Guidelines for PIECES of my RELATIONSHIPS

"It's about belonging to a community." – Elder Jerry Otowadjiwan

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1.0 Introduction and Background

Age-related dementia is a growing concern among Indigenous communities in Canada. The number of First Nations people over the age of 60 is expected to more than triple in the coming years to 184,000 plus by 2031 (Caron Malenfant & Morency, 2011). Indigenous communities report that memory loss seems to be more frequent (Sutherland, 2007), which is supported by research suggesting rates of dementia are 34% higher in First Nations communities and increasing faster than in the general Canadian population (Jacklin, Walker, & Shawande, 2013). Researchers also found that average age of onset was 10 years younger, and that First Nations men were diagnosed more often than in the general population (Jacklin & Walker, 2012). Indigenous populations may be underdiagnosed, due to lack of access to health care, physician attitudes toward dementia, and the historic relationship between Indigenous people and the health care system (Jacklin & Walker, 2012). Many Indigenous people with dementia and their caregivers value aging in place, surrounded by loved ones and on familiar territory (Hulko, Antifeau, Arnouse, Bachynski, & Taylor, 2010; Jacklin, Pace, & Warry, 2015; Lombera, Butler, Beattie, & Illes, 2009), and present with unique health and social service needs.

Ensuring equitable access to dementia services requires that dementia care strategies for Indigenous peoples be culturally grounded and culturally safe. Currently available dementia care strategies and tools have been shown to have varying degrees of cultural, educational and language bias, impairing their application in Indigenous communities. Through support from the NELHIN, Mamaweswen, the North Shore Tribal Council, and Dr. Kristen Jacklin's CCNA Team 20 staff, North East Behavioural Supports Ontario (NEBSO) began developing an Indigenous Engagement Strategy in 2014 to increase outreach and adapt services and tools as necessary to better support Indigenous communities. A partnership between NEBSO and Dr. Kristen Jacklin's CCNA Team 20 staff was established to address the need for culturally safe dementia care strategies and tools. This guide outlines the process for adaptation of the PIECES of my PERSONHOOD tool for use with Indigenous people in the catchment area of the North East Local Health Integration Network (NELHIN); offers examples and details to assist in appropriate approaches when implementing the adapted tool; and contains recommendations for continued relationship development between the NEBSO and local Indigenous communities.

The PIECES of my PERSONHOOD tool is a foundational component of behavioural care planning used by NEBSO team members, grounding the person and their unique lived experience as central to their care from the beginning. The original PIECES of my PERSONHOOD tool was developed in 2012 through a Kaizen event engaging various NEBSO care partners. The purpose of the tool is to uncover pertinent details of the individual's personhood that can be incorporated into care planning, and create understanding amongst the person's care partners that these elements are important. All persons who use the tool receive education on proper administration. Typical administration would be formatted as a casual conversation with the individual or their substitute decision maker rather than a structured formal assessment approach (NEBSO, 2013). The tool may be completed over a period of multiple visits, as the care provider builds a relationship with the older adult or their care partner. In some cases, the individual may wish to complete the tool on their own, in which case an NEBSO staff would first meet with the person to explain the tool and how the information is to be used, and debrief following receipt of the completed form to clarify any areas where necessary. The information is then used to inform behavioural care plans, and may be posted with consent in the person's room, with the more sensitive components redacted; for example, *significant low point(s) in life/trauma*.

This tool is named after a term first coined by Thomas Kitwood in 1997. According to Kitwood (1997), personhood is "a standing or status that is bestowed upon one human being, by others, it implies recognition, respect and trust," and is integrated into every aspect of NEBSO services. Basing care plans on each individual's personhood allows care partners to meet the needs of the person with dementia, including their need for comfort, safety, inclusion, occupation, and identity (Kitkwood, 1997). Responsive behaviours are the individual's way of communicating when these needs are not met, and learning about their personhood allows us to understand their way of communicating, and understanding how their needs can be met.

Personhood is one of several aspects reviewed by NEBSO teams when a referral is received, and fits into the larger holistic P.I.E.C.E.S framework (Hamilton, Harris, Le Clair, & Collins, 2010) that guides all NEBSO assessments, and seeks to identify unmet **p**hysical, **i**ntellectual, **e**motional needs as they interact with the person's **c**apabilities, **e**nvironment, and **s**ocial history.

Through discussions between NEBSO staff and Dr. Kristen Jacklin's CCNA 20 team, it was identified that the concept of "Personhood" in the context of how an individual views themselves may not be relevant for Indigenous populations, but rather, importance is placed on the person in the context of their relationships. The teams agreed to adapt the PIECES of my PERSONHOOD tool into the PIECES of my RELATIONSHIPS (working name pending feedback from our Indigenous partners) in order to learn information that could support Indigenous patients in a way that is culturally safe.

1.1 Cultural Safety

Culturally safe care and tools are considered a best practice remedy for the situations in which colonial history (section 3.5) bleeds into clinical practice (Hole, Evans, Berg, Bottorf, Dingwall, Alexis, Nyberg, & Smith, 2015). Originally developed by Maori nurses in New Zealand, cultural safety has been useful in addressing health care gaps (Smye & Browne, 2002). While cultural safety might not seem different from awareness or sensitivity, it asks more of health care providers. Providers are asked to take responsibility for introducing cultural safety into their practice and to address inequities however and whenever possible. Some providers find it useful to consider cultural safety as the final destination on a spectrum of learning (Jacklin et al., 2016).

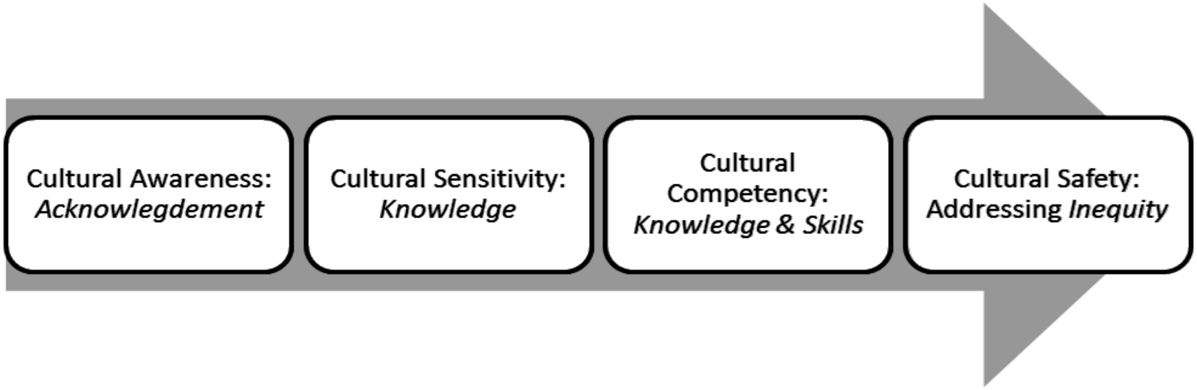

Figure 1: *Cultural safety spectrum as described by Jacklin et al. (2016) at AAIC 2016.*

Cultural safety embodies a **change in attitude**. In culturally safe care, it is the responsibility of the health care system to adjust to the needs of the person seeking care, and not the responsibility of the person seeking care. It recognizes that certain groups of people are more vulnerable in health care encounters than others and seeks to **address that inequity** (Baker & Giles, 2012). It is also **widely applicable** among professions; doctors, nurses, specialists, personal support workers, therapists, and many others can benefit from cultural safety training and use it to improve practice. With cultural safety the focus is on adapting the behaviours and approaches of providers and organizations, not those of the patient and families. Of particular importance is that cultural safety is measured by the people receiving care, not by the health care provider.

The adaptation of the PIECES of my PERSONHOOD tool, and the development of this guidebook is grounded by a cultural safety framework developed by Jacklin et al. (2016). This cultural safety framework grew out of our original *Perceptions* work and the ongoing work with the north east communities during the CCNA. It does not replace cultural safety training or training regarding Indigenous history. Those who wish to use the PIECES of my RELATIONSHIPS tool are expected have basic knowledge of colonial history and how it has impacted local Indigenous communities.

1.2 Key Terms

Throughout this guide and the adapted tool, we will be using consistent language. Some key terms you might encounter include:

1.2.1 *Dbaajmowaanhsan* (Small Stories)

Each section of the guide contains small stories from participants involved various dementia research projects related to aging and brain changes in Indigenous communities. The Community Researcher calls these Dbaajmowaanhsan, and they offer deeper insight into the reasons behind certain guidelines.

1.2.2 Loved one

The term “loved one” is used to describe a person with dementia. Although mainstream practice and current recommendations suggest steering away from using the term “loved one”, our Indigenous partners have expressed that this term is appropriate for use in Indigenous communities. Elder, Jerry Otowadjiwan teaches that the person with dementia is in need of a lot of love at that point in their lives. They are also loved by someone, whether that person is the caregiver or not. Using the term “loved one" serves as a reminder of how care providers should be treating and respecting the person with dementia.

1.2.3 Second Childhood and Coming Full Circle

The terms "second childhood" and "coming full circle" are culturally-rooted descriptions of cognitive impairment in later life. They do not come from an insulting place. In fact, it is considered a natural process and is accepted by families and communities. In the *Perceptions of Alzheimer's Disease and Related Dementias among Aboriginal Peoples in Ontario* project[1], these terms came up often:

> *"Well, for me it is a natural process. I think that if you, you know, like again, back to being a child as you get older as we get older to the point of as, so as, like a child. We have to, a child has to learn to walk so how to, you know, it's a, you forget how to... going back to being a child, like an infant so it's like I said. We finished our circle of life, you know?" (Senior, Manitoulin Island, Perceptions Project)*
>
> *"The older people they always refer to that term of going back into their childhood, but they use the Anishnawbe word for that, and that term is "keewayabinoocheeaway." That's returning back to childhood." (Senior, Thunder Bay, Perceptions Project)*
>
> *"He has or she has back to her childhood again. Like the person has lost all her memories in her future life and she was going backwards into her childhood. I remember that." (Loved one, Sudbury, Perceptions Project)*

1.2.4 Covered or Buried Memories - *Ni-ngoshkaani wi gaa gkendang*

"Covered" or "buried" memories are another way of describing the onset of memory loss. This perspective is rooted in the Anishinaabemwin language, and memories are not viewed as "lost." Rather, they are buried, and inaccessible to the loved one at this time. This way, their identity, roles, and knowledge remain with them, but are covered for the time being. Memories that are covered might be brought to the surface again by sounds, smells, or other stimuli. This is particularly the case with important, cherished childhood memories.

> *Wenesh e-moonji zaagtoowin?*
> What is something that you love and cherish?
>
> *Wenesh gaa waamndaman gii bi-nojiinhwiyin?*
> What are the things you loved as a child?
> (Anishinaabeg Language Expert Group)

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[1] The *Perceptions of Alzheimer's Disease and Related Dementias among Aboriginal Peoples in Ontario* was led by Dr. Kristen Jacklin and Dr. Wayne Warry. The purpose of this research was to speak with Indigenous people with dementia, their caregivers, healthcare practitioners and other key informants in order to gain knowledge about the attitudes, beliefs and behaviours related to Alzheimer's disease and other dementias in diverse Indigenous communities in Ontario. This research took place from 2009-2014 across six geographic and culturally diverse research sites and involved 168 participants. For more information go to https://www.i-caare.ca/indigenous-perceptions-of-dementia. To read the community reports, go to https://www.i-caare.ca/reports.

2.0 Building Relationships

The North East Behavioural Supports Ontario (NEBSO) Indigenous Strategy was developed in response to a need identified by key NELHIN and NEBSO partners during discussions in January 2014. Dr. Kristen Jacklin, from the Northern Ontario School of Medicine (NOSM) was asked to serve as an advisor on the NEBSO Indigenous Engagement Strategy due to her expertise in Indigenous dementia research.

Dr. Jacklin has 18 years of experience working with First Nations, and particularly with the First Nations on Manitoulin Island. She has expertise in participatory and community-based health research with Indigenous populations, Indigenous health policy, cultural safety, qualitative methods, and cross-cultural medical education. Dr. Jacklin is a principal investigator on the Canadian Institutes of Health Research funded Canadian Consortium on Neurodegeneration in Aging (CCNA) and co-leads the team concerned with Indigenous and rural dementia care, also known as CCNA Team 20. For more information about this work and other resources and activities related to Indigenous cognition and aging, go to www.i-caare.ca.

Behavioural Supports Ontario was created to enhance health care services of older adults with, or at risk for, responsive behaviours associated with dementia, complex mental health, substance use, and/or other neurological conditions. Inclusive in this mandate are adults with age-related neurocognitive conditions (such as early onset dementia) and support for family and professional care partners in any setting where they might reside.

Initially, NEBSO was hoping to strengthen partnerships with Indigenous communities and partner organizations, and wanted to find a way to increase accessibility and applicability of services. It was identified that if they could increase awareness of services offered and provide services that are sensitive to the unique cultural needs of Indigenous peoples, they would be able to better support these communities. The strategy has five key areas for action:

1) Improved outreach/access of services to/with Indigenous communities
2) Education on dementia/responsive behaviours provided to care partners in Indigenous communities
3) BSO staff continuously pursuing opportunities to participate in cultural sensitivity training (to be able to provide culturally safe care)
4) Development of a “Core Competency” related to providing culturally safe care to Indigenous persons, as part of the BSO Core Competencies
5) Development or adaptation of culturally safe tools (such as PIECES of my RELATIONSHIPS)

A Kaizen[2] working group meeting was held on June 12, 2015 to bring together NEBSO staff and community partners to work towards key areas 4 and 5 of the Indigenous Strategy. Dr. Jacklin’s team participated in the event. Partners from Mamaweswen, the North Shore Tribal Council were asked to identify individuals to review the existing PIECES of my PERSONHOOD tool and Core Competencies and contribute to the development and adaptation of culturally safe tools and competencies.

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[2] Kaizen is a Japanese word that means continuous improvement.

2.1 Adaptation process

Follow-up meetings were held between NEBSO care providers and Dr. Jacklin's research team to discuss the next steps. A formal plan to adapt the PIECES of my PERSONHOOD tool was established in the spring of 2016. The groundwork for the adaptation took place in the fall with focus groups being conducted in spring of 2017.

The current PIECES of my PERSONHOOD tool is used by NEBSO staff and partners in the care of those supported by the initiative. The care team, the older adult, and their care partners work together to identify information that should be shared with health care providers, including preferred name, favourite foods and memories, important spiritual practices, and who loved ones are. The older adult and their care partner shares only what they wish to share and the tool is a living document that keeps staff updated on the preferences of the person (Appendix A). Some examples of how this tool is used in practice are to develop individualized interventions and supports for the older adult, explore how past experiences may impact current responsive behaviours and positive experiences around care, and to build a better therapeutic relationship with that person. The tool is not a diagnostic tool or a legal document. The tool can be used anywhere the patient lives, and is shared across care transitions.

The adaptation was an iterative process between CCNA Team 20 and NEBSO staff. CCNA Team 20 consulted Elder Jerry Otowodjiwan and the CCNA Team 20 Anishinaabeg Language Expert Group. Elder Jerry Otowodjiwan regularly provides Team 20 with spiritual guidance and advice to make sure that their research is conducted in a good way. He met with Team 20 on September 1, 2016, to review the PIECES of my PERSONHOOD tool and guide the team in the adaptation by focusing on approach, asking the questions in a good way, and being aware of the use of nonverbal cues. He stressed the importance of taking the time to build a relationship, this includes sharing information about yourself, who you work for, why you are there, what you would like to discuss, and when would be a good time to come back and ask those questions, all in a gentle, non-direct way. This initial conversation with Elder Jerry helped the team prepare for the larger group discussion with the Anishinaabeg Language Expert Group.

The Anishinaabeg Language Expert Group is composed of fluent Anishinaabemwin language speakers from the seven First Nations on Manitoulin Island. They are known in their communities for their knowledge of the language and deep understanding of culture. The Language Group works with CCNA Team 20 on a variety of projects. Team 20 and staff members of NEBSO met with the Language Group on September 19, 2016 and October 17, 2016. Both meetings were facilitated by Karen Pitawanakwat, the community researcher, who is a fluent Anishinaabemwin speaker, and were audio recorded. Karen used a PowerPoint presentation to help guide the conversation. The Language Group discussed each category from the PIECES of my PERSONHOOD tool, starting with how to approach an older Indigenous adult to how to ask the different questions. They also stressed the importance of taking the time to build a relationship and to be mindful of nonverbal cues. Within each category, the Language Group discussed key concepts and shared stories on how they understood what the question was asking. The Language Group then discussed how the question would be worded in Anishinaabemwin to get at the core concept of each category and back translated to English. The key concepts from both meetings were brought back to CCNA Team 20 and NEBSO staff members to discuss and further analyze.

Once key concepts had been applied to the tool, a draft PIECES of my RELATIONSHIPS tool was brought to three focus groups in geographically and culturally distinct areas. One focus group was held in the North Shore region, between Sudbury and Sault Ste. Marie, Ontario. This group was comprised primarily of older Anishinaabeg adults who live on reserve in a rural context. The second focus group was held in Sudbury, Ontario, an urban context, and participants belonged to several nations. The third group was held in Cochrane, Ontario, and attended not just by participants from around the Cochrane area, but by participants from Moose Factory on the James Bay coast. Participants were providers, older adults, and caregivers from the Cree nation in these regions. The locations were chosen to represent as much of the NEBSO's catchment area as possible given the constraints of the project, and to get a mix of urban, rural, and remote perspectives. The stories, comments, and concerns of these participants shaped the PIECES of my RELATIONSHIPS tool significantly. Participants suggested new categories, new questions, adapted wording, and discussed the best approach that staff using the tool could take when working with older Indigenous adults in their communities. While there were differences between regions and communities, key aspects of the tool and approach were met with consensus; for example, that a trauma-informed approach (see section 3.6) is utilized and that first language preferences are prioritized. The tool was finalized by the research team and this guidebook was created both to provide education to NEBSO staff and to honour and share the voices of the participants who so generously shared "pieces" of their experiences and relationships with us.

2.2 Building the framework for Indigenous specific dementia resources and tools in Ontario: Previous and Associated Research

A growing concern was highlighted in January of 2007 when First Nations Health Authorities in the Manitoulin District, Ontario, identified the need to address memory loss in aging in their communities. In March of 2007, Mnaamodzawin Health Services Inc. and Noojmowin Teg Health Centre held a roundtable forum on Alzheimer's disease and other dementias concerning Indigenous peoples. At this forum, communities came to a consensus that dementia was indeed a growing problem, and that more information was needed for planning (Sutherland, 2007). Two years later, Drs. Kristen Jacklin and Wayne Warry embarked on a five-year research project titled "Perceptions of Alzheimer's Disease and Related Dementias among Aboriginal Peoples in Ontario" to learn more (also referred to as the "*Perceptions Project*").

Using community-based, qualitative research methods, they interviewed older Indigenous adults with and without memory loss, and Indigenous caregivers of people with dementia in 6 unique geographic areas in Ontario. They also held focus groups with health care providers in each area. With stories from 168 participants from Moose Cree First Nation, Thunder Bay, Manitoulin Island, Sudbury, Ottawa, and Six Nations, key themes about dementia in Indigenous communities emerged. The findings have been shared back with participating communities and built upon to address gaps within dementia care for Indigenous people, their families, and communities. Additional knowledge translation activities include presentations (Jacklin & Warry, 2011; Jacklin et al., 2016), an article about Indigenous caregiving (Jacklin, Pace, & Warry, 2015), factsheet development for Health Canada (www.i-caare.ca/factsheets), and cultural safety curricula specific to dementia.

2.3. Using the PIECES of my RELATIONSHIPS tool

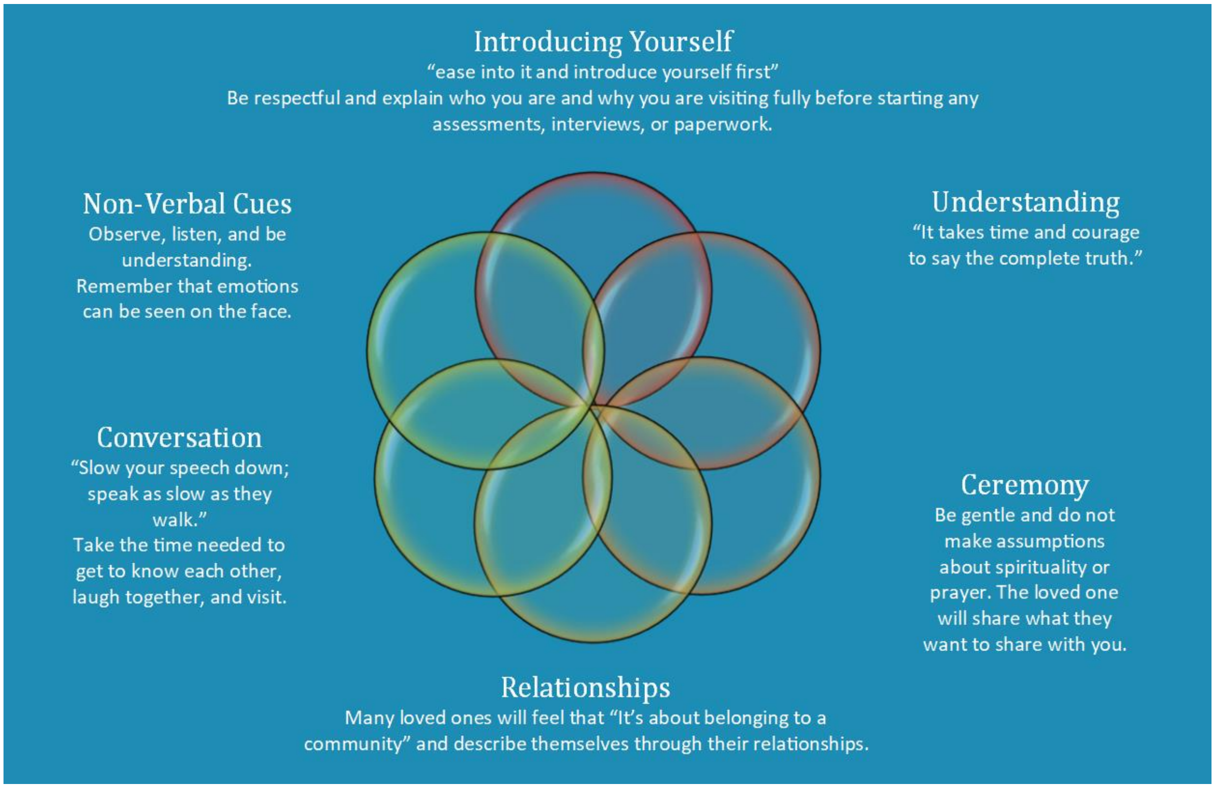
Approach

Elder Jerry and the Language Group stressed the importance of approaching older Indigenous adults the right way. Allow ample time to build trust and develop the relationship. This includes sharing information about yourself with the loved one. Use a soft or gentle tone and try to use indirect questions. Participants suggested bringing a small gift, like some food or a cup of tea to share. Explain the purpose of the tool and ask if they would prefer to use the mainstream tool or the adapted tool. Some people may feel comfortable answering the questions in one sitting, while others may want more time to think about their answers or have family help them go through the tool.

> *That was so important. We heard that over and over again. Make sure the visit is special. (Karen PItawanakwat, Community Researcher)*

Nsaaknigewin wii nbwaach'iding – opening the door; a spiritual encounter

The interlocking circles in the diagram below represent the interconnectedness of all aspects of your growing relationship with the loved one. Depending on the encounter you are having together, you might travel closer to the heart of this relationship or you might be farther out. The following section of this guidebook will explore each aspect of the interconnected approach to the PIECES of my RELATIONSHIPS tool.



Introducing Yourself
"ease into it and introduce yourself first"
Be respectful and explain who you are and why you are visiting fully before starting any assessments, interviews, or paperwork.

Non-Verbal Cues
Observe, listen, and be understanding.
Remember that emotions can be seen on the face.

Understanding
"It takes time and courage to say the complete truth."

Conversation
"Slow your speech down; speak as slow as they walk."
Take the time needed to get to know each other, laugh together, and visit.

Ceremony
Be gentle and do not make assumptions about spirituality or prayer. The loved one will share what they want to share with you.

Relationships
Many loved ones will feel that "It's about belonging to a community" and describe themselves through their relationships.

Figure 3: *An interconnected approach to P.I.E.C.E.S. of my Relationships.*

2.3.1 Introducing Yourself

Mii go zhiwe ni-mooksemgag waani zhi nbwaach'iding – beginning of a thought and the growth of an idea; a powerful spiritual time together

Be respectful and ease into introducing yourself. Make sure to tell the loved one who you are and why you have come to see them. Explain that you are speaking to many older adults, and that you have not singled them out. You may wish to share your spirit name, clan, and a story about yourself (see section 3.4). It is important for them to know which communities and families you come from. If it is morning, ask if they had a good sleep, but don't ask about dreams, as these are deeply personal spiritual experiences, and considered private. The loved one may be more comfortable talking to an older person than a younger person.

> *"And if it has to be a young person gathering this kind of information, that they ease into the introduction. That they're not just going in there and asking information, that they really take it casually and indirect, and that they ease into it and introduce themselves first. They talk a little bit about themselves as the young person. What family they come from... all those kinds of things are important." (Karen Pitawanakwat, RN, Manitoulin Island)*

2.3.2 Understanding

Gmoozh'aa gego e-zhiyaad – you feel and know you are in the presence of the loved one's energy

Remember that you are in the loved one's personal space. Whether you are in their room, house, or apartment, this is their home. Begin by giving the loved one an idea of what you will be asking. Reassure them that you will not press for any answers that they are not ready to share or that they feel are private. Explain also that they are not the only loved one you are visiting, and that you are asking many people for their stories. This way, they will not feel singled out or picked on. The loved one may repeat themselves or need time to think on a question. Certain things may be harder for them to do than they were years ago.

> **Sensing another Energy**
>
> *Sometimes what happens is you feel another person. For example, I may go see someone. I would ask them something and in turn they may think – I am not going to talk to you – they are not comfortable with me asking questions. And then again sometimes someone else may go over there. The person being asked the questions would immediately start telling their story they talk about everything. I know this happen to me…when my son died I was getting invites from all over, I didn't want to go anywhere I didn't know what I wanted. It wasn't until my younger siblings showed up that's when I knew what I wanted, my sisters. And this is what happens, you feel the other person –* ***Gmoozh'aa gego e-zhiyaad*** *– if they have a mean heart you feel this. This is what I think; a baby, this happens to them too. A baby knows when you aren't thinking about the baby out of love with good thoughts, when you are treating the baby badly. It is exactly the same with someone of old age, we become the same way. A baby is afraid fearful at birth, and we become fearful again in old age. This is what I think about when I reflect, you feel it right away when you walk into a room. (Translated from Anishinaabemwin - Anishinaabeg Language Expert Group)*

If the mood seems off today, offer to return another time. Children and older adults in particular are more sensitive to energy and mood. Participants in Sudbury shared that what was important to older adults as younger people might not be part of their everyday lives anymore. They suggested offering small, thoughtful supports.

> *Then I noticed when she was sitting outside, they supplied hats for the sun in the afternoon, because there's lots of sun where she is. So I said, 'Do you want me to buy you your own hat? Is that your hat?' And she said, "No it belongs to the activity.' So I said, 'Okay, I'll get you a hat.' So I went up there the other day and she said it blew off. So the next time I go, I've got to tie some little things so that if it blows off it's not going to be on the ground because she can't stoop to pick it up. So I said, 'Next time I come, I'll sew some little things in there so that if it blows off it'll blow on your shoulders and then you won't lose your hat.' So she says, 'Okay.' You know, there's a lot of things you can do. Little things. (Sudbury Focus Group)*

2.3.3 Ceremony

"Ceremony is everywhere" – Elder Jerry Otowadjiwan

If the loved one follows a spiritual path, you may wish to bring an offering of tobacco[3] and a small gift that they will enjoy (e.g. food). It is very important not to interrupt the loved one while they are talking. Some of the Language Group members felt that asking about spirituality, religion, or cultural traditions was too personal and suggested other question that might make it easier for the loved one to answer.

> *Aaniish gegii eshchigeyin wii miigwech wendman?*
> *What are some of the ways you express you are thankful?*
>
> *Aaniish gegii eshchigeyin wiya aakzid?*
> *What do you do when someone you love is sick?*
>
> *Wiika na debenjged gnakwetaak nam'aayin?*
> *Did the Creator ever answer a prayer for you?*

Be gentle and do not make assumptions about spirituality or prayer. The loved one will share what they want to share with you.

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[3] Tobacco is considered one of the four sacred medicines (sweetgrass, sage, and cedar being the other three) and is used by First Nations and Metis people in ceremonies, assist with prayers, give offerings, and ask for requests. The tobacco offering can be in the form of a tobacco pouch or tie (loose tobacco wrapped in a small piece of broad cloth). No additive loose tobacco, ceremonial tobacco or kinnickinnic may be used. Tobacco should not be handled by women on their moontime or people who are within their one year of grief after the death of a loved one. In preparing your offering, think about what you are requesting of the loved one. When you offer the tobacco pouch or tie to the loved one, be specific in what you are requesting of them. Protocols may differ according to region and cultural practices followed. Please ask the community you are working with what protocols you should follow before visiting with the loved one.

2.3.4 Relationships

"It's about belonging to a community." (Elder Jerry Otowadjiwan)

Be understanding of the importance of family attachments and relationships. The loved one may view themselves as part of a larger whole, with distinct roles based on what they bring to the fabric of their community and nation (e.g. grandparent, Elder, knowledge keeper, storyteller, auntie, etc.). These roles may also be based on their clan.

> Wenesh kitsiimag*? – Who are your parents?*
>
> *Wiya na gna-naakwenmaak? – There are little pieces of things you can no longer do in life. Who catches those for you and helps you to continue to live as full as you can?*
>
> *(The Anishinaabeg Language Expert Group)*
>
> **Come Back Again!**
>
> *I did this kind of work, visiting the elders. That is what I did, I prepared them for my visit beforehand. I said: I am going to be around tomorrow what would be an opportune time to come? And then I asked: what food do you enjoying eating?, what can I bring with me? I can pick it up at the store. They will tell you. I start visiting and even when I am leaving they say: I really hope you come again, come back again we will visit again they say. I worked with an elder once while he was still able we made a farm fence together, there were many of us. I got used to this elder. Later on I was in a meeting (language gathering), I sat with a nephew of the elder. I mentioned to the nephew how his uncle and I visited and really got along, he answered in surprise: oh wow! I try go visit my uncle sometimes, he doesn't visit me at all. So this is a miracle how you were able to do this! and this is why we were able to have this experience cause we got to know one and other while working on that fence, this elder knew me – he told me to come back there will be some more to talk about when you are around again he said. Elders miss this it makes them lonely –* ***Mme-ndaaji nbwaachwewag*** *- this is how I find them. (Translated from Anishinaabemwin - Anishinaabeg Language Expert Group)*

Independence is viewed in the context of relationships. Older adults are expected to do what they can and receive support as the need arises. Helpers will take on different "pieces" at the direction of the older adult. To be "monitored" or "taken care of" comes with the negative connotation that you can no longer care for yourself.

2.3.5 Conversation

Zhigiizhwewin – dialects; a different way of saying something, understanding is still conveyed

Remember that the loved one may prefer to speak in the language, and that dialects change by community and region. Speak with kindness and respect, taking care not to insult or interrupt. Remember that humour is good for the spirit. Some of what they are sharing may be difficult to share or not have been shared in many years. Be patient.

> *"Slow your speech down; speak as slow as they walk."*
>
> *"We're not used to talking about ourselves; we are a humble people."*
>
> *(Elder Jerry Otowadjiwan)*

2.3.6 Non-verbal Cues

"It takes time and courage to say the complete truth" (Anishinaabeg Language Expert Group)

Pay attention to the non-verbal cues the loved one is communicating. Observe how they look when they are thinking or working hard to remember something. Listen to the tone of their voice. Are they comfortable, joking, or sharing something especially important? Be aware of trauma and the loved one's response to trauma – emotions can be seen on the face (see 3.6 Trauma-Informed Approaches with Indigenous Populations).

> *"As soon as they nod their head that means you have to be quiet for a little while, because they're in thought. They want to put it in a way that is going to come out right, whatever they're going to say." (Elder Jerry Otowadjiwan)*
>
> *"When they start to speak, the elderly people, we have to stop. Just listen. No questions until they're done. They won't say, 'okay I'm done.' They won't say that. They'll look down and stop for a while, then when they're done, they'll look at you. They won't say nothing. They'll just look at you. That means they're finished." (Elder Jerry Otowadjiwan)*

3 Considerations for using this tool

3.1 A wholistic view of health vs. biomedical understandings

Members of the Anishinaabeg Language Expert Group and Elder Jerry Otowadjiwan described health in wholistic ways. The "w" in wholistic is used by many Indigenous scholars and healers to differentiate Indigenous wholism from holistic health practices in the Western health care system. This means that health is viewed as more than just physical and is treated as such. It is also distinct from biopsychosocial models of health in that there are spiritual and emotional components included in this view. Further, the person is viewed in the context of their family, clan, community, nation, and the world; never in isolation.

For example, many of the Anishinaabeg participants in the *Perceptions Project* used the medicine wheel to describe the prevention of memory loss and maintenance of overall health.

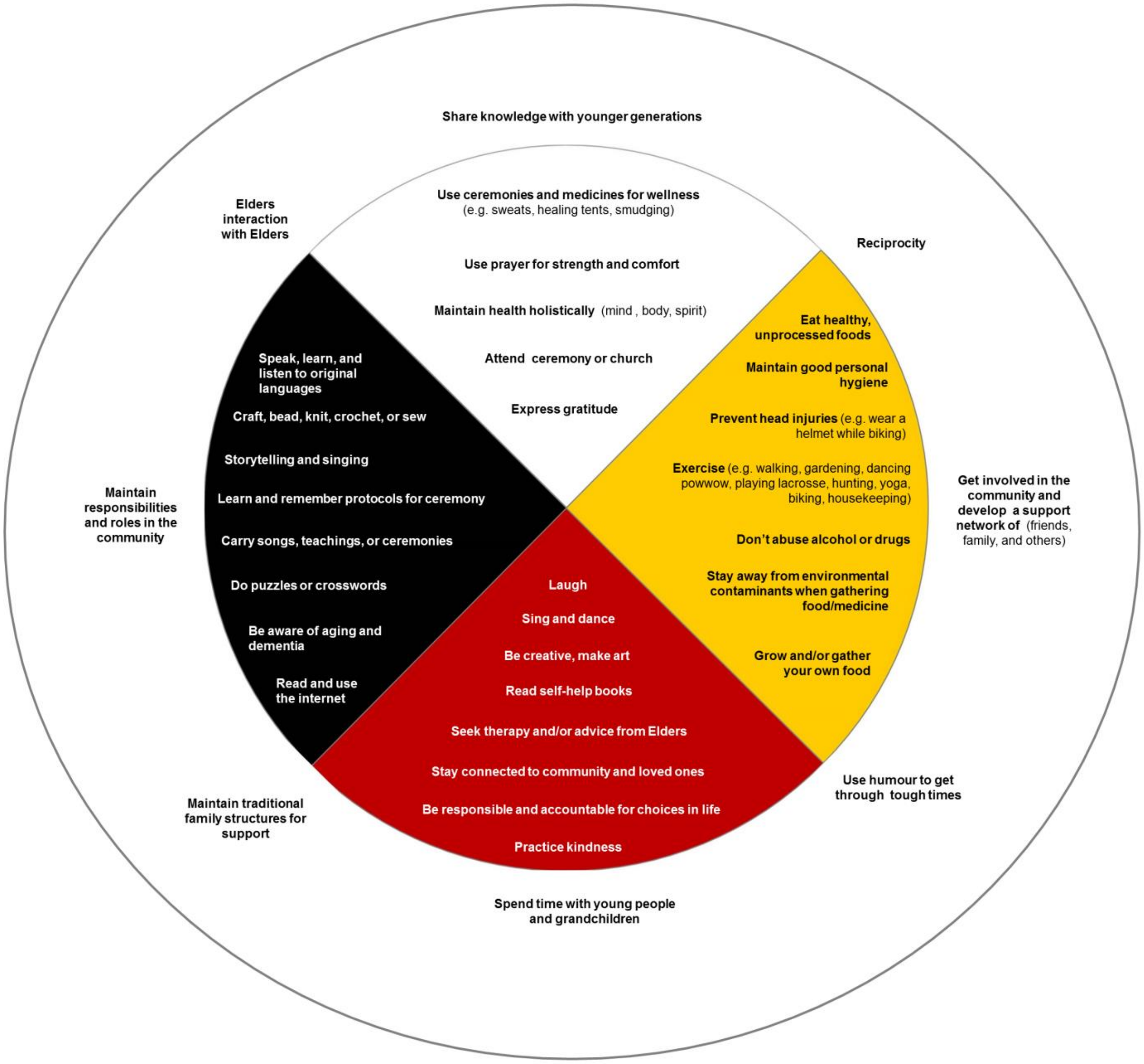

Figure 4: *Medicine Wheel for preventing dementia developed using participant voices from the Perceptions Project in collaboration with Elder Jerry Otowadjiwan and the CCNA Advisory Group. For a pdf version of this medicine wheel and more information, visit www.i-caare.ca/factsheets.*

3.2 Dementia and aging are grounded in Indigenous knowledge and culture

This speaks to the importance of meeting loved ones and caregivers where they are culturally as well as geographically. Dr. Jacklin and her team repeatedly heard that aging and memory are natural parts of the life cycle and are accepted by family and community members. Dementia was often described as a "second childhood," meaning that the loved one was literally travelling back to the Creator along the circle of life. This was also described as "coming full circle." There was often acceptance of visions as spirit-driven, rather than as hallucinations.

> *Elders with dementia [are] in a time of preparation to leave this physical earth. When the Elder with dementia is not making sense in conversation or talking about another place or time that is*

> *not being experienced by all those listening, their spirit is actually travelling and amongst their next life (after life experiences/on the other side). These experiences are verbally passed on in stories and not considered hallucinations but a real part of what we know as the circle of life* (Language Group meeting Nov 16, 2015).

> *Well, for me it is a natural process. I think that if you, you know, like again, back to being a child as you get older as we get older to the point of as, so as, like a child. We have to, a child has to learn how to walk so how to, you know, it's a, you forget how to, like, going back to being a child, like an infant so it's and, ah, like I said, we finished our circle of life, you know? (Wikwemikong Senior)*

> *The Code talks about, it's more of a natural thing, it's not looked at as a disease, you know, some people go back that way and, and this is how they're going back to the Creator. (Knowledge Keeper, Six Nations)*

The influence of culture on how community views dementia positively impacts the experience of dementia for loved ones and caregivers. Indigenous perceptions of dementia fostered healthy family and community caregiving, promoted self-care, and helped maintain balance using teachings like those of the Medicine Wheel.

> *Oh yes because you can't participate in them [spiritual activities] if you drink or do drugs. I don't know what it does, dancing, not only lifts your spirit but I guess brings up whatever you need in your mind to need... what do you call those things... like the serotonins and chemicals, yeah to bring 'em up. (Senior JK04, Ottawa)*

While Indigenous cultural perceptions had positive impacts on the dementia experience, other aspects of Indigenous experience did not. Historic and ongoing colonization disrupted supports for healthy aging such as Elder roles, access to healthy foods and activities, and cultural resources. Loved ones, older adults, and caregivers spoke about the trauma of residential school experiences, forced relocation, industry pollution of the land, stolen children, and removal of culture.

> *Being around the kids is actually healing for the elderly too, because you have the kids and they're engaging in new things with you all the time, so that's good for the memory so, and because of a lot of the residential schools incidents too, that has also affected the family dynamic so you find a lot of grandparents just isolate themselves so families are not there doing their role as a grandparent's roles, eh? Which actually keeps you young... (Traditional Healer from Manitoulin, Perceptions Project)*

3.3 Caregiving

Culture also affects the experiences of both formal and informal caregivers. It influences the amount of care that is provided to the individual in need, who is responsible for the delivery, and how caregivers perceive this duty. In turn, culture has an effect on caregivers' coping strategies, self-care routines and their use of support services (Dilworth-Anderson & Gibson, 2002). Canadian research suggests that Indigenous caregivers underuse mainstream care services. This is often due to poor access, preference for informal caregiving within communities, and lack of culturally safe services (Buchignani & Armstrong-Esther, 1999; Habjan, Prince, & Kelley, 2012).

> *I don't think she would do well in non-Aboriginal programs so trying to find programs that are specific to our culture is hard. (Caregiver from Sudbury, Perceptions Project)*

> *Participant 1: A couple ladies here... --, her husband is in a home in Timmins. It's sad. It's sad seeing that. She's only there for three hours, and it's her husband, and she has to travel back to Moose Factory. And she lived with him all her life. That's the down side. Separated. Just her not living there too, to him day to day. It's hard.*
> *Participant 2: He has dementia.*
> *Participant 1: but he comes out of it for two minutes or so and he knows her, and that's when the greatest smile, the smile that lasts for a couple of minutes comes. That he knows her for that moment. But he's always saying 'home.' (Cochrane Focus Group)*

Caring for loved ones in the community, and within the family, is considered a duty and an important role by many Indigenous people.

> *"That the cultural idea, the cultural piece for me is that accepting the role that we care for, you know, our elders, for me that's just a given." (Caregiver from Sudbury, Perceptions Project).*

> *Wiya na gna-naakwenmaak?*
> There are little pieces of things you can no longer do in life. Who catches these for you and helps you to continue to live as full as you can?
> (Anishinaabeg Language Expert Group)

> *Ah, I think what made it easier or more natural is that being Aboriginal that's one of the traits is family care. And it became an automatic sort of thing too . . . even though we made have had [to] fight so that traditional feeling was still there as being family and so that, that made it easier. (Caregiver from Six Nations, Perceptions Project)*

At the same time, caring for an Indigenous loved one has unique challenges. Due to high rates of diabetes, heart disease, arthritis, and other disorders, diseases and disabilities are often co-morbid with dementia in older Indigenous adults. Indigenous caregiving also occurs within a unique set of policies impacting access to care and medications and, in many cases, is carried out in isolated communities. Studies have found that **upwards of 80% of caregiving for the elderly in Aboriginal communities is informal care provided by spouses, siblings and children.** Older Indigenous adults are also more likely to be living in larger family structures and households and are often providing care to young children (Buchignani & Armstrong-Esther, 1999).

Caregivers in Indigenous communities are most often women, and often rely on spirituality to cope (Jacklin et al., 2015). They report finding caregiving rewarding, but also experience stress concerning the quality of care they are providing (Jacklin et al., 2015; Jervis, Boland, & Fickenscher, 2010), the psychosocial aspects of care, strains on family relations, and negative effects on personal well-being (Hennessy & John, 1996). Common issues faced by Indigenous caregivers include role conflict, negative feelings, doubt concerning caregiving abilities and guilt (Wade, 2008). Other major burdens carried by caregivers include financial stress, sleep deprivation, fear about their loved one's future, and emotional and spiritual drain (Bourassa, Blind, Jacklin, Oleson & Ross-Hopley, n.d., forthcoming UBC Press).

> *I think a lot of that has to do with our spirituality, you know. Like every day, for me anyways, I put my tobacco down and ask for guidance for that day to be strong. (Manitoulin, JPCG02)*
>
> *And ah, yeah I believe that, one other thing to that I had prayed about, in fact, was that I would become a more compassionate person because I felt I was harsh, like I could just feel that hardness and so I had prayed that the Lord would help me to become more compassionate and through this he has. It's been a long haul, haul, you know. It's been hard. But patience comes through hard things and I believe he's given me that more compassion than I had before. (Six Nations, TMCG02)*

In Indigenous communities, the family is often viewed as the primary or sole provider of care (Buchignani & Armstrong-Esther, 1999; Chapleski, Sobeck, & Fisher, 2003; Hennessy & John, 1996; L. L. Jervis & Manson, 2002). This stems from necessity in some cases, but more often because of a cultural emphasis on familial interdependence (Hennessy & John, 1996; L. L. Jervis & Manson, 2002), and the cultural value of reciprocity (L. Jervis et al., 2010). However, dependence on family for care is sometimes the only option as many First Nations reserves do not have trained home care staff for people at later stages of dementia (Bourassa, Blind, Jacklin, Oleson & Ross-Hopley, n.d., forthcoming UBC Press).

> *I would consider moving her to a home if there was one here, yeah, where that I could regularly see her, yeah and that I, if I knew there was something here that was really culturally relevant. Like the one thing that makes my mom really happy is eating wild food. (Moose Cree, JRCG04)*

Some caregivers also set aside their own career and education goals in order to fulfill their caregiving duties (K. Jacklin et al., 2015). The struggle to balance caregiving duties with other roles was discussed with Indigenous caregivers in a Canadian study where "several participants spoke of missed work or unemployment due to the amount of time required for caregiving. Individuals needing up to 24-hour care required a nearly constant presence making employment both difficult and physically tiring" (Bourassa, Blind, Jacklin, Oleson & Ross-Hopley, n.d., forthcoming UBC Press).

This is not to say that caregiving experiences were negative. Overall, despite the challenges Indigenous caregivers face, participants in the *Perceptions Project* and in the consultation focus groups felt that caregiving was a deeply rewarding experience. Participants discussed how much they enjoyed this precious time with their loved ones, often relating this experience to the value of reciprocity by describing how they were giving back to the one who had cared for them for so long. Some caregivers also shared stories of finding new sources of joy for themselves in the care they provided.

> *We have our annual traditional powwow, and then the big powwow. So that's what I did. I took my Dad to the powwows. That's where I started dancing. I started dancing for my Dad. He'd say I don't want to go over there! I don't know anybody over there! So I said, I'll dance for you. So that's where I began dancing as a traditional dancer. I dance for my Dad. That's what I do for him, because that's what he loved. (Sudbury Focus Group)*

Further Reading:
Jacklin, K., Pace, J. E., Warry, W. (2015). Informal dementia caregiving among Indigenous communities in Ontario, Canada. *Care Management Journals, 16(2),* 106-120.

3.4 Kinship Systems and Clans

This duty is related to the value of reciprocity for some caregivers. Caregivers often shared that their loved one had cared for them as children, and that it was now their turn to provide support. This interdependent care model is supported by **kinship systems**, which are networks of extended family available to the loved one and their caregiver(s). This interdependence does not mean that the loved one is less independent; they decide who in their networks will help with which tasks and strive to continue to do as much as they can. Kinship systems support independence and aging in place. Because of this interdependence and reciprocity, the Anishinaabeg Language Expert Group felt that completing the PIECES of my RELATIONSHIPS tool would be an excellent family activity. Older adults also contribute, as they have roles in their families.

Wenesh gezhgtoowiin waazhi naadmaageyin ngo-doodiwziwin?
How you are able to help in anyway in your household?

> *"In the past, many children were raised by their grandparents for periods of time. It was difficult to care for many children born one right after another. This is where family members would help raise some of them." (Anishinaabeg Language Expert Group)*

Some loved ones may also identify with roles related to their clan. Different clans take on different roles in their communities and nations. For example, members of the Bear Clan may serve as the protectors the community or may carry knowledge around plants or medicines (Benton –Banai 1988).

> *"You're forming your character as you age. And it also follows that clan that you are, how that Clan behaves." (Elder Jerry Otowadjiwan)*

3.5 Impacts of Colonialism

Since contact, many Indigenous peoples have suffered assaults on their culture, beliefs and physical persons because of colonization. During the last century and a half, Indigenous people in Canada were forced onto reserves, placed under the Indian Act and subject to policies directed at assimilating

Indigenous people. Examples of assimilation include the banning of ceremonial practices, compulsory attendance at residential schools, forced relocation, and the removal of children through the 60s scoop.

The physical, emotional, mental, and spiritual abuses residential school survivors endured had and continue to have long-lasting traumatic effects for many Indigenous peoples. Indigenous communities face challenges created when residential schools and numerous government policies took their language, took away parenting, disrupted kinship systems and forced disconnection from culture. Many older Indigenous adults, survivors of the schools, still live with this trauma today and were unable to stop the trauma from being passed on to their children and grandchildren. Some older Indigenous adults may have returned to cultural and/or spiritual practices at one point or another in their lives, while others took solace in Christian churches. These choices and histories are exceedingly personal and will impact the loved one's worldview.

> *We had a client that went to residential school. She liked it there. She learned lots there. But on the other side, the next question, they took her language away. So you got to watch. Sure residential was good for her, but other people it wasn't. But she will never forget that they took her language away. (Sudbury Focus Group)*

The legacies of the residential schools continue today. In the mid-twentieth century, child welfare agencies began willfully participating in the removal of children under the guise of protection. Thousands of children were adopted out of healthy Indigenous families and placed with white families in Canada and the United States in what is known as the "Sixties Scoop". Screening processes were lacking and many children faced abuse in their new living environments. Others were disconnected from culture and language, and grew up feeling like something was missing. Though child welfare agencies have modernized considerably, due to the continuing impacts of residential schools in the form of intergenerational trauma as well as culturally unsafe organizations, there is still a high proportion of Indigenous children in care today.

> *Our Dad did not want to speak the language in the nursing home because of him being in residential school... there was a situation with one person that was not pleasant, and he did not want to speak the language. And he was very fluent. (Sudbury Focus Group)*

In the Manitoulin Island area, the Spanish Residential School operated from 1913 into the early 1960s. Many of the older Indigenous adults in this area attended this school (Jacklin, 2007). The Anishinaabeg Language Expert Group, based in this area, discussed the removal of children from communities, primarily as part of residential school policies, at length. There was much discussion about original names being taken by the priests and how some families are proudly returning to these names and the accurate history that they hold. They also cautioned that when asking "Who are your family?" what may come up is "what about those taken from your family?"

> *"Sometimes you think families are dying out but there are relations in other communities"*

> *"Residential schools gave away children who come back to find their families. From one of Manitoulin's First Nations there are band members in Australia and London, England."*
>
> *"Sometimes out of tragedy children are placed, but they remember and come back. Sometimes it takes a while because of fear. Sometimes there are sad outcomes when parents want their children back later in life."*
>
> *(Anishinaabeg Language Expert Group)*

In Moose Factory, an "Indian boarding school" operated by the Anglican Church took students from 1855 to 1905, when it was converted into a residential school called "Bishop's School" to coincide with the signing of Treaty 9. Bishop's School existed in various forms until 1938, when it was rebuilt and named Bishop Horden Memorial School, and later simply Horden Hall (Anglican Church of Canada, n.d.). Participants in the Cochrane Focus Group explained that the school, known simply as "Bishop Horden" to community members, operated into the 1970s, and that many of the older adults who were born and raised on the James Bay Coast were forced to attend this institution. Despite some of their families living within walking distance of the school, students were prohibited from seeing them regularly, returning only during the summer months and sometimes for Christmas holidays.

In Sault Ste Marie, the Shingwauk Indian Residential School operated for almost 100 years, from 1873 to 1970. Now the site of Algoma University, the legacy of the school is being carefully archived and used for educational purposes. The Shingwauk Residential Schools Centre offers educational tours and services for survivors and their families (Algoma University, n.d.). It is vital that workers recognize the immediacy of these colonial events. In Saskatchewan, the last residential school did not close until 1996, and here in the northeast region of Ontario, most schools operated into the 1970s. To this day, students from remote communities on the James Bay coast have to board with families in southern communities because high school classes are not available in their areas.

In the Perceptions Project, participants drew a direct link between the legacy of the residential schools and adverse experiences of older Indigenous adults. Intergenerational trauma, a direct result of the residential schools where traumatic experiences, loss of culture, and lack of healthy coping skills are passed from one generation to the next, was identified as a cause of elder abuse.

> *"So that's a whole consideration: what do we do when we have unhealthy caregivers with poor coping skills? Well, that why we have elder abuse. That's why we have the money missing. You know, her cupboards are pretty much empty and she hardly had any clothes, you know."*
> *(Caregiver, Sudbury, Perceptions Project)*

This trauma and subsequent effects on later life was also referred to as "living backwards." This was used to describe the reliving of past traumas. Living backwards was viewed as a possible cause of memory loss or other illness in later life.

Participants also shared that disruptions in their traditional ways of life were major contributors to adverse health effects, including dementia and memory loss. Older adults pointed to loss of family and community roles and the isolation experienced as a result. They also had concerns about the change in diet, indicating that store-bought foods are not as nutritionally valuable as foods harvested from the land. However, even those who continued to harvest some food from the land had worries. They spoke of pollution and other contaminants and their potential effects on wild foods.

> *"Foods... they're not preparing the stuff that used to be prepared by the people way back, eh? Now they just buy it so there's no brain stimulation in knowing how to prepare those foods. And in those days they didn't use recipes. They just had to think and process the foods to preserve them." (Knowledge Keeper, Manitoulin Island, Perceptions Project)*

Further Reading:

Truth and Reconciliation Commission of Canada. (2015). Volume One: Honouring the truth, reconciling for the future. *Final Report of the Truth and Reconciliation Commission of Canada*. Ottawa: Government of Canada.

Warry, W. (2007). *Ending Denial: Understanding Aboriginal Issues.* Toronto: University of Toronto Press.

3.6 Trauma-informed approaches with Indigenous populations

Building on the approach Elder Jerry shared with us above, and with knowledge of colonial processes, it is vital that as workers we engage in trauma-informed approaches. We will often find that loved ones have experienced or interacted with trauma in their lifetimes. First and foremost, we must recognize that older Indigenous adults may carry some fear of health care and social service professionals. It was white social workers who removed children from their parents' care during the Sixties Scoop and the residential school years. In many communities, this legacy relationship is still played out by modern day children's aid societies, as Indigenous children are still greatly overrepresented in the foster care system. We must also consider that white teachers and white doctors were responsible for children in residential schools, and were also responsible for considerable abuse and neglect (TRC, 2015**). Though it is not their intention, white service providers carry this legacy into their current work.** An example of this was explained in one of the consultation focus groups held for this tool. The participant shared that seeing white service providers with black notebooks immediately caused her to associate them with her traumatic experiences interacting with a children's aid society many years ago.

We must also consider that most Indigenous people we meet have been exposed to trauma or interacted with it. Even if the traumatic incident did not happen to them, it may be affecting them collectively, historically, or intergenerationally. Collectively, members of communities in which individuals rely on the cultural value of interdependence to survive and thrive may experience vicarious trauma when one or a few members is affected. Further, the transmission of historic trauma is ongoing:

> *... historic trauma is understood as a cluster of traumatic events and not as a disease itself. Hidden collective memories of this trauma, or a collective non-remembering, is passed from generation to generation, as are the maladaptive social and behavioural patterns that are*

> *symptoms of many social disorders caused by historic trauma... In short, historic trauma causes deep breakdowns in social functioning that may last for many years, decades, and even generations (*Wesley-Esquimaux & Smolewski, 2004, p. iv).

Wesley-Esquimaux and Smolewski (2004) suggest that ongoing historic trauma leads to several outcomes in Indigenous populations, including learned helplessness, in which people stop believing that their actions affect their future in positive ways. This may also lead to internalization of negative outcomes, in which people believe situations out of their control are their fault. According to this model, one of the modes of transmission of historic trauma is **intergenerational trauma**. A model of trauma in its own right, intergenerational trauma is perhaps best described by Yellow Horse Brave Heart (1999):

> *With the break-up of the extended family, many Indigenous women found they had no role models to teach them parenting skills. As many Native people were raised in boarding schools, the traditional roles and ways of parenting by both Native men and women were lost. The attitudes and norms, which then sprang up in parenting styles, such as harsh physical punishment, emotional abandonment, lack of parental involvement, and insensitivity to children's needs added to imbalance in the family. As generations continued with these ways of parenting, the trauma was passed down until many believe it has become a cycle of despair and desperation (*p. 70*).*

Given this unique manifestation of trauma among Indigenous peoples, **sometimes called universal trauma because it is so prevalent** (Wesley-Esquimaux et al., 2004), the focused section regarding trauma from the original PIECES of my PERSONHOOD was eliminated. Project Elder Jerry, and the Language Group both indicated that this could be very painful for the loved one, and that it might harm the therapeutic relationship. They, as well as focus group participants, explained that the loved one's dislikes and fears would likely be related to trauma, and should be treated as highly important. In the focus groups, it was determined that knowing a loved one's triggers (i.e. dislikes and fears) was appropriate, but asking more directly about trauma experiences was not.

> *Someone who has trauma almost experiences a tear up of every essence of who they were, so much that the pieces could not be put back together to be any kind of whole being ever again. (Anishinaabeg Language Expert Group)*

This practice of **respecting a person's trauma story without asking that they relive it** closely mirrors the current best practice, evidence-based approach in trauma care: trauma-informed. In a trauma-informed approach, it is acknowledged that the trauma exists, but also that talking about it often causes re-traumatization. Trauma-informed care is being recognized as essential in screening, and in the administration of tools and assessments by the Centre for Addictions and Mental Health and the Evidence Exchange Network (CAMH PSSP, 2016), among other networks.

Trauma-informed approaches focus on **safety and empowerment for the loved one**. Loved ones are not ever required to explain or speak about their trauma, and their boundaries and triggers are respected, even if the reasons for those boundaries are unclear. These differ from trauma-specific approaches, which are specific to healing from that trauma. By offering a trauma-informed approach, service providers can support loved ones in pursuing further healing, or not, and ensure they are remaining safe and cared for either way. Key aspects of trauma-informed approaches include grounding and centering exercises, strengths-based approaches, maintaining open communication in the therapeutic relationship, and keeping control over how trauma is discussed (if ever) in the hands of the loved one (BC Provincial Mental Health and Substance Use Planning Council, 2013).

This approach aligns with what focus group participants in the North Shore region of Ontario asked us when we brought this tool to them**: "Why do you need to know?"** In truth, we do not need to know the entire trauma story of a loved one to offer respect for their boundaries and support them in grounding when they are triggered. Focus group participants also suggested that we tell loved ones why we want to know their dislikes and fears; that we wish to avoid harming them unintentionally while we are offering care to them.

Further Reading:
Aguiar, W., & R. Halseth. (2015). Aboriginal peoples and historic trauma: The processes of intergenerational transmission. National Collaborating Centre for Aboriginal Health. Retrieved from: www.nccah.ca.

3.7 Appropriate care strategies for older Indigenous adults

Appropriate strategies for older Indigenous adults were found to be lacking in many regions. In this area, it is important to consider communication as cross-cultural. In health care encounters with older Indigenous adults, Western approaches may not be reflective of Indigenous culturally safe approaches. Below is a quick summary of the historical major differences, described often in academic literature and reflected in the "Perceptions" project. The partners involved in this study, in collaboration with many partners in care are working towards harmonizing with Indigenous Care Approaches. For example, the P.I.E.C.E.S framework (Hamilton, Harris, Le Clair, & Collins, 2010), which is the primary framework used by BSO, values a holistic approach, looking for all possible causes for a change in behaviour, including those that may not initially be obvious, and allows for care planning based on the person's own values and needs.

Western/Biomedical Care Approach	Indigenous Care Approach
• Direct questions • Authoritarian tones • Fast-paced • Technical language • English/French • Focussed on physical symptoms • Health care provider as expert	• Indirect • Gentle or soft • Taking the time needed • Descriptive language • Indigenous languages • Wholistic approach (physical, mental, emotional, and spiritual) • Relationship centred

Many loved ones and caregivers also valued humour in their relationships with health care providers, and shared again and again the importance of patient-centred care. Loved ones and caregivers value long-standing relationships with their health care providers, and greatly appreciate continuity of care.

> *"I found that when I changed over to a house call system for seeing the elderly people its vastly, vastly improved method of seeing people for so many reasons: one is the flexibility of time and the fact that you can take more time and the other is you are seeing the person in the context of how they function." (Physician, Manitoulin Island, Perceptions Project)*

> *"And she talks, she talks the language too, so it's really nice to hear that too. When anybody comes in and talks the language she's right in her peak then." (Caregiver talking about the personal support worker that assists their loved one, Manitoulin Island, Perceptions Project)*

3.8 Organizational, policy, and individual barriers can work to prevent health equity in dementia care

In Canada, there are barriers to accessing health care which primarily affect Indigenous peoples. Many Indigenous people in Canada fall under federal healthcare first and provincial care second. Federal funding for health is very poor for most First Nation communities. Indigenous people are often stuck between the two jurisdictions or get caught up in complex legislation and policies when trying to access services. Aside from jurisdiction, there are also access concerns related to receiving a formal diagnosis, culturally appropriate screening tools, timely appointments, and transportation. This is understandably frustrating and exhausting for loved ones and caregivers. It also means that workers need to be hyper aware of eligibility criteria for programming when making referrals or suggestions about funding programs.

> *"So those little elderly people will have to come back again. We have no ability to see an elderly person 4 times in 8 weeks here or in Wiky [Wikwemikong Unceded Indian Reserve], even more so in Wiky. The ability to follow a chronic illness in Wiky, because we just don't have enough appointments in Wiky to have people coming back at the frequency of having them come back to get all the work up done and then to follow them up." (Physician, Manitoulin Island, Perceptions Project).*

> *"Travel is always a problem. The travel budgets in the communities are always exhausted usually by the summer time, so they're always looking for more funding through Health Canada and sometimes it comes and sometimes it doesn't. So that's just an additional burden, you know, on the communities." (Care worker, Manitoulin Island, Perceptions Project).*

4.0 The Evolution of PIECES of my RELATIONSHIPS

The use of personhood information in clinical settings plays an instrumental role in reducing stigma, fostering respect, increasing safety, enhancing empathy, promoting care continuity, and enhancing the overall care experience (Behavioural Supports Ontario Lived Experience Advisory, 2018). Personhood tools, including the PIECES of my PERSONHOOD, have been incorporated as common-practice in many organizations. In order for the PIECES of my PERSONHOOD to promote similar positive outcomes for Indigenous patients, focus groups participants made several recommendations around question formatting. In response, the research team reframed the categories into five sections with simpler, more inclusive language.

4.1 Who I am

This section combines a number of areas from the original PIECES of my PERSONHOOD, including:

- Name/Preferred Name
- Family Background
- Pets/Animals
- Significant Persons in Life and Relationships

The title "Who I Am" was chosen to reflect the way that focus group participants spoke about identity and introduced themselves. Participants offered many specific instructions for asking questions in this section. First, they suggest that you always start with yourself and a greeting.

> *"We never had roads. We had paths and there were always bends in the path, and you didn't always know who was coming. So you would say 'Aanii!' because you would hear something coming at you and you don't know if it's an animal or a human being, so you yell out 'Aanii!' and you wait... that's where that came from. It's a greeting. You want to know who's coming." (Karen, explaining the Language Group's preference for the word aanii as a greeting to focus group participants in Sudbury).*

Once you have shared who you are and asked for their name, the loved one may choose to share spirit name, clan, colours, but may also choose not to (see section 3.4). Do not ask for an English translation if the loved one shares this in their language. Sometimes there is not a direct translation, and meaning is often lost. They will translate for you if they feel it is appropriate. Names, especially spirit names are considered sacred.

> *"Our names are very sacred. So if you're going to ask that question, make sure you're going to be really attentive to what they say and everything, because that's really important because of the sacredness." (North Shore Focus Group)*

Introductions were always made in the context of where participants were coming from, including which community they were born in and where they currently lived. If you are local to the area, you may share who your grandparents or even great-grandparents are to foster a connection with the loved one. It is common for elders to go back in time and tell stories of their families where they came from or events they experienced and these stories are very enchanting to listen to. This is a gentle way of learning more about the loved one.

Many included their family roles in their introductions. Participants in Sudbury suggested looking at family photos together. In the North Shore and in Cochrane, participants felt it was important to find common ground, and offer information about your own background. Pets were added to this section because participants viewed them as relatives and as special members of the family, sometimes calling them "little brothers" or "little sisters." In every focus group, participants were visibly delighted to talk about animals. In the North Shore, they felt pets were a lighthearted topic that could be asked about or brought up again after heavier topics. Participants reminded workers that pets and animals may not be the usual domestic companions like cats and dogs. They discussed animals that visited near their homes often and wild animals that became domesticated pets.

> *"My mom had left – behind [when she died]. –'s her dog. So my sister's taking care of --. We call – our brother." (Focus group participant, Cochrane)*

> **Little Bear**
> *My dad got a small bear who lost the parents. My dad was a trapper he found a small bear they brought it home, I saw the small box but he didn't tell us what was in it. When my siblings and I went out we could hear the bear I thought it was a cat, but it was the bear. It was so small, we kept care of it and it got this big. The bear got so big that he could bat around his owner, the bear wanted to wrestle wanted to play. My dad used to take him to the small store everyone enjoyed feeding him ice cream and the bear really enjoyed this and pop. The pop used to come in bottles, he would drink it all and be given another one. Oh that's enough he would be cautioned, no the bear didn't listen. He really enjoyed little children coming around, the bear was never allowed to play though he was kept tied up and taken around this way. One time we were eating over there, the little bear was outdoors tied up there was a sound from outside, my dad wondered and went to investigate. Well the little bear had climbed up the veranda outside the house and fell off. All the boys ran outside and went to get the bear but there were no injuries. This happened twice the bear climbed up there. And he ate all kinds of food. When winter came my father went to the top of the hill where the pigs were kept there was an old hut he filled with earth and hay, this is where the bear was. The little bear looked like it was almost falling asleep that's when they hibernate in the fall. This is where he was taken for all of winter, this is where he was. And when spring would come we would be constantly running over back and forth, wondering when the little bear would come out. The bear got bigger and bigger ate more and more, my dad used to have to wear protective gear because the little bear wanted to wrestle. He wore gloves to hold him. (Translated from Anishinaabemwin – Anishinaabeg Language Expert Group)*

Participants suggested asking "Where are you from?" but avoiding more specific wording such as "Where were you raised". A story about this was generously shared by a participant in Cochrane:

> *"I went to residential school. My mother went to residential school. My grandmother went to residential school. If I was asked where were you raised... When I went back to school... one of my assignments was about residential school. I was to interview somebody about residential*

> *school. So I chose my mom. One of the questions was 'How many years did you actually live with your mom and dad?' And then she said 'In my family I'm the only one that went to residential school. I was the well educated one.' That short period that she was in there had a great impact on her life. And it showed, it showed in my mom. I know she had a hard time in life. But she loved her mom and her dad, but the relationship was broken when she was young. Thirteen years old. When she was in her early teens, with those that age, she was in residential school... By the time she came out...*
>
> *And, you know that, from the questions I was asking her, she had a hard time answering, so when I see this, 'Where you were raised...' if you're looking for the specific place you were raised... I was raised in residential school, away from my parents. I did my own. How many years I was away from my parents and how many years I was actually raised by my parents. I went into residential school at the age of six. I became a mother at the age of 19. I was in residential school for seven years for ten months out of a year. Summertime was the only time I saw my parents. Sometimes Christmas if we were allowed to go... Anyways, I calculated how many months, how many years I was actually raised by my parents from age six to age 19. When I started high school I had to leave [the James Bay coast]. There was no high school. I went to high school [in southern Ontario]. So I included those, from which I became I mother at 19. I had my first child at 19.*
>
> *When I calculated how many years I was actually with my parents, it was only 39 months. From age six to age 19, I don't know how many years that is... I only actually lived with my parents 39 months."* (Cochrane Focus Group)

Caregiving and significant others were also considered a part of who people are. Participants explained that even though the questions only talk about caregivers, information about spouses and other family members would arise naturally throughout the conversation. They felt that the type of relationship the loved one had had with their spouse could make asking about them inappropriate. In two areas we visited, participants talked about arranged marriages and different definitions of marriage, and in all three areas participants indicated we should not ask directly about spouses or partners. In Sudbury, participants said "Let them lead," in this topic area. The Language Group also cautioned that what people call their spouse may seem insulting or unusual to outsiders, but that is not necessarily the case.

> *In one of the language group meetings, I gave an example of how some older couples call each other old lady, old man, and one of the language speakers, a man, he said, you know some people will think that that's rude and it really isn't. It's actually an honour to be called that. He said, do you realize the real translation of Mdimowenh ? Mdimowenh is the old lady. And he goes, it's really Nmindmowenh'im my wife, this is the woman who carries my children, that's what you're saying in the language... So you lose those meanings for a while, and then somebody from another culture tells you that's rude! I wouldn't want to be known as an old man or an old lady. But that's not the origin. (Karen Pitawanakwat, Community Researcher)*

> *You don't want to bring that up if their spouse has been gone for ten years. You don't want to bring that sadness up. If they want to bring it up, okay, but you let them bring it up. You let them lead. (Sudbury Focus Group)*

An indirect way of determining who the closest caregiver(s) is/are is by asking who hurries to protect you from doing things that could hurt you (in a way that a parent might stop a child from touching a hot stove). Some of these questions may be directed at a caregiver or substitute decision maker, but be aware that they may not know all the people that do help the loved one. It is best to get a second opinion as well because the loved one may be challenged with fear of being admitted into a nursing home when they admit how much help they need. This was linked back to the colonial legacy by participants. Historically, the movements of Indigenous peoples in Canada have been restricted and controlled by the state. Many older adults in the focus groups expressed concern they would be taken away from their communities and placed in long-term care without their consent. This fear is not unfounded; some participants were survivors of the residential schools or the foster care system, and had either been taken away before, or had watched loved ones disappear.

Culturally, older Indigenous adults also value doing as much as they can for as long as they can. In interdependent communities, this means that older adults may direct a few different helpers to support them in completing tasks that are becoming difficult. They retain independence in that they have complete control of their circle of care. In Anishinaabemowin, you would never ask "who cares for you?" Rather, you acknowledge that they do as much as they can, and ask who picks up the little pieces of things that they cannot do anymore. Literally, "who catches that for you?"

> *She still wanted to do what she had always done. So that change, adjustment to slow down, is hard for them.*
>
> *Some of them, too, they're in denial that they can't do this anymore. They need help.*
>
> *(Cochrane Focus Group)*
>
> **I still have it in me**
> *It's really, I feel it from my older sister she wants to do things herself, when I go into her home she tells me she is going to clean her kitchen cabinets but she shouldn't be doing this work but she's going to. I still have it in me she thinks. Someone should be there though in case she falls. She shouldn't be climbing at all, everything can be placed lower so she could clean them. At least she will be busy with something, even if things were placed on top of the counter easier to clean. Don't you dare climb up I am always warned even at work, I wasn't allowed to use a step ladder. But when no one is around I would climb. I was brought a step ladder with a hand rail they knew I was sneaking to climb. (Translated from Anishinaabemwin – Anishinaabeg Language Expert Group)*

4.2 A day in my life

This section is a combination of the following sections:

- Mealtime Preferences
- Sleeping and Waking Preferences
- Socialization Preferences

The title of this section was chosen by participants in the Sudbury focus group. One participant described how much a “Day in the Life” video had been useful in the care of a particular client, and participants enjoyed this description very much. They felt it was a fuller description of all the person’s needs and preferences than questions focused only on food and sleep.

> *“Simple things like the man liked country music, and here the PSW is putting on rock music and wondering why the man is getting upset.” (Sudbury)*
>
> *“Some Aboriginal people like a smudge. It might help them if they are used to having a smudge every morning, or in the evening, or whenever. The first thing I do every morning when I come into work is I lay a smudge downstairs and the staff smudge there... that’s what I do. So if I did have that Alzheimer’s, that would help. I might not remember to do it, but as soon as I started I would know the feeling.” (Sudbury)*

Participants suggested paying special attention to food preferences around texture and colour of food, and cautioned that when asking about sleep, we should not ask about dreams. The loved may choose to share or not, as dreams are personal, spiritual experiences.

4.3 What keeps me going

This section combines the following sections:

- I am most proud to be known as/known for...
- Interests and Hobbies
- Significant High Points in Life
- Sources of hope, comfort, joy, and/or favourite things

In mainstream use, each of these four items yields distinct responses, however, participants felt that in their own context, these four items could be combined to shorten the tool.
They also felt that many of the questions would generate storytelling on the part of the loved one that would answer many of these questions. Pride was considered inappropriate, as there is a deep cultural value placed on the practice of humility. This is why a family/caregiver supplement was included with PIECES of my RELATIONSHIPS. These questions may best be answered by a family member or friend.

Remember that different clans have different roles and this might be part of the answer. Names may also indicate gifts or special roles therefore are sacred (see section 3.4). Do not mention occupation or job unless the loved one brings it up. Having to be away for work felt like abandoning family and community for many older Indigenous adults, and they may not wish to discuss this difficult time of separation. Some loved ones may identify with their employment role, but that will come up naturally.

Some examples of activities that brought joy to participants included:

- Hunting - - *Giwse*
- Planting – Gtige-win
- Children – *Binoojiinh'ig*
- Animals – *Wessinh'ig*
- to feed others - *Shangeng*
- making maple syrup - *ziizbaakdokeng*
- picking strawberries – *Diwminkeng*
- picking blue berries - *Miinkeng*
- picking high bush cranberries - *Niibminkeng*
- generation you made (your bloodline - great grandchildren) - *Gdaankoobjignag*
- dancing – *niimiding*
- *fiddle music* - Naazhaabiig'igeng
- Step dancing - *Kwejgaadeseng*
- square dancing - *Biimskogaawin*
- visiting/laughing - *Nni-bwaachweng/baabaaping*
- story telling - *aansokehwin*
- reminiscing - *Zhizhe waajmotaading*
- sewing - *Gshkgwaasang*
- singing – *Nnagmang - naango taagzing*
- feasting/honoring offering to ancestors - *Tasewang*
- eating favourite foods - *Mnopjigeng*
- picking medicine - *Mshkikiikeng*
- Cree Gospel
- Trapping - *niigeng*
- Making goose down blankets
- Cleaning and preparing hides
- Doll - *Damno waagaanhs*
- Chewing spruce gum - *Zhaashaagmin gaawaand-go bgiw*
- Cooking moose nose - *Mnozming moos jaanzh*
- Eating dry seaweed
- Homemade wooden guitar - *Mchwe zhitoong mdwe waabiigbijgan*
- Homemade wooden hockey stick -
- Toy made with a hip bone of a beaver
- Toy made with the feet of an otter

Participants shared many stories of unique and beautiful roles, especially when speaking in Anishinaabemwin.

> **Miracle Hands**
> *I always tell the story of the elderly woman who raised a boy in my neighborhood, she was so poor there was no help back then. Her log home was exposed to the outdoor elements, wind and cold blowing through. It had a wood stove alright but even though she made a fire it just didn't warm it up enough to live. She used to ask to sleep in other people's homes, this is where she raised 2 children. This elderly woman was completely blind and she was a midwife. I truly believe the creator blesses these kinds of people, poor people-people who have less than. She was able to manipulate an unborn child while in the womb, she was able to care for high risk pregnancies. I don't know how she put her hands but she was able to move unborn babies. My mother used to take her in all the time, the children would be following her looking for a place to sleep. They were so poor. I always think of her she went nonstop to heaven, she didn't see anything here-nothing bad but she was gifted.* ***Mmaandowzi*** *means to have lived a life creating miracles with her hands. (Translated from Anishinaabemwin - Anishinaabeg Language Expert Group)*

> **Careful Crafting**
> *Especially in the summer as a child I would watch all kinds of merchandise being created with quills, birch bark canoes, and even small bird houses - cars would be filled with crafts asked for by the white skinned. I used to see those bird houses they were this size, it was a round house, the roof was this shape and it was bent this way to hang and there were even little windows. This is what they were especially gifted at, they were very careful. These are the types of things that are no longer seen like working with quills all of these kinds of things. (Translated from Anishinaabemwin - Anishinaabeg Language Expert Group)*
>
> **Sailing over snow dunes**
> *These ancient people I use to hear of, they were exceptionally good at wood boats even sail boats. They're stories are shared sometimes. How did those boats look that used to take our ancient ones around? Not like the sail boats today, I had the privilege of seeing one, it had a hole in the middle, there was a machine in that hole and it made a putt putt sound. It was named after this sound:* ***medwewebdehing****, which is a moving sound in the heart. It was a sail at the same time. He was from Wiikwemkoong a very well-known boat builder. His name was* ***Kuknaangwe****. He lived on an island, the island beside the island where they blow up the rock. He made many of these kinds of boats. He even had the ability to build – for the wind blowing the snow over the ice in the winter. This ancient one made a sail that is blown over the ice. He was that gifted, that wise. The island where he lived is named after him. His name describes small particles moving over one and other by wind, these particles being small parts of a base of the same particles, like sand dunes, but it can also be snow. (Translated from Anishinaabemwin - Anishinaabeg Language Expert Group)*

4.4 How to keep me safe

This section combines and replaces the following areas:

- Significant low points in life
- Coping mechanisms/validation phrases
- Dislikes and fears
- Significant Dates and Meanings

In the original tool, these items provide information that is instrumental to behavioural care planning, however, in consideration of trauma-informed approaches; these items were merged and reworded. All sections were identified as potentially related to trauma by participants in all three focus groups. Keeping a loved one safe rather than discussing trauma directly is consistent with best practices in trauma-informed approaches (see 3.6 for a full description of this approach and its necessity for work with Indigenous peoples).

The question "What memories do you carry in your heart?" arose from discussion around significant dates and meanings in the Cochrane focus group. Participants felt that memories carried in the heart could be positive or negative, and that this question was open enough that loved ones could choose how much to share.

> *I have a special story of my own. It was my first doll. I don't know how old I was, maybe eight years old... Christmas time, I got a doll. I finally got a doll. And I remember the smell of that. A*

> *vinyl smell like shower curtains. Every time I get a new shower curtain that memory is always there. My first doll. Any smell, vinyl-like smell, I love that smell. (Sudbury Focus Group)*

> **I will never forget**
> *It's so different for us when we are given a gift. You know I will never forget for my family there were ten of us - seven sisters and three brothers. My cousin came to our home, my mom and dad could not buy us toys because there was too many of us. She gave to us, and I never forgot that. Me and my sister were the oldest, we got coloring books and crayons. And while they were visiting we went behind the stove and laid down on the floor and we were coloring our coloring books. We never, I never forgot that. That was a big gift that she gave us. (Sudbury Focus Group)*

While the above story was positive, the community researcher shared a story about a woman from her area who honoured a specific day every year. This day was the day that her baby had died many years ago, and she carried this memory in her heart. This also allowed for complicated memories in which emotions varied between positive and negative. In Sudbury, a participant shared that her sibling had died when they were young, but that shortly afterward, her parents adopted a young boy. These memories are mixed in her heart, in that she grieves for the lost sibling and rejoices in new family.

It is vital to explain why dislikes and fears are being explored, and that the loved one does not have to share the reason they are afraid of or do not like something. Explain that you just want to make sure you do not hurt or upset them unintentionally. The question regarding deep down fears asks about a fear related to an experience that they may dread to have to re-experience. This is a heavy question and may relate to past traumas, so be clear that they do not have to answer if they are feeling unable to. The question around smudging was chosen because smudging (with smoke or water, depending on traditions, situation, and preference) may be done during times of stress, fear, unease, or discomfort, and is an indirect way of asking if a participant has a fear or a negative emotion they feel the need to care for regularly. Some participants also spoke about offering prayers with a pipe, and others covered mirrors or windows during storms. These are practices that they should be supported in continuing if they enter long term care or assisted living. The Language Group indicated that this was particularly important because smudging and other spiritual practices were historically banned by Church and state.

> **You don't get scared when you smudge**
> *My nephew they used to live in that little place, it's about to storm you can hear the thunders. He was moving so fast my sister told me, she asked him what he was looking for. He was looking for what he needed, our mother told us to give him some tobacco you can also put cedar if you want. My sister helped him, he was such in a hurry this has to be done he was saying he could hear the thunders. Ok so how were you taught he was asked, what does grandmother do. So he was on, he went to retrieve a little pie plate and put it on the stove, then matches. Ok I will start it on fire he was told, but he wasn't taking this he had to do it himself. Carefully he was watched and he started it on fire. He was smudging in the smoke, his fear was relieved. He doesn't get scared when he does this. We laughed at him he was maybe 6 about that. What do you say he was asked, he replied as a child would: to look after the cat and so on. (Translated from Anishinaabemwin - Anishinaabeg Language Expert Group)*

4.5 How I care for my whole being

This section replaces the following section:

- Spirituality, Religion, and Traditions

This also adds a key piece about traditional medicine and wellness that participants were afraid would be lost. Caring for my whole being reflects the value of wholism in Indigenous cultures (see 3.1 A wholistic view versus biomedical understandings). Participants in Sudbury described the importance of being able to continue their wellness practices, such as smudging and using specific plant-based medicines. In Cochrane, participants shared that being able to eat certain wild foods was highly important to older adults in their lives and to themselves. They felt that these foods and their connection to the land supported their health and wellbeing.

Being thankful and caring for oneself when sick were viewed as spiritual, connected experiences in all areas.

> *There was an elderly lady that came in because she was sick, and she always had stories to share. She used to say that she was thankful for the Creator. He's watching she said, because there were times they were out on the land, and they were starving... they only got two little birds, that's what fed the family. And she always says she's always thankful for that. (Cochrane Focus Group)*

> **I was answered**
>
> *For me while we are talking about prayer, when I was a farmer I was cutting hay up the hill where the big garden was where the highschool and big town is now. That's where I was cutting hay, I asked the new owners of this garden the leaders of Wiikwemkoong if I could cut the hay. I got to where I was going to cut the hay I was going to tie the hay together they are already getting dry I was gathering the hay. Exclamation, after I was done gathering the hay I already had the metal to tie the hay that's when I could see it over there the clouds were rolling in. The big thunders were coming, the clouds were black. That's when I started to pray. I am praying and I am driving the tractor, this is what I said: this is your garden Creator, I am not talking to this tractor, I am not talking to these trees, I am talking to you stop this for a while I said. Exclamation, the wind stopped – yes it waited for me to finish tying the hay. That's it I got an answer that time. This is what I said to the Creator: the animals will eat this hay this is why I am doing this, the animals do not belong to me they belong to you as well. I work for you while I am doing this work hear me, and that was it. After I got home that's when it hit, the thunders and rain hit hard. I was answered. We were all taught this growing up, to talk to the Creator in your own language – you will get answers. (Translated from Anishinaabemwin - Anishinaabeg Language Expert Group)*

End of life care was immediately talked about when we discussed spirituality and coping in all of the focus groups. Participants shared the concept of "ever after happiness" as vital to this final transition in life.

Preparing for Ever After Happiness

The way we understand as Anishinaabeg the old ones and those who are preparing to leave for the spirit world, when this is not understood it gets very difficult to prepare. The one that is leaving is actually being stopped held back from continuing to walk their life the way it was meant to be. There are some who fear leaving and they need to be visited about how happy it is where they are going. They need to get to the place where they give up their life and believe they are ready. Sometimes they show this by refusing medication. Uncle Ben's niece told the nursing home staff he was preparing to go, and just to keep him comfortable. He slept for four days and four nights. When he woke up he asked for tea and complained of feeling hungry. They gave him left over soup and tea. "Well, I am leaving soon," he announced. He travelled there, he told her. He saw it. "It is of the most beautiful place anyone could ever imagine," he said, "they sing so well/the melody on the other side." There let it be he ended, not yet he announced but it's going to happen anytime I will leave, he was gone in a month's time. Grandfather was different (before I understood this), he said he was leaving soon, I asked where he was going? where you have ever after happiness, where the dead go he replied. How do you know? he was asked. My father came to me he said, at first he was far away and now he is closer he is coming to get me anytime. He came to him to prepare himself, he told me to prepare ahead of time. To set his clothes he's to wear and moccasins not shoes.

Grandmother was forgetful but sometimes she was with it, once she said she had a dream she doesn't know where but it was beautiful she saw a beautiful woman in a blue dress. When I leave that's what I want to wear she told me, the dress was found for her. I showed her the dress and she agreed it was the one she saw, the one she will wear to the other side. (Translated from Anishinaabemwin – Anishinaabeg Language Expert Group)

5.0 Conclusions and Recommendations

Throughout this work, participants expressed that they were very happy to have been asked what they wanted in older adult care in their communities. They felt that they had so much more to say, but that this was a good first step. Participants emphasized how important it is for care providers to understand and respect Indigenous cultures and history, and support incorporating spiritual practices and plant-based medicines in care. Participants insisted that care providers interact with older Indigenous adults in ways that did not disrupt their cultural practices or kinship networks, iterating that the approach workers take is often more important than what they ask or do.

Participants in all three sites reminded the research team that long-term care settings may trigger feelings and fears related to residential school experiences and family separation, and the importance of being aware of this in practice. The Language Group reminded us that older adults want to "smell the perfume of the flowers and feel the rain on their faces" sometimes, and the importance of continuously advocating for older adults and giving them an opportunity to have their voice heard throughout their care journey through the use of tools such as the PIECES of my RELATIONSHIPS. Many participants discussed keeping older Indigenous adults at home for as long as possible, a finding that is not unique to this study (Jacklin et al., 2015). The Anishinaabeg Language Expert Group insisted that this work should become a routine part of NEBSO care practices and spread across day-to-day work. This is encouraging for NEBSO as part of their continued advocacy work for loved ones and their families, through various platforms, including the promotion and use of tools such as the PIECES of my RELATIONSHIPS.

Participants had questions about loneliness and depression that were not addressed directly by this study.

> *So where does depression and loneliness come from? That's what a lot of our elders are going through. Even if they have a big family they still go through it. (Sudbury Focus Group)*

Although the PIECES of my RELATIONSHIPS tool will be useful for care planning around nonpharmacological treatments for depression, it should be used in conjunction with culturally safe depression screening tools, which should be explored in future adaptation work. Finally, a trauma-informed approach was discussed and will be promoted with the use of this tool in practice.

5.1 Recommendations

The discussions that emerged during the focus groups validated the current work and direction taken by NEBSO as part of the NEBSO Indigenous Engagement Strategy, and helped identify key next steps for future work.

- NEBSO staff are encouraged to continue with regular training concerning the provision of culturally safe care in an Indigenous context.
- NEBSO will promote and engage in trauma-informed approaches in an Indigenous context.
- NEBSO will continue to advocate for further inclusion of Indigenous culture in long term care facilities in the North East region. Specific suggestions from participants included:
    - Offering and allowing wild foods
    - Conducting activities older Indigenous adults may be familiar with
    - Creating talking circles for older Indigenous adults, and ensuring that language preferences are respected.
    - Availability and visibility of smudging, sacred medicines, and other spiritual items and practices Visibility is of key importance because these practices were banned by government institutions historically, and older Indigenous adults may not be sure if they are allowed to engage in or request these activities.
    - Suggestions from participants for accomplishing these goals included planning regular visits from life-long care workers from the local friendship centre, engaging a residential Elder, and offering training to existing staff.
- Activities and outings that engage older Indigenous adults in the natural world should be encouraged and planned. Suggestions included nature walks and medicine walks.
- NEBSO will partner with Indigenous communities and service providers in the North East to create and maintain a list of local translators for communities they offer services in. Translators should be offered a standard honorarium consistent with existing community practices.
- Indigenous community partners are invited and encouraged to continue to partner with NEBSO towards ongoing cultural safety measures through sharing of feedback and open dialogue, and to help support access and awareness of services amongst the community

- Anyone who wishes to use the PIECES of my RELATIONSHIPS tool should receive training that follows these guidelines and have prior cultural safety training in an Indigenous context. To learn more about Indigenous protocols in your region, reach out to the local Friendship Centres or Aboriginal Health Access Centres. If you have questions about PIECES of my RELATIONSHIPS training, please contact the Indigenous Officer for the LHIN or the Psychogeriatric Resource Consultants (PRC) at the BSO. RC's at BSO.

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