



NATIVE WOMEN'S  
ASSOCIATION OF CANADA

L'ASSOCIATION DES FEMMES  
AUTOCHTONES DU CANADA



*The national voice of Aboriginal women in Canada since 1974.*

# Understanding From Within

**Research findings and NWAC's contributions to Canada's National  
Population Health Study on Neurological Conditions (NPHSNC)  
June 2013**



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*Chi-meegwetch.*

## Executive Summary

In 2010 the Native Women's Association of Canada (NWAC) was successful in obtaining funding through the Public Health Agency of Canada (PHAC) to undertake a three-year research project entitled *Understanding from Within: Developing community driven and culturally-relevant models for understanding and responding to neurological conditions among Aboriginal peoples (UFW)*. The project was one of thirteen that were funded as part of a four-year National Population Health Study focused on filling gaps in knowledge about individuals with neurological conditions, their families, and caregivers.

The goal of the UFW research project was to develop a better understanding of how Aboriginal peoples conceptualize neurological conditions and the impacts on their families and communities, and the resources and supports needed to provide culturally safe and appropriate care. The research was qualitative in nature and used an Indigenous Research Methodologies (IRM) approach to guide the design, collection of data, and analysis of the research.

Two methods were used to collect information: In-depth interviews and research circles (focus groups). A total of 80 people participated in the research, 69 women and 11 men. In-depth interviews were undertaken with key informants (22), with Aboriginal peoples living with a neurological condition (18), and with Aboriginal peoples caring for someone with a neurological condition (40). Major themes and sub themes emerged in the research, along with a series of recommendations intended to improve relations between the medical community and Aboriginal peoples, and to promote the importance of Aboriginal control of health care services.

Throughout this study it became apparent that more research is needed. Recommendations for new or continued research surfaced from the research participants themselves, and from interactions between advisory committee members and the research team that occurred during the research design, data collection, and reporting processes. Further examination of the UFW research data and the application of a culturally relevant gender based analysis will highlight more clearly how Aboriginal women experience multi-layered impacts, and how those impacts are magnified due to socio-economic status, the interactions of co-morbidities with their neurological conditions, and elevated risk factors such as those associated with alcohol and drug abuse, and violence against Aboriginal women.

## Background

In June of 2009 the Federal Minister of Health announced the commencement of a four-year National Population Health Study to fill gaps in knowledge about individuals with neurological conditions, their families, and caregivers. Thirteen research projects were funded, each falling into one of five categories: Scope, impacts, risk factors, health services, and multiple focal points. A comprehensive report providing a clear picture of the state of neurological conditions

in Canada will be published by the PHAC upon conclusion of the study. This report will be used to aid governments and stakeholders in program and service planning and will identify the scope of prevention needs. (PHAC, 2010)

NWAC argued that there was a specific need for research focusing on Aboriginal women. They have a longer lifespan than Aboriginal men and experience disproportionate rates of poor health, including chronic disease and factors that enhance their risk for developing neurological conditions, than non-Aboriginal women. Aboriginal women also represent the majority of caregivers in Aboriginal communities, whether formal or informal, paid or unpaid. Assessing the impact of neurological conditions on the lives of Aboriginal peoples, and women in particular, was anticipated to shed light on the social and economic (real and opportunity) costs of this particular set of health conditions for our communities and the governmental bodies responsible for addressing Aboriginal health. (NWAC 2010)

NWAC proposed that the application of a culturally relevant, gender-based analysis would enable consideration for the unique experiences, challenges, and contributions that Aboriginal women have in responding to neurological conditions, whether as individuals diagnosed with a condition, or as caregivers, family, and community members (NWAC 2010).

The UFW research project was implemented in three stages. First, a systematic literature review of available knowledge that addresses neurological conditions in Aboriginal communities and an environmental scan of existing services available to Aboriginal peoples affected by neurological conditions. Second, an examination of how Aboriginal peoples conceptualize neurological conditions and the impact on their families and communities, and the needed resources and supports to provide culturally safe and appropriate care. Third, a review of how the findings might be translated and applied to policy, programming, and practice was conducted (NWAC 2010).

To ensure that the project remained transparent and accountable to Aboriginal peoples and communities it formed an advisory committee made up of representatives from the three distinct Aboriginal populations (First Nations including status and non-status Indians, Métis and Inuit) from various jurisdictions across Canada. The advisory committee was engaged at the onset of the project through to the analysis and dissemination phases of the project (NWAC 2010).

It is important to note that of the thirteen funded projects the UFW project is the only project that sought to examine neurological conditions through the lens of Aboriginal realities, culture, and worldviews. It is hoped that the authors of the national report at PHAC will use UFW outcomes to ensure that the findings from other projects are interpreted in a manner that respects the unique and diverse needs of Aboriginal people who are affected by neurological conditions.

## Key Findings

### Impacts

The project's main objective was to better understand the impacts of neurological conditions on Aboriginal people, families, and communities by speaking with Aboriginal women who were either caregivers or living with a condition. The project team explored how neurological conditions impact Aboriginal women directly and indirectly, through one-on-one interviews and research circles (focus groups). Three open-ended questions were presented to research participants utilizing a narrative approach to data collection. The open-ended nature of the questions allowed participants to tell their story in a way that was most comfortable to them, privileging the *story* as a culturally informed interpretation process. The following quote is a participant's reflection on how the UFW research team approached information collection:

*Our bodies know what to do to heal itself, but often times we don't recognize it or worse, we don't listen to our bodies. Researchers often talk about the conditions, but they don't talk about the implications. They don't talk about how it impacts our mom, our families, our spouse, ...*

Research participants were encouraged to talk about any impacts they were comfortable sharing but were asked to speak to the physical, mental, emotional, and spiritual impacts, in keeping with Indigenous worldviews that everything is connected, as explained by this participant:

*One thing, spiritually is I'm glad that I was already starting my journey spiritually because I know that you gotta balance all four and when your physical is suffering then the other three directions are definitely suffering.*

The range of impacts that emerged through this research was extensive. Research participants spoke about how they were impacted personally (as someone with a condition) and collectively (through family and community experiences). Some participants talked about how their condition was all consuming and how it affected every aspect of their day-to-day lives, and those of their families. They talked about how they felt upon receiving a diagnosis, and how their new reality forced them to adjust their lives and even their hopes for the future. Researchers heard stories about how the impacts of neurological conditions are interconnected. The following quote by a key informant highlights this interconnectivity and the fact that there is still so much the medical community does not understand about neurological conditions and the impacts on the Aboriginal community:

*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.*

## Physical Impacts

Some of the women interviewed who suffered pain as a result of their condition spoke of how it impacted every part of their lives, particularly in terms of not being able to get enough sleep and being physically, mentally, emotionally, and spiritually exhausted. The following is a quote by a participant with trigeminal neuralgia, a neurological condition that causes extreme pain:

*It's a nerve disorder that causes extreme stabbing pain in parts of my face. The pain is so bad sometimes, that no amount of Advil or Tylenol can touch it. I've had days where I can't eat, I can't talk, I can't even lay down because any movement sends shooting pain throughout my head and face. I take upwards of 30 pills a day to manage the pain. I'm not pain free, but they do help. Living with this condition has impacted every aspect of mine and my family's life.*

Part of the exhaustion people experienced was associated with dealing with “other physical symptoms” like pain, nausea, dizziness, and headaches. Some reported that they experienced pain so intense they had trouble moving, talking, and eating. People talked about not being able to sit, stand, or lay down for long periods of time, and about being disorientated, losing their balance, and even falling or fainting as a result of their condition. Other symptoms were in fact side effects caused by the medication they took, like hair loss, shakiness, Parkinson-like tremors, weight gain, weight loss, grogginess, confusion, and loss of balance. One participant describes how she came to terms with the side effects of her medication:

*Physically, the effects of the medication on my body, weight gain, you know, I used to be like 120 pounds girl. I weight more now than I was full-term with any of my four children. So, physically my own – I'm not pleased with my physical body, you know but, then...My neurologist, he was very good and helping me to at least gain more of an acceptance of it by saying, you know, he took out his hands and he said “Ok, in this hand we have pain and we have you incapacitated and this hand we have drugs, pain-free, weight, short-term memory loss but, when you weigh the two, which one weighs out better?” And I go like this [hand gesture] because of quality of life; it may not be what I would choose it to be but, at least I have life, you know, and I'm able to do – and I'm able to be a nana and you know, be a wife and be a mom and be a worker and be content and be happy.*

Research participants talked about how the pain interrupted their day-to-day routines, and how chores or yard work became impossible because of the physical impacts of lack of energy and strength. One stroke victim spoke about impacts on her mobility and how she had to come to terms with the fact she needed help showering and dressing herself. Participants with epilepsy,



especially those who experienced uncontrolled epileptic seizures, talked about not being able to go certain places or do certain things, such as driving or exercising, because they were worried about having a seizure.

## Emotional Impacts

Being diagnosed with a neurological condition or caring for someone with a neurological condition can be overwhelmingly emotional. For many Aboriginal women the emotional impacts were the most debilitating. Research participants talked about emotional responses to their condition, like fear, anxiety, helplessness, stress, worry, and ultimately, emotional exhaustion. Participants described feeling angry, and worried about how their lives would change, and how their condition would impact their families and their loved ones. Some participants worried about being able to access services, and about who would be there to support them. One mother describes how she felt when her daughter was diagnosed with a neurological condition:

*I'll go back to the diagnosis part and the time following that when a lot of the symptoms were starting to appear. A huge part of that for me was, it's almost like I felt like being attacked, it's almost like- Well it is like something is attacking S----- and hurting her and there's absolutely nothing that I can do about it. That helplessness and anger that I felt, even though I understood and I read up about everything.*

Caregivers spoke about the frustration and guilt that they felt with not being able to do more for their loved ones. They talked about how it was both emotionally draining and stressful it was to see their loved ones slipping away from them. They talked about how some of their family members reacted; it was not uncommon for families to feel uncomfortable around the person with a condition, and not know what to say or do. Some families were so uncomfortable they would avoid or ignore the person with the condition. The caregivers interviewed spoke about how devastating a negative reaction was to the person living with the condition.

Being ignored can create feelings of isolation and guilt. Participants interviewed who had a condition said being ignored made them think they were a burden on their family. They talked about how it caused them to put up emotional walls and hide their feelings. Some talked about becoming completely detached as a result of the isolation.

Research participants spoke about the emotional turmoil and frustration they felt losing their independence and not being able to do the things they used to. One participant talked about how this made her realize that she was not the same person, and would never be the same person again. Here, she describes how she came to accept her new reality and concentrate on coping:

*I was really independent, it really bothers me. I need to hang onto my husband's arm, before I like holding his arm but now I need it. The neurologist said you need a cane. I didn't want one and I said, "No, I'm so vain," but he said "Get over it." So I got one and it really was helpful. Then awhile after that I got a walker, I held*

*out for a year before getting it. I feel more independent with it, but it is like another appendage, so I don't take it everywhere. Sometimes I just take my cane.*

## **Mental Impacts**

Neurological conditions impact mental capacity and can change how people manage in their day-to-day lives. Research participants who suffered a traumatic brain injury (TBI) described having short-term memory loss; and those with more severe TBI experienced word miss-association, disorientation, memory loss, and confusion to the point of not knowing where they were or how they got there. They also described difficulties concentrating and problem solving, as in the following story:

*In the beginning I couldn't even feed myself. I had to have someone with me all the time. My ex's little brother was with me all the time and helped take care of me. When he wasn't with me, five of my girlfriends would take turns taking care of me. I don't really remember any of that time. I lost a lot of my short-term memory – I don't remember much two months before the accident. And everything up to seven months after the accident is fuzzy.*

Some participants talked about the impacts medication had on their mental capacity. They spoke about losing their memory and their ability read and retain new information. A couple participants with epilepsy spoke of how the seizures, along with the medication, severely impacted their short and long-term memory. As one patient describes,

*The side effects of the medications are that I am constantly tired, I have no energy, I can't sleep at night, I have put on 70-80 pounds, lack of memory; like an 80 year old person. The medicine and the seizures take a little bit of my memory at a time.*

Caregivers of dementia or Alzheimer's patients spoke about the symptoms, and about how, at first, their loved ones start forgetting simple, habitual things such as how to cook, manage household finances, do chores, and take care of their personal hygiene. As the condition progressed, their mental capacity decreased and they experienced more symptoms such as not knowing what was going on, not knowing what day or time it was, and not recognizing people. One daughter describes the progression of her mother's condition:

*So, as her symptoms increased, you know, I think it was denial, like as the way that we kind of just put it off to that this is [what happens when you] age. You know, something that would be normally coming with aging. So one of the things that she, and my younger sister noticed that because my mother had plants in her house and slowly, she kind of became, she didn't clean up as often in her house. She didn't water her plants. So it became very obvious then that they needed to do something. And there were times when she would burn food. And that was really not, she wasn't a cook but these were kind of just little things beginning to show, reveal themselves to us*

Both caregivers and those with a condition spoke about the need for more information related to what they should expect, and how the condition can progress. Several people talked about needing additional support to help cope with some of the changes they were experiencing. The level of support people talked about ranged from community information sessions on certain conditions, to mental, emotional and spiritual supports in the form of Elders and traditional ceremonies.

## Spiritual Impacts

The impacts of neurological conditions were less about impacts on spiritual wellbeing and more about how people used their spirituality to cope with the other impacts. In some cases spiritual needs were not met, making it more challenging to use spirituality and ceremony as a coping mechanisms. This participant spoke about the need to accommodate Aboriginal spiritual customs such as smudging within the health care system:

*So, I think if they're gonna have sections for Aboriginal people, have a room where you can smudge at any time where you don't have to get the firemen to shut off the- you know, like have it set-up for people, you know. And, and we need that definitely*

Some participants described how, over time, they lost touch with their culture and traditions and as a result were unable to draw on them to cope with their condition. Participants who were able to connect with Elders and traditional healers as a source of support talked about finding solace in being able to revitalize their traditions. Smudging, sweats, and other ceremonies can be invaluable coping mechanisms for Aboriginal people. This participant talked about how the Eagle Moon Health Office met its Aboriginal clients' health care needs:

*So 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*

One participant said she relied on meditation to feed her spirit:

*Meditation for me is very important. It's meditation-prayer. It's something I need every day; I have to remind myself to be thankful for whatever state I'm in. To be thankful... I'm thankful that I can still do what I can.*

## Family and Community Impacts

Living with a neurological condition or caring for someone with a neurological condition affects and connects everyone around that person. Research participants talked a great deal about the support they received from family and friends, and about the type of support that comes with

acceptance. One participant talked about how her sisters came together to help out with everyday activities:

*But I got to admit I have five great sisters and I can honestly say today I don't think I'd be sitting here if it wasn't for them because their love and their dedication to me that's what got me through all this and you know like I can't even cut meat, like anything on my plate I can't do it myself so my sisters always have to do that for me*

Family can contribute significantly to the recovery process. Unfortunately, not all of the participants had family members or friends who were as patient or understanding as they could have been. Some less fortunate people interviewed talked about how their neurological condition negatively impacted their relationship with family. As this person explains, family dynamics change with a diagnosis. First, her family was in denial of her condition, and then later, they seemed to deny her:

*I used to have very, very in-depth conversations with a few of my brothers that probably think similarly as I do and now it's more difficult for me to have those conversations. It's affected my relationship with family members; I have a large family, 14 brothers and sisters. And at first- yeah, little acceptance: "Oh, it's all in your head," "You can manage pain," you know, "It's all a decision." And I'd be going "Yeah, to a certain degree." I do believe that if you have a good sense of spiritualism and whatever else in your life, you know there is- it's how, you know- it's how you look at it, it's not actually what you're experiencing so, it caused- it has caused some, in the beginning lots, of just un-acceptance and then un-acceptance of me because I couldn't, "Oh, well M----- wouldn't come to this," but I didn't want to go because I wasn't feeling well or because the other things.*

It can be hard for family members to see their loved ones deteriorate from being strong and active to being weak and frail. Some caregivers spoke about having unresolved guilt about not being able to do more for their loved one. Other caregivers spoke about "burning out" and losing patience with the person they were caring for.

As children, or siblings of someone with a neurological condition, feeling helpless can be particularly frightening. Children don't often understand what's going on and as a result don't know how to deal with or cope with the situation. One of our participants spoke about how her daughter's condition impacted her son:

*He was a little older for his age pretty much all through his life. Seems like with our kind of situation you mature a lot faster and he was having an imbalance because he could understand so much on a certain level and under other levels he couldn't understand authority. He was having problems with authority; it's weird, like a teen. I was always aware not to treat him like a – like they talk about siblings that become adults so I was always careful not to do that. Everything was always as a team because I wanted him to feel secure and have a part, have a say.*

*But, he wasn't understanding when it came to be around teachers and then, he had a lot of triggers with paying attention. I realized that it was when he was in situations that he couldn't control, that it was just not good for him; he didn't handle that well at all. I think that's because he had all of those feelings of not having control over what was happening to him with his sister.*

## Life Impacts

Participants spoke about having trouble concentrating, or reading and retaining new information. One participant, who lives with a TBI from a motor vehicle accident, spoke about having to leave school shortly after the accident:

*I had to take a leave from some of my classes of school. I had dizziness, see spots and couldn't focus to read a book. I had difficulty walking and couldn't get out of bed. I was put on different medications that made things worse.*

Both caregivers and those living with a condition spoke about how the condition interfered with their work life. They talked about exhausting their sick and vacation days at work, eventually taking leave without pay or quitting their jobs. They talked about the stress they felt with falling behind at work and the lack of understanding by some co-workers.

People talked about missing work, medical, and other appointments because of mobility issues. Some talked about having to relocate their families because it was cheaper than renovating their homes to accommodate ramps, lifts, and fixtures. One participant, whose daughter was in a wheelchair, spoke about the daily challenges she experienced before getting a wheelchair accessible van:

*Then I'd have to take the wheelchair apart, put it back in the trunk, get us home, take it apart- sometimes I still had to get what we were going to eat for supper, you know!?! And so, I'd have to take her wheelchair and put it back together so we could go into the store and then, get stuff to make for supper and then- yeah, so I don't even know how many times a week I would have to take the wheelchair down and take it apart and put it back together. Yeah, so then if I was late for work I'd get comments like "Oh, you must've had a relaxing morning," because I'd strolled into work late and so that would be like really frustrating because like, you know, you don't have any idea- like I just did a day's worth of work before I even came to my job where I actually got paid for what I do so. Yeah, that was really- that's one of the frustrations as well.*

People living in the north talked about having to travel long distances for medical appointments. People talked about how doctor's appointments took them away from their home and community, sometimes for extended periods of time, and the time and expense involved with each appointment. Participants talked about having to take time off work and how with each appointment, they had to make special arrangements for family and pets they leave behind. Several participants talked about the financial burden they suddenly had to carry as a result of the

neurological condition. One participant talked about her husband staying in a job simply because it had medical insurance coverage:

*It provides us with a really good health plan where my medication is \$5 a prescription and so, he's staying at a job that he wishes he wasn't in simply because we can't- if he was to go to something else, there may not be a health plan, there may not be the benefits that I need because my medications dependent is usually around \$700 and some dollars a month. Like, for me that's almost a full paycheck and you just have to do what you have to do.*

The impacts associated with living with a neurological condition or caring for an individual with a neurological condition are extensive. Researchers understood that the stories shared with them, and reported here represent a small fraction of what Aboriginal women, their families, and communities deal with on a day-to-day basis.

## **Gaps**

### **Healthcare Gaps**

The high number of undiagnosed neurological conditions in the north is in part due to the fact that many health insurance policies do not support all the costs associated with accessing services. Researchers heard stories about transportation and accommodation costs deterring or delaying patients' access to health and other services, such as this participant, who describes a reality for people in her area of the country:

*Everything – you can't even donate blood here. People have to be flown out to Vancouver for everything. You can't even get tested to donate bone marrow. We don't even have anywhere to go to advocate for health services. Yukon health doesn't pay for hotel costs or food unless you are in the hospital for three days. So oftentimes if people don't have the money to pay for a hotel, they are forced on the streets or in places that are dangerous.*

In addition to the lack of services, there is a lack of service providers, as explained by this participant:

*Oh, definitely! And- like along with the whole healthcare system, you know, the health providers there's not enough homecare workers, there's not enough healthcare providers, there's not- you know, you can go into the hospital, I mean- (Place) I mean- total ONE DOCTOR, well there's two but, only one doctor that is on-call.*

One participant talked about systemic barriers preventing access to services. Here she describes a situation with social service policies:

*Like what do you do? The guy makes \$1,500 or \$150 an hour and they're handing him a form to fill-out and they're offering to pay him \$25. And- and that day that I went in with my form to be filled out he says, "I'm not filling that out." I just came from my doctor and I have a very bad heart, I'm not supposed to over-work myself, so he says, "I'm not filling out that form." So, I go back to my worker "So, what am I supposed to do? He doesn't want to fill it out!" "Well, you have to get it filled out!" He was sending me to my family doctor and the welfare was sending me to the neurologist and I said but, he doesn't want to fill it out, like what am I going to do?*

Participants experienced a lack of family and caregiver support. One participant talked the lack of child counselling services in her son's school system. As the brother of a child with a neurological condition, this participant's son started to act out in school and received little support:

*I would understand that and I would try to talk to the school, talk to the school counsellor and I found that extremely frustrating because I would tell them: "You guys know that he has a sister with a severe disability and there should be some supports in place to help him through – to help him understand."*

### **Knowledge and Information Gaps**

A common story researchers heard was related to the lack of "easy to understand" information about their condition. Participants described not knowing what to expect, or how to manage their conditions.

*I think it would be really great to have more information, like a lot more information. And if there was a place we could go to, like where we can get this information from, and a person to talk to too. Like someone who knows a lot about it. We need to have someone in (Place)*

Similarly, this participant talked about the need for more awareness about neurological conditions generally:

*A lot of it is lack of understanding and lack of openness to understand. I think that it's just really easy for people to just turn the cheek and I can probably admit that I would be there myself if I didn't have this experience firsthand but mainly awareness, I guess and if there were tools to help people understand, that would take a lot of hardness out of the situation.*

And, greater awareness among the general population was thought to address the stigmas so often associated with neurological conditions, as explained by this participant:

*Awareness would help people with epilepsy not feel ashamed of having the disease. I don't usually tell anybody that I have epilepsy. My application for life insurance was denied because I have epilepsy. I only tell my family and I've told my boss what to do in case it happens.*

Several stories emerged around the lack of information available to assist people coping with their feelings. It was widely felt that if more information were available, people would be better informed and be better equipped to deal with certain situations. One participant described her experience with dementia:

*But I really think there is definite dementia and that people need to be educated about that. That, you know, that they can still recognize people. They may be relying on older memory but they can recognize you. And they're still human, you know. Really felt that there really needs to be more education about the condition.*

The lack of available information was thought to feed into stereotypes around conditions that are less visible, or obvious, as explained by this participant:

*I think- they were starting to do a lot of education of hidden disabilities and- and they touched on it but, they let it go and I think- I think to help everybody understand, you know, like they were saying "Oh, look at that 19 year old, he's on social assistance." But, nobody knows how that kid's feeling, you know and a lot of neurological, we can walk around quite fine a lot of the times, other times we're more crippled up. At least in my case, some of us are always stuck that way but, it's the hidden disabilities that I feel sorry for because unless you're on- have the walker or canes or in a wheelchair, people treat you like you're- I don't- not weak, like they don't want to help you or they don't wanna- like they don't give you the same compassion. And they think that you're just making it up or you just wanna not do it, you know. I get accused of that a lot but, I think- I think we don't understand hidden disability. And I think there should be a lot more education in that.*

One participant with a child with an extremely rare condition talked about how valuable it would have been to have someone to help her understand the condition and what to expect:

*Rett Syndrome is rare: 1 in 20,000 get it so, it's quite rare. Just trying to get all of that information, it would've been nice for someone to say "Here, this is what Rett Syndrome is, this is what you need to know and now if I can help you through these steps and this is what you can expect." There's was no support through that, it's been an emotional rollercoaster ride*

Ultimately, this caregiver and mother turned to whatever she could find on the Internet a source of information neither easily accessible by everyone nor reliable:



*I have had to do research on my own about his condition online in any free time that I have but, I don't have much opportunity to do so. I'm just taking it as it comes from the doctors but, mostly from friends or other people that have more information. It's hard because I don't have access at home and I only have lunch hours to do this at work because they monitor everything that I do from my computer's internet. So, I don't like doing that.*

Participants said they would have liked to have someone to talk to and guide them through the difficult process and coming to terms with their new reality. Support groups were thought to be a good source for information about neurological conditions, as this participant explains:

*I think that a support group would be really good. Like really great and like... I don't know, maybe if they just-, like they talk about it in the schools too, like to the kids. So that they would know too and be prepared for it more. And so they know what their parents are going through, and what they might be going through since they eat a lot of fish too.*

Participants spoke about how confusing new technical terms were, and how the language used during their medical appointments was confusing and made them feel helpless and isolated. This participant has a condition that he cannot pronounce, explain, or understand:

*I was then put in hospital, then given a spinal [tap], which impacted me so badly, I was on my back for about three weeks after that, and that's when my family all came together, but still nobody could tell, we didn't know what was wrong, and nobody could tell us, he said it was [demalative] something, something disease, demalative that's, I can't remember the name of it but it was just so, it didn't make any sense, we didn't have internet, we didn't have access to the information we have now, you know. And my family just started to treat me differently, yeah so that's huge impact of how it all started to change my life.*

When people are provided the information they need to better understand the condition, the impacts can be significantly reduced, as explained by this woman:

*And now the girls like they all know what to do when aunty has a seizure. You know they know how to lay her on the floor you know and to do all the other things to look after her while she's ... because like you said you don't have to go to the hospital you know. She's having a seizure, she comes out of it, it takes her a little while but she's fine after you know. So our girls know how to do all that sort of thing.*

This key informant spoke about the importance of patient advocates as one way of addressing health care gaps:

*I think bringing an Advocate with you and helping people who want to see a doctor or are trying to enter the healthcare system, I think one of the skills that*

*people might- that people should learn to bring a friend along so they can hear things and the questions can be answered correctly and also, if they don't feel...there's always a way to call a number and say "I need care and it wasn't given to me."*

## **Risk and Protective Factors**

### **Risk Factors**

Some neurological conditions participants spoke about were genetic (e.g. Epilepsy and Seizures). Other conditions were affected by lifestyle factors (unhealthy diet, alcohol and drug use, and smoking), and participants explained they thought lifestyle played a role in their getting a neurological condition and the perceived severity of it. For those living in areas with severe environmental contamination for example, traditional practices such as fishing and hunting became a risk factor for certain neurological conditions.

Many of participants interviewed were dealing with multiple issues and conditions. Diabetes, cardiovascular disease, obesity and other injury were most common. Many of the Aboriginal women who participated in this research talked about what they understood to be risk factors, such as this woman who explains the prevalence of seizures in her family:

*And I don't know if, I think it runs, it kind of went to her kids too. Something like that because once in a while they have seizures and her daughter's been going through a bunch of surgeries. Stuff to do with her brain and her heart and stuff like that. She has seizures too. And two of her kids were like that, seizures. And I think her son stopped breathing I think one time.*

Other participants revealed how anxious and fearful they were about the extent of the conditions in their communities. This participant wonders aloud:

*My mom, with her being diagnosed with arthritis in her spine, she had to take eight months off of work. And then she's allowed to go back to work but only 50% of the time. And I don't know, I'm just paranoid I'll get all this stuff. You know like diabetes also runs in our family and cancer, and it's like, aren't any of us normal?*

One participant relayed how important prior knowledge is to prevention:

*So I don't know like because she passed everything else to me and I want to know like what exactly this means, I don't want to find out 20 years down the line oh this is what could have happened you know or I could have prevented it or something you know.*

Another participant normalized her condition and the fact that it may materialize in her children:

*I have these every little while, these little spells every little while. I just kind of deal with it and whatever - try to pass through it and everything and I keep telling my kids it's not very good and whatever. I have five children - I had one miscarriage - so I figured one of my kids down the line will probably end up having it.*

Some participants recognized the importance of changing their lifestyles in order to better manage their conditions, such as this person:

*You know we take like for granted, our health for granted most of the times, we could be doing something different. As you realize what you're doing wrong you should be able to stop and think about it. I've known a lot of people that never came to realize that are not here no more because they just refused to change their lifestyle. I changed mine three years ago, smoking, drinking ... so I can be around to see my great grandchildren a little more than you know what they are now.*

Participants shared stories about lifestyle choices such as drinking, smoking, and drug use that were thought to have an impact on their condition. Some participants felt that lifestyle had an impact on the health of the whole person. One participant shared a story about how grief led a family member to alcohol abuse and how this was thought to have affected her neurological condition:

*So she turned to alcohol and she was a real businesswoman at one time, you know. They owned a store up north. They even owned a hotel one time too. So since then ... Since Grammy died she's been drinking a lot and all this and then she doesn't eat of course, you know. You haven't got nothing to eat and just stays in your body and you're slowing down and she gets these seizures and all that, epileptic seizures and all this, you know. A few times she'll be hospitalized and she won't even know you when you see her.*

At least one participant talked about the importance of physical activity, but how she avoided doing things outside the home because she was afraid of having seizure in a public place. Fears like these can lead to isolation:

*Lack of sleep, water, eating and stress are all triggers for my seizures... I don't drink alcohol either because that can also trigger seizures... Loud noises are also triggers. My husband wanted to go to a hockey game after I was hospitalized and I had an episode. Everything was spinning; I felt really dizzy and couldn't stand up. It was probably not the best thing to do after being in a quiet space for so long to go somewhere very noisy.*

Hunting and fishing are important traditional practices in many Aboriginal communities, especially in areas where store bought foods are poor quality and expensive. These activities would normally be considered positive, protective factors, but in contaminated areas hunting and fishing can increase the risk of some neurological conditions:

*Yeah like that's like my son, he comes from that line of family where, like her family there, they have a lot of those. Like even my son's father, like he gets cysts on his head. I don't know if it's on his head but somewhere up there he just. But yeah, like my son comes from that line of family and they have like a strong history of like fishing you know. And we kind of think it's probably from the mercury contamination, poisoning. And so that's how it's affected me I guess. And I see other community members that have, like that what you said.*

Several research participants talked about how their neurological condition was not the only medical condition they had. Diabetes, cardiovascular diseases, and cancers are prevalent among Aboriginal peoples and many of the participants of this study shared stories of how these diseases affected their lives:

*I've been living with diabetes for maybe six or seven years now. I also have epilepsy. I had that all my life but I have that under control. I also do want some new information because I'm going through some tests and stuff; find out more about my history, about myself. But my family lives with diabetes and they're ... Well, my mom does and I've lost family members due to cancer and strokes and stuff like that ...*

One participant thought that some co-morbidities came about as a result of their medication:

*Currently I am on 3 different epilepsy medicines and there are a lot of effects. The doctors found that I have a leaking heart valve and I have a low thyroid. My body seems to be falling apart.*

## **Protective Factors**

Some research participants talked about how they were able to tap into an internal strength in order to cope with their condition, yet others talked about how a lack of coping skills. Researchers heard many stories of resilience and what people did to maintain a positive attitude. Participants talked about how important it was to stay busy and active. Humour was coping strategy that was common among participants. At least two of participants dealt with the pain and emotional turmoil of their condition with humour:

*I've been blessed to have a wife where, you know, things are bad - she doesn't get mad, she doesn't get upset - we usually kind of make it a joke and carry on. That way of life, that which people just want to put into a little phrase saying, 'Oh, humour is an important part of life' - what does that really mean? Well, that means... you know, exactly what that means when someone is in pain, living in pain and a caregiver; that means making a little joke; that means acknowledging*

*somebody's mad. You're going to get mad; that's just how we deal with those things.*

As one participant explains, it is not always clear where resilience comes from, but it is important that those who are resilient help those who are not:

*You know, some of us are stronger than other, some of us could've been sexually abused and hurt in a thousand ways and they seem to be able to function and learn and to grow. Others don't have that, you know, so why condemn them because they don't have that? Thank the Creator that some of us have strength that help the ones that don't.*

Participants welcomed the opportunity to talk about what they did to cope:

*My sons are very helpful, they seem to really want to help, but I to do it myself. My husband changed our shower to add a rail and a seat for me to sit on. I exercise everyday – I was at risk for osteoporosis and now I have it, so I exercise daily. I walk on the treadmill every other day for 30 minutes, and every other day I do weights. I meditate for half an hour every day. I devour books, I still feel like I'm going to university – always studying and doing researching. I love jigsaw puzzles, the really challenging ones. They absorb my attention, I don't want to just sit there and wallow in self-pity.*

Sometimes experiencing difficult circumstances can build confidence and resiliency. One participant relayed a story of how she overcame a fear of public speaking by remembering what she had been through:

*When I started going to university I hated doing presentations, I hated them and I sat down and said you've been through the residential schools – if you can go through that you can go through anything. That's how I overcame my fear of presenting.*

Resilience involves finding ways to cope with adversity and can vary from person to person. There were a variety of ways people said they managed their condition and the stress that came with caring for someone with a condition. One participant talked about maintaining a positive attitude and finding ways to keep occupied, which helped her concentrate on other things besides the pain:

*It's not pain-free but, it's live-able, manageable and I can get on with my day and do what I need to do, in order to exist and be happy and I'm lucky that I'm a very positive person as it is because through it to not be sitting on that couch and like ooh. I have this to be done before you know, these things in my life will look at the...you know, I was always- I was trying to always find something to feel positive about or, or- I guess trying to almost like a form of a meditation, trying to get my head off of what was actually- what I was actually experiencing, putting myself in a different place.*

Another participant told a similar story about staying active and enjoying life:

*Honestly, I'm a Métis, you know, and I love joking around and talking about life and all this, you know. Everything in a Métis person is happiness, like you know. You love to be ... Music. You love your music, you love dancing, you like entertaining, all this stuff, and I do that. I still do that but what I need actually is work, you know. I do my own little work at home. Like you know, I do beadwork and all that. I picked it up when I was young. So that became my hobby at home and that's what gives me some ... some ... something to do.*

This participant found relief in riding her bike:

*Some days I suffer from a lot of pain, I'm tired, I suffer from chronic pain and fatigue and depression. So I'm trying to get back into my routine of taking care of self and some days it's hard like I said but I'm going to try and get back on my bike and get to the doctor and get the medicines I need and got to manage those allergies and my stomach ulcer and all the stress stuff. But I find when I'm biking it de-stresses and people couldn't understand why I was always all over town biking around well it helps me manage and it makes me feel good inside to get away from it and just go on my own journey on my bike and then when I feel better I go home.*

Hard times and negative circumstance brought on by neurological conditions can change peoples' perspectives on life. This caregiver talked about how her whole view on life changed for the better as a result of her daughter's condition:

*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.*

All Aboriginal women interviewed displayed considerable resilience in the face of difficult circumstances. Their stories can be a great source of strength for others dealing with neurological conditions.

## Environment

Contaminants within local and traditional food sources are a reality for many of the research participants. Several participants came from communities that have dealt with mercury poisoning for generations. Mercury poisoning can have negative neurological effects on individuals and at its most severe can lead to Minimata Disease (Harada et al, 2011). The following two stories that are told by two participants relate how this environmental poisoning has affected their community and the people:

*I think like our reserve has had neurologic problems since the '70s, but prior to that though because our system has been polluted by mercury. And these are third generations now, these young women sitting here. I was the second generation; my parents were the first generation. So it's a ripple effect, they'll see this for a while because mercury is still in our system, in our river system.*

*Well, I know it does have an impact because all the older people, like they definitely have it. Because they've been here for a very long time and they eat all the fish and all the animals around.*

Beyond the physical effects of environmental contamination there is the added risk factor related to the psychological stress that fear, lack of control and helplessness that many participants feel. This story explains this well:

*Here in our community, as you mentioned, a couple of times we're overburdened by environmental stressors and exposure that we've had to them for decades. The psychological issues of living near that and having absolutely no control or impact to your life and your lifestyle. We're here, we'll always be here, our children will always be here, but what are they going to build across that road in ten years? What's that going to be like?*

## Recommendations

### *Improved Relationships*

Research participants were asked to reflect on their experiences with neurological conditions and talk about what they felt would promote and support neurological health and wellbeing. Caregivers and key informants often echoed the sentiments of those who suffered with a neurological condition. A number of participants pointed to the need for improved relationships between Aboriginal people and the medical community. Some participants reported that their experience with the health care system was marred by what they perceived to be a lack of respect, empathy, compassion, understanding, and cultural competence, as well as an overall inability by health care providers to effectively communicate with Aboriginal patients.

Further examination of the UFW research findings and the application of a culturally relevant gender based analysis will highlight how Aboriginal women experience multi-layered impacts of colonization that are magnified by a neurological related condition. In addition to the stigma associated with the neurological condition, Aboriginal women also dealt with racism, discrimination, and stereotyping. These experiences in turn, created frustration, anger, confusion, sadness and despair. And while the women interviewed reported they were negatively impacted by why they experienced, they were quick to offer tangible solutions, five of which are as follows:

#### *1. Provision of Aboriginal Patient Advocates*

Participants reported that they often left medical appointments more confused than when they arrived due to the language used or because they were given too much information all at once. Aboriginal Patient Advocates were suggested as one way to address communication issues and to improve Aboriginal peoples' overall experience with the health care system.

#### *2. Promote the use of plain language*

One participant reported that several weeks after her diagnosis, she was still unsure what her condition was and what she was supposed to do about it. Participants felt that health care providers should take whatever measures necessary to ensure their patients understand the information they are given, and to use plain language at all times. Plain language should also be used for all written material provided to patients.

#### *3. Respect for traditional ways*

One participant reported the dichotomy between traditional and western medicine and felt that there should be more respect for traditional approaches to health and healing, including treating the whole person, not just the condition. Several research participants talked about how a balance of traditional and western approaches would lead to better health outcomes for Aboriginal patients.



#### *4. Implement a national cultural competence program for all health care providers*

One research participant described her experience with the health care system as “dehumanizing” and another described hers as “discriminatory”. A number of participants reported that their symptoms were dismissed as alcohol or drug induced; one participant was described as “drug seeking”. These types of responses delay diagnosis and treatment, and conditions can progress at a much faster rate. Research participants felt that cultural competency training is needed to address these issues and improve relations overall.

#### *5. Provision of dedicated space for spiritual ceremony and cultural practices*

Researchers heard stories about space being available for traditional purposes in some health centers and hospitals, but where it was provided, it was rarely “dedicated space”. One participant talked about performing a smudge at a facility and the fire alarms going off. A number of participants felt that the provision of space for spiritual connections would have improved their experience with the health care system.

### ***Aboriginal Driven Health Services***

In addition to recommendations intended to improve relations, participants expressed the need for higher levels of engagement in health service delivery, programming, and policy development. Several research participants were from rural and northern areas of Canada where health care services are limited, and specialist appointments require them to travel at significant personal expense. The following recommendations reflect participants’ hopes for a health care system that better reflects their unique needs.

#### *1. Bring more services to the community*

The lack of specialized and diagnostic services in some of northern and rural communities has led to problems like delayed diagnoses and treatment, unfair financial burden on patients and their families, and in some cases, homelessness. Participants thought that if more services were available locally more people would receive the care they need.

#### *2. Aboriginal health programming for Aboriginal people by Aboriginal people*

Research participants felt that if more programs were developed and delivered by Aboriginal people there would be more uptake, which would result in better health outcomes for Aboriginal people. One caregiver said that her brother did not participate in the dementia support program because it was not lead by an Aboriginal person.

#### *3. Aboriginal engagement in Aboriginal health policy*

Participants talked about the need to adapt healthcare policies to better reflect the realities of Aboriginal peoples' lives and circumstances, and spoke about “meaningful engagement”. Participants recommended that a patient-centred and culturally relevant approach to healthcare be adopted in order to promote greater equality and respect.

#### *4. Aboriginal specific data collection*

Aboriginal-identifiers on hospital and health care center intake forms were thought to be a useful tool to develop baseline information on Aboriginal peoples' health and to monitor patients' progress. People who suffer with neurological related conditions that impair their memory need to be reminded to follow their treatment plans; this is especially true for those living in areas where health care services are limited.

## **Research Needs**

Throughout this study it became apparent that more research is needed. Some of the recommendations for new research originated from the stories collected, and some from the interactions with advisory committee members and the research team that occurred during the research design, data collection, and reporting processes of this research project.

### *Aboriginal men's health*

Some research participants indicated that Aboriginal men's neurological health should be a future research priority due to the fact that "our men are so unhealthy". One participant stated that Aboriginal men's health status is a direct reflection of the community's given their role as leaders and decision makers.

### *Interactions of co-morbidities with neurological conditions*

There is a need to look at the interaction between neurological conditions and co-morbidities in greater detail. It became apparent during this research project that many, if not most of the participants, suffered from multiple conditions including ones that were not neurological in nature. Diabetes, cancer, cardiovascular disease, mental health disorders, and others came up repeatedly as co-morbidities with neurological conditions. One participant admitted: "*I had it all, I had blood pressure, cholesterol, I had all the risk factors and then I think that's what kind of led up to me having the stroke.*"

New research looking at neurological conditions within the Aboriginal population, and the interaction of these with the myriad of co-morbidities that Aboriginal people have is needed using a social determinants of health approach.

### *Aligning impacts with available supports*

Another area requiring further research is in aligning the impacts of neurological conditions with available supports. Aside from studies on dementia and Alzheimer's, there is not a lot of information on how neurological conditions impact Aboriginal people, their families, or community. A lot of people do not know what kinds of supports are available in terms of counseling or financial assistance.

### *Examine how Aboriginal specific risk factors differ from mainstream*

A more in-depth exploration of Aboriginal-specific risk factors is an area where new research should focus. This project highlighted the fact that many Aboriginal people are exposed to different environmental, lifestyle, and other factors that create certain risks to developing neurological conditions. Utilizing a social determinants of Health (SDH) approach would be best in the investigation to ensure the research is inclusive, holistic, and reflective of the realities.

### *Examine relationship between risk factors and prevalence*

Discussion among the research team has led to the idea that there is a need to look at the relationship between risk factors and prevalence to see what impact this has on the severity of neurological conditions among Aboriginal peoples. This research should also be approached from a Social Determinants of Health (SDH) perspective to ensure that a holistic look at the health and well-being of those under study is considered.

### *Examine conditions that cause higher morbidity rates*

After conducting a thorough environmental scan researchers identified research needs based on a lack of literature and data sets. It was suggested that more research occur on the neurological conditions of stroke, transient ischemic attack, and headache because these conditions were associated with higher levels of morbidity for Aboriginal peoples and there was a lack of data on them. Fetal alcohol spectrum disorder (FASD), posttraumatic stress disorder (PTSD), Asperger's syndrome, Friedrich's Ataxia, and child developmental delays are also relevant for future research on neurological conditions due to the potential for multiple morbidity.

### *Relevance, subpopulations, violence*

There is a need for further research around the specific relevance of established risk factors of neurological conditions for Aboriginal populations. Researchers also suggested exploring risk factors associated with alcohol and drug abuse and looking at sub-populations such as, homosexual persons and the impacts of AIDS related dementia based on a lack of data. Lastly, they draw attention to violence in Aboriginal communities and the role this may have on traumatic brain injury rates.

## Narratives

The following section is a collective representation of what Aboriginal women told researchers. The names, dates, places, and conditions have been changed and do not reflect any one of the research participant's situation or circumstances.

### Epilepsy

My name is Cynthia. I'm Métis and live in Winnipeg. I'm 46 years old and have two kids and two grandbabies. My daughter is 26 with two little girls of her own and my son is 17 and still lives at home. Eight years ago, completely out of the blue, I had a seizure. I was at home getting ready for work. Luckily my daughter was there and called 911. I was in the hospital for a time after that. They did a lot of tests and told me I had a grand mal seizure. I was referred to a neurologist and learned shortly after that that I have epilepsy.

I've had a number of smaller seizures and two grand mal seizures. It's pretty scary. My doctor keeps prescribing different medication hoping that something will stop the seizures. The meds seem to work for a little while before the seizures start again. My kids worry about me a lot. They get frustrated too, that I can't be there for them or help them out as much as they'd like. I've discovered that stress triggers my seizures. Loud noises, flickering lights, and crowded areas, can trigger them too, which basically means I stay home a lot. My son plays competitive hockey and I used to be an avid concertgoer, but I've had to stop going to the arena altogether. I'm so afraid of something happening in public.

My son was only 11 when the seizures started so he had to grow up a lot faster than most kids. He's helped me out a lot. I don't know what I would have done without him. He's become very protective, which I kinda like. He's the big man around here [laughs]. He got into a couple fights at school because some of the other kids were teasing him about my seizures. I think it's hard for kids to understand a disability like this. My doctor gave me a couple of brochures to go through with him, but I'm not sure it really helped.

My daughter was 18 and was in her last year of high school when I got sick. She was pretty busy with her own stuff and was at the age where she wanted to be out of the house more than anything. She's got a family of her own now and wants me to spend time with her kids, but I'm scared to be alone with them because what if I have a seizure?

This has really impacted my life. I feel like I have no control. I can't drive. I don't like being alone, but I want to stay home. It's so hard. I don't really talk about my seizures much. Whenever I tell someone I have epilepsy, they usually ask some stupid question or bring up the commercial about Dr. Penfield and burnt toast – thanks Canadian heritage minutes! I told my boss at work, but not too many other people know. I don't like being referred to as the “epileptic.” I have epilepsy, but it's not who I am.



I also have high blood pressure and am pre-diabetic. I'm on a bunch of different medications. It makes me sick. I don't know if my high blood pressure medication throws off my seizure medication or what, but it's really frustrating that nothing seems to work. I have all sorts of other side effects too. Lately I feel like I have no energy. I'm constantly tired and have a lot of problems remembering things. I've started to write things down, which helps. But it's all very concerning. My doctor wants to send me for additional tests to see if surgery might help stop the seizures, but I need to wait until I have enough sick time saved up at work.

I'm Métis. Not status. That means I don't have health coverage through the Indian Department. I applied to blue cross to help with the cost of my medication, but haven't heard back yet. Some of my medication is pretty expensive and I don't get reimbursed from work for all of it. I keep asking my doctor for sample packs of stuff. It's embarrassing. He says I shouldn't change my medication too often because I could have a bad reaction to it. So yeah, having epilepsy has definitely changed how I live my life. I wish there was more information out there for people, and I wish there wasn't so much stigma or stereotypes.

## Environmental Contaminants

My name is Kasey. I'm Anishnabe, originally from Winnipeg. I moved to northern Ontario five years ago to be with my boyfriend, now husband. I'm 23 years old. We have two little girls, one three and the other nine months. I don't have a job. Neither does my husband. There aren't a lot of jobs here in the community. We live with my husband's parents. We help out a lot, especially with my husband's dad.

He shakes a lot and can't look after himself too well. He needs help with almost everything. He has problems seeing and needs help walking. We were finally able to get him a walker, but it took a long time because we had to wait for NIHB to approve it. For the most part it helps, but he can't really go outside with it. There aren't any sidewalks and the roads aren't paved. It's dangerous. The roads are all full of potholes and ground is too uneven for a walker. He really needs a wheelchair.

His symptoms started about ten years ago. The doctors haven't figured out why he shakes. They said he had Parkinson like tremors, but he doesn't have Parkinson's. Some people from the university have been coming around here for a couple of years and they think his shakiness may be from eating the fish from the lake all his life. They think the fish may be poisoned from the mill upstream.

It's pretty scary. I mean everyone here eats the fish. Except me; I won't eat it. When I moved here right away I noticed there were a lot of people with health problems. A lot of the old people around here shake like my father-in-law. My husband is only 25 his hands are starting to shake too. He tries to hide it from me, but I catch him sometimes spilling his tea everywhere. Some of the babies are born with cysts on their brain. We don't know why. I was lucky. My girls are fine.

We asked the government and the mines to clean up the water, but they said that the water is good. When we spoke out about all the people getting sick around here, they said it wasn't from the fish or the water. They even had someone come in and say that people are sick because of alcohol.

I worry about my kids. I want them to grow up here, but I don't want them to get sick. I try not to let them eat too much fish, but some days that's all we have. We don't have a big grocery store here. We have a little corner store, but we don't always have money to go buy stuff. Plus they don't have fresh foods. The fish are free. And we don't have a full time doctor here. We have a nurse's station and a doctor that comes in once every other week. Lots of people just drive to town to see the doctor. The band also has a van that takes people in for appointments; that helps people who don't have a car.

Some of the staff at the hospital in town can be pretty ignorant. They don't always treat my father-in-law well. One of the nurses thinks that we are exaggerating when we tell her about his symptoms. They rush us in and out. And they're rude sometimes. I know they're busy, but we are just trying to get him some help. When the doctor writes a prescription to help control his

shakiness, we need to double check that the pills are covered by NIHB. A couple of times we went to the drug store and found out his pills weren't covered. Luckily the pharmacist was able to call and get the doctor to send over a new prescription for other pills that were covered under NIHB.

I wish someone could tell us why so many people here are getting sick. If the water is polluted, they should clean it up. I guess they don't understand that some people eat fish three times a day because it's all they can afford. And we should be able to eat the fish! We shouldn't have to worry about getting sick. We need answers. It's so frustrating. It's like no one knows we're here. I just want to know that my kids will be okay.

## Acquired Brain Injury

My name is Jenny. I'm 32 years old. I'm married with two boys, one 5 and the other is 3. I help take care of my little brother Tom from time to time. Tom is 23 and has what they call a "traumatic brain injury". He was out with his friends at the bar about a year ago and was attacked near the end of the night by four guys. They beat him pretty good, but instead of taking him to the hospital, his buddies took him home and cleaned him up. He had a couple bumps and bruises but nothing major.

When he came over to the house the next day he was in a lot of pain. He couldn't remember what happened. Still can't. He knows he was out with his buddies, and he remembers going out for a smoke. But he doesn't remember who jumped him or why, or how many there were. At the time I kept thinking there was more to the story, but didn't push. But as the day progressed, the pain got worse. He kept saying his head was pounding and he felt nauseous. By that evening he was vomiting uncontrollably. My husband stayed home with the boys and I took Tom to the hospital.

We told the nurse he was jumped and I could see by the look on her face she didn't believe it. She probably thought my brother was a drug addict and just wanted oxy or something. Tom's a rough looking guy. He works construction and is outside all day long – summer and winter. He's a tough kid. Anyway, she got him started on fluids because he was so dehydrated. I heard her tell the doctor that she thought he was just hung-over. I pretty much had to beg the doctor to take a closer look at Tom and make sure he was okay. The doctor said he might have a concussion, and told me to just make sure he didn't get any worse. After a couple hours they sent us home.

Over the next couple of days, Tom's symptoms got a lot worse. He would forget what he was saying mid-sentence. That happened a lot. He went back to work that Monday, but couldn't concentrate and said he had trouble remembering basic things. I remember that week he became really quiet and moody and flew off the handle over any little thing. I told him to go back to the doctor's. He went, and the doctor just told him to take it easy and take and gave him a doctor's note for a few days off. Of course Tom didn't take it easy, and he didn't take any time off. Said he would tough it out. Before too long he got fired from his job. His boss called him an "accident waiting to happen". Said he didn't want to risk the rest of the crew's safety because Tom couldn't concentrate on what he was doing.

It's been tough on all of us. Between his headaches and memory problems he can't hold down a steady job. His friends have abandoned him because he didn't have as much disposable cash as he used to. He has started to isolate himself too, not just from his friends, but also from the family. It's sad seeing my brother become a shadow of his former self. My boys don't understand why their uncle doesn't come and play with them as much. When he does come over, he yells at them for being too loud. He frustrates my husband and that causes fights between us. I hope things get back to normal soon. Everything changed so fast. My brother's not my brother any more. I want to know what I can do to help him, or even if I can help him. It's hard for me to see my little brother in pain, and alone.



## Early Onset Dementia

My name is Tricia. I'm Cree and Saulteaux, from northern SK. I'm treaty. I'm 38 years old. I have four brothers – two older, two younger. I'm a single mom with two boys, one 5 the other 15. I don't work. I can't. I take care of my mom. It's a full time job.

My mom moved in with me a few years back. We live in a two-bedroom apartment. My mom has dementia. She was diagnosed just last year but has been suffering with the disease for almost 10 years now. She's young. Just 58 years old. Her health isn't good. She has diabetes real bad. Has to take shots. The doctor has her on a few different pills. Some have to be taken on an empty stomach, some with food... it's hard to keep track sometimes. I do my best to stay on top of it. She has high blood pressure too and takes medication every day for that. I think these meds are making her sicker. I don't know.

My dad passed away about 12 years ago. He was a lot older than my mom. He died of a heart attack.

I love my mom. I'm her favourite I think, because I'm the only girl. She grew up in a residential school here Saskatchewan. My dad did too. They had it pretty rough. She talks a lot about those days now that's she's deep into the dementia. Sometimes it makes her sad. Most times it just makes her mad. It breaks my heart.

I remember years ago, when the dementia first started. Mom always got us kids mixed up, especially the grandkids. There are eight of them. [Laughs] We used to make fun of her until we realized it was getting serious. I remember one day back then she completely lost it on one of the kids for letting the dog out. She was gone for hours after that, out looking for the dog. Thing was, we never had a dog.

It was only after the fire when us kids realized she needed round-the-clock care. She left a pot of grease on the stove and the whole kitchen burned. That was pretty scary. She moved in with me after that.

My mom's doctor is pretty good. Most times. I'm not sure he really understands how hard it is though. He doesn't deal with a lot of Indian patients. And he doesn't understand the NIHB. Sometimes he prescribes meds that aren't covered. We end up back to his office more than we should. It's tough cuz I don't have a car. We take the bus to appointments. My mom hates the bus.

I don't have health insurance. Neither does my mom. Just NIHB. Last year they covered meds that worked real well for her. NIHB changed the coverage and we had to change her meds. It caused a real problem for her, and we still haven't worked that one out yet.



NATIVE WOMEN'S  
ASSOCIATION OF CANADA  
L'ASSOCIATION DES FEMMES  
AUTOCHTONES DU CANADA

My brothers think I should put her in a home. But they're not as attached to her as I am. I could never do that to my mom. Maybe I'll put her name on a waiting list somewhere and deal with it when a spot comes up. I don't know. It's all so overwhelming.

It's been very hard financially. My boys are having a hard time with it all. They see their Kokum deteriorating. She's a different person than she was a few short years ago. And they see how exhausted I am every day. I carry a lot of guilt for not spending time, quality time with my boys. But she's my mom.

## Project Details

The UFW team received \$785,278.00 over the course of three years to study the impacts of neurological conditions on Aboriginal women, their families, and communities. The team looked at the impacts of neurological conditions, the risk factors associated with those conditions, and at health services utilized including any gaps in services. The National Population Health Study on Neurological Conditions (NPHSNC) consulted with over 50 experts from the Canadian neurological research community on which neurological conditions were to be included in the study. The following 14 conditions were selected based on the lack of knowledge and potential population disease burden:

- Alzheimer's disease and related Dementia
- 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
- Tourette Syndrome (see Appendix 2 for more details)

The UFW research team, along with its advisory committee, recognized the knowledge gap in regards to neurological conditions within the Aboriginal community, and as such did not limit the scope of the study to the prescribed conditions. Instead, the UFW team expanded the scope to include any condition that impacts the brain, the spine, or the nervous system. The research team spoke with participants who lived with a condition or cared for someone with a condition that fell outside of the listing, including people with migraine headaches, stroke, ataxia, and trigeminal neuralgia.

Literature on the impacts of neurological conditions on Aboriginal people was found to be lacking, despite the fact that Aboriginal people have higher rates of chronic diseases, such as diabetes and cardiovascular diseases (Loppie-Reading, 2009), and bear disproportionate burden of mortality and morbidity (Tjepkema et al, 2009), which can increase the risk for developing neurological conditions.

Additional risk factors that impact Aboriginal women at a greater level than their non-Aboriginal counterparts include a wide array of social determinants of health such as poverty, inadequate housing, poor access to health care, food insecurity, lower education levels, increased risk of violence, higher rates of incarceration, as well as environmental factors like air and water quality. These need to be considered in any examination of the health and wellbeing of Aboriginal peoples (Haskell and Randall, 2009).

The decision to focus on Aboriginal women was supported by the fact that Aboriginal women live longer than Aboriginal men (Statistics Canada, 2013), and they represent the majority of caregivers in Aboriginal communities, whether formal or informal, paid or unpaid (Korn et al. 2009; Hennessy and John, 1995, 1996).

### ***Research Team Members***

#### ***Dr. Carrie Bourassa, Associate Professor, First Nations University of Canada***

Dr. Bourassa is a Métis academic specializing in Indigenous community-based research methodologies as well as Indigenous health. Dr. Bourassa holds a Ph.D. in Social Studies (Special Case Inter-Disciplinary) where she examined Métis health status. Dr. Bourassa is the NPI for the Indigenous Peoples' Health Research Centre (IPHRC) and has extensive experience in engaging in research with First Nations and Métis communities, developing research agreements, facilitating research circles and conducting research interviews, as well as analyzing data. Dr. Bourassa has authored or co-authored several peer reviewed publications in relation to Aboriginal women's health and is a member of the Canadian Institutes of Health Research Standing Committee on Ethics. She provided guidance, mentorship, and training to the team.

#### ***Melissa Blind, Research Coordinator, NWAC***

Melissa is Cree and Ukrainian and is a member of the George Gordon's First Nation in Saskatchewan, Canada. Melissa completed her BA honours and MA in Indigenous Studies through First Nations University of Canada and the University of Regina. She is also working on her PhD in American Indian Studies at the University of Arizona. Her research interests include oral narratives (creation stories, sacred stories, family and life stories, counselling stories, and treaty stories), health and well-being, Indigenous contemporary situations, and issues surrounding identity.

#### ***Devin Dietrich, Data Analyst, NWAC***

Devin is Métis, originally from Winnipeg, Manitoba, and is a member of the Manitoba Métis Federation (MMF). Devin has a BA in environmental studies from the University of Winnipeg and a Masters of City Planning from the University of Manitoba, specializing in planning with Aboriginal communities. Devin has considerable experience doing Aboriginal specific research including research design, data collection, analysis, and community engagement from his time working at the MMF, the National Aboriginal Health Organization, and now at NWAC. Specifically for this project, Devin brought expertise in qualitative data management and analysis.

***Erin Corston, Project Manager, Director, Health and Environment, NWAC***

Born and raised in Treaty 9 Territory in north western Ontario, Erin is an active member of the Chapleau Cree First Nation. Erin has a BA in Environmental Health from Ryerson University. Over the last decade her work has focused on Aboriginal issues and social determinants of health. She has worked in various capacities with three of the five National Aboriginal Organizations in Ottawa and is currently Director of Health and Environment at the Native Women's Association of Canada. Erin's strengths are in Aboriginal health research and policy analysis, and in health management and administration. She is a Ryerson University graduate. Erin is a proud First Nations woman committed to improving Aboriginal peoples' health outcomes.

***Eric Oleson, Indigenous Community-Based Health Research Lab Coordinator, First Nations University of Canada***

Eric has a BA in Sociology and Political Science from the University of Regina, a Certificate of Economics from the University of Regina, and a MA of Public Administration from the Johnson-Shoyama Graduate School of Public Policy specializing in social and health policy. Eric has experience with community-based research, most notably as a researcher, documentarian, and analyst for two Community-University Research Alliance longitudinal projects on the topic of intimate partner violence. He provided research support to the team.

***Research Ethics***

This research was conducted in accordance with established ethical guidelines. Health Canada's Research Ethics Board, the University of Regina, and the University of Saskatchewan provided ethics review and approval for the project. Ethics review documentation detailed how the research would be conducted and what measures the team would undertake to ensure that the research process was ethical by:

- summarizing the project, explaining the methodology, and describing the analysis plan
- conducting the research using an Indigenous research based approach, specifically by using the 4 R's (Relevance, Relational, Respectful, and Reciprocal) to guide designing and undertaking the research
- introducing the research team and Advisory Committee, and explaining institutional roles
- describing target participants
- explaining what was required of participants and what the risks and benefits to them would be
- documenting what the recruitment strategy would employ to gain participants
- detailing the need for a small honorarium for participation
- describing how confidentiality would be maintained
- explaining how data would be securely stored and how access to it would be managed
- laying out the knowledge translation plan

- providing support services or information on how to get support for those in need
- providing Elders on site for the research circles to provide support and opening and closing ceremonies

## **Methodology**

This research was qualitative in nature and used an Indigenous Research Methodologies (IRM) approach to guide the design, collection of data, and analysis of the research. The 4R's of research involving Aboriginal peoples – Respect, Reciprocity, Relevance, and Responsibility – originally described by Kirkness and Bernhardt (1991), provided a simple framework for understanding and engaging in research with Aboriginal peoples in a culturally appropriate and safe manner. The Centre for Aboriginal Health Research (CAHR, 2013) 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.*

These principles were actively considered when purposefully engaging the expertise of the advisory committee to add community voice to the project. These principles were also considered in creating safe environments for Aboriginal women to share their stories and experiences. They guided our choice to use a narrative approach to data collection, emphasizing the need to allow the participants to tell their story and privileging the *story* as a culturally informed interpretation process. This research was then capable of findings that provided an accurate interpretation of the information gathered and reinforced the views of Aboriginal women living with and experiencing a neurological disorder. Some suggestions contained within the 4R's were not possible to undertake given the proposal format and limited time-frame budget (for example, getting community input into the design of the proposal/project or bring information back to the community in a personal manner like doing community presentations of findings).

A narrative approach was also used for the analysis of the data because it emphasizes a story-based approach to understanding a given phenomenon by taking as its object, the “story” (Liamputtong and Ezzy, 2005). This is consistent with and respectful of the oral tradition of storytelling as a method of transferring knowledge among Aboriginal peoples (Kovach, 2009). This research project's advisory committee is made up of Aboriginal and non-Aboriginal individuals. Each committee member possesses experience with Aboriginal and neurological research and knowledge of traditional methods of gaining and transferring information. Each committee member also supports the idea of drawing out and analyzing the participant's knowledge in the form of stories. Taking the advice of the advisory committee was one way to ensure the research was respectful and that the project remained relevant to the Aboriginal communities under study. Details of the analytic process are explained further in the following section on data collection and analysis.

## Methods Used

Two different methods were used in this study to collect data: In-depth interviews and research circles (focus groups).

In-depth interviews are one of the best methods to gain insight into a person's lived experience and to hear their story by allowing a less structured process in guiding the questioning of participants (Kovach, 2009). In-depth interviews were undertaken with three distinct groups of people:

- Key Informants (KI) – Knowledge holders, health administrators, or health practitioners who had some expert knowledge to share on the subject of how neurological conditions affect Aboriginal women or just on health care experiences of Aboriginal peoples.
- Traditional Knowledge Holders (TKH) – This group was characterized by knowledge of traditional healing practices.
- Aboriginal peoples experiencing a neurological condition or Aboriginal peoples caring for someone with a condition (ID).

The interviews were conducted in a space of the participant's choosing (such as their home, another place of their choosing, or a place provided by the researchers) and a small honorarium was provided as compensation for the knowledge shared. Three open-ended questions were asked of each participant. The questions posed differed slightly between the KI, TKH, and the ID participants.

Research Circles (RC) were another method used to collect stories. Research circles are based on the sharing circle format used within Aboriginal cultures both for sharing and gathering knowledge that has been adapted for research purposes (Kovach, 2009). They are similar to the format of a focus group. Instead of trying to get people in the group to build dialogue through discussion, a person is encouraged to tell their story and then passes the floor to the next participant (Kovach, 2009). The UFW research team worked with a community contact person to ensure the research circles were culturally appropriate. Research circle participants were offered food, refreshments, and an honorarium for their participation. Transportation and childcare costs were provided for individuals who would otherwise not be able to participate.

Elders opened and closed the circles with prayer. Where appropriate, they were presented with tobacco, cloth, and an honourarium. The facilitator explained the purpose of the research and outlined the process that would take place. Three questions were presented to the circle. The facilitator asked a question and each participant was invited to share their story and then passed the floor to the next participant.

Before data collection began, consent forms (one for their records and one for the interviewer's records) were provided and explained to participants. All participants completed the forms. Researchers asked if the session could be digitally recorded prior to doing so. All circles and interviews were recorded and transcribed. Transcripts were sent back to each participant for review and editing.

## **Environmental Scan**

The research team conducted an environmental scan of Aboriginal-specific neurological health services. An online search was performed on Canadian websites to identify programs and services offered to First Nations, Inuit, and Métis peoples who suffer from neurological conditions. The online search consisted of approximately 160 national, provincial, and regional organizations that deal with ABI and other related neurological conditions, focusing on Aboriginal programming. The majority of national websites did not offer Aboriginal-specific initiatives or programming.

The following search terms and combinations thereof were used in the searches: "Acquired Brain Injury," "Alzheimer's," "ALS or Lou Gehrig's disease," "Brain Tumours," "Cerebral Palsy," "Dementia," "Epilepsy," "Huntington's disease," "Multiple Sclerosis," "Muscular Dystrophy," "Parkinson's disease," "Stroke," "Spina Bifida," "Tourette Syndrome," and "Canada." Other conditions such as migraine headaches, and stroke were not included in the environmental scan because of parameters set by the Public Health Agency of Canada (PHAC) for this NPHSNC study.



The advisory committee later judged this inappropriate for studying neurological conditions among Aboriginal populations and these additional conditions were included in the data collection phase of this research. Furthermore, within national organizations' websites the following search terms were used: "Aboriginal," "Métis," "First Nations," "Inuit," "Indigenous," and "cultural." For websites that did not have a search bar or did not list programs under their "Programs and Services" section, searches were performed of their online newsletters and annual reports. Not all websites were up to date and some did not provide information on the programs or services offered on their website.

### **Report on Existing Data**

Under the suggestion of the Advisory Committee and later the NPHSNC Scientific Advisory Committee (SAC), the research team focused on collecting qualitative data only. In order to better understand what other data existed on neurological conditions with regard to Aboriginal peoples, NWAC contracted Dr. Janet Smylie and Sam Kooshesh, from the Centre for Research on Inner City Health at Saint Michael's Hospital in Toronto to:

- review and expand the existing scoping literature and database review
- review and analyze the gaps and opportunities existing in existing Canadian datasets
- analyse the prevalence of known determinants of neurological disease among Aboriginal populations in Canada

Smylie and Kooshesh expanded on the original literature review by adding 137 new articles and databases. Canadian datasets were examined to determine whether they collected Aboriginal-specific data regarding neurological health and very little data was found. Four out of the ten sources had an Aboriginal identifier and three sources included neurological health data dating back to 2000-2001. The earlier surveys focused on Alzheimer's disease and epilepsy, while the latest Canadian Community Health Survey asked about Alzheimer's, MS, epilepsy, Cerebral Palsy, Spina Bifida, Hydrocephalus, Muscular Dystrophy, Dystonia, Tourette's, Parkinson's, Huntington's brain injuries, and brain tumours.

Risk factors for neurological conditions within the general population were categorized into four main groups: demographic and social determinants, genetic, environmental, and medical conditions. Risk factors for Aboriginal people include age, socio-economic position, sex, vascular disease, obesity, diabetes, insulin resistance, traumatic brain injury, smoking, alcohol, and other substance abuse. When looking at risk factors amongst the Aboriginal population, the prevalence rates appear to be higher among Aboriginal people than the general Canadian population.

It was recommended that future research look at the additional neurologic conditions such as stroke, transient ischemic attack (TIA), and migraine headache within the Aboriginal population. Even though registries do exist for these conditions in the general Canadian population, there is a lack of Aboriginal specific data when it comes to stroke, TIA and headache. Additional research

could look at other conditions and co-morbidities that are more prevalent amongst Aboriginal people.

## **Role of the Advisory Committee**

This research project had the guidance of an advisory committee made up of Aboriginal peoples that are experts in Aboriginal and neurological research and have knowledge of traditional ways of gathering and translating that knowledge. The role of the Advisory Committee is described by one of its members below:

*As part of the advisory committee for the Understanding from Within research about Abori, Inuit, and Métis (FNIM) communities. By engaging in informative dialogue, the advisory committee and members of the investigative team provided the necessary conceptual framework and/or lens for exploring common neurological conditions in FNIM women that is inclusive of many of the health beliefs and practices that are part of the knowledge base of these communities. Issues of poverty, increased violence, and abuse were also discussed for their potential to impact neurological conditions and incidence in FNIM women, in addition to what may be categorized as an accumulated grief from the often prolonged periods of distress that many of these women endure.*

*The first gathering of this expertise explored the necessary elements for investigating these topics within a culturally sensitive and safe approach. The gathering also assisted in the identification of the neurological conditions to be studied and advised on suitable methods of data collection for the project. The second in-person gathering of these two groups involved detailed discussion on the challenges in meeting deadlines for the work from within an Indigenous frame of investigation, the strategies being utilized by the investigative team to overcome these challenges, the emerging themes of the study, and forward going plans to complete the data gathering processes and begin the analysis phase of the project. The final gathering of these two groups provided all participants with an overview of the project findings and involved two important discussions: one on an inventory of the best available databases for collecting information on FNIM people in relation to the identified themes of the study and information on an evaluation of the project. It should be noted that all members of the advisory group identified the many positive outcomes of this research and emphasized the significance of this work as a beginning understanding of neurological disease experience in Aboriginal women. Further, the critical need for further investigation, on a national level, to build upon this work was agreed upon by all members of the research team and the advisory committee.*

*My final involvement in this work included an online daylong session to assist with some aspects of data analyses. The data and its analysis revealed that the information collected during this research is sufficient to provide a clear picture of the experiences of FNIM women facing a neurological disorder and shows that the methods and framework of the study were successful in producing information*

*that is rich in detail while identifying the common concerns of these women and their caregivers. Throughout all of my involvement in this work, I observed that the principle investigator and her team demonstrated a well developed knowledge of the cultural aspects of the discussion, an attitude of openness toward learning from the committee and a sound understanding of the topics and issues that were seen as critical to the success of this project. During women and neurological disorders, I attended in-person, teleconference, and online meetings for the duration of the project. My responsibilities toward the project were to provide information and expertise with regard to Aboriginal women, the challenges to health they often face, the socio-political and economic environments in which they often live and the strengths that these women and their communities often possess by virtue of being part of First Nations*

### **Challenges and Lessons Learned**

The UFW project is significant in that it is the first time NWAC conducted primary research to feed into a national population study. While this endeavour resulted in many first time successes for the organization, there were also a number of challenges encountered along the way. Some of these challenges include:

#### **Delays with funding**

The project was supposed to take place over the course of three years. The contribution agreement was not signed until January 2011, shortening the length of the project to 27 months. This delay resulted in a later than anticipated hiring of the research coordinator and research assistant, which further delayed parts of the project, including when the data collection process could begin.

#### **Delays with ethics approval**

The UFW project received research ethics board (REB) approvals from three institutions – the University of Regina (UofR), the University of Saskatchewan (UofS) and Health Canada. Both the University of Regina and Health Canada Research Ethics Board (REB) applications were submitted at the end of September 2011. The University of Regina application was approved near the beginning of October, while the Health Canada application was not approved until late December 2011. We did not receive a signed certificate stating we could start data collection until January 2012. As a result of the delay, the UFW team revised the timelines for data collection, which shortened the time available for analysis and reporting.

#### **Staff turnover**

In August 2011 the research assistant position (RA) was moved from Regina to Ottawa. It took some time to fill the position and the team operated without an RA for several months. The co-principal investigator (Co-PI) for the project resigned in May 2012. The UFW team did not fill this position and instead brought on the health director as the project manager to oversee the project.

## Research capacity

Staff at NWAC had not previously worked on a project of this scope. The co-principal investigators and the rest of the research team were in different locations and did not have in person planning meeting dates set in advance. There was no contingency plan to deal with any foreseeable challenges.

Inconsistencies with how the research methodology was labelled and described were caused by inconsistent staff interaction and some staff turnover. This was discovered and corrected, but caused some confusion among the Scientific Advisory Committee provided by Public Health Agency of Canada to provide assistance with the research project and with the consultant hired to evaluate the project processes.

A data analyst was not hired until January 2013. Prior to this hiring, the research team did not have the capacity to complete the analysis in a timely manner.

## Lessons learned

From the challenges encountered, the UFW team were able to learn many lessons along the way and will apply them to future projects. Some of the lessons learned include:

- All processes need to be documented (minutes for all meetings, progress reports, process reports, and research design). This documentation should set out changes, action items, and who is responsible for each task.
- Consistent and clear process need to be in place for organizing all project documents. When working with a research team that are located in different cities, it is important to establish weekly or bi-weekly teleconference meetings and in person planning meetings once a month that are scheduled in advance.
- Future projects need to account for potential staff turnover and have a plan in place that accounts for the temporary distribution of responsibility and hiring of a replacement.
- Future projects that engage an advisory committee should create and maintain terms of reference that set out roles and responsibilities in order to ensure the active ownership of the project by the committee. These terms of reference would also outline how NWAC would keep the committee informed and implement their input into the project.
- A formal communications and recruitment plan should be developed earlier in the project's timeframe. This would help to systematically achieve recruitment goals.
- Future projects should set out a reasonable set of achievable goals based on the relative timeframe and budget available. As an example, this project originally was to include a

quantitative survey of 1000 persons. In hind sight, this was an unreasonable and unachievable goal, given the timeframe and budget, particularly when taking into account the other set out goal of doing 60 plus qualitative interviews and research circles.

- Projects of this size evolve and change over time and this is normal.

## ***Data Collection and Analysis***

### **Recruitment Strategy**

The target population was Aboriginal women (First Nations, Métis, and Inuit) living in urban, rural, or remote settings who either lived with or were caring for someone with a neurological condition. Recruitment activities included attempts to develop research relationships with communities and organizations and a multi-media campaign. This multi media campaign included:

- the distribution of posters to NWAC and the Assembly of First Nations regional affiliate organizations, to Métis community locals, to Friendship centers, First Nations communities, health and other centers both on and off reserve where Aboriginal people access services, and at Aboriginal forums/events/assemblies
- letters and emails to communities and organizations
- health professionals directly
- radio spots in some geographic areas
- a social media and web campaigns
- word of mouth (snowball sampling) in the final year of data collection (which proved to be the most effective recruitment method)

Participants were not required to have an official diagnosis. Many Aboriginal people face barriers accessing health care services and previous research by advisory committee member Dr. Jacklin showed that neurological conditions are under-diagnosed in Aboriginal populations (Jacklin and Warry, 2011). Participants who cared for individuals that live with a neurological condition did not have to be formal, paid caregivers. A review of the literature showed that the vast majority of caregivers within an Aboriginal context are family members and friends or community members performing formal and informal paid or unpaid work (Korn et al. 2009; Hennessy and John, 1995, 1996). Participants were offered a \$25.00 honorarium to participate in the project. Transportation costs and childcare were offered where necessary.

### **Data Collection**

The UFW research team took a four directions approach to collecting the data. The goal was to ensure that Aboriginal women from each of the four directions (N-S-E-W) had the opportunity to have their voices heard. Individual interviews and research circles were conducted in both urban and rural areas across Canada. The researchers also travelled to four provinces and one territory. Locations were selected based on personal and professional contacts within each of the regions.

In many cases a local contact person was in place to help with the recruitment process and ensure the research team was informed of local cultural protocols. The researcher's contact person made herself available following the interview or circle for participants who had any questions or concerns they felt uncomfortable approaching the research team with.

The Research Coordinator conducted the majority of interviews and research circles, with assistance from various members of the research team, including the Principle Investigator, co-principle investigator, research assistant, as well as the project manager. Telephone interviews took place when travel was not possible.

Data collection took place from January to the end of August 2012 engaging a total of 80 participants. The breakdown between individual interviews, research circle participants, and key informant interviews is outlined Figure 1 below. For all interviews and research circles participants were asked to identify whether they were of First Nations, Métis, or Inuit heritage and where they lived. All participants were asked if they lived with a specific neurological condition or if they cared for an individual who lived with a neurological condition. They were also asked what their age range was (age ranges were not disclosed in front of the rest of the group). Appendix 1 provides detailed demographic information.

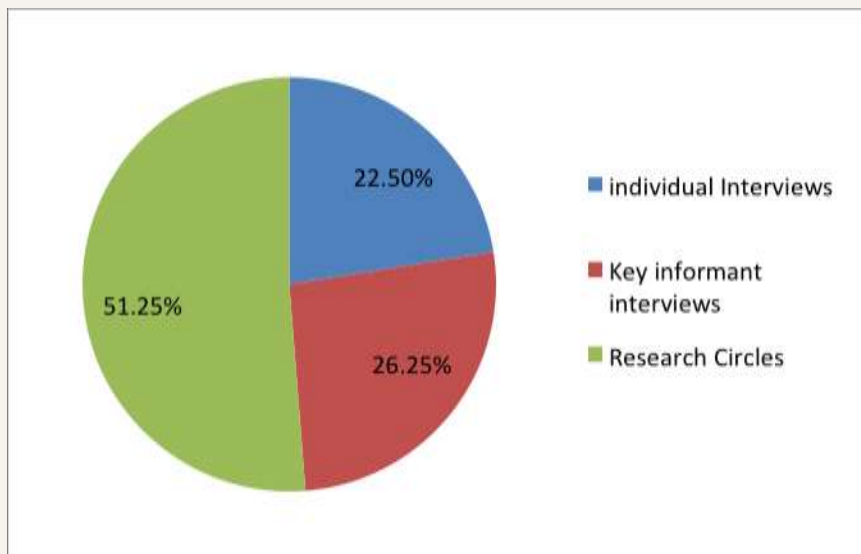


Figure 1 - Data collection breakdown

## ***Data Analysis: Collectively Coding, Reducing, Contextualizing***

### **Initial Coding Process**

Coding of the data collected for this project proceeded in a manner common to doing this kind of qualitative research. The transcriptions (data) were read through and using the qualitative data program (NVivo) the text was separated into logical chunks and placed into newly created nodes

or existing nodes which were named to reflect the data. This process was repeated for all of the data types (KI, TKH, ID, and RC) together. The initial plan for the data analysis was to look at all of these groups together. Unfortunately, due to reasons explained in the next section, that was not possible.

## **Separating the Data**

Following a process of review, it became evident that different questions were asked of the KI's, the TKH's, and the ID's and RC's. The data for these four groups should not have been coded together and could not be looked at collectively. The KI and TKH data had to be separated out and analyzed independently. Since the ID and RC were asked the same set of questions, they could be analyzed together once the KI and TKH data were removed from the collective nodes. The process to accomplish this involved opening the data in NVivo, manually recoding the KI data under a new node folder titled KI, while keeping the initially given node names. The next step involved un-coding all of the KI data from each node within the ID and RC node folder. A similar process was followed to remove and recode the TKH data.

## **Recoding the KI, ID, and RC Data**

The research coordinator and data analyst then examined each node in great detail. Since the KI data was coded into nodes with the ID and RC data, the node names and the data contained within them needed to be confirmed for both the KI group and the ID and RC group (TKH data was recoded because there was not much data and it was more efficient to recode this way). Each node was opened and each piece of data was read out loud. The research coordinator and the data analyst then deliberated and decided whether the data belonged under its current node or whether it should be transferred to another existing node, be put in a newly created node, or be removed entirely. Once all the data in a node was reviewed, text was entered into the node properties that described what was found within the node. The node names were reviewed and changed to more accurately reflect the data contained in it. This was repeated for the 80 plus nodes. The same process was then followed for the ID and RC data nodes. The following section labelled Data Display first lists then describes the themes and sub-themes that came out of the collective process for each of the three data groups. First the KI themes are listed and described, then the ID and RC themes, and lastly the TKH themes.

## **Collectively Analyzing the ID and RC Data**

The UFW project collected data through interviews and research circles with Aboriginal persons with a neurological condition and those caring for a person with a neurological condition. All stages of this project endeavoured to engage in research that was guided by an Indigenous research methodology. The data was analysed in a manner that was consistent with Indigenous research methodologies in order to allow the most positive outcomes possible to emerge for the Aboriginal communities under study. Collectively organizing and analysing data of this type is in line with Aboriginal research norms of building relationships, sharing mutual respect, facilitating reciprocal information sharing, and ensuring that research findings are relevant and meaningful to community. This process allowed the research team and Advisory Committee to build camaraderie and share perspectives, which enhanced building reciprocal relationships. This

process also facilitated a collective understanding and shaping of the research data, ensuring respectful interaction and relevant research outcomes.

## Collective Process

The ID and RC data went through a second phase of collective analysis based on the Collective Consensual Data Analytic Procedure (CCDAP) described by Bartlett et al. (2007). This collective process allowed the team to elicit input from a wider group of experts (the entire research team and some members of the AC) to help ensure that the research findings remained relevant and that respectful inclusion of Aboriginal experts occurred. 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 “wall” in columns, the clusters are rechecked for accuracy and then given names that typically become the main themes of the study.

The CCDAP process was adapted for this research project in two ways: First, rather than having a piece of coded data on one side of a card and a short description of that data on the other side, data that had already gone through some thematic analysis (as described above) was analyzed. For the adapted collective process, on one side of the card was the sub-theme name (a short title) and on the other side was a summary description of what data was contained within the sub-theme.

Second, the CCDAP would normally be undertaken with the entire group together in one room because of the need to physically *see* the themes on the wall and to facilitate discussion. This was impossible due to budget, geography, and time constraints. A method was developed to conduct the collective analysis process remotely. Text that would have been written on both sides of a card was put onto a PowerPoint slide, with the theme name in the title box and the theme summary within the text on a single slide. A virtual wall was devised using tables in Microsoft Word, with symbols as headings at the top of each column of the table. Then, using the online meeting service called GoToMeeting, the group met virtually for approximately eight hours until the process was complete. The facilitators read the sub-themes and descriptions from the slides aloud, and the group collectively placed them under the symbols headings on the prepared virtual wall, a wall they could see on their computer screens. The raw data itself was available to the facilitators to clarify and answer questions as necessary as the process moved forward.

The process is detailed below:



1. create a PowerPoint presentation with theme names in the title box and a summary description in the body of a single slide
2. create a blank table with symbols at the top of each column. Symbols are used to avoid pre-naming the themes
3. gather a group of people involved with the research (in this case, the Advisory Committee and research team)
4. two facilitators take turns reading out the titles and descriptions
5. the first sub-theme's name and description is read out and then it is placed on the "wall" under the first symbol column
6. the next sub-theme name and description is read out and the group decides if it is the same (similar) or different than the first theme name that was placed
  - a. if it is the theme is the same, it is placed under the first symbol; if the theme is different, it is placed under a new symbol
7. this process is repeated, placing themes under existing symbols or new empty symbols in columns until all of the themes are placed
  - a. if there is difficulty placing a theme it is put to the side and will be read out again when all the other sub-themes are placed
8. once all the sub-themes are placed and the columns are established, the facilitators read out the sub-theme names contained in the first column, reading the summary description if necessary
  - a. the group collectively decides if all of the cards underneath that symbol still belong there or should be moved; once that column has been finalized the group gives it a name that describes the content
9. this process is repeated with all the columns until they are all named and the major themes are established
10. reflection on the process and the themes is undertaken
  - a. each member of the group is encouraged to think about what is contained within a single column/theme and to share any analytical thoughts with the group; reflection is typically recorded and notes are taken
  - b. this information is used to help guide the writing process
11. the theme areas are then entered into NVivo (and potentially in an Excel spreadsheet for greater accessibility), grouped according to the collective process, and linked to the appropriate underlying data



## The Data

### *Key Informant*

#### Major Themes and Sub-Themes

##### Diagnosis

- Co-morbidities
- Diagnosis
- Examples of Neurological Conditions
- Misdiagnosis
- Symptoms of NC's

##### Health Care

- Access to Health Care
- Advocate
- Culturally Relevant Care
  - Worldview
  - Patient Centred Care
  - Holistic Approach to Health
- Gaps - Health Services
  - Language
- Governance
- Health Care Policy
- Health Promotion and Prevention
- Home Care
- Jurisdiction
  - Communication btw agencies
- Medication
- Navigating Health System
- Resource Materials
- Support
- Traditional Approaches

##### Impacts

- Cultural Impacts
- Emotional Impacts
- Family - Friends - Community
- Financial Impacts
- Housing Impacts
- Mental Impacts
- Physical Impacts
- Spiritual Impacts
- Transportation Impacts

##### Knowledge

- Education
  - Messaging
- Gaps in Knowledge
- Research
  - Data
- Traditional Ways of Knowing

##### Discrimination

- Racism
- Stereotype

##### Recommendations

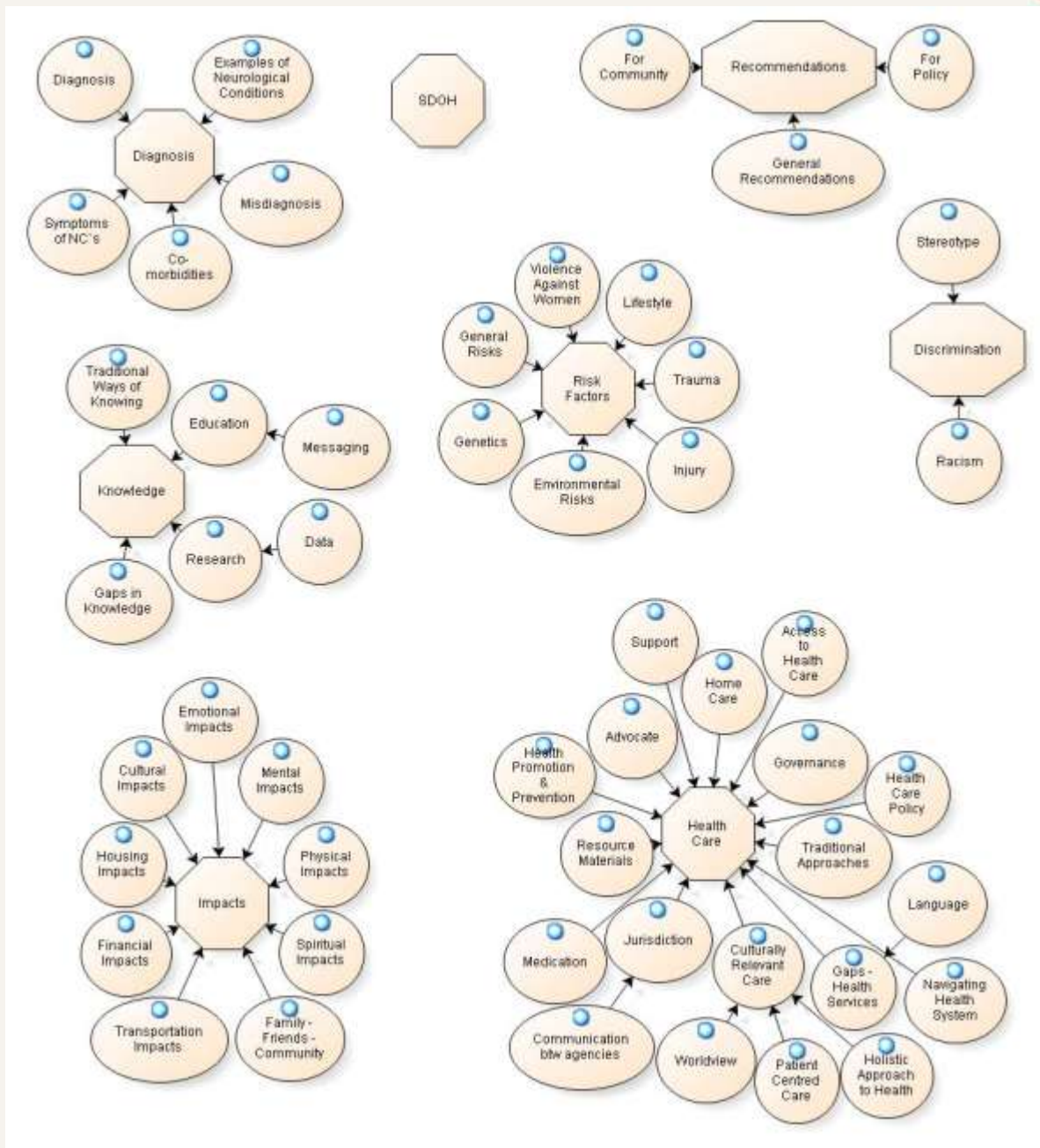
- For Community
- For Policy
- General Recommendations

##### Risk Factors

- Environmental Risks
- Violence Against Women
- Trauma
- Lifestyle
- Injury
- Genetics
- General Risks

##### Social Determinants of Health

## Data Display



## Theme Descriptions

### *Diagnosis*

- *Co-Morbidities* - Other conditions related to or symbiotic with neurological conditions or having an impact on each other (for example, diabetes)
- *Diagnosis* - Ideas related to a diagnosis with a neurological condition, problems with getting it, access, and others
- *Examples of Neurological Conditions* - In Aboriginal population from the experience of health care providers
- *Misdiagnosis* - The impact of misdiagnosis of a neurological condition, mistakenly diagnosed with a non-neuro condition (usually mental health issue) when one exists
- *Symptoms* - Symptoms experienced by patients, described by KI

### *Health Care*

- *Access to Health Care* - Issues with access to care (geographic, transportation, financial, equity, referral issues, wait times, lack of family physicians, lack of health care capacity in the community)
- *Advocate* - Examples of health providers advocating for patients and individuals self advocating, examples of reasons that advocating is necessary
- *Culturally Relevant Care* - Examples of culturally relevant care and programs, also incorporated different worldviews, continuum of worldviews, sub themes underneath
- *Holistic Approach to Health* - Examples of health care approaches that try to tackle more than just the bio-medical things
- *Patient Centred Care* - Examples of patient centred care related to culturally relevant care
- *Worldview* - differences in worldview, from very traditional to not very (continuum)
- *Gaps in Health Services* - Gaps in health services, type of services available, capacity of existing health services, and staffing issues
- *Language* - Issues of bad communication, and health care related to language issues
- *Governance* - Transformation of Health Services; issues of communication, and roles
- *Health Care Policy* - Issues with policies that impact health care, communication and implementation issues between policy makers and practitioners
- *Health Promotion and Prevention* - concepts around preventative care, related to SDOH, health promotion
- *Home Care* - Issues in home care services related to jurisdiction issues and access issues, and some examples of existing home care programs
- *Jurisdiction* - Instances where there are issues in health services (i.e., who pays for what?), how jurisdiction affects level of health care delivered, wait times, financial implications on individuals (while Ottawa decides)
- *Communication Between Agencies* - Examples of communication between health care agency and health insurance agency
- *Medication* - Issues with medication (affordability, NIHB coverage, controlled drugs such as opiates), stereotypes

- *Navigating the Health System* - Examples of help or issues with navigating the health care system
- *Resource Materials* - What types of information about neurological conditions are available and what types are needed
- *Support* - Describing types of supports such as transportation, housing, advocacy, interpreting, Telehealth, family, community, child care, food and shelter, information, holistic health services, also includes instances of lack of support
- *Traditional Approaches* - Access to traditional medicines, Elders, traditional healing, and holistic care (potentially connected to "Culturally Relevant Care")

### ***Impacts***

- *Cultural Impacts* - Impacts of condition on culture
- *Emotional Impacts* - Stress and emotional impacts from condition and from issues with care
- *Family, Friends, Community Impacts* - How neurological issues affect family/friends/community
- *Financial Impacts* - Financial impacts related to neurological conditions, and issues of jurisdiction in payment for care
- *Housing Impacts* - Impacts of condition and subsequent treatment related to housing (for example need to find housing when forced to come to southern hospitals in large cities), overcrowding on reserve
- *Mental Impacts* - Impact of mental capacity on how individuals deal with condition, impact of condition on mental capacity
- *Physical Impacts* - Impacts of physical impairment related to neurological conditions, lack of infrastructure for persons with mobility disabilities (impaired mobility)
- *Spiritual Impacts* - Impacts of condition on individual's spirituality
- *Transportation Impacts* - Impacts of needing specialized transportation for health care and diagnostic treatment, mobility related issues

### ***Knowledge***

- *Education* - Need knowledge of what to do related to symptoms of condition (for example, seizure, turn on front/side), need for more awareness of what health care services can do for conditions
- *Messaging* - Potential ideas on appropriate types or mediums to get out information on neurological conditions, data related to messaging that may be helpful to us for products for example, "resources for Health Care Providers in the community"
- *Gaps in Knowledge* - Knowledge gaps about conditions, symptoms, prevalence rates, how to access services
- *Research* – Issues about research in Aboriginal communities, time issues, permissions, etc., examples of community-based research, need for research on neurological conditions and Aboriginal health
- *Data* - Issues with data or lack of data on neurological conditions

- *Traditional Ways of Knowing* - Traditional knowledge related to healing and health, traditional worldview related to illness and end of life, i.e. fighting illness to the bitter end not always preferable to accepting death, quality of remaining life vs. treatment (sometimes incapacitating)

### ***Discrimination***

- *Racism* - Examples of racism in health system, systemic and or individual
- *Stereotype* - Examples of stereotypes related to health care services/ Aboriginal peoples, for example, drug seeking behaviours assumed

### ***Recommendations***

- *For Community* - Recommendations for community as a whole or individuals within in it to help navigate the health system
- *For Policy* - recommendations for policy related to consultation for policy changes, information and resources for health care providers to help with Aboriginal patients, referrals policy, culturally relevant service policy (consistent identification of Aboriginal peoples), patient centred care recommendation (includes ensuring more time spent with patients), population based data needed, services and health care providers needed where patients are (for example physio or neurologist in the community)
- *General Recommendations* - Don't blame the patient, SDOH, concentrate on youth (health promotion, changing health outcomes), get health care providers out into the community building relationships, need health men to have health women

### ***Risk Factors***

- *Environmental Risks* - Risk factors related to environmental contaminants (linked with genetic factors)
- *General Risks* - SDOH as a risk to being unhealthy (related to neurological conditions, other health factors/co-morbidities as a risk factor)
- *Genetics* - risk factors related to genetics, heredity
- *Injury* - neurological conditions related to injury
- *Lifestyle Risks* - General lifestyle risks associated with poor health but not necessarily directly linked to neurological conditions (alcohol and drug addiction, obesity, and gangs)
- *Trauma* - various types of trauma as a risk factor for neurological conditions (physical trauma, emotional, sexual)
- *Violence Against Women* - Trauma and violence specific to women as a risk factor

### ***Social Determinants of Health***

- Housing, food security, poverty, loss of land, stereotypes, mistrust of institutions, transportation, isolated geographies (urban and rural), child care (all issues that need to be addressed by people experiencing neurological conditions that are higher on their ladder of needs than medical care for their conditions)

## *Individual Interview and Research Circle*

### Major Themes and Sub-Themes

#### Challenges and Recommendations

- Fighting for Rights
- NIHB
- Recommendations for Health Care Providers
- Recommendations for Policy

#### Circle of Support

- Care Giver Experiences
- Community Issues
- Friends Impact
- Lack of support
- Support
- Support Groups

#### Colonial and Systemic Factors

- Abuse
- Discrimination
- Environmental
- Intergenerational Impacts
- Stigma
- Trauma

#### Disease Process (Pathology)

- Conditions
- Diagnosis
- Medication
- Symptoms
- Treatment

#### Impacts of Neurological Conditions

- Community Impacts
- Educational Impacts
- Emotional Impacts
- Family Impacts
- Financial Impacts
- Housing Impacts

- Mental Impacts
- Mobility Impacts
- Physical Impacts
- Social Determinants of Health
- Spiritual Impacts
- Work and Career Impacts

#### Interaction with the Health Care System

- Access to Health Care
- Culturally Relevant Care
- Health Care Gaps
- Homecare
- Navigate
- Negligence of Care
- Positive Health Care Experience
- Respite

#### Knowledge and Information

- Communication Issues
- Information Needs about Neurological Conditions
- Knowledge Gaps
- Knowledge of Health Care Providers

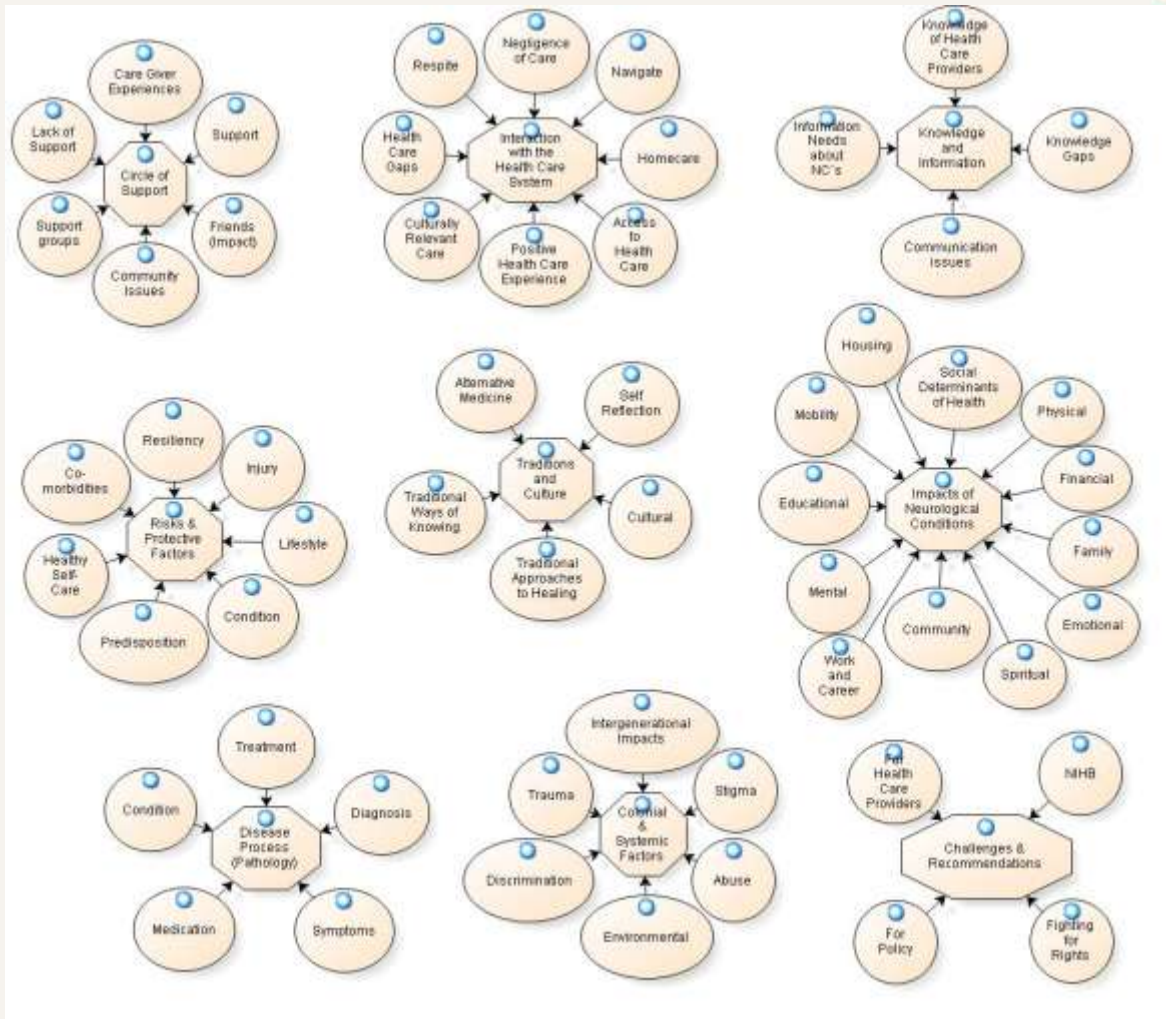
#### Risks and Protective Factors

- Co-Morbidities
- Conditions
- Healthy Self-Care
- Injury
- Lifestyle
- Predisposition
- Resiliency

#### Traditions and Culture

- Alternative Medicine
- Cultural
- Self Reflection
- Traditional Approaches to Healing
- Traditional Ways of Knowing

## Data Display





## Theme Descriptions

### *Challenges and Recommendations*

- *Fight for Rights* - Stories of fights that individuals had with government to get their healthcare needs met
- *Non Insured Health Benefits (NIHB)* - Problems associated with what NIHB will pay for, what they won't, who gets benefits, lack of communication between NIHB and other agencies
- *Recommendations for Health Care Providers* - Recommendations for health care providers or professionals on how to provide care to Aboriginal peoples with Neurological conditions, treat people as people, not as conditions
- *Recommendations for Policy* - Recommendations for policy makers and analysts for appropriate health care for Aboriginal peoples with Neurological conditions, Tri-partite agreements, culturally relevant care, etc.

### *Circle of Support*

- *Care Giver Experiences* - Stories given by caregivers about taking care of people with neurological conditions (often family care givers but not always)
- *Communication Issues* - Communication issues between persons with neurological condition, or their care-givers and Health care providers
- *Friends Impact* - Impacts of Neurological conditions on friends, care giver roles taken on by friends
- *Lack of Support* - Lack of support or supports needed related to community, information, counselling, support workers, unsupportive institutions, health care setting supports, for single families; need for confidentiality and professionalism, mental health support, home care, support from family
- *Support* - Stories of support: Family support, professional support (healthcare), community support, school support, friends, clergy, monetary, social support, First Nation band support, people with neurological condition experiences supporting others in similar situations
- *Support Groups* - Stories of support group experiences, conferences, online forums, being able to connect with others who have similar experiences, learn new things from people who have been through same experience, lack of access to support groups (isolated), issues with support groups, and feeling uncomfortable in a support group

### *Colonial and Systemic Factors*

- *Abuse* - Stories of types of abuse for example, alcohol, drugs, physical, emotional, and sexual
- *Discrimination* - Experiences of discrimination from health care providers, law enforcement; stereotypes, withholding care based on stereotypes, responses to discrimination, experiences of racism

- *Environmental* - Relationship between neurological conditions and other health conditions to exposure to environmental contaminants and pollution (for example, mercury), includes the concept of government negligence related to environmental contaminants
- *Intergenerational Impacts* - Examples of trauma passed down by experiences of the previous generations (for example, residential schools experience), stories of other effects that are shared through the generations (for example, mercury poisoning related to generational practices), older generation being abused or taken advantage of
- *Stigma* - Stories of stigma related to Neurological conditions (for example, child in wheelchair with Rett's syndrome being asked if they is Fetal Alcohol Syndrome)
- *Trauma* - Trauma related to being a family care giver, Indian residential school survivor, physical and sexual abuse, emotional trauma, childhood trauma, unresolved trauma (alcohol abuse and suicide ideation), Post Traumatic Stress Disorder (PTSD)

### ***Disease Process (Pathology)***

- *Conditions* - Descriptions of neurological conditions that have come up in the interviews - ABI, epilepsy, stroke, Fibromyalgia, cysts etc.
- *Diagnosis* - Stories of how participants were diagnosed with a neuro condition, issues with diagnosis and misdiagnosis, stories of self-diagnosis
- *Medication* - Stories of medications: taken as the only thing doctors offer, side effects, expense of medications, lack of information regarding medications and side effects, and not taking their medications
- *Symptoms* - Descriptions of peoples symptoms, including memory issues, migraine, pain, vomiting, obsessive behaviour, seizures, hunger, hand motions, physical issues (can't walk), night terrors, tremors, lack of nerve sensation, disorientation, fainting, nausea, hair loss, word miss-association, speech impairment, depression, muscle deterioration, aggression, delusions (physical, visual, auditory, cognitive), rash
- *Treatment* - Description of treatments: surgeries, recovery, alternative treatments, antibiotics, self-medicating, research around treatments, and treatments not working

### ***Impacts of Neurological Conditions***

- *Educational Impacts* - Impact of neurological conditions on ability to go to school or continue education. Stress about finding appropriate services at school
- *Emotional Impacts* - Emotions directly related to neurological conditions or care giver experience of neurological conditions, such as fear, guilt, hopelessness, etc.
- *Community Impacts* - Impacts of neurological conditions on community relationships and capacity
- *Family Impacts* - Impacts on family related to neurological conditions, care giving roles, fear, denial, getting left behind, growing up faster than most kids, other kids receive less attention, loss of memory and impact on other family members and family relationships

- *Financial Impacts* - Stories about financial impacts of having a neurological conditions or caring for someone with a neurological conditions, cost of medication, travel for appointments, missed work, unable to work on disability
- *Housing Impacts* - Issues with housing not meeting disability needs (for example, two stories versus bungalow)
- *Mental Impacts* - Stories of cognitive decline related to neurological conditions, short and long term memory loss, stress, worry, impacts on school and work (cognitive), word miss-association, poor judgement leading to financial impacts
- *Mobility Impacts* - Mobility issues, issues with care giver needing help with transport of person with neurological conditions, administrative impacts on mobility, financial costs, lack of transportation interfering with medical care (can't get to appointments), issues with driving and licensing
- *Physical Impacts* - Stories of the physical impacts of neurological conditions on people and their caregivers, exhaustion, lack of energy, additional help needed, having to rethink everyday occurrences due to physical impacts, mobility decreased, and pain
- *Social Determinants of Health* - Stories of how economic situation and education levels affect lives
- *Spiritual Impacts* - Stories of how neurological conditions impacted people's spirituality, using meditation, finding solace in spirituality, to help deal with pain
- *Work and Career Impacts* - Impacts on work and career related to needing to have accommodations at work, needing time off (using holidays, sick time, banked time), judgement at work, having to go back to work for social interaction, work place support, balancing work with family, amount of time getting family ready for work (lateness), relapses during work, mobility issues, cognitive issues, staff not understanding, fear of going to work, job security issues, work capacity changes, and needing to be able to drive

### ***Interaction with the Health Care System***

- *Access to Health Care* - Stories of access or problems of difficult access to health care, access issues due to poverty
- *Culturally Relevant Care* - Examples of culturally relevant care, recommendations, examples of lack of culturally relevant care where it is needed
- *Homecare* - Stories about homecare experiences from the perspective of the families of persons with neurological condition or the persons themselves, or health care providers, of family needing homecare for loved ones
- *Health Care Gaps* - Gaps in health service: cannot get diagnosis within community, specialized services, basic medical care, mental health care and supports, etc.
- *Navigate* - Stories of having difficulty with and needing assistance with navigating the health system

- *Negligence of Care* - Stories of neglect in a health care setting, stories of doctors not doing proper tests for neurological conditions, lack of training of available health care staff (remote areas)
- *Positive Health Care Experience* - Stories related about health care experiences that were positive: health care provider going extra mile, making effort to be culturally sensitive, accepting of other healing practices
- *Respite* - Stories of: experiences getting respite, funding challenges, family as respite, trouble with access to respite, lack of specialized respite services in some areas

### ***Knowledge and Information***

- *Community Issues* - As a support, about giving back to the community, supporting the community, lack of support from the community, issues related to small communities, on-reserve issues
- *Information Needs about Neurological Conditions* - Need for information about neurological conditions, different ways to educate about neurological conditions, educating peers and colleagues, need for places to get info and supports, stories of how people got their information, need for training to care for people with Neurological conditions
- *Knowledge Gaps* - Stories of a lack of knowledge: lack of knowledge/training to deal with people with neurological conditions, lack of awareness or understanding of neurological conditions, invisible disabilities
- *Knowledge of Health Care Providers* - Interviewees perspectives on the level of knowledge or lack thereof, held by those who deliver health services

### ***Risks and Protective Factors***

- *Co-morbidities* - Stories of people with neurological conditions, specifically about other health problems that they are experiencing: Diabetes, heart disease, cancer, psychological issues, pain, arthritis
- *Conditions* - Descriptions of neurological conditions that have come up in the interviews, such as ABI, epilepsy, stroke, Fibromyalgia, cysts etc.
- *Resiliency* - Stories of ways/methods of coping, stories of successfully managing neurological conditions, for example, strength, maintaining perspective, pushing through, educating ones-self about neurological conditions, keeping active, maintaining positive attitude, self-reflection
- *Lifestyle* - Stories of risks associated with diet, exercise, smoking, drinking, drugs, stress, and traditional ways of supporting risks (fishing for Mercury contaminated fish)
- *Predisposition* - Stories of diseases that run in the family (some may be genetic others may be related to passed on lifestyle issues and obesity)
- *Healthy Self-Care* - Stories of what people do to take care of themselves and what motivated them to do it: exercise, eat better, getting sleep, lifestyle habits, mental

health responses, beauty days, and measures to prevent illness and to deal with current illnesses

- *Injury* - Stories of injuries/accidents that may have caused Neurological conditions (for example, head injury related to seizures)

### ***Traditions and Culture***

- *Alternative Medicine* - Examples of people seeking alternative medicine treatment, or their experiences of this (chiropractic, acupuncture, massage, herbal, meditation etc.)
- *Cultural* - Cultural expressions of: ways of thinking about death and coping, visions, cultural practices, traditional foods, ways of understanding (for example, you chose this path), seeking out traditional healers or Elders, the dichotomy of individual vs. collective responsibility, and being private about health
- *Self Reflection* - Stories about backgrounds, family life, and how people think about neurological conditions.
- *Traditional Approaches to Healing* - Stories of: meditation, use of traditional plants, prayer, failure of traditional treatments, conflict btw western and traditional approaches, integration of western and traditional, balance of four directions, access issues to traditional approaches (affordability)
- *Traditional Ways of Knowing* - Stories of acceptance of people for who they are, how they are different, traditional knowledge passed down, the land and its relation to healing

## ***Traditional Knowledge Holders***

### **Major Themes and Sub-Themes**

#### Education and Information Needs

- Communication gap
- Conditions and symptoms
- Information needs
- Messaging

#### Healthcare Concepts

- Access to healthcare
- Alternative medicine
- Culturally relevant health service
- Diagnosis
- Medication
- Negative healthcare experiences
- Positive healthcare experiences
- Treatment

#### Impacts of Neurological Conditions

- Emotional
- Family
- Financial
- Housing
- Physical
- Social Determinants of Health (SDOH)

#### Recommendations

- Community services
- Policy recommendations
- Recommendations for healthcare Providers
- Support needs

Systemic Issues:

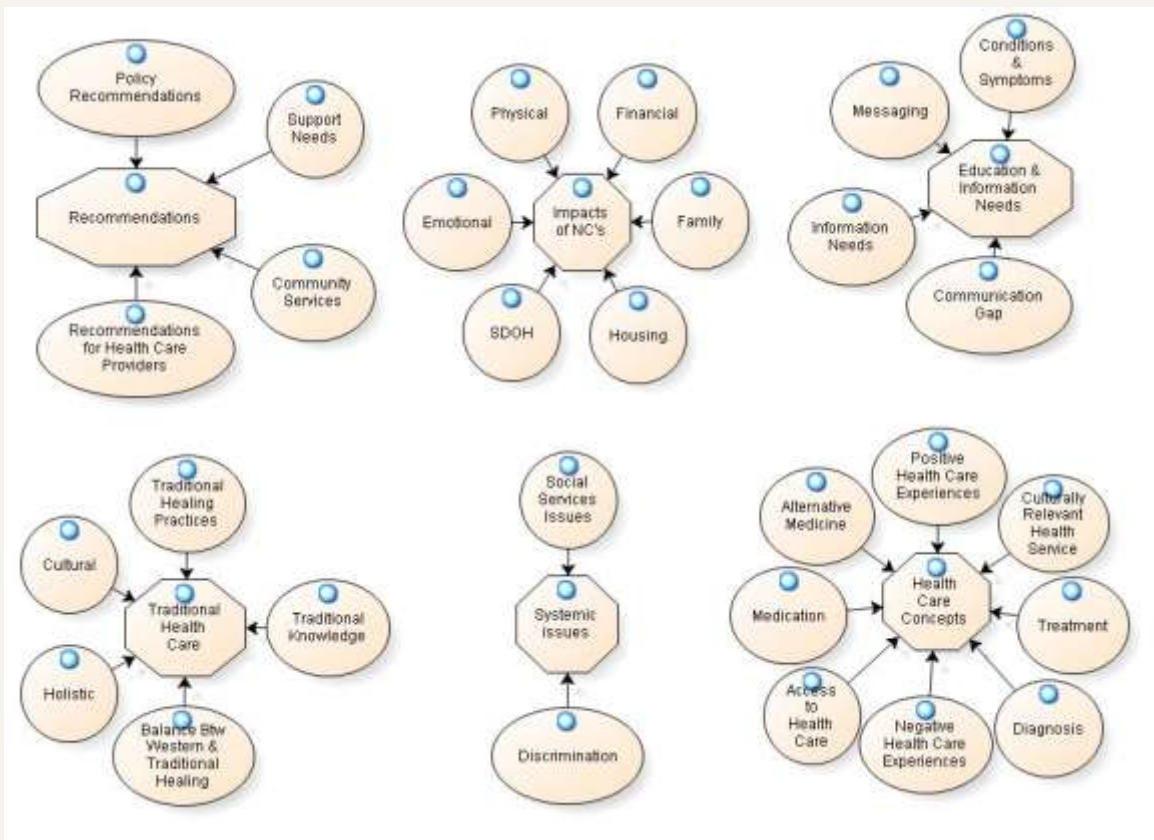
- Discrimination
- Social service issues

Traditional Healthcare

- Balance between western and traditional healing
- Cultural
- Holistic
- Traditional healing practices
- Traditional knowledge



**Data Display**



## Theme Descriptions

### *Education and Information Needs*

- *Communication Gap* - Issues with communication between health care providers and patients
- *Conditions and Symptoms* - Descriptions of conditions and related symptoms
- *Information Needs* - Stories of participant's lack of information regarding their conditions and their need for this information to be accessible
- *Messaging* - Suggestions of what format information should come in to have an impact on Aboriginal communities

### *Healthcare Concepts*

- *Access to healthcare* - lack of healthcare services up North
- *Alternative Medicine* - Stories of alternative medicine used
- *Culturally Relevant Health Service* - Need to make sure that current cultural services (i.e., Aboriginal liaisons) are properly informed and traditional
- *Diagnosis* - Stories of experience getting diagnosis and related negative issues
- *Medication* - Pharmaceuticals are most often the solution in Western medicine and this does not always work with traditional methods
- *Negative Healthcare Experiences* - Stories of negative Healthcare experiences
- *Positive Healthcare Experiences* - Stories of positive healthcare experiences
- *Treatment* - Details of treatments received for conditions

### *Impacts of Neurological Conditions*

- *Emotional* - Impacts of neurological conditions on emotional wellbeing
- *Family* - Impacts of neurological conditions on families
- *Financial* - Impacts of neurological conditions on finances
- *Housing* - Impacts of housing choices on individuals with neurological conditions
- *Physical* - Impacts of neurological conditions on physical wellbeing
- *Social Determinants of Health* - Impacts of the social determinants of health on individuals with neurological conditions

### *Recommendations*

- *Community Services* - Need for community-based services
- *Policy Recommendations* - Recommendations for changes to policy to help persons with neurological conditions
- *Recommendations for Healthcare Providers* - Recommendations for healthcare providers to help persons with neurological conditions by changing the way they approach care

- *Support Needs* - Suggestions of what is needed to support those with neurological conditions

### ***Systemic Issues***

- *Discrimination* - Stories of racism and discrimination
- *Social Service Issues* - Stories of barriers to services and funding for services

### ***Traditional Healthcare***

- *Balance between Western and Traditional Healing* - need to balance traditional healing practices with western medicine, stories told of where this balance is skewed toward medicine
- *Cultural* - Stories of Aboriginal communities being accepting and accommodating of neurological conditions, sometimes it is cultural to hide conditions or be private about neurological conditions and other diseases, cultural ideas around death and dying, story of disconnect from culture and tradition
- *Holistic* - Holistic methods of coping
- *Traditional Healing Practices* - Examples of traditional healing practices and medicines
- *Traditional Knowledge* - Examples of traditional knowledge and knowledge that has been lost. Language issues with translation. Conflict between traditional practices and Western religions



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## Appendix 1 Participant Information

Total number of research participants: 80

- Individual interviews 17 (21.25%),
- Key informant interviews 22 (27.5%)
- Research circles 41 (51.25%)
  
- Women: 69 (86%)
- Men: 11 (14%)
  
- First Nation: 65 (81%)
- Métis: 7 (9%)
- Non-Aboriginal: 4 (5%)
- Did not specify: 4 (5%)
  
- Living On-Reserve: 33 (41%)
- Off-Reserve: 43 (54%)
  - 32 were First Nations
  - 7 were Métis
  - 4 did not specify
  
- Total Caregivers: 40 (50%)
- Total living with a neurological condition: 18 (23%)
- Key informants: 22 (4 traditional knowledge keepers (18%); 18 health care providers (82%))
  
- Age ranges: For the individual interviews
  - 20-24 (2)
  - 25-29 (4)
  - 30-34 (0)
  - 35-39 (2)
  - 40-44 (2)
  - 45-49 (0)
  - 50-54 (5)
  - 55-59 (2)



- Location
  - North - Yukon/ NWT/Nunavut/Labrador – 10 (13%)
  - East - Ontario/Quebec/Maritimes – 36 (45%)
  - South - Saskatchewan/Manitoba – 31 (39%)
  - West – Alberta/BC – 3 (4%)

## Appendix 2 Neurological Conditions

The following is a listing of terms and definitions of neurological conditions that were the focus of this research project. All information from Neurological Health Charities of Canada website <http://www.mybrainmatters.ca/> unless otherwise stated.

**Amyotrophic Lateral Sclerosis (ALS)**, also known as Lou Gehrig's disease, is a devastating neurodegenerative disease. Those living with the disease become progressively paralyzed due to degeneration of the upper and lower motor neurons in the brain and spinal cord.

**Alzheimer's Disease (AD)** is a progressive, degenerative disease of the brain, which causes thinking and memory to become seriously impaired. It is the most common form of dementia. (Dementia is a syndrome consisting of a number of symptoms that include loss of memory, judgment and reasoning, and changes in mood, behaviour and communication abilities.)

**Traumatic Brain Injury (TBI)** has become a significant medical and societal concern within the last 30 years. With advances in medical technology, many people who would have died are now surviving severe brain injuries. At times the cost is astronomical: financially, socially, and emotionally. Concussion, the most common form of brain injury, is considered to be a Mild Brain Injury most often associated with sports. While the seriousness of a concussion is regularly downplayed as short-term dizziness or confusion, new Canadian research shows that the effects of a concussion can be observed as mental and physical decline more than 30 years later.

**Brain Tumours** a condition that spreads and becomes potentially lethal — these growths always are serious because they can interfere with normal brain activity. Symptoms vary according to location and size, but seizures and headache are among the most common. As a tumour expands it can increase pressure within the skull, causing headache, vomiting, visual disturbances, and impaired mental functioning.

**Cerebral Palsy** is a term used to describe a group of disorders affecting body movement and muscle co-ordination. The medical definition of cerebral palsy is a "non-progressive" but not unchanging disorder of movement and posture, due to an insult to or anomaly of the developing brain. Damage to the brain may result in cerebral palsy. At its mildest, Cerebral Palsy may result in a slight awkwardness of movement or hand control. At its most severe, Cerebral Palsy may result in virtually no muscle control, profoundly affecting movement and speech.

**Epilepsy** is a neurological disorder – a physical condition that causes sudden bursts of hyperactivity in the brain. This hyperactivity produces “seizures” which vary from one person to another in frequency and form. A seizure may appear as a brief stare, an unusual movement of the body, a change in awareness, or a convulsion. A seizure may last a few seconds or a few minutes.

**Huntington's Disease** is an inherited brain disorder that causes cells in specific parts of the brain to die. Huntington's Disease is a genetic disorder. About one in every 10,000 Canadians has Huntington's Disease, but Huntington's Disease touches one in every 1,000 whether at risk, as a caregiver, family member or friend. The symptoms of Huntington's Disease include emotional turmoil (depression, apathy, obsessive behaviour), mental loss (inability to focus, think and recall, make decisions), and physical deterioration (weight loss, involuntary movements, diminished coordination, inability to walk, talk, swallow). The disease leads to complete incapacitation and, eventually, death.

**Hydrocephalus** comes from the Greek word “hydro,” meaning water, and “cephalous,” meaning head. It is a neurological condition that exists when excess cerebrospinal fluid (CSF) builds up in cavities, called ventricles, inside the brain. Fluid accumulates in the ventricles when the body produces more CSF in a day than it can reabsorb. This accumulation causes enlargement of the ventricles, resulting in hydrocephalus. If untreated, hydrocephalus can cause serious brain damage. Even when treated, it may still cause some injury to the brain. Some cases are more severe than others.

**Multiple Sclerosis** is unpredictable, affecting vision, hearing, memory, balance and mobility. Its effects are physical, emotional, financial, and last a lifetime. There is no cure. Multiple Sclerosis is thought to be an autoimmune disease in which the body's natural defences act against the myelin and nerve fibres in the central nervous system as though they were foreign tissue. The most common symptoms of Multiple Sclerosis are numbness, fatigue, blurred vision, and clumsiness

**Muscular Dystrophy** is the name for a group of neuromuscular disorders that are characterized by progressive weakness and wasting of the voluntary muscles that control body movement. As muscle tissue weakens and wastes away, it is replaced by fatty and connective tissue.

**Parkinson's Disease** is a neurodegenerative disease resulting from the death of brain cells that produce dopamine – a brain chemical that carries signals between nerves in the brain. As these cells die, the symptoms of Parkinson's Disease appear and are characterized by rigidity or stiffness of the arms, legs or neck, tremor, usually of the hands, bradykinesia or slowness and reduction of movement, and postural instability (loss of balance). Other symptoms may accompany the main features, including depression, dementia or confusion, postural deformity, speech and swallowing difficulty, drooling, dizziness on standing, impotence, urinary frequency and constipation.

**Spina Bifida** is a neural tube birth defect (NTD) that occurs within the first four weeks of pregnancy. The spinal column fails to develop properly resulting in varying degrees of permanent damage to the spinal cord and nervous system. This results in varying degrees of paralysis of the lower limbs, depending largely on the location and severity of the lesion.

**Stroke** is a sudden loss of brain function. It is caused by the interruption of flow of blood to the brain (ischemic stroke) or the rupture of blood vessels in the brain (hemorrhagic stroke). The

interruption of blood flow or the rupture of blood vessels causes brain cells (neurons) in the affected area to die. The effects of a stroke depend on where the brain was injured, as well as how much damage occurred. A stroke can impact any number of areas including your ability to move, see, remember, speak, reason, and read and write.

**Tourette Syndrome (TS)** is a neurological or "neurochemical" disorder characterized by tics -- involuntary, rapid, sudden movements or vocalizations that occur repeatedly in the same way. The most common first symptom is a facial tic, such as rapidly blinking eyes or twitches of the mouth. However, involuntary sounds such as throat clearing and sniffing, or tics of the limbs may be the initial signs. For some, the disorder begins abruptly with multiple symptoms of movements and sounds.

