I had been having about, for about a month before all this started happening, I was being visited by a little person, a little, he was like a little gnome of some sort, little person and I would never tell you this except for the fact that years later when I was at a [Sundance] one of the medicine people there asked me that very same question, if I had been visited before all of these things began to happen to my body, and I was so relieved, anyway so I had been visited, and he was bothering me, this little gnome, he was just little person, he was just and he was telling me that I had to stop shutting down, I had to stop that no matter what I will always feel, feel my body, and anyway that's enough about that. (ID08)*

She later found out that this little person that visited her was her son, who was born in 1992/93. This will be revisited later on.

She stated that when she was a teenager she was very active in a Friendship Centre youth group and learned a lot about her identity, but did not know too much about ceremonies. She learned about ceremonies later on when she was in a treatment centre to deal with her alcoholism. In 1988, she had a relapse and was taken back to her parents' house, where they could look after her. During this time, her Mother told her that she was born very weak and that her spirit was not ready. As a result, she was born with a large birthmark on her back. When she was three, her Father took her to the hospital and had the birthmark removed. Her Grandfather was upset that her Father would do this, believing that he removed the ability for the spirit to fully enter and stay in her body. Her Mother said removing the birthmark sealed her spirit inside of her and that she was able to go through so many things because of this, where if it were not sealed, she probably would have died. She said that knowing this helped her later on in understanding her diagnosis. It also helped her to trust in their traditional ways.

This participant shared many details throughout her life. She left her husband in 1986, went to school, and completed her degree in Native Studies. She had a son, and taught classes at a Native Education Centre, while going to law school. She was so determined to not let her diagnosis slow her down.

The following excerpt outlines her experience at the Sundance and contains a wealth of information about cultural beliefs and understanding, ceremonies, the power of visions, along with strength that comes from honouring that mind, body, spirit connection.

*I was invited to go down the Sundance in [place] of that year, that was in 1994 /95 actually because my son was just about two, so the whole class went down there, down to Sundance outside of [large urban centre]. And while we were there my son got this very bad eye infection, so I took him immediately to the*

doctor. When I got him back to the Sundance, because I had stayed there with my students, this man came up to me from the fire and he said one of the ladies here said that your son became ill, he must have seen something, so she wants to talk to you, she would like you to come visit her. So I went over to where she was and she was an older lady and she seemed to know everything that was going on. She said there's...your son is, he will need to stay back. He is very gifted so you will need to keep him in your tent and you know play around the fire with him, and take him down to the water and wash him all off. And she said you know your son, did you recognise him, I said of course I...well I don't know what you're talking about. She said okay turn your son around, just in your mind, turn your son around, just look at his back, look at his shape. One of my students were looking after my son, so he wasn't sitting with me, he wasn't sitting at the fire with me, but I did that in my mind and I just got this amazing shock, realising that little person that was coming to see me back there in 83 that was my son. That was, you know when I looked at it from behind it was the same shape, the same size as my son, and my whole body just... I will never forget that feeling of...I felt like I was on fire. She said that's a good, that's a very very good thing because you cannot stop feeling. Your spirit will, wants to stay with you but you keep wanting to let it go, you should never feel guilty for what, you know for wanting to stay with the creator longer than you needed to be there. [The Elder then commented about her back] Look at you, look at your back, like and she didn't see me, I didn't even know her. And she said you know that marking that you have that you carry on your back, she said that, you didn't have anything to do with that being closed off. It had to be, and your spirit is staying with you, so don't give that up, don't feel badly because your spirit, your physical body will carry you through it. It will just be harder, and she said and sometimes it will hurt too much, so that's why your body will shut down. (ID08)

I didn't have a clue what she was talking about, so she said tell me about your illness, and I said I guess you are talking about what MS...and she goes, she just smiled and kind of said if that's what you want to call it. And it was such a relief to talk to her to tell her that it has been given such a scientific name but I really have so much control over it. It felt like I did. It felt like I can tell you when...I can wake up in the morning and within half an hour I will know something is going to shut down on that day. I have had this disease for so long but I can tell you that I wake up one morning and just based upon how I was, that I was dreaming about or how I woke up feeling, I am thinking oh no today is the day I am not going to be feeling my hands today, or I could wake up feeling that my feet were tingling and by noon I'm not walking, or wake up feeling my eyes are feeling shadowed, and I think oh no today is the day that I am not going to be able to read today. And so when I was able to talk to that lady about that I felt a lot of...a surge of strength came to me that I have the ability to deal with whatever is going to happen to my physical self, that my spirit is going to protect me, or is going to stay with me during it. So that's kind of what I learned there. (ID08)

This participant went on to share other experiences she has had with different healers and the ceremonies that she took part in and how she views her illness as part of her path in life. She has stopped wondering why it has happened to her and simply wants to know how she can manage through this journey and feel like her traditional beliefs are being respected by health care providers. Changing the “why did this happen” to “how can I manage my symptoms and be supported” requires a shift in thinking and in practice. She did have one neurologist, the person who diagnosed her, that asked about her experiences and encouraged her to keep doing what was best for her including continuing to go to ceremonies and follow her cultural practices. All the other physicians and specialists have only treated her physical symptoms, and have not acknowledged that this condition also affects her on a mental, emotional and spiritual level.

*I have numerous neurologists since then, and they only treat it from a physical place. They don't ask me what, you know what emotionally I am going through, they don't ask me spiritually what I am going through, you know and I think that's something that really needs to be laid out for them when dealing with Aboriginal women and neurological disease. It's very involved with the spirit you know and how they are feeling. And maybe they will start to do their research, looking at it outside of the box you know. (ID08)*

She felt that when she does bring up her experiences, beliefs and cultural practices that help her, she is patronized and undermined or seen as depressed and delusional. Rather than labelling patients as non-compliant for resisting Western pharmaceutical treatments, she wanted health care providers to work with their patients to understand what they need and support alternative therapies and plant based medicines. She stressed the need for more cultural awareness and training within the medical education system.

One of the other areas that this participant talked about is needing to listen to her body, mind and spirit and truly feel the emotions as they come. Healing is more than just

the absence of physical pain. It requires addressing past traumas and understanding that if one tries to ignore or block out those memories or emotions, it will start to manifest in other ways. A number of participants talked about past traumas from their childhood and later on in life contributing to their illness. Quite a few participants in both the individual interviews and the research circles talked about the impacts of residential schools for themselves, their families and communities. They also discussed the impacts of child welfare policies, such as the 60s scoop and being taken from their families.

*I think that a lot of our illnesses is caused from holding in too much garbage. I know a lot of it, mine is. I think that our past, women especially, when I tell people- when I go around the circle and I tell women smudge your stomachs too. Smudge your bellies because we have a tendency to hold everything in, you know, and that's what happens to us, we hold it in and we hold it in and I think that's what my problem was outside of the dystonia and I don't know if it was even neurological. I think it could've been psychological, I think a lot- I- I had my spleen was full of poison and I kept saying over the years; "Oh, I just feel like I'm being poisoned inside." I was called a hypochondriac, of course, and so- I think- I think spiritually we hold things in and it makes us physically ill. (ID18)*

A couple of the participants spoke about needing to address the imbalances in one's own life and try to figure out what one needs to help heal. For some people this meant going to ceremonies and becoming more involved in their culture. Other people talked about the power of prayer and living a positive lifestyle. One participant was told by an Elder that part of the healing process included confronting her abusers. Another Elder encouraged her to sponsor a sweat or some other ceremony and ask for healing. She stated that while she would like to follow the protocols and sponsor a feast after the ceremony, she barely has enough money to feed her family. If Elders and traditional Healers were covered under provincial health funding, more people in need could access culturally safe and appropriate services.

Other cultural practices that were brought forward by participants to help them or their loved one have the strength to deal with their illness included connecting with the land and water, acknowledging the spirit helpers that surround us, as well as naming ceremonies and the healing aspects of growing a child's hair. Many caregivers and people who live with neurological conditions referenced being able to go out on the land and reconnect with Mother Earth as being essential to their wellbeing. One of the Elder's leading a research circle spoke about the healing places that are all around us and we just need to go out and experience it. She stated that *"we have that connection to Mother Earth because she created our body. We have that connection to Father Sky because the Great Spirit is what gave us our spirit, that spark of life that's in us. And the thing that places body and spirit together is ego and we all have ego"* (RC06).

One participant shared that on the day of his mother's funeral, he and his brother were walking near the river when they saw an eagle fly past. Being able to see this even though it was foggy gave them a sense of peace. The eagle, being able to fly the highest, is able to carry prayers to the Creator. Another participant spoke about culturally significant markers and how her family did not want to acknowledge these signs that kept appearing to them. After her mother's diagnosis, they realized that the spirits were with them all along and trying to warn them, which made it easier for them to accept the diagnosis.

*So that was really something when she got that feather and we had warnings of this coming. We didn't acknowledge them at the time. It's just in our human nature not to want to accept that we're going to have pain or receive those signs that we're being given. I collided with a turkey on the highway, opening day of turkey hunting season, so I'm a legendary hunter now! I've never had a crash with my truck ever and I know from our understanding that that animal is giving his life up for you because you're going to be dealing with a loss of life in your life, and I didn't want to acknowledge that at the time. Then we got this diagnosis*

*a few months later and then having that message made it easier to accept the diagnosis that we were given. (RC03)*

## **Interactions with the Health Care System**

The narratives from individual interviews and research circles briefly touched on the length of time it takes to get a diagnosis and focused more on the interactions within the health care system. They shared stories related to their ability to access and use western and traditional services and treatments, their experiences with health care providers, and the need for more coordination between service providers and government agencies. The participants also had a number of recommendations for health care providers, management, and policy makers. Throughout this section general perceptions regarding western health care, stories of western and traditional treatments, interactions with health care providers, and stigma within the health care system will be looked at. Jurisdiction and coordination of services, information needs, and recommendations for culturally safe care will also be touched on. Two caregiver interviews are drawn upon to highlight some of the differences in access to care and the need for better coordination of services. One is a caregiver to a young child with epilepsy and the other is a caregiver to a young child with Rett Syndrome. Both live in the same territory and need to fly out to access services. The young child with epilepsy is not registered with the caregivers First Nation and does not qualify for NIHB services. The second child with Rett Syndrome is registered and considered a status First Nations person under the Indian Act. The first interview will look at how the caregiver and her husband came to look after the young child and have him recognized within the community as their son, as well as the difficulty they have had with the medical system and not having their needs met. The second interview will look at the difficulties of living in a northern medically remote territory,



where they need to fly out to access specialist services. These stories highlight some of the differences between bureaucracies for registered status First Nation versus non status Indigenous people and the level of coordination that is involved in caring for young children with neurological conditions.

### Caregivers Stories

The caregiver (ID10) in the first part of this narrative is an Oji-Cree Mohawk woman from the prairies that now lives in a northern territory with her husband and five children. She is a social worker and her husband is a school teacher. As explained in the health care provider findings, the territories have limited health infrastructure and residents need to travel outside of the territory to access specialist services. Her youngest child, “C”, is actually her middle sister’s child. Her sister has a number of addictions and mental health issues. When her sister went into labour, there were some complications and the sister had to admit her drug use throughout the pregnancy.

Her sister and the baby were under a 24 hour supervision order that was to be revisited at three months’ time. The sister and baby ended moving in with her mother and the mother ended up taking care of her grandchild. She realized that she could not continue to care full time for a baby and called ID10 and asked if she and her husband would care for him. They had to go through the court system to move the baby from the prairies to the territories. The birth mother did not want to relinquish custody, but did not have a choice as she was continuing to use drugs and was not well. In order to take custody of the baby, ID10 and her husband had to go through an in depth home study for the courts (very similar to the process to become a foster parent). They received court ordered custody until the child is 18. This is considered kinship care, so they do not qualify for parental leave benefits or employment insurance benefits. Since they could

not legally adopt the baby, they also could not register him with the husband's First Nation. With kinship care, the provincial Child and Family services will cover certain costs, including daycare expenses until he is school aged, a monthly stipend for medications, and two paid visits a year for each birth parent.

The baby came to the territories when he was 9 months old. A year after he was with them, he started having nocturnal seizures. He had a seizure on a Saturday, she took him to see the doctor on Monday and he was admitted overnight. The next day her husband flew with "C" and he was admitted to the BC Children's Hospital by Thursday.

*So, he went down to the neurology department; they did an EEG, they try to induce seizures with EEGs but, they didn't even have to they could see all the abnormal brain waves, even without him seizing. So, they knew something was up right away. And so then, they did a CT Scan, well, they tried to do a CT Scan and they had to put him under for it. And so, they attempted it without sedating him and it didn't go over so well. And then, they did another so they had to stay down there, I think, almost a week.*

*So, they were able to see that he has a brain lesion so he has a left-frontal lobe brain lesion and so at that point, they didn't know if it's a tumour, if he was born with it; they have no idea! And, all we know is that that's what's causing the seizures. (ID10)*

"C" would have seizures throughout the night, so both parents had a very hard time sleeping. They did get a baby monitor that was able to record the seizures and keep track of everything. The neurologists at this point also put him on medication for the seizures.

*The first medication made him like- He still had seizures, like it didn't really help the seizures, maybe decreased it a bit, like they were fewer and farther in between but, he was still having them, just not as often- Ah, I don't think it actually made a difference the first one, hardly at all. He was on Clobazam and usually it would cause drowsiness but, in a small percentage of children it causes hyper-activity, guess which small percentage we got! So, we had C----- hyped up and it causes like behaviour disturbances. The children were scared of him, he would like pull their hair, like Chucky<sup>19</sup>, he was like Chucky, it was crazy! And like, the children would be like [crying], scared of him. The cat almost died, I swear, he would just- he would go after the cat. Like- I was starting to worry about-are these drug*

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<sup>19</sup> A possessed doll by the name of Chucky from the horror film series, *Child's Play* (1988)

*tendencies or these like homicidal tendencies in this child? Is he going to be a serial killer when he's older? I was starting to think like "Oh my god!" But, anyway so- Then we changed to another medication, to Tegretol? and so he was on both for awhile. Then he came off the Clobozam. (ID10)*

A couple of months later they were able to do a repeat CT to measure the lesion and make sure it did not grow. Since it did not change shape or size, they knew that it was not a tumour. The lesion was most likely something that he was born with due to his exposure in utero. He was seen by a neurologist after he was born as he was going through withdrawal symptoms, but there were no CT or MRI scans done at the time.

The caregivers were not keen on western medications. They wanted to know if there were alternatives to medication, such as a change in diet or plant based medications, but the neurologists did not acknowledge their concerns and wanted to keep trying different medications to see if something helped. When asked about her interactions with the neurologists, she stated the following:

*neurologists are a whole different breed of people, they're another race, I think they come from Mars. They're condescending, they're rude, they give you some pamphlets, they don't like to answer questions and like, if you question them at all they take it personally. And they're really- they're mean about it and like. Yeah trying to find resources for alternative services or programming, it's not really- (ID10)*

The neurologists did not support the use of alternative therapies and made this well known to the caregivers. As a result, the caregivers did not tell the neurologists about any alternate therapies or plant based medicines that they were using on “C”. The caregiver and her husband did research different plant based medicines and they did find one that was good for seizure disorders. They were able to harvest the bulbs from the plant late in the season, boil it, and after testing it, they would add a cup to “C’s” bath water. It did seem to help reduce the seizures and help calm the child for a while and then it stopped.

They did not tell too many people that they were using this plant based medicine because they were afraid that they would be judged.<sup>20</sup> The neurologists started “C” on new medication and when that did not work they brought them back to BC for an epilepsy surgery consult. As part of the consult “C” has to go through a number of assessments including a week long EEG.

*They're going to do like a week-long EEG. So, he'll be admitted to BC Children's and S----- and I are going to switch off. They always want both parents there but, that's not really realistic for us because well we have 4 other children and yeah, it's just not realistic for us. So, we're turning it into a road-trip so, we can only really do what we can do so, they want both parents there because it's a week-long EEG. The lights have to be on all the time, he has to be hooked up all the time and they video-monitor everything for a week. (ID10)*

The neurologists want to do surgery and cut out the lesion and the caregivers want to try more traditional medicines and healing ceremonies before they do brain surgery.

*So, we do a lot of praying, we do a lot of smudging. We smudge him A LOT, like we sit and we cleanse him and we smudge him. And, we give him [traditional medicinal plant], we always test it first and bathe him in it, and it did seem to help for a while but, everything seems to help for a while. But, we haven't really found anything that sustains, you know. And so we really want to talk to healers and there's not a lot of people up here that practice medicine-medicine, like lots of people do the herbs and traditional medicines like that but, not a lot of people do medicine ceremony and we'd love- We'd really like to take him to a healer, you know, before we start cutting into the kid's brain, you know. Then S----- knows this medicine man in Utah and I keep thinking that we just need to go see him, you know. And we do know other medicine people, there's strong medicine people around but, I feel so isolated here, you know. Plus our jobs, like we- like some days I think we should just drop everything and move and go to these medicine people not the neurologists, you know. Of course, we're dropping everything and going for them. Why can't we do it for a healer? (ID10)*

Living in the far north does present a number of challenges in accessing care. For this family, finding a traditional healer who can perform healing ceremonies and lives in the area is extremely tough. Traveling to see the medicine man in Utah is approximately

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<sup>20</sup> If the plant is harvested too early it can be very strong. If a large amount of this strong plant and bub are ingested, it can be toxic and it can be fatal.

2400 miles (3862 km). Since “C” is not a registered with the husband’s First Nation or considered a status Indian under the Indian Act, the family would be responsible for all travel costs, plus payment for the healer. When you factor in time away from work, and if both caregivers travel, they would need to either bring their four other children or find childcare for them.

When ID10 and her family do travel for medical procedures for “C”, the territorial government does cover necessary medical travel and will reimburse accommodations after the first night up to 90 days at a rate \$75 per night (<http://www.hss.gov.yk.ca/medicaltravel.php>). The caregivers have extended family they can stay with when they go to the Children’s Hospital. When they both go to the Children’s Hospital for the weeklong EEG, they will drive down with a camper, taking all their children and do a tag team approach where one parent is with “C” and the other parent is entertaining the other four children. While this is not ideal, nor what they would like to do, they are rather limited in their ability to seek out alternative care for their child.

The other caregiver that I will focus on is a Cree woman, who is a single mother to two children. She lives in the territory and has family in the prairies. Her youngest child, “S” was diagnosed with Rett Syndrome when she was approximately one year old in 2001. She was in a private day care and swallowed a piece of dog food and was rushed to the emergency department as it was caught in her throat. This incident triggered the pediatrician to take a closer look, where he noticed some delays and sent her to the BC Children’s Hospital for further tests.

*We were all over the place in BC Children's Hospital, seeing the genetics team and then, going to Sunnyhill to also see the genetics team and, they did all sorts of*

*testing on her. And then, when she was about a year and a half, it was pretty intense, the testing part of it, it was really intense! And, then when we went back to the final meeting with the specialists...there was about 5 or 6 or so, but- The end meeting was that- they sat me down in a room and they arrange for someone to take S----- and they told me what they were talking about- S-----, the tests and what they did- you know, what the results were, what they found and then they told me that they weren't certain but, they were pretty sure that she had something called: Rett Syndrome. And, I wasn't sure what that was and...like a mixture of emotions and then- yeah, I just remember in that meeting that was like- I was outside of myself, almost while I'm listening to everyone and trying to keep my composure at the same time and then, at the end of the meeting...one doctor, she kept- the neurologist, she kept going over that bit of information and explained a bit about Rett Syndrome. It still wasn't really registering, you know- I was paying attention but, it still wasn't really registering and then, I just wanted to leave the room. I just wanted to get out of there and then, it was like- almost like internally combusting while I was sitting in there, like that's pretty much the first really intense moment of it. (ID06a)*

After that first appointment where she found out her daughter had Rett Syndrome, she started researching the condition, the symptoms and the different stages. She found that that there were four stages and her daughter was in the early onset stage. By the age of four, her daughter needed to be tube fed. She went to the BC Children's Hospital every year for more tests and follow up appointments. She spoke about the anxiety that she would feel when she had to travel to appointments. In the beginning, she was travelling by herself and her son would stay home with other extended family.

*I remember thinking that I can't believe that I had to feed my daughter through this tube to keep her alive. It was just really traumatic. The doctors are quite used to it, I started getting anxiety. It was almost like I would feel anxiety before we'd go, especially if she had to go for a surgery or something. Just her feeding tube surgery, the first time, I remember that was a tough one because I was by myself with her. Just putting her to sleep is really shocking because once they put whatever sleeping serum, they're [the child] instantly gone, like she didn't even have time to close her eyes. She was instantly gone. But, they're aware of that and they're [healthcare professionals] actually really good helping you before and after but, still. You see it, right!? And, it's your child. So, it's difficult. (ID06a)*

After the surgery, she came home and tried to keep her daughter in daycare while she worked. She applied to the childcare subsidy office to get a one-on-one worker at the

daycare. She said that applying for the funding was a battle, as she had to prove that her daughter needed the extra care. Shortly after that, the daycare gave her notice that they could not take care of her daughter anymore. They told her that it was too difficult with all the other kids running around and that she should quit her job, go on welfare, so she could be home with her child. She was able to find another daycare that was able to care for special needs children across town. Once “S” was enrolled there, ID06 started working more with the Child Development Centre (CDC) to try to figure out what supports they would need for “S” to go to school. The CDC is the only option for services before school and was to be used as a resource. ID06 commented that her relationship with the CDC was quite strained as she did not feel supported and often felt like they were talking down to her. During this time, “S” was starting to need more services and support.

*We had to go to (urban centre) quite often, mostly in the Spring and Summer, between 5 to 7 times in the Spring and Summer. We had to see neurology, and dental, ear, nose, and throat, swallowing; all sorts of things. S----- was starting to have a lot more difficulty walking so; I'd have to carry her all of the time. She was about 4, 4 and a half so she was getting pretty heavy to carry. She couldn't walk long distances or anything so, I'd have the stroller for her but, she was big in the stroller and people would be staring. She was still on the bottle too because of the tube feed, that's the only way that I could get any fluids into her. Yeah, so I'd have people staring at me. I remember being in the hospital waiting room and someone asked me if S----- had FAS [Fetal Alcohol Syndrome] and, I was like “No!” (ID06a)*

ID06 talked about the frustration of having other people judging her and thinking that she brought this on her daughter. She said she was often stereotyped as a young Indigenous single mom with a child with a visible disability, which many people thought was caused by drinking alcohol during pregnancy. Not many people know about Rett syndrome, as it

only affects one in every 10,000-15,000 girls

([http://www.ninds.nih.gov/disorders/rett/detail\\_rett.htm](http://www.ninds.nih.gov/disorders/rett/detail_rett.htm)).

In talking about Rett syndrome and some of the symptoms her daughter has, ID06 shared this:

*S----- ended up getting her wheelchair. She can still walk but, very assisted with her orthotics. She can't talk; she doesn't have any words and no purposeful hand movements or usage. Rett Syndrome is a neurological/developmental disorder, neuro-developmental disorder. It's been tracked to a gene mutation on the X chromosome so; boys who get it usually don't survive because they have an X and a Y. Whereas girls survive because they have a back-up, 2 X chromosomes. It's really actually interesting, the scientific-medical sort of way. On a day to day basis of dealing with the symptoms, seizures started becoming prominent and that was really difficult because sometimes they can just be fainting spells or you can tell what a seizure is and what's not, for the longest time. She started having full-blown- not grand mal seizures but, full-blown where her body is going crazy, her eyes are rolling in her head. For my son was- because it was so visual, it was pretty difficult but, I think he still handled it pretty well. I just explained to him "she's just having a little electrical storm in her brain, once it's over, she'll be fine. We just have to make sure that she's still breathing." That sort of thing. (ID06a)*

"S" is now on medication, which stopped the seizures, but she has other symptoms including sleep apnea, night terrors, and Parkinson's type tremors. ID06 stated that her son would hear his sister in the middle of the night and would get up to help.

A second interview was conducted three months later to follow up, get some more details about "S", and care that she needs. During this interview, ID06 talked about the process she had to go through in order to access respite services, as well as additional information on what was needed to take "S" to her specialist appointments. When ID06 first started accessing respite services, the territorial government would provide a set amount of funds so ID06 could privately hire someone. ID06 would hire family members that she trusted to look after her daughter. After her mom moved away, she was encouraged to access respite services offered through the long-term care facilities. The



territorial government at the time would pay for her to access the services twice a month.

ID06 visited all five facilities that offer respite services and found one that she was comfortable leaving her daughter with. Most of the facilities offered care for elderly adults, so finding one that could offer individualized care for a child was difficult. She did eventually find one, but preparing to take her daughter there every other week for a few days turned out to be very stressful.

*They only took- they didn't do intakes on Fridays so, we couldn't just do the Friday-Saturday which is what I wanted, like twice a month and that was totally ideal for us if we could split it like, like every other weekend, do it like that. So, they only did the intakes on, I think Tuesdays or Wednesdays so, in order to get that Friday and Saturday we had to put her in there the Tuesday or Wednesday before and then, I think it was 72 hours before we had to have her medication information sent from her doctor's office to there otherwise-I had to run to the doctor's office, make sure that they have all the information. S----- was on an increase-decrease because she was switching seizure meds and so, it changed every time. So, they couldn't just have a standing order of her medicine and there was some confusion and I noticed the one time that S----- was increasing one and she was almost off the one but, they weren't doing the same thing up there. It was getting- like the information and then, so I go to doctor's office and said "This is happening." And "Oh we sent the information," and then it was really stressful because they're getting mad at me and then, I'm talking to the intake people at (Place) and "Well we didn't get the fax or we didn't get the information." So, ok, between me and you and I'm going- I'm personally and you're still not getting the information? (ID06b)*

The last time they took “S” there, ID06 went to pick her up and found her sleeping in the TV room by herself with vomit all over her. The respite care was supposed to be 24 hour supervised care. When ID06 talked to the nurse on duty and questioned why her daughter was all by herself with vomit on her, the nurse said that she did not realize that “S” would vomit. “S” could have aspirated and died. After that incident, ID06 refused to take her back to the facility and tried to get the private respite funding back.

*And then the fight was on with the Government to go back to the old way and I was told that services through that department are seen as the last resort and since we've accessed services at (Place) and there's a facility able to do those*

*services that unfortunately we're denied respite funding through the office and I just stood up, like I was mad and this is unacceptable and you know, I'll come back and we'll talk about- we'll discuss this further and I told them that I was going to seek legal counsel. That was the only thing that I could think of but, like when you're sitting there across the table from someone that makes \$70-\$80,000 a year and they're saying "Sorry, we can't give you funding" for \$470 a month for respite that I was getting. (ID06b)*

The amount that was funded by the government was \$70 a day for a 24 hour period. Her family was willing to help her, but most other people stated that they would not work for less than minimum wage.

The follow up interview was also used to ask more detailed questions about travel out of the territory for specialized services and appointments. ID06 talked about working with the different departments and jurisdictions and how confusing it can be. Living in a medically remote territory means that ID06 and her daughter have to travel to a different province for specialist appointments. When asked about the process, ID06 stated that she often needs to call numerous places to make sure that everything is coordinated. The medical staff in BC calls her and lets her know when “S’s” appointment is. ID06 then needs to relay that information to the local medical staff, as the two offices do not communicate appointment days or times or what prep work needs to be done. She tries to coordinate with “S”’s other specialists appointments so that she does not have to travel as often. Since “S” is a status Indian under the Indian Act, her travel is covered through NIHB. ID06 coordinates with their office, as all travel benefits must be preapproved by the Health Canada Regional Office. This process can be very confusing, especially if the medical staff are not aware of the jurisdictional differences between First Nations and Inuit people and people who are covered by the territory.

*And, so for us it all goes through Non-Insured Health and they don't contact you, and they don't contact you until there's a pickup for travel. So, in the beginning it*

*was really confusing so and a lot of the medical people too had no idea about how that process was so, yeah. (ID6b)*

As “S” was getting older and needing more care, they had to apply for a second non-medical escort to help transport everything that “S” needs when they fly out to appointments. NIHB does not cover compassionate travel, so family members wanting to accompany their loved one to appointments need to pay for their own way, unless they qualify as a non-medical escort. In order to qualify, a request needs to be made by a health professional stating that the client has one of the following:

- “a physical or mental disability and cannot travel without help;
- is medically incapacitated;
- is a minor and needs to be accompanied;
- requires legal consent by a parent or guardian;
- requires a translator, if translation services are not available at the health facility” (<http://www.hc-sc.gc.ca/fniah-spnia/nihb-ssna/benefit-prestation/medtransport/index-eng.php>).

Since “S” is a minor and cannot travel by herself, ID06 is already approved as a non-medical escort. A couple of times ID06’s sister would come with her to help but would need to pay out of her own pocket to go. In order to get her sister approved as a second escort, she needed to fight with the NIHB regional office.

*We fought to have another escort and- even still every time we go, we have to remind Non-Insured Health but, they look at our file because we're approved for a second escort. Yeah, now I always have someone come, unless it's just a couple of day then it's no problem but, we usually go for about a week at a time or a week and a half at a time. And, I have to take cases of Pediasure because S-----'s tube fed and then, a package or two of her diapers and her clothes. She has more clothes than I do and she goes through them like you wouldn't believe! So, like for me to go on my own and she's getting so big now, so I'm managing her wheelchair with one hand and I've got her luggage with the other hand, and then you know, along with what we're carrying with us, with all of her tube feeding gear and everything. We have a portable bath-lift that sometimes I just don't even bother with it because some things can just be more of a hassle, you know. If I can just do it, I'll do it and get it over with but, yeah now we have a second escort so, at least I have someone to push her or pull one of our luggage and open doors because trying to open doors and everywhere you go maybe 2 out of 3 buttons,*

*those wheelchair opening- automatic door opener buttons and they don't- they don't work 2 out of 3 times there's something wrong with them. (ID6b)*

ID06 shared her frustrations in dealing with the different agencies and the amount of advocacy she needed to do in order to get services for her daughter. Even after traveling multiple times a year over ten years, she still needs to call NIHB each time and make sure all her travel documents are correct, that the hotel is booked and transportation will be covered. NIHB covers transportation, accommodation and meals for the client and non-medical escort(s). The First Nations and Inuit Health Branch NIHB regional office arranges and pays for the flights and hotel. If the client wishes to stay at a different location, then the client would be responsible for the cost between the two. Meals can be reimbursed as per the regional rates ([http://www.hc-sc.gc.ca/fniah-spnia/pubs/nihb-ssna/\\_medtransp/2005\\_med-transp-frame-cadre/index-eng.php](http://www.hc-sc.gc.ca/fniah-spnia/pubs/nihb-ssna/_medtransp/2005_med-transp-frame-cadre/index-eng.php)). She stated that when it comes to her children she has no problem advocating and fighting for services, but knows that not everyone has the strength to do that. She stressed the need for a disability navigator to help people understand what steps they need to go through to access services. She also wanted medical staff and government agencies to communicate with each other and be accountable to the people they are supposed to be helping.

Trying to access services for oneself or for a loved one who lives with a neurological condition can be extremely frustrating. The two caregiver stories speak to the complex issues they face in trying to access services for their children, while living in a medically remote community. Unfortunately, their stories are not unique in that many Indigenous people need to fight to access services and fight against stereotypes and racism present in the healthcare system. In terms of accessing services, medically remote

communities are not just limited to the three northern territories, but include much of the northern parts of provinces, as discussed in the other two findings chapters.

In addition to these two stories, participants in the individual interviews and research circles brought forward additional stories dealing with the complexities of accessing care. These include difficulty in seeking a diagnosis, access to services, interactions with the health care system, including stigma within the health system, and recommendations for more education surrounding neurological conditions and for culturally safe care.

### **Seeking a Diagnosis and Other Unknowns**

Many of the participants were frustrated with their interactions with the western health care system and felt that there were still too many unknowns when it comes to treating the human body. Participants felt that the western medical system tends to just focus on one part of the body and not look at the whole person. One participant stated, *There's so much that they don't know about the brain or about how it interacts with the rest of the body or anything else. It's just so many unknowns out there* (ID12). This was reiterated and expanded upon by another participant who stated,

*We don't understand very much about neurological conditions. They are difficult to diagnose, difficult to treat because we don't know very much about them. We know so little about the brain. Doctors don't even really understand amnesia. Over 50% of people in a coma have normal brain scans but yet the medical profession doesn't know why they're in a coma.* (ID01)

This participant has a traumatic brain injury from a motor vehicle accident that occurred when she was 22. Since it was not a high speed accident, her family physician did not ask for any follow up examinations even though she was experiencing migraines, dizziness, nausea, difficulty with balance and walking, as well as mild cognitive impairments. Her

family physician believed that she was depressed and that was exacerbating her symptoms. He prescribed antidepressants and narcotic pain medication, which she did not want to take as her family has a history of addiction. She knew something was wrong with her body and kept fighting to be referred for further diagnostic examinations. Five years later, after moving several times, she was able to get an MRI, where they discovered that her back was broken in two places. It took her over five years to get a diagnosis and close to seven years to receive treatments that are actually helping her symptoms. She expressed frustration over the “god complex” she encountered with some of the physicians and specialists she went to see and wanted health care providers to listen to their patients and work with them to look at the bigger picture in terms of the mind, body, spirit connection.

Throughout the project, some people were able to get a diagnosis quite quickly, and others who knew something was wrong, were not able to get a definite answer. Their physicians and specialists acknowledged yes, something was wrong, yet they were never able to receive an accurate diagnosis. One participant went to a number of specialists, had numerous tests done and was finally given a diagnosis of dystonia. Her neurologist left the city, so she found a new neurologist and he did not believe that she did have dystonia. He ordered another battery of tests, and he could not figure out what was wrong with her so he left the diagnosis as is. We also heard this from another participant in a different province who was given a diagnosis of ataxia.

*The neurologist saying finally we can't diagnose you, I think what you have is hereditary. And I said “Well how can that be? I'm the only one in my family with this”. So “Ataxia” is what he calls this, he doesn't really know. (ID09)*

A lack of a diagnosis could be troubling for individuals who want to know if they should be aware of any risk factors, possible triggers, what they can do to alleviate symptoms and if there are treatment options available. It may also mean that the person may have trouble accessing certain services or benefits without a clear diagnosis.

Many of the women commented that the medical system really does not know a whole lot about these different types of illnesses. The physicians and specialists make educated guesses and try different therapies, but they do not know for certain what is happening in all cases. When the women asked for other therapies or wanted to use plant based medicines, they felt ridiculed by many of the doctors they were dealing with. This type of behaviour further disengages the patient and in many cases prevents them from having an honest relationship with their care provider.

*So I felt like you know some of these issues are real barriers to getting well and to you know moving on in a positive way. It's out of balance and everything on a medicine wheel is in balance, perfectly in balance and I see a lot of these areas where all these people are supposed to help cut that in half, it's a grey area because you're not respected when you're not well. You're treated less than you know and it's pretty disappointing when you're trying to get ahead and you're being held back because of their stuff you know and I've seen that with one of my friends recently. (RC05)*

It is important for health care providers to understand that not every sign or symptom can be explained by western science. ID08 did talk about her condition as being much more spiritual and that health care providers need to at least acknowledge the mind, body, spirit connection and not just look at the signs and symptoms from a purely physical place. Asking questions related to social determinants of health, childhood trauma, as well as reactions to stress can give a broader picture of what else is going on that may be

negatively affecting the person. This is where a team approach to care would come in handy.

### Access to Services

Overall, access to health services was lacking. Many participants wanted more access to culturally safe health care services, Traditional Healers and plant based medicines. They wanted these services to be funded by the federal and provincial health systems and widely available to everyone. One participant in an urban research circle wished that there were more access to cultural services. She felt that access to Elders, ceremonies, and cultural teachings were limited to people who lived on reserve, or were involved in child and family services or social assistance programs (RC06). Another participant in this same circle wanted access to more health clinics that offered both traditional healing and western medicine.

*Healing places – inclusion of Indigenous beliefs and practices with western medical practices I think if there was more places like Eagle Moon Health Office where they offer like traditional healing and healers and medicine people and access to like healing gatherings and you know, ceremonies or you know, like talking circles and venues where people could actually go and practise their own culture and spirituality and not have to walk into a church and be like okay, I'm going to try this or try that but actually have a place. Like to me it just boggles my mind that there's churches on every other corner but when you want to find a sweat or an elder you have to dig and search and call ten different people to find an elder and I don't think that is healthy for community. (RC06)*

This health office, along with many other health offices that offer both primary health care and Indigenous programming, has to apply for federal funding in order to support the Indigenous based services (<http://www.rqhealth.ca/primary-health-care/eagle-moon-projects>). The primary health services would fall under provincial jurisdiction, while the Indigenous programming would fall under federal jurisdiction, and some of the services



in between possibly falling under municipal jurisdiction. Program based funding may be based on year-to-year agreements or fixed term agreements. Sometimes these agreements are renewed, but it is not guaranteed. Not all participants understood the jurisdictional issues around eligibility for services and who pays for which services. They simply felt like their health needs were not being fully supported. Offering these programs in urban areas for Indigenous people regardless of status is a great step in the right direction. More coordination between federal, provincial, and municipal governments is needed to establish long term institutions, not just piecemeal programs.

One research circle on a reserve spoke about access to services and that not everyone has easy access to physicians, specialists, or even pharmacies. Being able to access plant based medicines, ceremonies and alternative therapies can help relieve some of the symptoms associated with a person's condition (RC03). The participants in this research circle also talked about some of the improvements they have seen in regards to western medicine, especially with pain management. They liked that pain management teams try to address the body, mind, spirit connection by including general practitioners, specialists, allied health professionals, such as physiotherapists, occupational therapists, rehabilitation counselors, and psychologists, social workers and support staff. They feel that it is easier to work with a family physician that is involved in a team practice, as they would be more open to patients who want to take part in ceremonies or use traditional plant based medicines (RC03).

One participant who lives with trigeminal neuralgia commented on the lack of services in her town. She lives in the prairies and is approximately 75 km (46 miles) from a larger urban centre. She said that in her community there is one doctor and one nurse

practitioner servicing a town of 2500 people, plus the surrounding catchment areas. She also stated that there is a lack of overall health services, including home care, mental health and addiction services. When she goes to the hospital she finds that the staff are overworked, and are burning out because they often work short staffed.

*It- so, even healthcare providers that because they're so stressed, there's not enough- enough- they're not given also maybe times to decompress to have stress management, to have self-care, if they're not having the self-care they need, they are not in turn- able to give the care that they need to other people. So, the whole system is whacked! You know, the whole system is whacked. (ID12)*

Another person who lives in a different prairie province in a large urban area with access to two tertiary hospitals, four community hospitals, and numerous health centres, community based health facilities and clinical and community programs also spoke about the difficulty in accessing services.

*I accept the medical system as it is and whether I like that or not really doesn't kind of influence that change in that medical system. You know regardless I'm going to sit ten hours in the emergency room, I'm going to wait one year for a referral regardless of what I say. So no my needs aren't being met medically in all kinds of ways. (RC02)*

Many of the provinces and territories contend with long wait times and lack of family practitioners and specialists. One caregiver who lives in the territories talked about some of the difficulties she had with managing her brother's care. He is a status First Nations man with dual citizenship. He lives with HIV related dementia and hepatitis C. When he was first diagnosed he was living away from the family in the USA and his doctor recommended that he be sent to a location where there are other Tlingit people and placed him in a "dignified living home – a place where people were put to die" (ID 11). She had to fight to bring him back to Canada and took his case to a health review board

to find him a spot in the community. A case manager was appointed to his case and was supposed to find him a place to stay, but the caregiver had to find a place as the case manager was not looking.

*My brother was on a waiting list for the homecare facilities here but, I believe that they don't want him there because he's a First Nation and HIV-positive probably not because of the dementia. He had a case manager but, they never really did anything. He has a supportive living worker and they decide when they are going to provide services. I advocate for him all of the time. (ID11)*

She also talked about the lack of communication between the facility where he lives, as well as his doctors. She has power of attorney over his medical care, but said that none of his doctors have explained the progression of the condition to her. Many other participants, who felt they were not given enough information and were left to research conditions on their own, shared this sentiment.

### **Need for More Information**

The participants stated that they would like a place where they could go to learn about the conditions or a contact person that they could talk to or call for more information. One community that is greatly affected by mercury poisoning wanted more information about the long-term effects and if the damaged caused by mercury poisoning could be reversed. The people in the community are suffering from tremors and problems with their nervous system, while many of the children are born with cysts, tumours, and suffer from seizures. A paper company dumped mercury into the river near their community between 1962 and 1970, contaminating the river and the fish for the community. Because of the contamination, the commercial fishing industry closed, resulting in high levels unemployment and poverty. The nearest grocery store is an hour and a half away, which means that many people continue to eat the fish, even though they know there are high levels of mercury present.

Scientists from Japan came to the community in 1975, and confirmed that the community was suffering from mercury poisoning. In 1984, a provincial and federal scientific panel released a report stating that the river should be cleaned up. The provincial government decided to let the river remediate itself. No provincial or federal monitoring has taken place since that time. The Japanese scientists have been back to the community and have conducted tests in 2002, 2004, 2010, 2012, and 2014 and found high levels of mercury present in hair and blood samples (Crowe, 2014, found at <http://www.cbc.ca/m/touch/health/story/1.2752360>; Harada, et al., 2011, found at <http://freegrassy.net/wp-content/uploads/2012/06/Harada-et-al-2011-English.pdf>). The community and the province commissioned a research team to report on the human and ecological health in the community in 2016. Even with the release of the report showing rising contamination levels, the provincial government are still dragging their feet on cleaning up the river. The province still believes natural remediation is the best course of action and that trying to clean the river will disrupt the sediment and cause even more damage (<https://www.thestar.com/news/investigations/2016/06/20/province-ignores-information-about-possible-mercury-dumping-ground-star-investigation.html>). The ongoing contamination has affected three generations of First Nations people and will continue to affect even more if the river system is not cleaned up. Community members could apply to the mercury disability board for compensation, but only 27% per cent of applicants are approved for a disability pension (<http://www.cbc.ca/news/canada/thunder-bay/japanese-mercury-experts-push-canada-to-help-grassy-narrows-1.2750849>). Participants in the research circle and individual interviews wanted to know how to help their loved ones, as well as how to protect their children and grandchildren. One

participant in the focus group wanted information sessions on the signs and symptoms of mercury poisoning, as well as medical education on seizures available for the entire community, starting in the schools.

Quite a few participants called for more education and outreach on hidden disabilities for the general population. They wanted people to know there are many neurological conditions that have no visible markers. They also wanted people to be more understanding and empathetic and less judgemental. There was a definite need for more information about epilepsy. One participant shared that she told her boss of her condition, but does not want her coworkers to know as she is afraid they would treat her differently. In one research circle, two participants living with epilepsy shared their frustration on the lack of general knowledge on how to care for people who are having a seizure.

*I'd like people to know that you don't have to call an ambulance because I'm really tired of paying those bills and that I can self manage as long as someone just makes me feel safe that we can self manage our seizures, at least I feel that I can but people are just like really scared of you and so they call the ambulance and off you go. I mean that hasn't been experience for a long time because I really have stabilized so I haven't gone for an ambulance trip for a while. But yeah at first when I was first diagnosed and they were trying to figure out what drugs would work for me I was often in the hospital yeah when I didn't have to be. (RC02)*

*I hear lots of comments about epileptics. You know it's not you're a person who has epilepsy, you're an epileptic. You know there's that commercial I think goes back to the seventies, "oh I smell burned toast", I hear that joke all the time. It's kind of just so dated for me or I'll hear people talking about people who have seizures and how they flop around like a fish or they do this and they don't know that this is who you are. (RC02)*

One participant stated that knowing the different types of auras that can occur before a migraine or a seizure would have helped her understand what was going on. Prior to being diagnosed with epilepsy, she would have auditory auras and did not want to tell anyone or go to the doctor out of fear that social services would be contacted and they

would take her young son away from her. She ended up having a seizure in public and was taken to the emergency department where the physician was able to examine her and explain what happened and why.

*I think that probably telling someone that because if you tell someone “I hear voices” they can make a real quick leap to some other place and you know for mental health stuff like I try and understand mental health issues but you know twenty years ago I would have just wrapped it up to being crazy, you’re being crazy. I thought I was going crazy by hearing voices and I didn’t want to tell people that so I was really afraid of the fact I heard voices and that I was going to be put away somewhere or they’re going to take my son away. So I’d want to tell somebody that it’s a medical condition and this is what’s occurring for you yeah.*  
(RC02)

This participant was diagnosed shortly after this incident and the neurologist was able to prescribe medication that controlled the seizures. She said that her neurologist helped her understand what was going on and eased her fears about social services trying to take her son away.

### **Interactions with the Health Care Providers**

In talking about their experiences with health care providers, participants had some mixed reactions. Participants either spoke very highly or very poorly of their health care providers. For example, ID08 spoke highly of the neurologist that diagnosed her with having MS. He was open to her using traditional medicines and attending healing ceremonies. ID16 also spoke highly of her neurologist and stated that he was very reassuring in discussing a procedure that would help reduce her seizures. One participant, ID06, discussed her relationship with her daughter’s specialists as one of efficiency and professionalism. This was probably the most neutral response that was given throughout the project.

We had many participants who were not happy with their interactions with their health care providers. ID10 did not like her child’s neurologists and felt that they were

not open to alternative treatments or use of traditional plant based medicines. ID09 commented on the number of specialists that she was sent to and that they only seemed to give her five minutes to explain what was happening. A number of participants brought forward the limited amount of time given for appointments and how they did not feel like they were being heard. This could lead to people not getting the care that they need and in some cases giving up trying to seek help. One participant in a research circle (RC03) who had severe diabetic related neuralgia shared that she stopped going to her doctor because she was afraid of the nurse. She said that the nurse would yell at her and it frightened her. Because of this negative experience, the participant stopped interacting with the health care system. She tried manage her diabetes on her own, but was not able to. The contact person at the site informed us that this participant died a month later due to complications with diabetes. Her story was heartbreaking, on so many levels.

There were many more negative stories when participants started talking about their experiences in a hospital setting or with emergent care. Many of the participants talked about the physicians, nurses and other hospital staff not respecting their wishes, nor their culture. One participant who was in the hospital after having a stroke commented that the nurses did not treat her very well because she was Native. Her family pinned a medicine pouch to her shirt to help her heal and the nurses would remove it whenever they would come in to check her vitals. Finally, the minister who would come to see her told the nurses that they needed to show more respect for her and her culture. From this story it is obvious that the hospital staff did not undergo any cultural safety training, even though the hospital had a healing lodge where patients and their families

could go and smudge, as well as ask for traditional plant based medicines and healing ceremonies.

In some of the smaller locations, racism is huge problem. One community that we visited has a health centre with nursing staff that operates during the week, with a physician visiting the community about once a week. For evenings, weekends, and emergencies residents need to travel an hour and a half to the nearest hospital. Almost every participant at the research circle spoke of their interactions with the hospital staff and how they are judged and discriminated against because they are Indigenous. One participant shared that her daughter had a bad seizure when she was traveling and took her to the hospital and they discovered that her daughter had epilepsy. She was grateful that she was in a large urban centre because the last time it happened she had to take her daughter to the hospital near her home community and the staff accused her of abusing her daughter and did not want to release her. The doctor finally stepped in and told the staff that he has been her family doctor since she was born and that the child would be safe and to let them go home.

*Like I'm kind of glad it happened in [northern urban location] because you know when it happened in [Place], they didn't have no idea what the hell was going on with her, you know. And they were like racist actually towards me where they were accusing me of abusing my child. And I was like "I don't hit my kids."*

*And you know my family doctor had to tell the hospital staff you know, "I know this family, I grew up with this family for over 30 years. I practically delivered her." He was talking about me right. So he ended up saying "Send her home with her baby. If anything happens, keep in touch." (RC01)*

Another caregiver from this same research circle also spoke about the racism she faced as a young Indigenous mother whose baby started having seizures at three days old.

*my daughter, she's 12 years old, she'll be 13 in October, she was diagnosed when she was three days old, she had seizures already. She was sent to [large prairie*



urban centre] *and basically stayed in the hospital for a month after she was born. And I felt that I was discriminated when she was born. They were asking a lot of questions about the drugs, if I was an alcoholic and all that. They did a lot of tests on her, like toxicology, and it came out negative, she didn't have nothing in her, and then they started taking me seriously.* (RC01)

For this mom, knowing that her baby was being rushed to a large children's hospital was scary enough, without having to also worry about the hospital staff judging her, having the social worker meet with her and accusing her of endangering her child. These experiences really speak to the need for more cultural safety training for health care providers. Interestingly enough only a couple of participants called for more training for physicians and nurses.

### **Recommendations for Culturally Safe Care**

Most of the recommendations were aimed at direct services to help people living with a neurological condition or caring for a loved one with a neurological condition to understand their condition and access services. Many of the participants expressed a need for disability navigators in their communities. They wanted to be able to call or visit with a person that was compassionate and knowledgeable about the different services they could access to help them cope with their own or their loved one's condition. For example, one participant needed extra assistance moving around her home, especially when her husband and son were at work and wondered if she was eligible for homecare services or if there was a visiting service that she could access without having to pay a lot of money out of pocket. This is a very valid concern for people who may need a bit of extra assistance, but have a fixed or limited income.

Many participants also expressed the need for more affordable and culturally appropriate counsellors to help them process what it means to be an Indigenous people living with a neurological condition or caring for a loved one with a neurological

condition. One participant was trying to figure out how to access services and care for her mom who had a stroke was able to qualify for a couple of counselling sessions with a non-Indigenous counsellor. When the participant explained that she would like to be able to access a healer for her mom, she was told by the counsellor to go back to the reserve. The participant did not find this helpful and never went back to her for her follow up appointment. A couple of other participants talked about the need to have more government funding for Elders or culturally appropriate counsellors to help people work through their emotions in dealing with living with or caring for a loved one with a condition. They thought this would help people actually talk about their feelings without self-medicating with drugs or alcohol. NIHB does have a wellness help line that is toll free and open 24 hours a day, 7 days a week. People who are eligible for NIHB services can apply for a “maximum of 15 one hour sessions per mental health crisis over a 20 week period” (<http://www.hc-sc.gc.ca/fniah-spnia/nihb-ssna/benefit-prestation/crisis-urgence/index-eng.php>). Prior approval is needed for counselling sessions. Most provinces and territories do have a toll free help line that is open 24 hours a day and 7 days a week, but access to funded counselling services differs by region.

A couple of participants expressed the need for more patient centred care centres, where patients and their families could go and seek out compassionate care. They wanted these locations to operate similar to multipurpose health centre where there would be childcare services, a kitchen with tables, where people could stop in and visit over tea and access traditional healers and nurse practitioners. A couple of other participants wanted every hospital to have a medicine lodge or room where people could go and access traditional medicines and smudge without having to have the fire alarm shut off. They

felt that if most hospitals have a chapel or a rectory, then they should also have a space where people could smudge and pray in their own way.

Other recommendations included more funding for health care services and staff. Many of the participants understood that health care providers were often over worked and understaffed. They saw this as a major barrier to health care providers and staff treating people with compassion and respect. A couple of participants did call for more education and training to help combat stereotypes and racism within the health care system. A few participants who lived in more northern or remote locations wanted providers to undergo cultural awareness and safety training before moving and working in these areas. One participant who lived in the territories wanted more funding to go towards basic traditional first aid where people, including schoolchildren, can learn how certain medicines and plants can be used, especially in cases where people do not have easy access to western medical services.

## **Conclusion**

The interviews and the research circles uncovered a wealth of information about what it means to live with a neurological condition or care of a loved one with a neurological condition. A few participants shared that this was the first time that anyone asked them to share their thoughts, experiences, and found the process to be therapeutic. Many of the participants who took part in the research circles found comfort in knowing that they are not alone in their experiences and were able to gain a lot from the stories shared. The cultural understandings and perspectives shared was quite eye opening in that people who were further along in their spiritual journey were not so concerned with why this happened to them or their loved one, but more concerned with how they are going to

live well with this condition. Many of the participants also talked about what brought them comfort or joy even though their stories are quite heart wrenching.

The interactions with the health care system called attention to the need for more patient centred and culturally safe care. More needs to be done to combat the racism and stereotypes that are present in the health care system. Diversity training, cultural awareness, and impacts of colonization need to be included in all levels of education, starting with preschool and elementary school aged children. It also needs to be reinforced in secondary, postsecondary education and all health care training.

## ID and RC Participant List

Participant	Role	Memo links on Condition and key notes
ID01	Lives with a condition	Acquired Brain Injury caused by a motor vehicle accident. Family has a history of addiction. Has debilitating migraines. Uses Traditional Medicines to alleviate symptoms.
ID02	Caregiver	Mother had Alzheimer's disease He shared stories about his mother; also shared that traditionally people did not talk about their illness to other people. It would be something that you would keep to yourself. As the disease progressed, certain characteristics became more pronounced. For example, his mother would give away items to people who would come and visit her. This is a Cree tradition that she did. Mentioned that when after his mother died and him and his sibling were walking to the funeral arrangements, he saw an eagle and felt that was his mom giving them a sign that everything would be okay.
ID03	Caregiver	Uncle has mercury poisoning. Does not know if he take traditional medicines. Concerns over the fish, lakes and animals being contaminated because they continue to eat the fish and the animals from the area.
ID04	Caregiver	Cousin had epilepsy; grandma had Alzheimer's Did not really mention much about culture or about traditional medicines This interview is from a small community that is dealing with mercury poisoning - some of the challenges around accessing care, especially when the hospital is 45 minutes away. There is a health centre and nurses in the community during the week.
ID05	Caregiver	Husband exhibiting signs and symptoms of mercury poisoning The caregiver has only lived in the community for 6 years. She came to live with her spouse. They have 2 small kids. Is a little worried about mercury poisoning and does not eat a lot of fish because of that. Did not have any recommendations around health care. Would like to have the opportunity to have community gardens and have someone come in and teach the women how to plant and tend to the gardens.
ID06a	Caregiver	Her daughter has Rett Syndrome First interview conducted in February. Lives in a medically remote area and needs to fly to a nearby province to access specialist services. Sees her daughter as a gift, teaching her many things. Wanted to know more about the cultural teachings. Does smudge and feels that it helps.
ID06b	Caregiver	Daughter has Rett Syndrome Second interview conducted in May. Follow up to the first interview. More questions asked around supports and what it needed to help. Again talked about her daughter and the condition being a gift. Saw the positive that caring for her daughter brought to her

		and her son.
ID07	Caregiver	<p>Fears that her husband has mercury poisoning and is worried about her children. Will not take part in cultural activities in the community because she fears that she will be subjected to mercury poisoning, either through the food that is given or the water.</p> <p>Big impacts in terms of not being able to participate in traditional cultural activities. Will not go to community feasts. Tends to stay at home and isolates herself. She does not go out fishing with her husband. Enjoys going fishing, but will not do it in the community because she does not want to eat the fish from there. This also means that she is not taking her kids out into their community. She waits until she goes back to her community (her parents' community) to take part in fishing, hunting, eating traditional foods.</p>
ID08	Lives with a condition	<p>Living with MS</p> <p>experienced sexual abuse as a child</p> <p>Signs and symptoms started in 1983; diagnosed in 1990. Shared many experiences relating to culture, traditional healing, differences between western and traditional medicines.</p> <p>Many different healers approached her throughout her life. Was born with a large birthmark - was told that she was not ready to leave the spirit world and that was part of that connection. Her grandfather (non-Indigenous) took her to the hospital and had the birthmark removed. Was later on told that by removing that birthmark, her spirit was kept inside of her.</p> <p>A little person came to her and later on, after her son was born, the healer told her that her son was very gifted and that he had come to her beforehand, as this little person.</p> <p>Took part in traditional ceremonies - Sundance's; sweats, bathes, smudging.</p> <p>Sees illness as something impacting our whole being. Feels that western medicine just deals with the physical aspects of illness.</p>
ID09	Lives with a condition	<p>Lives with Ataxia</p> <p>Residential School survivor; experienced physical and sexual abuse from other children</p> <p>Went through a lot of different tests, but they couldn't give her a definite answer, so they stated that it was ataxia because of the limited mobility. Have troubles with balance.</p> <p>Does not adhere to any particular religious or cultural beliefs / practices and is completely open to try anything new - spiritually liberated. Spoke a lot about resiliency factors and how she enjoys staying busy, exercising, reading, learning new things.</p>
ID10	Caregiver	<p>Caregiver to young child with seizures</p> <p>Her and her husband are taking care of her younger sister's little boy. Sister is a drug addict and used all throughout the pregnancy. The caregiver took the boy in when he was 9 months old. They have protective custody of him until he is 18, but they did not adopt him, so do not have all the benefits of having a child - such as getting 1 year parental leave, EI, nor can they register him with Indian Affairs.</p> <p>Lots of impact on the family; financially;</p> <p>Family follows traditional culture. Wants to take boy to a healer, but the medical staff (neurologists) do not support any type of alternative medicines / even diet.</p>

ID11	Caregiver	<p>Brother has HIV related dementia and Hep C.</p> <p>Lives in a medically remote area, needs to fly out for any specialist services. Spoke about the lack of medical supports in the community. Her brother is in a nursing home, but there aren't any culturally appropriate activities or care provided. Feels there is a lot of misunderstanding and a lot of stigma towards her brother.</p> <p>Need more support for family members as well.</p>
ID12	Lives with a condition	<p>Lives with trigeminal neuralgia - diagnosed 6 years ago.</p> <p>Head injury</p> <p>Has been in a controlled state for about 2 years. Not pain free, but more manageable. Worries about when the medications will stop working.</p> <p>Lots of impacts. Tried to see a traditional healer, but the person did not understand what was going on with her, so they couldn't help at all.</p> <p>Recommends more information so that people will have a better understanding of the invisible illnesses. Also wants more money to be put into health care. Feels that the system is overworked and not enough people are getting the care they need.</p>
ID13	Caregiver	<p>Son has cerebral palsy.</p> <p>Lots of cultural references - step dad is a healer, they have sweats in the backyard.</p> <p>Believes that her son chose the path he is on. He is a blessing and has taught them all so much in terms of simplicity, patience, and love.</p>
ID14	Lives with a condition	<p>Lives with severe PTSD</p> <p>Experienced severe physical and sexual abuse</p> <p>Shares a lot about the community and the frustration that she has with band politics. Feels that there is so much distrust, nepotism, and trauma that they need to work through.</p>
ID15	Caregiver	<p>Grandmother and husband are affected by mercury poisoning.</p> <p>She is worried about her health and the health of their children. Eat a lot of fish from the surrounding lakes. Hard because they don't always have groceries and have a hard time going to town - town is about an hour away and they don't have a vehicle, so it costs around \$100-150 for a ride and then to buy groceries.</p> <p>Wants more information on the reserve. Feels that they have lots of services and access to services and health care.</p>
ID16	Lives with a condition	<p>Lives with epilepsy. Diagnosed over 12 years ago. Lives in a medically remote area and needs to fly to a nearby province to access specialist services.</p> <p>Lots of challenges in terms of being afraid to exercise, babysit her grandbaby, etc.</p> <p>Does not know of a traditional medicine for epilepsy. There is something out east – heard that the Plains Cree are supposed to have some medicines for that.</p>
ID17	Lives with a condition	<p>Person who had a stroke</p> <p>Still has difficulty with her left side.</p> <p>She spoke a lot about resiliency and how she works hard to regain her strength and independence. Does see a traditional healer and is trying to learn more about the traditional ways of healing.</p>

ID18	Lives with a condition	<p>Was diagnosed with dystonia</p> <p>Was an alcoholic; experienced domestic abuse</p> <p>Lots of cultural references - went to a Sundance and was healed. Still has pain, but not the crippling twisted up episodes.</p> <p>Talked a lot about needing to let go of past hurts and baggage. Needing to heal and live life in balance.</p>
RC01	16 participants and 2 Elders All Caregivers	<p>Participants brought forward stories of loved ones having epilepsy; tumours, head injuries, and symptoms from mercury poisoning.</p> <p>Big group of people; Some came to share and some came for the honorarium. Need for more education in the community on the different conditions and basic care, especially working with people who have epilepsy.</p>
RC02	2 participants and 2 Elders – participants live with a condition	<p>2 participants - both diagnosed with epilepsy</p> <p>1 participant had a major head trauma and scar tissue on her brain. Has auditory auras.</p> <p>1 participant also experienced head trauma - is on medication and seizures are largely controlled.</p>
RC03	8 participants and 1 Elder includes caregivers and people living with a condition	<p>1 - caregiver to a PWD</p> <p>1 - son had migraines</p> <p>1 - community nurse</p> <p>1- severe diabetes; lots of complications. found out later on that she passed before the project wrapped up</p> <p>1 - caregiver - to her mom and sister. Spoke a lot about the linkages between pain, pain management, emotional and mental health. Also shared about the power of a positive attitude. Role of culture in understanding what is happening and how all the signs are in front of us, but we need to be open to it.</p> <p>1 - lives with shingles; also has diabetes, cancer, pain. Spoke about the power of humour and keeping a positive mental attitude.</p> <p>1 - suffered from a stroke; spoke about the stroke as a gift as it helped change her life around and helped her quit drinking and focus more on living a healthier life.</p> <p>Community is located in chemical valley - lots of pollution; lots of impacts on the surrounding environment. Loss of cultural activities b/c of this. Also spoke a bit about the impacts of IRS and how the community needs healing.</p>
RC04	5 participants and 1 Elder	<p>Dementia; stroke; epilepsy; a couple of people didn't understand the study - had a lot of people in their family who had cancer and thought that cancer counted as a neuro condition.</p> <p>Talked about needing more supports in the community; need for counselling services; need for more supports for Metis families. Need for more readily available home care services.</p> <p>Some people talked about traditional healing and wanting more traditional services; one person also stated that they were wary about going to an elder because some of the older women talk behind each other's backs.</p>



RC05	4 participants. all caregivers, and 1 Elder	<p>1 - grandma has dementia</p> <p>1 - friend had Kennedy's disease</p> <p>1 - was a janitor at a seniors home</p> <p>1 - took care of her mom (schizophrenia), grandma and grandpa had AD and dementia; daughter is an addict - a lot of historical trauma. Also talked a lot about intergenerational trauma, residential schools, sexual abuse, incest.</p> <p>role of culture was also addressed - using culture to heal.</p>
RC06	5 participants and 1 Elder. 2 caregivers and 3 people who lived with a condition.	<p>happened same day as when Prince Charles came to campus – session was disrupted.</p> <p>Had quite a few people talking about head injuries and the impacts it had on them. Also discussed Alzheimer's disease and dementia; ABI/TBI; Diabetes related neuralgia; Epilepsy; Stroke; Rheumatoid Arthritis</p> <p>Spoke about role of culture and how that plays into healing and praying.</p>

## Chapter 7: Conclusion

This research examines the role culture plays in understanding neurological conditions and how these understandings influence how Indigenous people access health care. A secondary analysis of the data was conducted with different questions being asked of each data set. The theoretical framework used in the analysis is a “two-eyed seeing” approach that utilizes Indigenous knowledge and Critical Medical Anthropology. My background in Indigenous Studies, American Indian Studies, and my work with Cree traditional narratives, along with the many teachings I have received over the years has helped me make sense of the stories that were shared. Applying a Critical Medical Anthropology lens helps to explain why it is so important to look the colonial history, along with the current policies, and social determinants of health in relation to the health and wellbeing of Indigenous people.

The key informant interviews with health care professionals were analyzed with special attention paid to experiences in working with Indigenous people living with neurological conditions and their understandings of culture or traditional practices being used as part of the care routine. The two research questions for this data set are: 1) What are the experiences of HCP in caring for Indigenous people who either live with a neurological condition or care for a loved one with a neurological condition? and 2) Do they know if their patients are using cultural ceremonies / or traditional practices as part of the care routine? The Traditional Knowledge Keeper interviews were analyzed with the following two research questions being applied to the data: 1) Are neurological conditions fairly new or have Indigenous people always experienced these types of

conditions? and 2) How were people with neurological conditions traditionally cared for?

The research questions applied to the interviews and research circle data are: 1) How are neurological conditions culturally understood? and 2) Does this understanding influence how people access care?

### **Health Care Professionals**

Many of the key informant interviews spoke to the inequities that exist within the health care system. In reanalyzing the data, issues relating to access to care, social determinants of health, geographic location, along with systemic and jurisdictional issues were brought forward. All of the key informants spoke about the need for better access to care, while a couple of key informants pointed out that people who live in urban areas may have just as hard of time accessing services as people who live in rural or remote areas, especially when you factor in social determinants of health. Poverty was described as a competing factor to accessing care with urban poverty being greatly underestimated. In discussing their experiences with Indigenous patients with neurological conditions, key informants shared their frustration in having to contend with jurisdictional issues. They wanted the federal and provincial governments to work together to offer health care services and not fight over who would have to pay.

In looking at the understandings of culture or traditional practices being used as part of the care routine, many of the key informants were open to their patients taking part in cultural ceremonies or using plant based medicines, as long as they shared this information with their physician. Many of the nurses, physicians, and specialists talked about the relationship that is needed for patients to share this type of information. They also commented that not everyone who is in the health care field has the time or capacity to provide culturally safe, patient centred care. This was evident in the number of stories

of racism and discrimination aimed at Indigenous patients and their families. Cultural safety training is needed across the country to address institutionalized racism that still exists.

### **Traditional Knowledge Keepers**

The other key informant interviews were with the Traditional Knowledge Keepers. They shared that certain neurological conditions are not new, but how we talk about them is relatively new. They gave examples of how the names of certain conditions, such as epilepsy and arthritis are framed in the language. The Traditional Knowledge Keepers also talked about how people born with a neurological condition were seen as a gift in that they would bring a different perspective. They discussed the connection to spirit and that we are all spiritual beings, having a human experience. Use of prayers and ceremonies helps in reconnecting us to our spiritual side. They believed that people with a neurological condition would have been treated with respect and taken care of by their families and communities. One of the Traditional Knowledge Keepers also cautioned against romanticizing the past and stressed that not everyone would be taken care of during times of war or famine.

In discussing the differences between the past and the present and how people with neurological conditions are cared for today, the Traditional Knowledge Keepers spoke about the silo approach within western medicine. The specialization of western medicine does not account for the mind, body, spirit connection to deal with the whole person. This is problematic in that past traumas are not accounted for or are pushed aside. The Traditional Knowledge Keepers stressed the need for culturally safe care. They wanted health care providers to take the time and listen to their patients and provide patient centered care.

A couple of the Traditional Knowledge Keepers spoke about some of the nursing stations in northern parts of the country and how the nurses need additional training to recognize the severity of certain symptoms. They also wanted the nurses to be held accountable and reprimanded in cases of neglect and discrimination. Typically, complaints against health care providers would go to a provincial or territorial board. Nursing stations on reserve are under federal jurisdiction and not subject to provincial or territorial review. Other jurisdictional issues that were brought forward included the funding structure for services and the lack of communication between departments. Health services are funded through Health Canada and First Nations and Inuit Health, while Indigenous and Northern Affairs Canada fund education, environment, economic development, infrastructure and housing, and social programming. In order to address health inequities, all the factors relating to health need to be addressed together. This requires open communication between departments.

### **Individual Interviews and Research Circles**

Many of the participants talked about the normalization of neurological conditions and that neurological conditions were something that people just dealt with. People who live with a neurological condition spoke about finding a new normal and being able to live with their condition. In most cases, the concern was geared towards “how can I better manage my symptoms”, as opposed to “why did this happen to me?” Individuals with a neurological condition also spoke about the role spirituality plays in living with and understanding their condition. For people who were diagnosed later on in life, they spoke about the gifts that came with their condition, in terms of being more attuned to their mind, body, spirit connection. A couple of participants did discuss the role of ceremonies, prayer and plant based medicines that helped in managing their symptoms.

The caregivers also talked about the gifts in terms of being able to care for their loved one with a neurological condition. For some participants, being able to look after their aging parents was a gift in that they were able to return the love, care, and support given to them when they were younger. Other caregivers spoke about the different perspective that their loved one helped them see, especially in terms of how people are treated. Many of the participants also brought up the role of humor and how important it is to laugh or look on the bright side. The gifts and normalization of neurological conditions were brought forward throughout most of the interviews and research circles. Some participants did discuss their cultural understandings of neurological conditions in depth, as outlined in the two narratives. Other participants spoke about colonization and the impacts it has had on their culture, use of language, and interactions with the land, and how this in turn has affected their ability to think about neurological condition, and in certain cases has even contributed to an increase of neurological conditions.

The participants spoke more about their interactions with health care providers, than whether their cultural understanding influenced how they interacted with the health care system. If a participant had a positive experience with their health care provider, they were more willing to share any cultural understandings, including if they were using cultural ceremonies or plant based medicines as part of their care plan. If their health care experience was negative, they were less likely to share if they used any cultural practices or plant based medicines as part of their care routine. One caregiver, who did use plant-based medicines as part of her child's care plan, shared that she did not tell the health care providers and expressed concern that they would not understand the treatment and call child services. One participant who lives with a neurological condition did share her

cultural beliefs and experiences with her health care provider and was encouraged to keep following traditional healing practices. She stated that this health care provider was the only one who actually asked her about her emotional and spiritual health and not just her physical symptoms.

In talking about their interactions with health care providers, many of the participants did express a need for culturally safe care. Health care staff and providers need to learn about the different cultures in their communities. They need to learn about the impacts of colonization and colonial policies that still affect the health and wellbeing of Indigenous people today. Participants called for more resources to help them with interacting with the health care system. This included access to culturally safe mental health workers, disability navigators, Indigenous coordinators and navigators, as well as traditional healers. They wanted these services to be available to all Indigenous people regardless of status. They did not want to be lost in jurisdictional limbo where the federal and provincial governments are fighting over who has to pay for services.

This research outlines the complexity of being an Indigenous person and either living with a neurological condition or caring for a loved one with a neurological condition. Outside of Indigenous dementia research, there is not much information or literature on the lived experience of Indigenous people with other neurological conditions. This research also outlines the need for more information about neurological conditions, including the risk factors, signs and symptoms, as well as treatment options. Many of the participants talked about needing to educate others around them about their condition and the misconceptions others had about certain neurological conditions. Misunderstandings and misconceptions about epilepsy came up a lot in the key informant

interviews and individual interviews and research circles. The secondary analysis of the three data sets captures the health inequities that still exist. The inequities that came up in the data include access to care and services, social determinants of health, as well as systemic and jurisdictional issues. Participants also talked about the need for culturally safe care. In order to address any of calls for action in the Truth and Reconciliation Commission, local, regional, provincial / territorial, and federal governments will need to work alongside Indigenous communities and governments to implement curriculum that will address the legacy of residential schools at every education level, from elementary to post-graduate.

## **Key Recommendations**

### **Quantitative Data is Needed to Support the Stories**

The qualitative data is important to share with the general population because it supports the real life experiences of Indigenous people who live with a neurological condition or care for a loved one with a neurological condition. This information only tells part of the story, and more funding to support this type of research is needed to get a clearer picture of the incidence and prevalence rates of neurological conditions in Indigenous people. Dr. Janet Smylie and Sam Kooshesh reviewed and analyzed existing health data to determine the incidence and prevalence rates of neurological conditions in Indigenous women (2013, unpublished report). They examined ten data bases to see whether or not Indigenous specific data regarding neurological health was being collected.<sup>21</sup> Only four out of the ten datasets had disaggregated Indigenous specific

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<sup>21</sup> The data bases that were examined include: Canadian census 2006; Canadian household survey 2011; Aboriginal people's survey (APS) 2001 & 2006; First Nations Regional Longitudinal health survey (RHS), 2002-2003, 2008-2009; Canadian Community Health Survey (CCHS) 2011; National Population health



neurologic health data. These include the Canadian Community Health Survey (CCHS), First Nations Regional Longitudinal Health Survey (RHS), the National Population Health Survey (NPHS), and the Report on Métis Health Status and Health Care Use in Manitoba. Smylie and Kooshesh found that only the RHS and the Metis Health Status and Health Care use report have readily available Indigenous specific data currently available. Identifying Indigenous specific data tabulations in the other two datasets would take much more work and would not include Indigenous people living on reserves. The CCHS excludes persons living on reserves and other Indigenous settlements in the provinces; full time members of the Canadian Forces, residents of institutions (inmates of penal institutions, patients in hospitals and nursing homes who have resided in the institution for more than six months). For the North, the CCHS covers 92% of the targeted population in the Yukon, 96% in the NWT, and 92% in Nunavut (starting in 2013).

From 2000-2001 onward the CCHS included an Indigenous identifier, where participants could respond with “North American Indian”, “Metis”, and “Inuit/Eskimo”. While including this identifier allows researchers to disaggregate the data to look at First Nations, Inuit, and Metis separately, Smylie and Kooshesh point out that the sample sizes may be too low in some provinces to get any meaningful data on Indigenous health (2013). This is unfortunate in that the CCHS recently expanded the number of neurological conditions it looks at over the years. From 2000-2001 up to the 2010-2011 survey, the CCHS only asked about three neurological conditions: epilepsy, Alzheimer’s disease and “other” neurological conditions. In 2010-2011 they expanded the survey to

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Survey (NPHS), 2004-2005; Manitoba Metis Federation chronic disease project; The Metis Nation of Ontario Healing and Wellness Branch’s Chronic Disease Survey Project (CDSP); Metis Nation of BC health Survey; Institute of Clinical Evaluative Sciences (ICES)

include 18 neurological conditions: Migraine headaches, Multiple Sclerosis, Epilepsy, cerebral palsy, spina bifida, hydrocephalus, muscular dystrophy, dystonia, Tourette's, Parkinson's disease, ALS (Lou Gehrig's disease, Huntington's disease, Alzheimer's disease or any other dementia, effects of a stroke, brain injuries, brain tumours, spinal cord tumour, and spinal cord injury (Statistics Canada, CCHS 2010-2011

<http://www5.statcan.gc.ca/cansim/a26?lang=eng&retrLang=eng&id=1051300&paSer=&pattern=&stByVal=1&p1=1&p2=31&tabMode=dataTable&csid=>). When using all conditions listed, it is estimated that 3.5 million Canadians live with a neurological condition; with the majority of people experiencing migraine headaches (2.7 million), followed by over 300,000 living with Alzheimer's disease or other dementias (Ibid.). The numbers could not be broken down by ethnicity for each province due to the rather specific sample cohort.

The NPSH was launched in 1994, to look at data related to health, including questions related to social, economic, demographic, occupational, and environmental data. From 2000/2001 to the 2010/2011 cycle, the NPSH was longitudinal and collected health information from the same 17,276 people each cycle. This survey has since ended after collecting data for over nine cycles

(<http://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SDDS=3225>). The NPSH collected neurological health data on Alzheimer's, epilepsy, migraine headache, effects from stroke and "other". Similar to the CCHS, this survey is not administered on reserves, leaving out Indigenous people who may experience greater health disparities with less access to specialized health care services. The sample sizes for each province were also too small to report on identity.

The RHS differs from the other surveys in that it is “the only First Nations governed national health survey in Canada” (<http://www.fnigc.ca/our-work/regional-health-survey/about-rhs.html>). The RHS is made up of a national team, who coordinates the survey on a national level, prepares reports, houses the data, and engages in partnerships, and ten independent regional partners, who collect information from their respective regions. The RHS is administered to First Nations people living on reserve by members of the community trained to deliver the survey. In each phase of the RHS, care and attention are taken to ensure that a community based participatory research approach is taken, where Indigenous values are evident throughout the design, collection, analysis, and knowledge translation pieces. All information coming from the national team is housed within the First Nations Information Governance Centre. The 2002-2003 & 2007-2008 RHS included questions around epilepsy, psychological nervous disorders, and ‘cognitive or mental disability’. Smylie and Kooshesh found the “prevalence rates were 0.9%; 3.3%; and 1.2% respectively in 2007-2008” (2013: 6). Regional offices that administer the RHS have been working with researchers and communities to see what additional questions need to be included in the next version of the survey in order to get a better picture of the health needs of Indigenous people living on reserves. Questions around Alzheimer’s disease and dementia have been piloted and used in some of the different regional surveys, but were not included in the national RHS.

The report on Métis Health Status and Health Care Use in Manitoba looked at population health data from 2002-2006 (Martens et al 2010, [http://www.mmf.mb.ca/docs/metis\\_health\\_status\\_report.pdf](http://www.mmf.mb.ca/docs/metis_health_status_report.pdf)). The purpose of the report was to examine the “population-based indicators of the health status, healthcare use, and

social determinants of health of the Metis of Manitoba,” and determine if there is a difference between the Metis population and the general Manitoba population (Martens 2010:34). The authors found that Metis people had higher rates of stroke and dementia than non-Metis, but did not look at other neurological conditions.

The Manitoba Centre for Health Policy (MCHP) in collaboration with the Manitoba Metis Federation (MMF) produced the Manitoba Metis Health Status and Health Care Use report using information from the Population Health Research Data Repository. This Repository accesses hospital claims, medical claims, physician files, home care records, personal care homes, registry files, vital statistics, pharmaceutical claims, immunization records, census files, CHS, education enrolment from the Ministry of Education, and information from the Ministry of Family Services and Housing for income assistance and children in care (Marten et al 2010). The anonymized data is linked through a fictitious number assigned to the records. In order to access and link the data the MCHP obtained a number of ethical approvals. In order to get the Metis specific information, the MMF shared their membership list with the Manitoba Health Information Management Branch, who linked the membership lists with the Personal Health Information Numbers. It is important to note that this type of research would not be possible without the full support of the MMF. Research involving Indigenous people needs to adhere to Tri Council Policy Statement on Research Involving First Nations, Inuit and Metis Peoples of Canada, as well as Ownership, Control, Access, and Possession (OCAP) principles.

The collaborative effort that led to the MFF partnering with the MCHP to produce the Manitoba Metis Health Status and Health Care Use report is a great example of what

Indigenous organizations can do to work with researchers to produce data that they could use to advance health and wellbeing and advocate for additional services or funding.

Each province has its own methods for tracking physician and hospital use, pharmaceutical use, and services such as home care and long term care. Not every province or territory has relationships in place to work with Indigenous organizations to link such data. Developing the data agreements often takes time to ensure the proper procedures and governance structures are in place. For example, in the province of Ontario, the Institute for Clinical Evaluative Sciences (ICES) and the Chiefs of Ontario (COO) have entered a Data Governance Agreement in 2012

([http://www.ihdlconference2014.org/sites/default/files/GEORGIA%20A\\_APR30\\_1445\\_COMBINED.pdf](http://www.ihdlconference2014.org/sites/default/files/GEORGIA%20A_APR30_1445_COMBINED.pdf)). This agreement allows ICES to access the Indian Registry System to conduct health related analysis for COO and other First Nations communities. As part of the agreement, OCAP principles must be upheld throughout; this means that ICES never has true ownership of First Nations data. In addition to having the data governance agreement in place, a data governance committee is being established, along with research request protocols that will ensure that any research is done by, for, and with the communities (Antone et al. Presentation “First Nations Health Data Linkage: A collaborative research approach.

[http://www.ihdlconference2014.org/sites/default/files/GEORGIA%20A\\_APR30\\_1445\\_COMBINED.pdf](http://www.ihdlconference2014.org/sites/default/files/GEORGIA%20A_APR30_1445_COMBINED.pdf)).

### **Need for Culturally Appropriate and Responsive Care Across Canada**

The health care providers, Traditional Knowledge Keepers, and the participants in the individual interviews and research circles talked about the stereotypes and racism that exist within the health care system. They also stressed the need for advocates within the

health care system in order to improve access to services. For patients who are living in rural or remote parts of the country, where health care services are limited, a diagnosis may never come without a certain amount of self-advocacy. Even if patients are persistent in requesting care, it does not always mean that the health care professionals will necessarily know what tests to run or what treatment should be administered. For example, in January 2016, the CBC reported that a First Nations mother was suing the province of Manitoba, the Northern Regional Health Authority and a doctor for negligence in the death of her almost three year old daughter. The First Nations mother took her daughter to the St. Theresa Point First Nation nursing station close to 40 times between March 2011 and December 2013. According to the article, the little girl was “consistently nauseated, had a fever, had no appetite, had a number of colds and ear infections and had bouts of vomiting and diarrhea that last days” (<http://www.cbc.ca/news/canada/manitoba/toddler-taken-to-nursing-station-40-times-gets-cancer-diagnosis-days-before-death-lawsuit-says-1.3390846>). The treatment administered by the nursing station mainly consisted of Tylenol and Pedialyte. The little girl was losing weight, vomiting frequently and holding her stomach and crying. The mother asked for referrals to specialists, but did not receive any referrals until it was too late. In October 2013, the nursing station took three blood samples and two stool samples. One test had to be redone because of an administrative error. It was not until December 2013, when a new doctor came to the nursing station that the little girl was medevac’d to the Children’s Hospital in Winnipeg. “The next day, a CT scan revealed a tumour larger than a softball on one of her kidneys.” The cancer by this point spread throughout her internal organs.

There are multiple stories of poor treatment at the nursing stations in the northern parts of Ontario and Manitoba. Nursing stations on reserves are under federal jurisdiction. On February 24, 2016, the Nishnawbe Aski Nation (NAN) declared a health and public health emergency for the Sioux Lookout area in Ontario. The emergency declaration was issued for a number of reasons, one of which included First Nations being denied access to health care by Health Canada's non-insured health benefits program. First Nations people who need to travel outside of their communities for specialized care need to have their travel preapproved. According to a CBC article on the declaration, "Health Canada denied 17 of 22 children under seven [years of age], access to a pediatrician, even though they were referred by a doctor because of developmental issues"

(<http://www.cbc.ca/news/canada/thunder-bay/first-nations-health-emergency-1.3460198>).

Other issues include the high rates of Rheumatic fever, invasive infections due to unsafe water and inadequate housing, and limited access to health services, with no resident doctors, and nurses not completing mandatory training.

In the spring of 2015, the Office of the Auditor General in Canada released a report on the Access to Health Services for Remote First Nations communities. The audit focused on "whether Health Canada had reasonable assurance that eligible First Nations individuals living in remote communities in Manitoba and Ontario had access to clinical and client care services, and medical transportation benefits" (2015: 6). The report did not examine the quality of health services and benefits provided. They found numerous deficiencies in the nursing stations related to health and safety. One of the residences at the nursing station that they visited had been unusable for more than two years because the septic system had not been repaired, which led to health specialists cancelling their

visits to the community. They found that only 1 of 45 nurses in their sample completed all five of the Health Canada's mandatory training courses. They also found that

Health Canada had recently defined essential health services that should be provided in nursing stations. However, the Department had not assessed whether each nursing station had the capacity to provide these services, nor had it informed First Nations individuals what essential services were provided at the station. (2015; 7)

This report shows much more work needs to be done to address health equity for Indigenous people.

### **Culturally Safe Care Needs to be More Than a Recommendation**

In 2012, the Health Council of Canada released a report called Empathy, Dignity, and Respect: Creating Cultural Safety for Aboriginal People in Urban Health Care. The two part report includes a commentary by the Health Council of Canada on why cultural competency and cultural safety is needed and the second part is a summary report on the regional discussions in urban health systems. The stories of racism and discrimination against Indigenous people within the health care system are frustrating and heartbreaking given the number of reports that have been released calling on governments to make changes to the health care system. Calls for culturally safe care emerged with the RCAP report in 1996 where recommendations called for more training and capacity building for Indigenous people within the health care system, a reorganization of health and social services under Indigenous control, more funding for community infrastructure to deal with urgent problems such as waste management, clean drinking water and safe housing. The report also called on mainstream health services “to accommodate Aboriginal people as clients and as full participants in decision making”

<http://www.collectionscanada.gc.ca/webarchives/20071207000543/http://www.ainc->



[inac.gc.ca/ch/rcap/sg/si24\\_e.html#3.%20An%20Aboriginal%20Health%20and%20Healing%20Strategy](http://inac.gc.ca/ch/rcap/sg/si24_e.html#3.%20An%20Aboriginal%20Health%20and%20Healing%20Strategy)).

The Romano report in 2002, recommended that non-Indigenous health care providers are trained so that they can meet the needs of Indigenous people they are serving. The report stressed the need to deliver health care services in a culturally sensitive way. Similar recommendations were made in the Health Canada Council reports from 2005 to 2013. The Health Canada Council was an independent, non-profit organization funded by the federal government to set national health standards and hold provincial, territorial, and federal governments accountable for health care reforms (<http://www.healthcouncilcanada.ca/index.php>; Boyle, 2014). On March 31, 2014, federal funding for the important work produced by the Health Canada Council was ended (CBC news April 17, 2013 <http://www.cbc.ca/news/politics/health-council-s-demise-just-made-sense-spokesman-says-1.1309302>).

Allen and Smylie (2015) wrote a report on the role of racism in the health and well-being of Indigenous people in Canada. They documented Indigenous health inequities and looked at the impacts of colonialism, institutionalized racism, race based policies and how these affect Indigenous people's access to health care (Allen & Smylie, 2015). Allen and Smylie give examples of the different standards, guidelines and core competencies that are in place, along with the recruitment and retention policies and training programs (2015). In their recommendations, they call for foundational changes to all Canadian social institutions, not just the health care system, and that Indigenous people are fully included in these conversations. They also stressed the need to improve

Indigenous health data collection to ensure that Indigenous people are included in any national survey (2015).

Foundational changes within Canada's social institutions are needed to address the colonial legacy that continues to affect the health and wellbeing of Indigenous people. The Truth and Reconciliation Commission aimed to address the legacy of the Indian Residential Schools and issued 94 calls to action to be implemented by federal, provincial, territorial, and Aboriginal governments. These calls to action are directed at child welfare, education, language and culture, health, and justice. The TRC also called on the federal, provincial, and territorial governments to adopt and implement the United Nations Declaration on the Rights of Indigenous people, to provide education and training to public servants on the colonial history and its legacy, and to support reconciliation in the media, and in social and economic programs (TRC 2015 Calls to Action). The recommendations under health called on all levels of government to:

- i. Increase the number of Aboriginal professionals working in the health care field.
- ii. Ensure the retention of Aboriginal health care providers in Aboriginal communities
- iii. Provide cultural competency training for all health care professionals. (Ibid.)

The calls for action also request that all medical and nursing schools in Canada require their students to take a course on Indigenous health, including the history and legacy of Indian Residential Schools (Ibid.).

The numerous recommendations over the last 20 plus years need to be implemented across all levels of government. In order to address the health inequities that exist, serious commitments need to be made throughout all levels of government. This

includes providing adequate funding in order to implement and evaluate programs and policies.

### **Striving for Health Equity**

The Public Health Agency of Canada defines health equity as “the absence of health inequalities which are avoidable or remediable differences in health among populations or groups defined socially economically, demographically or geographically” (PHAC 2014: 3). The inequities refer to the “differences in health status experienced by different groups in society, regardless of their cause” (Ibid.). From chapter 2, we know that Indigenous people in Canada have greater health disparities than the general population. The health surveillance data that does exist suggests that Indigenous people have higher rates of chronic diseases, cancers, and mental illnesses (Reading, 2009). Loppie-Reading and Wein (2009) link these lower levels of health to inequity, social exclusion, historical injustice and the social determinants of health. This can be seen through the proximal intermediate, and distal determinants of health, where the proximal factors have an immediate impact on a person’s wellbeing and include access to housing, education, food, employment, income, and a reliable support system. The intermediate factors are the policies, procedures and systems in place that influence the proximal factors and affects how people access services. The distal determinants are the underlying factors that include colonialism, racism, exclusion, and self-determination. All of these factors greatly affect how Indigenous people interact with the health care system.

The findings chapters dive into the many inequities that exist for Indigenous people seeking care for neurological conditions. In chapter 4, the health care providers gave examples of the different obstacles for care for Indigenous people face, with poverty

being a major contributing factor to poor health. Other areas that shed further light on the inequities of the health care system included access to care, referrals and wait times for specialist care and diagnostic tests, along with systemic and jurisdictional issues, such as needing preapproval from NIHB for travel and medication, can all impede treatment. In chapter 5, the Traditional Knowledge Keepers touched impacts of colonialism, legacy of residential schools and intergenerational trauma, as contributing to additional risk factors for neurological conditions for Indigenous people. They also discussed policies that negatively impact the environment and how this affects the health and wellbeing of Indigenous people who live off the land. Health inequities are also brought forward in chapter 6 in the interviews and research circles with people who live with a neurological condition or care for a loved one with a neurological condition. Examples include lack of access to care and services, lack of health information on the different conditions, negative interactions with health care providers, jurisdictional issues of dealing with NIHB for medical transportation, lack of communication between regional, provincial, and federal bureaucracies, along with stereotypes and racism. These are all massive barriers to accessing equitable care. Addressing these inequities will take time, money, and perseverance by many people at all levels of government.

The participant recommendations, along with the broader recommendations stated above seeks to address some of the health inequities for Indigenous people living with neurological conditions. At a local level this can include greater access and promotion of health literacy, making sure patients know their rights to equitable health care, know where they can access services, and who to contact if they have questions. At the regional level, more reflection may be needed to look who is accessing services and what is

needed to ensure equitable access. This requires analyzing, addressing, and reporting on the social, economic, demographic and geographic factors. Do staff and health care providers understand the challenges their patients face in accessing care? Do they have the time to deliver patient centered care? Work with community partners to understand what barriers exist and plan how to address these together. Cultural safety training can be tailored to each region to ensure that health care providers and staff know the history of the population they are serving. At the provincial, territorial, and federal levels this means working with community partners to ensure policies do not further marginalize Indigenous people. Strive for better ways to work with Indigenous organizations to gather and report on administrative health data and include Indigenous people in national surveys. Better communication and coordination of services are needed across federal and provincial jurisdictions. NIHB medical transportation services, along with the medication benefits needs to be revamped to support Indigenous people that need care. Better communication and coordination of services are also needed between INAC and FNIH. Education, environment, economic development, infrastructure, housing, and social programming are all linked to health. The federal and provincial governments need to look at all the factors that contribute to health and not just apply a silo approach to health and wellbeing.

The Canadian Medical Association, states, “health equity is created when individuals have the opportunity to achieve their full health potential” (<https://www.cma.ca/En/Pages/health-equity.aspx>). In order to improve health outcomes for Indigenous people, health equity needs to be integrated into policies, programs, and

practices at the local, regional, provincial, and federal levels. This also requires Indigenous people being included in any health equity planning from the very beginning.

### **Future Research**

The UFW project gathered important baseline information about Indigenous women and neurological conditions. This research dived more into the cultural understandings of neurological conditions and interactions with the health care system. From the literature review, much more research is needed in the areas of specific neurological conditions such as Ataxia, Rett Syndrome, Trigeminal Neuralgia, shingles or migraines and Indigenous people. Future research could also expand the scope of UFW project to include more participants, especially Indigenous men, along with a greater number of Traditional Knowledge Keepers. Having a network of research centres across the country working together to understand neurological conditions in Indigenous people would provide more insight on cultural understandings in relation to the geographic area, colonial impacts, and community resiliency.

## Appendix A

Definitions for each neurological condition included in the NPHSNC and Understanding from Within Study. The majority of the definitions are from the PHAC 2014 report – Mapping connections. Other definitions, including Ataxia, Diabetes Related Neuralgia, Minamata Disease, Severe PTSD, Shingles, Trigeminal Neuralgia are derived from the condition specific organizations.

**Alzheimer’s disease and other dementias** - Alzheimer’s disease is a degenerative disease of the brain with characteristic pathological features and is the most common form of dementia. Dementia is a syndrome characterized by loss of memory, the ability to think, as well as changes in mood, behaviour and ability to communicate. Other common types of dementia include vascular dementia, frontotemporal dementia, or Lewy body dementia, each with distinct clinical and pathological features. In this report, the term ‘other dementias’ includes these forms as well as instances of dementia not classified by type.

**Amyotrophic Lateral Sclerosis (Lou Gehrig’s Disease)** - A disease that causes progressive muscle weakness and paralysis due to the degeneration of the upper and lower motor neurons in the brain and spinal cord.

**Ataxia** – a specific degenerative disease of the nervous system that controls movement and balance. Ataxia may affect the fingers, hands, arms, legs, body, speech, and eye movements.

**Brain Tumours** - Classified either as primary (if it arises from cells within or surrounding the brain) or secondary (if due to metastasis originating from tumours in other parts of the body). Primary brain tumours can be benign or malignant. Depending on their location and size, brain tumours can cause a variety of neurological problems including seizures, headaches, or focal neurological symptoms and signs such as weakness, clumsiness, and impaired vision, sensation, or speech.

**Cerebral Palsy** - A non-progressive but not unchanging disorder that affects the ability to move or maintain balance and posture that is caused by an insult to, or an anomaly of, the developing brain.

**Diabetes Related Neuralgia** – a nerve disorder caused by diabetes. Some symptoms may include pain, tingling, or numbness, loss of feeling in the hands, arms, feet, and legs.

**Dystonia** - A movement disorder that causes muscles to contract involuntarily, forcing all or part of the body into repetitive, often twisting movements. Dystonia may be generalized (affecting multiple muscle groups) or focal (affecting only a single body area).

**Epilepsy** - A neurological disorder in which sudden bursts of electrical activity in the brain produce ‘seizures’ that can vary in frequency and form as a brief stare, an unusual movement of the body, a change in awareness, or a generalized convulsion. Most seizures last a few seconds or a few minutes.

**Huntington Disease** - An inherited disorder that causes cells in specific parts of the brain to degenerate. Symptoms include emotional turmoil (depression, apathy, obsessive behaviour), loss of mental function (inability to focus, think and recall, or make decisions), or physical deterioration (weight loss, involuntary movements, diminished coordination, inability to walk, talk, or swallow).

**Hydrocephalus** - A neurological condition in which excess cerebrospinal fluid accumulates in the brain cavities (ventricles). Hydrocephalus can be congenital (due to abnormalities of the developing brain), acquired (due to complications of intracranial haemorrhage, meningitis, head injury, or brain tumour), or idiopathic (due to an unknown cause). Depending on several factors (age of onset, rapidity of development, and severity) hydrocephalus can damage brain structures and cause neurological symptoms, including cognitive impairment or gait disorder.

**Migraines** - A type of recurrent throbbing headache that is often associated with nausea and even vomiting, sensitivity to light and sound, and, in about a third of those affected, visual or sensory auras.

**Minamata Disease** (mercury poisoning) – caused by a large amounts of methylmercury being discharged into areas where they could greatly impact the surrounding food sources. Exposure at high levels can impact the brain, heart, kidneys, lungs, and immune system. Symptoms may include impairment of peripheral vision, lack of coordination, impairment of speech, hearing, muscle weakness, twitching tremors, and stumbling gait.

**Multiple Sclerosis** - An autoimmune disease characterized by disseminated patches of demyelination (called plaques) in the brain and spinal cord. Multiple sclerosis is unpredictable, affecting vision, hearing

**Muscular Dystrophy** - A group of genetically transmitted diseases characterized by progressive weakness and wasting of the muscles that control voluntary body movement.



Different types of muscular dystrophy have distinct patterns of muscle involvement, age of onset, rate of progression, and type of inheritance. Even among individuals with a specific type of muscular dystrophy, symptoms and severity can be quite variable.

**Neurotrauma** (including brain and spinal cord injuries)

**Brain Injury (traumatic)** - An injury of the brain due to trauma (most often caused by vehicle crashes, falls, or sports activities) that can result in effects that range from mild and transient symptoms of concussion to profound and permanent impairments of neurological function.

**Spinal cord injury:**

Damage to any part of the spinal cord. Depending on the level of the spinal cord that is injured and the severity of the lesion, the arms and legs (quadriplegia) or legs (paraplegia) may be affected by weakness, paralysis, or loss of sensation. Bladder, bowel and sexual function are often affected as well. Spinal cord injuries are most frequently caused by vehicular crashes, falls, or sport/ recreational activities.

**Parkinson's Disease** - A neurodegenerative disease resulting from the progressive loss of brain cells that produce dopamine, a chemical that carries signals between nerves in the brain. The four main features are: rigidity or stiffness of the arms, legs, or neck; tremor (usually of the hands); bradykinesia (slowness and reduction of movement); and postural instability (loss of balance). The terms parkinsonism or parkinsonian syndrome are used to describe the motor features (rigidity, tremor, bradykinesia, or postural instability) whether they are due to Parkinson's disease, other brain diseases, or the side effects of certain medications.

**Rett Syndrome** - A rare genetic developmental disorder of the brain that occurs almost exclusively in girls. Girls with Rett syndrome usually develop normally until six to 18 months of age, whereupon their development slows and there is a regression of communication skills, loss of hand dexterity, slowing of the normal rate of head growth, and the appearance of stereotyped hand movements and gait disturbances. Other problems may include seizures, disorganized breathing patterns, or excessive irritability.

**Severe PTSD** – symptoms may include reliving the experience through nightmares, flashbacks, difficulty sleeping, feeling detached or estranged, avoidance, and isolating from other people, feeling on guard, irritable, or startling easily. These symptoms can interfere with interpersonal relationships and employment, and can be associated with depression, anxiety disorders and other medical disorders.

**Shingles** – viral infection that causes a painful rash. Symptoms may include pain, burning, numbness or tingling.

**Spina Bifida** - A spectrum of developmental disorders in which there is a defective closure of the neural tube during the first four weeks of pregnancy. This neural tube defect results in varying degrees of paralysis of the lower limbs and impairment of bladder or bowel function.

**Stroke** - A sudden loss of brain function caused by an interruption of the flow of blood to the brain (ischemic stroke) or the rupture of blood vessels in the brain (haemorrhagic stroke). The effects of a stroke depend on where the brain was injured, as well as how much damage occurred. A stroke can result in one-sided arm and leg weakness, known as hemiplegia, or can cause other impairments of movement, coordination, vision, speech, memory, or in the capacity to think.

**Tourette Syndrome** - A neurological disorder characterized by tics, which are involuntary, rapid, sudden movements or vocalizations that occur repeatedly in the same way. The onset of symptoms is usually before the age of 18 years, with the appearance of facial tics (rapid eye blinking or mouth twitches), involuntary sounds (such as throat clearing and sniffing), or tics of the limbs. Symptoms often lessen in early adulthood.

**Trigeminal Neuralgia** – a chronic pain condition that affects the trigeminal nerve, which carries sensation from the face to the brain. Symptoms may include episodes of severe, shooting or jabbing pain.

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