Exploring Traditional Roles of First Nation Older Adults to Promote the Quality of Life for Those Experiencing Alzheimer's Disease and Related Dementia's

By

Ashley Cornect-Benoit

A thesis submitted in partial fulfillment
of the requirements for the degree of

Master of Science (MSc) in Interdisciplinary Health

The Faculty of Graduate Studies
Laurentian University
Sudbury, Ontario, Canada

© Ashley Cornect-Benoit, 2017

THESIS DEFENCE COMMITTEE/COMITÉ DE SOUTENANCE DE THÈSE
Laurentian Université/Université Laurentienne
Faculty of Graduate Studies/Faculté des études supérieures

Title of Thesis Titre de la thèse	Fostering Traditional Roles of First Nation Older Adults to Promote the Quality of Life for Those Experiencing Alzheimer's Disease and Related Dementia's	
Name of Candidate Nom du candidat	Cornect-Benoit, Ashley	
Degree Diplôme	Master if Science	
Department/Program Département/Programme	Interdisciplinary Health	Date of Defence Date de la soutenance August 16, 2017

APPROVED/APPROUVÉ

Thesis Examiners/Examinateurs de thèse:

Dr. Kristen Jacklin
(Supervisor/Directeur(trice) de thèse)

Dr. Jennifer Walker
(Committee member/Membre du comité)

Dr. Darrel Manitowabi
(Committee member/Membre du comité)

Dr. Chantelle Richmond
(External Examiner/Examinateur externe)

(Internal Examiner/Examinateur interne)

Approved for the Faculty of Graduate Studies
Approuvé pour la Faculté des études supérieures
Dr. David Lesbarrères
Monsieur David Lesbarrères
Dean, Faculty of Graduate Studies
Doyen, Faculté des études supérieures

ACCESSIBILITY CLAUSE AND PERMISSION TO USE

I, **Ashley Cornect-Benoit**, hereby grant to Laurentian University and/or its agents the non-exclusive license to archive and make accessible my thesis, dissertation, or project report in whole or in part in all forms of media, now or for the duration of my copyright ownership. I retain all other ownership rights to the copyright of the thesis, dissertation or project report. I also reserve the right to use in future works (such as articles or books) all or part of this thesis, dissertation, or project report. I further agree that permission for copying of this thesis in any manner, in whole or in part, for scholarly purposes may be granted by the professor or professors who supervised my thesis work or, in their absence, by the Head of the Department in which my thesis work was done. It is understood that any copying or publication or use of this thesis or parts thereof for financial gain shall not be allowed without my written permission. It is also understood that this copy is being made available in this form by the authority of the copyright owner solely for the purpose of private study and research and may not be copied or reproduced except as permitted by the copyright laws without written authority from the copyright owner.

// Abstract

The emergence of Alzheimer's disease and related dementia's (ADRD) in Indigenous populations across Canada is a rising concern as prevalence rates exceed those of non-Indigenous populations. Culturally appropriate approaches to address the increased prevalence of ADRD are guided by the Indigenous Wholistic Theory and the Intergenerativity Model. Community-based participatory action research led by interviews, focus groups and program observations aid in identifying barriers and facilitators of success for intergenerational social engagements in the Anishinaabe community of Wikwemikong, Ontario. A qualitative thematic analysis guides future recommendations for programming opportunities to foster traditional roles of older First Nation adults and intergenerational relationships. This project results in culturally appropriate suggestions to improve healthy brain aging in older populations through increased social interactions with youth and the nurturing of traditional roles. The results of this study are relevant to other Indigenous communities who may wish to adopt the framework to their own community context.

Keywords: Indigenous Health Research, Community-Based Participatory Action Research, Dementia, Brain Aging, Traditional Roles, Intergenerational, Meaningful Social Interactions, Older Adults, Youth

Acknowledgements

I would like to begin this dissertation with acknowledging the traditional territories that have guided me throughout this degree and the many years prior. I am grateful to the past and present voices of the Atikameksheng Anishnawbek territory for their support and guidance throughout my early ventures in academia. This privilege has supported my development not only as an academic, but also as a Mi'kmaq First Nation woman. The stories shared and knowledge learnt during my time spent with the people of this territory encouraged me to find my voice from within. Through the progression of time, developed maturity and life experience, this voice has sought pathways towards positive opportunities that would improve the health and wellbeing of Indigenous people and communities in Canada. Similarly, I would like to acknowledge the traditional Mi'kmaq lands in Newfoundland and Labrador, specifically the Kitpu (Port au Port) region, where many of my immediate family members reside. The teachings from my ancestors continue to resonate through my daily life and strengthen my journey towards fulfilling my responsibilities as a Mi'kmaq woman. I thank my great-grandparents for their warm, caring and loving hearts. I cherish their appreciation for the land and the gentleness in their approach to living a good life. It is through their foundational teachings that I remain connected to the community and dedicate my career aspirations to improving the health and wellbeing of Indigenous people in Canada. I would also like to acknowledge the Wikwemikong Unceded Territory for their dedication and support in this project. The community's shared devotion to creating a meaningful outcome helped to establish many lifelong relationships between community members and myself. I am forever grateful to the community's receptiveness and warm welcoming of my being in

the community. Your open hearts led to open doors, Miigwetch for entrusting your voices, stories and knowledge with me.

The support of my mom, my dad and my brother throughout my commitments to academia has provided me with the strength to continue achieving my goals. The completion of this dissertation would not have been possible without their continued support, encouraging words, positive reassurance and unconditional love. To my mom for answering the late night phone calls when traveling through Northern Ontario to keep me company, I thank you. To my dad for never giving up on me, especially when I had given up on myself, I thank you. To my brother for being my best friend, remaining by my side regardless of the physical distance separating us, and for offering your expertise in advanced typing abilities, I thank you. To those who are no longer with us and have passed onto the spiritual world, I hope that my journey in life thus far has made you proud. I am forever thankful for the love you have given me, the stories you shared and the knowledge you taught me.

I acknowledge my friends, colleagues and professors who have helped guide me along the pathway towards success and for encouraging me to find my passion. Thank you for the time you continue to set aside to listen to me, to speak with me, to guide me, to ensure me and to help me. Your words of wisdom, strength, empowerment and continuous support are held close to my heart. I thank you for your continued companionship, mentorship, fellowship and most importantly friendship.

I would like to express my sincere gratitude to my supervisor, Dr. Kristen Jacklin, for her willingness to explore new areas of research with me. Your dedication and commitment to Indigenous health research has provided me with a tremendous amount of

knowledge that will aid in the development of my own learning journey in academia. Your continued encouragement and support over the last few years has guided the success of both this project and my development as an academic. Working with both yourself and your research team has been such an inspiration. I am thankful for all of the opportunities you have provided me with over the last two years, as these experiences would not have otherwise been imaginable. Gratitude is also extended to my supervisory committee, Dr. Jennifer Walker and Dr. Darrel Manitowabi, for their ongoing support in the development of this dissertation. I am appreciative of your feedback and constructive criticism in developing my journey as an Indigenous health researcher. Your dedication and attentiveness to ensuring the completion of this dissertation will forever be remembered. Also, to Melissa Blind for always being there in a time of need, especially when a warm hug was needed, I thank you. Finally, Louise Jones, your thoughtfulness towards the development of this dissertation and my development as an academic are greatly appreciated. Your shared resources will be forever valued.

Miigwetch to the community researcher, Karen Pitawanakwat, who guided the project's development with the community of Wikwemikong. Your shared time and willingness to guide me throughout this process are greatly appreciated. The teachings you have shared with me will remain cherished and close to my heart as I continue on my learning journey. Your dedication to improving health outcomes for your community is truly an inspiration and I hope to one day achieve as much as you have. I would also like acknowledge the administrative support provided by Rhonda Trudeau from the Long Term Care Centre in Wikwemikong. Your devotion to aiding in participant recruitment and providing a safe space to gather ensured the project's success. The project would not

have been possible without the guidance provided by the Community Advisory Group. Miigwetch to all members who provided their support, expertise, knowledge and personal input. Your voices and stories will remain as an imperative part of my being as I continue to collaborate with Indigenous communities on improving health outcomes and wellbeing across the generations.

The success of this project was strongly guided by the strong, determined voices of the community members. To all the participants who committed their time to sharing opinions, stories and knowledge with me, Chi-Miigwetch. Your contributions to discovering opportunities to explore traditional roles and promote intergenerational relationships will benefit many generations to come. To the participants whom I am privileged to continuously learn from, I look forward to our many years of friendship to come. Your words of wisdom, encouragement and insight helped guide me along the correct path in my journey.

Finally, I would like to acknowledge the funding provided through the Canadian Consortium on Neurodegeneration in Aging (CCNA), the Education Outreach Scholarship from the Mississaugas of Scugog Island First Nation and scholarships from Laurentian University.

Table of Contents

Abstract…..………………………………………………………………………….. iii

Acknowledgements…………………………..………………………………. iv

Table of Contents……………………………..………………………………..viii

List of Tables ...……………………………..…………………………………….. xi

List of Figures.……………………………..……………………………..……… xii

List of Appendices..………………………..……………………………………xiii

East – Vision and Awareness "See It"
Part I: Introduction……………………………..……………………………........... 1
1.1 Background...…………………………..……………………………………...1
1.2 Existing Gaps in Brain Aging Research and Care…………………………………….5
1.3 Situating the Research……………………………..…………………………..7
1.4 Research Questions……………………………..………………………………..8
1.5 Developing the Context and Understanding……………………………………..9
1.6 Alzheimer's disease and Related Dementias in Indigenous Communities…………..10
1.7 Perception of Illness Diagnosis and Associated Care……………………………..12
1.8 Challenges Arising from A Colonial Presence………………………………………14
1.9 Social Determinants of Health and Health Care Equity……………………………..17
1.10 Success of Intergenerational Programs……………………………………………..19
1.11 Purpose…………………………………………………………………………...23
1.12 Research Objectives……………………………………………………………...24
1.13 Locating Myself in the Research…………………………………………………...25
1.14 Outline to the Thesis……………………………………………………………..26

South – Time and Understand "Relate To It"
Part II: Theoretical Perspectives and Methodologies…………………………………...28
2.1 Indigenous Knowledge in Research & Indigenizing Research Perspectives………...29
2.2 Indigenous Research Paradigm…………………………………………………32
2.3 Responsibility and Accountability……………………………………………………...34
2.4 Theoretical Perspectives……………………………………………………………..36
Post-Colonial Theory………………………………………………………………….37
Indigenous Wholistic Theory…………………………………………………….39
Intergenerativity Model…………………………………………………………42

2.5 Connecting Indigenous Knowledge to Methodologies……………………………45
The Medicine Wheel………………………………………………………..45
Community Based Participatory Action Research……………………………48
Conversational Method……………………………………………………..51

West – Reason and Knowledge "Figure It Out"
Part III: Methods……………………………………………………………...52
3.1 Research Methods and Community Based Participatory Action Relationships……..53
3.2 Validity and Reliability…………………………………………………………55
3.3 Study Design…………………………………………………………………56
Project Guidance……………………………………………………………56
Community Engagement…………………………………………………...57
Participant Recruitment……………………………………………………57
Participant Engagement……………………………………………………59
Consent Process……………………………………………………………62
Incentives and Honorariums………………………………………………..63
3.4 Data Collection………………………………………………………………...64
Key Informant Interviews…………………………………………………..64
Preliminary Actions to Focus Groups………………………………………65
Older Adult and Youth Focus Groups……………………………………...66
Community Program Observations…………………………………………68
3.5 Journal Reflections…………………………………………………………...69
3.6 Potential Risks………………………………………………………………69
3.7 Modifications………………………………………………………………...71
3.8 Data Analysis………………………………………………………………...72
Qualitative Thematic Analysis……………………………………………...72
Validation of Thematic Analysis…………………………………………...74
3.9 Ownership……………………………………………………………………75
3.10 Ethics Approval……………………………………………………………76
3.11 Teachings and Guidance from the Seven Grandfathers……………………………76

North – Movement and Wisdom "Do It"
Part IV: Findings……………………………………………………………...80
4.1 Findings……………………………………………………………………...80
Theme One: Culture and Traditional ways of living are weakened and need to be nurtured……………………………………………………………………..82
Theme Two: Change present in society, family, community and relations deteriorate social engagements between the generations………………………...87
Theme Three: Opportunities for intergenerational inclusion encourage equality, community and self-worth…………………………………………………92

Theme Four: The fear felt by youth and older adults towards intergenerational relations perpetuates the hesitation for engagement ……………………………98
Theme Five: Barriers to intergenerational relations are facilitated by policy, which limit and constrain interactions between the generations………………………101
Theme Six: *Technology generates communication challenges yet sustains the potential for generating engagement opportunities across the generations*……105
Theme Seven: Natural, unique and fun activities empower intergenerational relationships……………………………………………………………107

Part V: Discussion and Limitations………………………………………………….....110
5.1 The Importance of Reflexivity in Research Findings………………………………111
5.2 Relating the Themes…………………………………………………………..113
5.3 Connection and Guidance from the Seven Grandfather Teachings………………...119
5.4 Ownership and Giving Back…………………………………………………..126
5.5 Strengths and Limitations……………………………………………………..127

Part VI: Implications and Conclusion…………………………………………….....128
6.1 Conclusion………………………………………………………………………128
6.2 Project Implications…………………………………………………………...131
6.3 Closing Thoughts……………………………………………………………...133

References ……………………………………………………………………...135

List of Tables

Table 1: Final Participant Count for Focus Groups and Interviews……………………68

List of Figures

Figure 1: Map of First Nation Communities on Manitoulin Island……………………….8

Figure 2: Medicine Wheel Planning Stages……………………………………………...47

Figure 3: Indigenous Community Based Participatory Action Research Model………...50

Figure 4: Word Cloud presented to the combined focus group to describe Older Adult and Youth Focus Group Thoughts, Ideas and Common Themes…………………………….81

Figure 5: Themes in Fostering Traditional Roles and Promotion Intergenerational Relationships in Wikwemikong, Ontario…………………………………………………110

List of Appendices

Appendix A: Laurentian University REB Ethics Approval……………………………143

Appendix B: Manitoulin Anishinaabek Research Review Committee…………………144

Appendix C: Youth Recruitment Advertisement………………………………………147

Appendix D: Letter of Information for Key Informant Interviews……………………..148

Appendix E: Letter of Information for Older Adult Focus Groups……………………152

Appendix F: Letter of Information for Youth Over 12 Years of Age………………….157

Appendix G: Letter of Information for Youth Under 12 Years of Age………………...162

Appendix H: Key Informant Interview Conversation Guide…………………………...167

Appendix I: Ice Breaking Activities for Focus Groups………………………………...168

Appendix J: Older Adult Focus Group Conversation Guide…………………………...169

Appendix K: Youth Focus Group Conversation Guide………………………………...170

East – Vision and Awareness "See It"

Part I Introduction

1.1 Background

There has been a growing interest around brain aging[1] in Indigenous populations, in particular, exploring culturally appropriate ways to provide suitable care. The emergence of Alzheimer's disease and related dementia's (ADRD) in Indigenous populations across Canada is a rising concern that is relatively new as longevity of the population increases. Prevalence of ADRD has been noted to exceed rates of non-Indigenous populations (Finkelstein, Forbes, & Richmond, 2012; Jacklin, Walker, & Shawande, 2013). However, there is little known about the increased prevalence and incidence of ADRD in the Indigenous populations of Canada. Research shows that there may be several factors that contribute to the increased prevalence including perceptions of the illness, impacts from the social, colonial, geographical, economical and biological determinants of health, increased vulnerabilities due to demographic transitions/isolation and various co-morbidities (Henderson & Henderson, 2002; Jacklin et al., 2013; Greenwood, de Leeuw, Lindsay and Reading, 2015; Smith et al., 2008). Health conditions such as heart disease, stroke and diabetes, which First Nations people are more susceptible to due to various influential factors, may be associated with the higher prevalence of ADRD (Jacklin et al., 2013). Numerous risk factors associated with Alzheimer's disease in Indigenous populations, both on and off reserve, have been noted in varying degrees to increase the prevalence of ADRD. The risk factors include diabetes, hypertension, obesity, physical inactivity, smoking and low educational attainment. The highest associated risk factor with ADRD for Indigenous

---

[1] 'Brain aging' is used frequently throughout this project as a substitution for 'Alzheimer's disease and related dementias'. Community members have expressed that medical terminology including diagnoses do not have a direct translation into the language (Anishinaabemowin) (Pace et al., 2013).

populations is physical inactivity. These risk factors are termed as modifiable and suggest that many projected ADRD cases amongst Indigenous populations may be preventable if addressed in an appropriate manner (MacDonald, Barnes & Middleton, 2015).

The increased prevalence of ADRD in many Indigenous communities has created the need for culturally appropriate health care services and supports, which are discussed in greater detail in the later portion of the Eastern direction (Part I). Through communal collaboration and participation in the development of community reports in Northern Ontario, family members, primary care givers and individuals experiencing signs and symptoms of ADRD have expressed this as an essential need. This demonstrates the multifaceted approach to addressing age-related illnesses in Indigenous communities (Pace, Jacklin, & Warry, 2013). Mainstream primary health care services and providers do not always address or incorporate the political, environmental and cultural determinants of Indigenous health, which are essential in providing appropriate and approachable care (First Nations Regional Health Survey, 2017; Maar, 2004; Williamson & Harrison, 2010). Western approaches to health care are at times weakened due to the lacked presence of consideration and trust for cultural differences and understanding of health and illness. Mainstream care deters many individuals from seeking medical attention, which lead to an increased potential for unaddressed health concerns (Tang & Browne, 2008; Twigg & Hengen, 2009). However, Western approaches to medicine are not the sole sought path to addressing health concerns. Many Indigenous people and communities combine Traditional and Western methods of healing to achieve beneficial health outcomes (First Nations Regional Health Survey, 2017; First Nations and Inuit Regional Health Survey, 1997). Collaboration between Indigenous healers and non-Indigenous health authorities strive to bridge the existing

gap between the health status of Indigenous and non-Indigenous people while also aiming to improve access to care (Kirmayer and Valaskakis, 2009).

Without demonstrating consideration for the importance of culture in understanding and maintaining Indigenous health, Indigenous communities continue to receive health care services that are not culturally appropriate. The frequent lack of understanding mainstream health care service providers have for cultural and environmental contexts to 'bio-western' diagnoses has led many First Nations communities to actively take control over their health services (First Nations Regional Health Survey, 2017; Maar, 2004; Twigg & Hengen, 2009). In taking over control of their health services, Indigenous communities are able to guide, change and develop approaches to addressing health concerns that become specific to the needs of their community. Indigenous voices become the leading reason for changes in health care, eliminating mainstream views and governance by 'outside' views (Jacklin & Warry, 2004; Lavoie, 2013; Maar, 2004). This creates solutions for health disparities to be grounded in Indigenous perspectives and increases the success of improving health statuses in Indigenous communities (Tousignant & Sioui, 2009). Current research suggests that Indigenous understandings of ADRD are grounded in cultural contexts and are often as viewed as a 'normal' and 'natural' part of life (Finkelstein et al., 2012; Henderson & Henderson, 2002; Jacklin, Pace & Warry, 2015; Pace et al., 2013). Cultural perceptions of illness and care are reviewed in greater detail throughout this thesis.

ADRD research led in non-Indigenous communities suggest that there is merit in approaches that shift from pharmacological treatment to psychosocial interventions (Park, 2014). These interventions are reviewed in depth throughout the Southern direction (Part II) of this thesis,

where focus is given to the theoretical perspectives and methodologies that guide the development of this project. This thesis explored one such approach that seeks to improve brain aging and resolve the currently existing gap in culturally appropriate health care services by exploring and fostering the traditional roles of older Indigenous adults. The exploration and fostering of traditional roles is done in relation to the increased need for intergenerational social engagements with youth in the community. The Intergenerativity model established by Dr. Peter Whitehouse inspired this approach and is described in greater detail in Part II. As explained by Dr. Peter Whitehouse, benefits for the use of this model with individuals experiencing signs and symptoms of ADRD include: reduced levels of stress, cognitive stimulation through engagement with youth, and an increased sense of self-worth (George, Whitehouse, & Whitehouse, 2011; George & Whitehouse, 2010; Whitehouse, 2013; Whitehouse, 2014).

The model of intergenerativity is an alternative approach to improving the quality of life for those experiencing ADRD in comparison to the traditional pharmacological approach. The development of this model was led by a community approach that was not specific to Indigenous communities. The model focuses on the inclusion of elderly adults with ADRD living in urban senior centres. Whitehouse and George (2008) refute pharmacological approaches and believe that health care approaches that focus on the mentally and physically active self, as well as incorporating the effect that ecological factors have on our cognitive health, will improve the overall quality of life experienced by individuals with ADRD (p. 147). The model is then not only a preventative method for ADRD but a treatment method as well. The foundational basis of this model is reflected throughout this project and opportunities for the model to be adapted to various cultural contexts are displayed. This psychosocial model is congruent with theoretical

perspectives that guide the research, which are described in depth in the Southern direction (Part II). The need for increased social interaction, expressed by Indigenous communities, must be viable, have meaning and be grounded in Indigenous perspectives (Pace et al., 2013) that reflect the mental, physical, spiritual and emotional self (Absolon, 2010). Such perspectives are reflected throughout this research and aid in determining the theoretical and methodological foundation.

1.2 Existing Gaps in Brain Aging Research and Care

Current research shows that there is a need for specific programming within Indigenous communities (First Nations Regional Health Survey, 2017; Pace et al., 2013; Twigg & Hengen, 2009) for those experiencing memory loss and signs of brain aging (Finkelstein et al., 2012; Hulko et al., 2010; Pace et al., 2013). In one study, programming was expressed to focus upon 'friendly visiting programs' in which 'meaningful social interaction' is occurring (Pace et al., 2013). Meaningful social interaction is referred to as being inclusive to the cultures and traditions of Indigenous people and receptive to the needs of the community. Community members state that in order for social interaction to be meaningful, traditional roles and activities need to be fostered (Pace et al., 2013). Community based reports from Indigenous communities in Northern Ontario show that in order for health care services and programs to be considered culturally appropriate by health authorities and members of the communities, honouring the importance of Elder's roles must be adhered to (Pace et al., 2013).

When knowledge translation occurs through approaches that are exclusively designed for Indigenous communities, there is a higher degree of effect (Smylie et al., 2004). An example that demonstrates how knowledge translation occurs when approaches to medical care and services

are exclusively designed for Indigenous communities can be seen through the core principles of Native American nursing (Lowe & Struthers, 2001). The core principles focus upon a) *caring*: relationships, wholism, knowledge and health, b) *traditions*: relationships, values, respect and wisdom, c) *respect*: relationships, honour, identity, strength, d) *connection*: relationships and foundation, e) *wholism*: relationships, balance and culture, f) *trust*: relationships, respect and presence and g) *spirituality*: relationships, unity, honour, balance and healing (Lowe & Struthers, 2001). The most prominent domain in the core principles of Native American nursing is relationships. Relations are prominent and highly respected in Indigenous communities as everyone and everything is seen in relation to one another. Relationships offer companionship, mentorship and friendship, but it also provides opportunities to learn, to teach, to engage, to think, to be respectful, to be kind and to be loved. Relationships are viewed as a 'we' instead of a 'you' and 'I" (Ermine, Sinclair, & Jeffery, 2004; Nagel & Thompson, 2006; Thompson, Cameron, & Fuller-Thomson, 2013).

The importance of relationships in health care services (Leon & Knapp, 2008) can be seen through the success of the intergenerativity model. The relationships created and fostered through the model encourage both generations to be active voices and to have active minds. The continued development of the relationship ensures an authentic and rich exchange between the generations (George et al., 2011; Whitehouse, 2013). The success of the intergenerativity model demonstrates that increased social interaction has specific benefits for older adults and provides opportunities to foster relationships between the generations. Incorporating the core principles of Native American nursing and understanding influential factors that may increase the current gap in the health status of Indigenous people in Canada (Lowe & Struthers, 2001; Menzies,

2008),assures that the model of intergenerativity can not only successfully guide the nurturing of traditional roles of older First Nation adults in order to improve the quality of life for those experiencing dementia but also adapt to the cultural contexts of Indigenous communities.

1.3 Situating the Research

This inquiry was set on Manitoulin Island, Ontario, Canada in the Anishinaabe community of Wikwemikong Unceded Indian Reserve. The Manitoulin area is comprised of seven First Nation communities which include: Zhiibaahaasing, Sheshegwaning, Aundeck Omni Kaning, M'Chigeeng, Sheguiandah, Wikwemikong Unceded Indian Reserve and Whitefish River. The island is home to decedents of the Ojibwa, Odawa, Pottawatomi people as well as non-Anishinaabe settlers. Participants for this project were welcomed from all Indigenous communities, however direct collaboration with the community of Wikwemikong led the project's development.

The Wikwemikong Health Centre's involvement with the Canadian Consortium on Neurodegeneration in Aging (CCNA) projects, being led by Dr. Kristen Jacklin and the Centre for Rural and Northern Health Research informed this research. The community's involvement in CCNA research and previous dementia studies promoted the acceptance of this project. Through the community's continuous involvement in aging projects a pre-established Community Advisory Group aided in the project's development. The community researcher and administrative staff at the Long Term Care facility in Wikwemikong guided participant recruitment and the project's connection to local programming agencies.

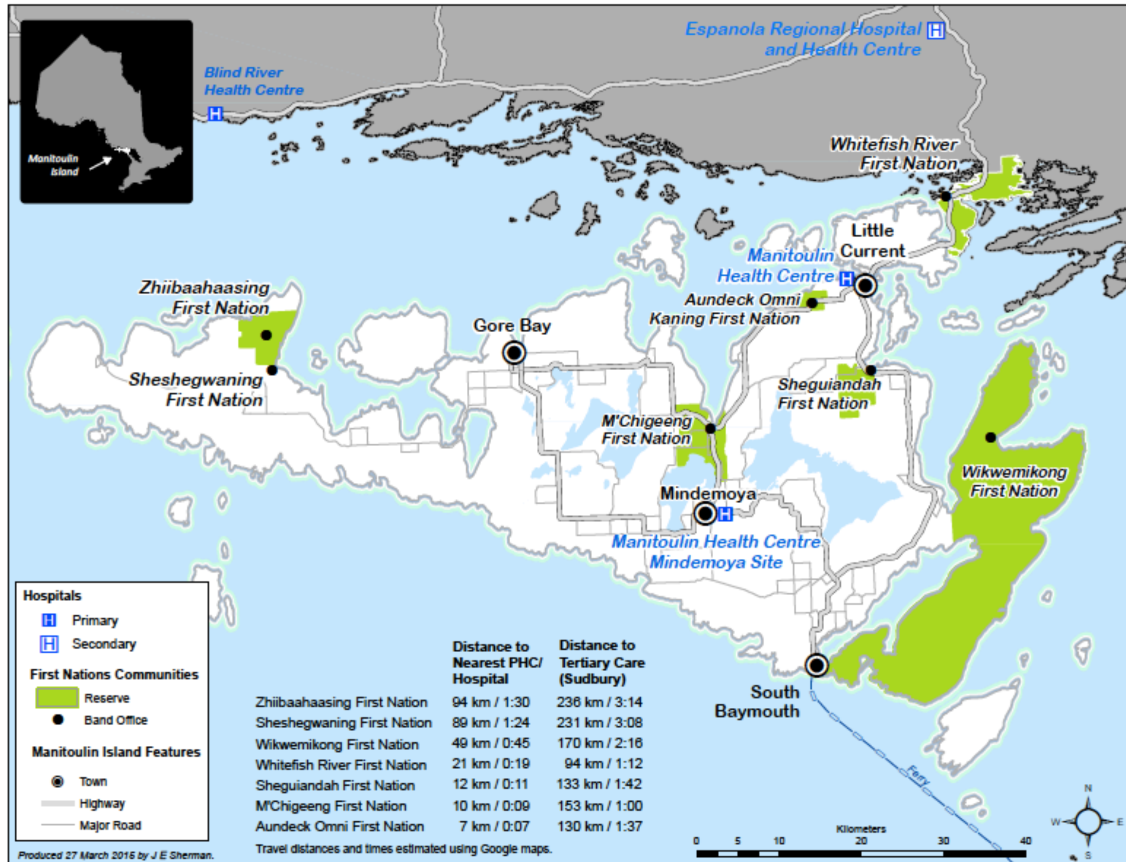

Figure 1 Map of First Nation Communities on Manitoulin Island
(Map provided courtesy of the Centre for Rural and Northern Health Research, Best of Both Worlds research team)

1.4 Research Questions

The research focused on intergenerational roles in Indigenous communities as a way to improve brain aging in order to address the communicated need for access to culturally appropriate dementia care by Indigenous peoples and communities. This research is specific to the Anishinaabe people in Northeastern Ontario, particularly individuals who live on the Wikwemikong Unceded Reserve on Manitoulin Island. The following research questions guided the project:

Primary Question: How can the Anishinaabe community of Wikwemikong on Manitoulin Island create and promote opportunities for older Indigenous adults to participate in culturally

appropriate intergenerational social engagements in order to enhance the quality of life for those experiencing brain aging?

Secondary Question: How does the Intergenerativity model apply to the cultural context of the Anishinaabe community of Wikwemikong?

1.5 Developing the Context and Understanding

Prior to exploring the purpose of this research, it is imperative to understand the consequences of past and present colonial constructs with respect to current communication gaps between the generations, the various determinants of health faced by Indigenous people and the need for culturally appropriate health care that incorporates the teachings of Indigenous peoples and their communities. In understanding the consequences that past and present colonial constructs might have on the factors mentioned above, an understanding develops for the prevalence and perception of brain aging illnesses. For example, the relationship between the effects of colonialism and intergenerational relationships potentially increases the prevalence of brain aging illnesses in Indigenous communities as there is a lacked presence of meaningful interactions. The increased prevalence of brain aging illnesses, such as ADRD, is noted in relation to the decreased presence of traditional roles for older adults, where meaningful social interaction occurs through knowledge exchange.

The presence of both a colonial past and present lens is required when aiming to understand the increased prevalence of brain aging, specifically ADRD, in Indigenous communities. Recognizing the continued presence of colonialism in Indigenous communities provides reasoning for the various disparities and inequalities encountered. In acknowledging the present colonial lens, effects on influential factors that increase the prevalence of ADRD in Indigenous

communities are brought forth. For example, the transfer of trauma that is experienced by many generations due to colonial policies is manifested into the daily lives of all the generations. The transfer of trauma caused by colonization affects many traditional relationships and roles in the community. In particular, relationships between the generations continue to separate and perpetuate a communal divide, which in turn gives purpose and need to this research.

1.6 Alzheimer's disease and Related Dementias in Indigenous Communities

A study conducted by Jacklin and colleagues (2013) demonstrates that the prevalence of dementia in Alberta First Nations was approximately 7.5 per 1000 people, in comparison to 5.6 per 1000 non-First Nations people in 2009. Researchers have demonstrated that the increased rate of prevalence and incidence of ADRD in Indigenous communities may be due to several contributing factors and associated conditions. Factors that may contribute to the increased prevalence and incidence include changing perceptions of the illness, earlier onset of chronic conditions, longevity of older generations, impacts from various determinants of health and increased vulnerabilities due to lack of culturally appropriate care (Blind, Dietrich, & Oleson, 2015; Finkelstein et al., 2012; First Nations Regional Health Survey, 2017; Jacklin et al., 2013; Pace et al., 2013). With high rates of dementia believed to be a relatively new phenomenon in Indigenous communities, there is a lack of knowledge regarding the distinct attention required to address care options (Finkelstein et al., 2012; Jacklin et al., 2013). Community reports demonstrate that a disruption or shift from traditional ways of living is termed as being a major contributor to the emergence of dementia in Indigenous populations. Participants from Manitoulin Island First Nations communities and others stated that shifting away from traditional roles in the community and cultural activities reduces one's ability to receive adequate cognitive and social engagement, making older adults more susceptible to decreased levels of cognitive

functioning (Hulko, 2004; Hulko et al., 2010; Lanting, Crossley, Morgan, & Cammer, 2011; Pace et al., 2013).

Qualitative researchers demonstrated that the concept of dementia and brain aging in Canadian and American First Nations communities is not well understood or seen as an issue that needs to be solved or treated (Hulko et al., 2010; Pace et al., 2013). The word 'dementia' itself has little to no meaning in many First Nations communities and many who are diagnosed believe that this is 'basically a Western diagnostic category' (Hulko et al., 2010). Communal roundtable discussions held in a First Nations community in British Columbia expressed that appropriate health care services were limited in rural settings, which discouraged many individuals to seek care. In turn, many individuals experiencing signs and symptoms of brain aging turn to natural helpers and familial supports in times of need (Hulko et al., 2010). In addition, community reports from Northern Ontario First Nation communities assert the desired need for culturally appropriate health care services that address the interpretations and perceptions of brain aging in Indigenous communities (Pace et al., 2013). Furthermore, confirming that the increased presence of culturally appropriate approaches to healthcare will aid in improving healthy brain aging through exploring and fostering traditional roles and improving intergenerational social engagements (Pace et al., 2013).

Cultural perceptions heavily influence the interpretations and understanding of illness and health care. In addition, health care practices of physicians, primary caregivers and the aiding services available for any given illness are also strongly influenced by cultural interpretations. These interpretations and understandings of illness impact the type of care sought and provided

(Dilworth-Anderson & Gibson, 2002). Hesitation associated with accessing social supports, specifically for individuals experiencing signs and symptoms of brain aging, furthers the need for culturally appropriate measures to be integrated into programming and care (Jacklin et al., 2015; Lanting et al., 2011; Pace et al., 2013). As expressed by the Anishinaabe communities in the Manitoulin Island Community Report, solutions for improving healthy brain aging amongst older First Nation adults must be grounded in cultural perspectives that are of importance to the community. Cultural perspectives that were deemed as important in order to address brain aging in this report include the need for meaningful social interactions across the generations and the fostering of traditional roles within the community (Pace et al., 2013).

1.7 Perceptions of Illness Diagnosis and Associated Care

Perceptions of Alzheimer's disease and related dementias in Indigenous communities can be seen at the initial diagnosis, or what many refer to as the label, of 'having dementia.' The word dementia is noted as being untranslatable in many traditional Indigenous languages. The inability to directly translate the word, demonstrates that perceptions of the diagnosis do not align with cultural understandings associated with brain aging (Jacklin et al., 2017, 2013; Pace et al., 2013). Instead, these perceptions of brain aging derive from cultural norms, values and beliefs that help guide the understandings associated to the illness. In discussing illness through a cultural lens, labels and diagnoses that are untranslatable increase the barriers associated with seeking medical attention. Specifically, communities are unaware of the experiences, symptoms and progression that health disparities including brain aging can endure, prolonging ones access to care. These increased barriers exemplify the need for culturally appropriate methods to diagnosing disease and illness. In addition, cultural norms, values and beliefs also influence caregiving experiences (Dilworth-Anderson & Gibson, 2002; Henderson & Henderson, 2002; Jacklin et al., 2015).

Many cultures view intergenerational relationships as significant and essential to the care and wellbeing of older generations who may be faced with illness. The cultural interpretation of dementia, or brain aging, has direct impacts on the amount and type of care provided to the aging population. Gender roles, coping mechanisms, self-care strategies and the use of social supports are a few care factors that are influenced by cultural and traditional beliefs (Dilworth-Anderson & Gibson, 2002; Jacklin et al., 2015; Lanting et al., 2011).

Familial presence and interdependent relationships have been noted as being the primary source of care for many elderly who are experiencing signs and symptoms of brain aging in Indigenous communities. However, with a change in the family dynamic due to geographic migration, financial constraints and the ongoing effects of colonialism, providing care for elderly family members can be difficult. Many family members become primary care providers as Indigenous values encourage the inclusion of familial support. This form of care and commitment comes from the teachings of the Seven Grandfathers[2] (Blind et al., 2015; Dilworth-Anderson & Gibson, 2002; K. Jacklin et al., 2015; King, Smith, & Gracey, 2009; Lanting et al., 2011). The inclusion of familial support and the significance of meaningful relationships can be similarly viewed as the foundational basis for the Intergenerativity model. This ensures the models the ability to adapt to various cultural contexts while adhering to its original basis.

Traditional teachings bring forth the understanding that 'dementia' is a normal occurrence, and

[2] The Seven Grandfather teachings are traditional teachings shared within many Indigenous communities. The Seven Grandfathers shared these teachings with the first Elder to ensure that people were living the good life through respecting the Creator, Mother Earth and one another. Over time, the teachings have been incorporated into various aspects of life to embrace balance between the physical, spiritual, emotional and mental self. The teachings are interconnected to one another and must be learnt through an inclusive understanding to the relations between each of the teachings (Maar et al., 2013; Native Women's Centre, 2008).

that the adult self is simply transitioning back to the born self. Some teachings perceive brain aging as the symbol to share all knowledge and maintain all relations. It is through these relations that the passing on of knowledge occurs. This is why primary care is normally sought through family members. This understanding of aging and life is viewed through teachings of the Medicine Wheel[3]. Many Indigenous people with signs and symptoms of brain aging, as well as care providers, explain the idea of aging as completing the full circle of life (Hulko, 2004; Hulko et al., 2010; Jacklin et al., 2015; Pace et al., 2013). It is imperative to understand cultural representations of aging to ensure that mainstream health authorities adapt their approaches in order to provide suitable care. Understanding such perspectives provides opportunities for Indigenous communities to centre healthcare on cultural and traditional perceptions as opposed to mainstream visions. It is through the inclusion of cultural views that significant and meaningful care is provided to individuals experiencing signs and symptoms of brain aging.

1.8 Challenges arising from a Colonial Presence

Weakened Indigenous cultures and traditional ways of being are direct repercussions of historical and current colonization processes. The process of identifying and taking apart colonization processes is referred to as decolonization (Kovach, 2010). An important component of decolonization is to revive Indigenous culture through the rebuilding of traditional teachings (Hulko et al., 2010; Smith, 1999). In order for traditional teachings and culture to be restored there must be an understanding of the specific cultural context for each Indigenous communities. Health status and care are also heavily reliant on incorporating cultural and traditional teachings.

[3] The Medicine Wheel represents various teachings in Indigenous communities. Each direction on the Medicine Wheel is responsible for specific teachings in relation to seasons, life cycles, states of being, planning stages and traditional medicines. The Medicine Wheel is also an adaptable tool that many Indigenous communities use to teach and learn from. Its adaptability to various teachings makes its presence prominent in numerous Indigenous cultures and traditions (Getty, 2010; Native Women's Handbook, 2008; Twigg & Hengen, 2009).

Without the presence of culture and tradition, the state of being is perpetuated by the colonial constructs (Absolon & Willett, 2004). The presence of culture and tradition must be viewed in all aspects of the self, as well as the community. As stated in Bruyere (1999) by Maurice Squires, "All problems must be solved within the context of the culture – otherwise you are just creating another form of assimilation."

Historically and presently, one of the most detrimental repercussions of colonization was the implementation of residential schools. Children who were forced to attend these institutions experienced various unjust conditions that in some circumstances lead to abuse and death (The Truth and Reconciliation Commission of Canada, 2015). Deliberate suppression of the language and culture was the most common condition experienced by individuals who attended the residential schools (Smith, Varcoe, & Edwards, 2005). Smith and colleagues (2005) describe emotional and spiritual abuse endured as an enforced rejection of values that had always given life a valuable meaning. The trauma endured following these experiences has left many generations impacted. Survivors, now adults, of the residential school system declare that the negative impacts sustained throughout their time spent at the institutions have negative ramifications that continue through to the following generations (Brasfield, 2001; Pace et al., 2013; Sherwood & Edwards, 2006).

Qualitative research guided by residential school survivors identifies that the loss of identity experienced has left survivors feeling as if they don't belong and continuously searching for 'what was left behind' (The Truth and Reconciliation Commission of Canada, 2015). Through the process of searching for what was left behind, relationship building with Elders and

traditional knowledge keepers becomes an important pathway towards restoring lost knowledge. Traditional Elders carry sacred teachings of culture and language that provide guidance for those who may have drifted away. The drift is noted as a repercussion of residential schools or as a result of the transfer of trauma across the generations (Chansonneuve, 2005; Gone, 2007). The inclusion of culture and tradition in daily living fosters the roles of each generation, which encourages the renewal of balance to the four directions and all relations.

It is imperative to understand the implications of historical trauma experienced by Indigenous peoples and communities when attempting to explore role restoration as a method to improve the quality of life for those experiencing brain aging. Changes in roles have succumbed to the presence of colonization through the exclusion of culture and tradition. In fostering the cultural and traditional ways of Indigenous people, communal roles are nurtured and give potential to improving intergenerational relationships (Blind et al., 2015; Canales, 2004; Ginn, 2009; Smith, Varcoe, & Edwards, 2005b; Tousignant & Sioui, 2009). Prior to engaging in qualitative research relationships with Indigenous communities, recognizing and understanding the experiences endured by the presence of colonization is imperative. Many inequalities faced by Indigenous people and communities (i.e., loss of traditional roles, prevalence of chronic disease, substance abuse, intergenerational trauma) are attributed to historical and present colonial occurrences (Czyzewski, 2011; O'Shane, 1995; Reading, Kmetic, & Gideon, 2007). As a researcher, understanding the pre-existing issues experienced by the community created in-depth and meaningful engagements with participants. The research becomes a trusted entity that is guided solely by the community through the creation of meaningful engagements with participants

(Wilson, 2008). Exploring research as a relationship with the community is reviewed in the later portion of this paper.

1.9 Social Determinants of Health and Health Care Equity

Social determinants of health refers to the humanly and socially factored influences that uniquely affect populations (Raphael, 2009). The humanly factored influence of social exclusion gives acknowledgement to colonialism as a broader social determinant of health in Indigenous populations. Many authors speak to the notion of colonialism as never having ceased, but instead is continuously 'spilling over into the present.' Colonialism is the guiding influence that controlled the historic, political, social and economic frameworks that shape Indigenous and non-Indigenous relations. These factors are viewed as collectively shaping and influencing the health and well-being of Indigenous peoples. Specific determinants of health as a result of colonialism include unfavourable conditions for employment, income, education, housing, and food security. The conditions of these environments, or the lack thereof, strongly influence health outcomes and behaviours (Czyzewski, 2011; Greenwood, de Leeuw, Lindsay & Reading, 2015; King, Smith & Gracey, 2009; Raphael, 2009; Warry, 1998).

There is a lack of attention given to the determinants of health for Indigenous people within mainstream approaches to healthcare. Individuals, communities and nations that experience inequalities through various determinants of health including ecological, social, economic, geographical, educational, colonial, political and physical are susceptible to an increased presence of health issues and limited access to appropriate resources and care (Greenwood, de Leeuw, Lindsay & Reading, 2015; King, Smith & Gracey, 2009; Reading & Wien, 2012; Richmond & Ross, 2009; Smylie & Firestone, 2016). However, not all Indigenous people and

communities share the same experiences and therefore do not endure the effects of determinants of health in the same manner (Allan & Smylie, 2015; Graham & Leeseberg, 2010; King, Smith & Gracey, 2009; Reading & Wien, 2012). Through understanding the uniqueness of each Indigenous community and person, health care solutions must be grounded in an understanding that each person is unique but equal.

The determinants of health are closely associated with an increased prevalence of illness and disease in Indigenous populations (Gracey & King, 2009; Greenwood, de Leeuw, Lindsay & Reading, 2015; King, Smith & Gracey, 2009; Raphael, 2009). In knowing this, it is evident that access to care will be required at some stage in life by those who are affected. However, many Indigenous communities are unable to access the required level of care for numerous reasons. Some communities are not able to house appropriate methods of care in their community, forcing many to seek medical attention from outside communities. This causes a gap in care as some families are unable to travel resulting in family members becoming primary care providers for those who are ill. The care provided through outside communities possesses its own potential for inequity. For example, some individuals are hesitant to seek help in fear of being judged. Racial discrimination and stereotyping are commonly amplified in mainstream health care system, which in some circumstance neglect to recognize and promote cultural safety and sensitivity (Allan & Smylie, 2015; Browne et al., 2016; Ly & Crowshoe, 2015; King, Smith & Gracey, 2009; Smylie & Firestone, 2016; Twigg & Hengen, 2009). Some families believe that care provided by family members centres the well being of the ill person first, whereas Western approaches to healthcare put the disease first. It is imperative that the person be before the disease (Hulko, 2004), specifically in an Indigenous context where maintaining balance between

all relations is of importance and perceptions of illnesses and diseases may differ from mainstream health care. Some families oppose seeking medical attention for dementia in that it brings back memories from childhood experiences with residential schools and 'Indian Hospitals' (Allan & Smylie, 2015; Drees, 2013; Goodman et al., 2017; Graham & Leeseberg Stamler, 2010; Jacklin et al., 2017; Tang & Browne, 2008).

In attempting to provide solutions to improve healthy brain aging, understanding the influence that the social determinants of health has on health care inequities, provides a foundational basis for community centred health initiatives. Removing the structural violence created by policies and institutional practices that are inherently unjust for Indigenous communities is essential to dismantling health inequalities (Browne et al., 2016).

1.10 Success of Intergenerational Programs

Medicalization and other social forces limit the public's ability to establish conceptions concerning ADRD. The imposition of medicalization and other social constraints limits the ways in which society can creatively and most importantly address ADRD in a cultural manner (Whitehouse, 2013). Dr. Peter Whitehouse suggests that a more effective way of addressing ADRD is to explore approaches that are less discipline-based and instead focused upon the relationships between humans (Whitehouse & Bendezu, 2000). This understanding of the model presented by Dr. Whitehouse is viewed in relation to the significance of relationships in Indigenous communities. This demonstrates the models ability to connect to Indigenous culture, pertaining specifically to the need for meaningful social interactions and relations as expressed by the community of Wikwemikong, Ontario. Research completed in collaboration with Indigenous communities explores the meaning of roles of older adults and the value that these

roles and knowledge give to the future generations (Pace et al., 2013; Hulko, 2004; Hulko et al., 2010).

Whitehouse (2013) describes an integrative care model, focusing on psychosocial approaches of care as opposed to pharmacological, which are embedded within the community and empowers self-efficacy for those it serves. The model of intergenerativity has been fulfilled in many community centres and empowers those who participate (Whitehouse, 2013). Success of the model has been noted in elementary schools, allowing generations to come together and collectively foster wisdom from one another. These interactions improve the overall health of the community through providing meaningful ways for the generations to learn and to teach one another (George et al., 2011). George and colleagues (2011) reveal that age-segregated learning environments lead to limited perspectives and are detrimental to the development of youth and well-being of older adults.

Another perspective that has arisen from the model of intergenerativity is the development and promotion of psychosocial interventions for individuals with dementia and memory loss. Developing psychosocial interventions for those experiencing ADRD can allow individuals to re-integrate (Morita & Kobayashi, 2013) themselves into meaningful roles, in turn postponing cognitive decline and improving cognitive functioning (George & Whitehouse, 2010). Research shows through an analysis of qualitative data derived from an intergenerational volunteer program, that persons with dementia who engage in meaningful, non-medicalized social engagements experience an enhanced quality of life. Quality of life enhancements fall within a variety of biopsychosocial pathways and stress reduction is duly noted by participants (George &

Whitehouse, 2010; Whitehouse, 2014).

Whitehouse and George (2008) refer to the Intergenerativity Model proposed through The Intergenerational School as an ‘intervention you needn’t swallow’ (p. 143). The Intergenerational School (TIS) represents a learning environment that services the community as a whole, encouraging participation from across the generations. Children aged six to twelve years of age engage in learning experiences with older adults, who participate in TIS on a volunteer basis. The older adults range in age from college students to senior citizens who are faced with the signs, symptoms and diagnosis of Alzheimer’s and Dementia (Whitehouse & George, 2008, p. 145). Volunteers engage with the children through reading, computer use, gardening and other activities that are deemed to stimulate the bodies and minds of learners of all ages. These activities provide opportunities for a mutual transfer of knowledge across the generations. This demonstrates a specific model of public education that provides improved learning for the children through mutual knowledge transfer, but also creates opportunities for older adults to partake in the future of their communities, engage in continuous social interaction and overall stay cognitively active (Whitehouse & George, 2008, p. 146). These experiences are noted to improve memory recall, increase the personal sense of self-wroth, give meaning to the daily lives of the elderly population and increase the presence of positive emotions including excitement and happiness. Whitehouse and George (2008) describe TIS as an educational model that can be altered and implemented into various settings, which strengths its inclusion in this project. They state that it is vital for society to incorporate aging persons into the education system due primarily to the fact that aging persons have so much to give back, with respect to the wisdom they have obtained (Whitehouse & George, 2008, p. 146). For the purpose of this

project, the incorporation of older adults into daily social interactions in the community provides the older population with opportunities to transfer their knowledge and engage in meaningful relationships. This also becomes beneficial to all the generations, both present and future, as opportunities to bridge the existing gap between the generations are strengthened through intergenerational programs.

Overall, the enhanced quality of life experienced through engagement with intergenerational activities by individuals experiencing signs and symptoms of ADRD provides preliminary results of success to improving ones experience and quality of life with the various degrees of brain aging. Areas of success include improved memory recall, knowledge translation, meaningful social engagement and reduced signs and symptoms of ADRD. In knowing that the presence of intergenerational relationships improves the experienced signs and symptoms of brain aging, communities can begin focusing on specific program components that will adhere to their community members. This allows researchers to adapt the intergenerativity model to specific environmental, cultural and ethnic variances. Specifically, Indigenous community based projects with individuals experiencing signs and symptoms of brain aging, as well as primary caregivers, have expressed the need for increased opportunities for meaningful social interaction. Meaningful social interactions were termed as opportunities to teach, engage with other generations and live in a traditional way. Indigenous communities have expressed that fostering of traditional roles is a way to promote meaning in their social engagements (Hulko, 2004; Hulko et al., 2010; Jacklin et al., 2015; Pace et al., 2013). Traditional roles differ within various Indigenous communities, but the transfer of knowledge has been recognized as a prominent responsibility and passion of the older generations (Braun, Browne, Ka'Opua, Kim, & Mokuau,

2014). Intergenerational programs and ways of living have been present in Indigenous communities for many generations. It is through the presence of colonization that intergenerational relationships have in some cases begun to deteriorate. The research aims to explore and foster traditional roles as a method to improve intergenerational relations and provide similar areas of success as noted in the intergenerational programs led by Dr. Peter Whitehouse. In listening to the opinions, stories, thoughts and suggestions of the community participants from Wikwemikong, the need for meaningful social interaction perpetuates the importance of culture, tradition and intergenerational relationships for providing healthier ways to age.

1.11 Purpose

The purpose of this research is to respond to the need for meaningful social interaction for those experiencing ADRD through culturally appropriate methods. Program recommendations will be developed by and for the Anishinaabe community of Wikwemikong in Northeastern Ontario through this research. Recommendations will incorporate personal inclinations of role restoration, individual meanings of intergenerational relations and disclose barriers that need to be overcome in order to promote intergenerational relations. The research will strengthen the need for meaningful social interaction by guiding the development of culturally appropriate program recommendations that explore and foster traditional roles in the community. These recommendations will encourage and promote current programs in the community to incorporate intergenerational perspectives. In addition, projects being implemented through the Canadian Consortium on Neurodegeneration in Aging (CCNA) will incorporate these recommendations into future projects that address aging in Indigenous communities. The project holds a high degree of potential for improving the quality of life for

those experiencing brain aging.

1.12 Research Objectives

Goals for the project were based upon the needs expressed by community members and revelations of previous research inquiries with the community of Wikwemikong. Community reports revealed that participants wanted meaningful social interactions fostered through traditional roles of older adults being present in daily living (Pace et al., 2013). Previous research engagements and discussions with the CCNA Community Advisory Group enabled the development of this project by providing guidance for its objectives and purpose.

The following objectives were established to ensure that the community's collective voice would direct the creation and promotion of intergenerational social engagements in the community. The first objective was to use community-based participatory action research methods in combination with culturally appropriate and respectful approaches to engage in a research partnership with the Anishinaabe community of Wikwemikong. Detailed explanations of these methods and approaches are described in Part III. These approaches assist with the development of a successful relationship between the community and myself in that it is built upon the Seven Grandfather teachings. The second objective was to work in partnership with the community in order to identify sustainable opportunities for the delivery of culturally relevant intergenerational programs. Through the partnership, various topics were addressed including traditional role restoration, opportunities for greater cognitive stimulation, and increasing social interaction across the generations. The third objective was to gather the shared voices and use qualitative thematic analysis approaches to illicit commonalities or themes that are deemed prominent or important to the fostering of traditional roles and intergenerational relations in the community.

1.13 Locating myself in the Research

The development, nourishment and growth of relationships aid in maintaining all relations and our overall well-being not only throughout daily living, but also throughout this project. It is through these relationships that we are encouraged to be natural and authentic in the expression of the self. It is through these relationships that we become interconnected, respectful, honest and determined in research. It is through being open and receptive that Indigenous voices are heard and ultimately guide the research (Absolon, 2010; Absolon & Willett, 2004; Chilisa, 2012; Hart, 2010; Kovach, 2010; Lavallée, 2009; Smith, 1999; Weber-Pillwax, 2004).

Absolon and Willet's (2004), *Indigenous research: Berry Picking and Hunting in the 21st Century*, paints a fitting picture of the researcher in Indigenous research:

> "Yet, I know that I speak and write truly from my own position, experiences and perspectives and do not represent the Indigenous peoples' voice. The only voice I can represent is my own and this is where I place myself."

The quote represents my place as an Indigenous community-based researcher working with the community of Wikwemikong. Through the development of research relationships with Indigenous communities, it is important to represent and include your own voice and lived experiences. Sharing voices and experiences in such a way allows the participants to learn about you who are and strengthens the research relationship. The perception of the relationship diverges from being termed as a research relationship to being relational beings. In turn, the shared and communal voice is granted as its own being that is relational. The shared voice may provide teachings of wisdom and guidance, yet the voice is not to be represented but to instead be shared. The honest and selfless understanding of the researcher's presence in the project is the

way in which I locate myself in this inquiry. The voices of the community are not being represented by me but instead shared. I do not consider the sharing of these stories to be my representation as they are not my words. It is through the sharing of stories that awareness and relation become the opportunity for change, development, exploration and fostering of traditional approaches to health and healing. I must acknowledge that the only voice I can represent is my own, but that I can share the voices of others simultaneously.

I am a Mi'kmaq First Nation woman and a member of Qalipu Mi'kmaq First Nation in Newfoundland and Labrador. My mom (Degrau, NL) and dad (Port au Port, NL) were born and raised in small, isolated Mi'kmaq communities on the Western coast of Newfoundland, traditionally known as *Kitpu*. I was fortunate to have developed a dualistic understanding of access to health care through living in an urban centre and frequently visiting to my family's community. I am a first generation post-secondary graduate. I am a daughter, a sister, a granddaughter, a great-granddaughter, a niece, a cousin and a voice. It is through the presence of these relationships in my childhood and into my adulthood that I am the person I am today. I am inspired by the multitude of voices throughout this project and I thank each voice for their encouragement and wisdom. I am inspired by the determination and strength shared by the community in discussing intergenerational relationships. I acknowledge their frowns, smiles, tears and laughter. This is their story.

1.14 Outline to the thesis

In Parts two and three, the research is related to pre-existing concepts and an understanding for what is required to address the research question and community needs are addressed. In exploring theoretical and methodological approaches to community based

qualitative research, we explore the developmental concepts of this inquiry. It is through the Indigenous research paradigm, theoretical perspectives and inclusion of Indigenous knowledge that the project is planned. Part three specifies the detailing of the project and how the research question will be answered. We begin to use the knowledge learnt in the previous two sections to provide us with reason for the selected approach.

Part four shares stories and discusses communal findings from the approaches taken to answer the research question. This section elaborates on the common themes elicited throughout the stories. The themes are termed as a guiding framework that will provide recommendations for the development of intergenerational programs in the community. Part five looks deeper into the meaning behind the stories and voices shared in Part four. This section incorporates the idea of the researcher and what time might mean for the project. Knowledge dissemination plans are disclosed through ownership of the project as well as what meaning this project will have to the community and participants. Limitations are discussed and changes to further studies regarding intergenerational relationships are recommended. Part Six expresses the implications of the project and what this research will provide to the Anishinaabe communities on Manitoulin Island with regards to improving the quality of life for those experiencing signs and symptoms of brain aging.

South – Time and Understand “Relate To It”

Part II Theoretical Perspectives and Methodologies

This chapter reviews the theoretical and methodological approaches to fostering traditional roles of older First Nation adults to promote healthy brain aging. These approaches are guided by Indigenous knowledge, more precisely the Anishinaabe traditional teachings of Wikwemikong Unceded Indian Reserve. In connection to Anishinaabe traditional teachings, an Indigenous research paradigm articulates my ontological and epistemological position. Through a symbiotic circular motion, Indigenous knowledge is reflected in the relational position of the community, the participants and me. Throughout the project, theoretical perspectives that relate to Indigenous knowledge guide community-based participatory action research practices. The vital presence of community-based practices in the project sustains accountability with the community of Wikwemikong and its members. Accountability is achieved and maintained through the establishment and guidance of the Community Advisory Group.

Connecting Indigenous knowledge to create community specific methodologies rejects mainstream approaches to qualitative research. This process advances a decolonized approach to research. The incorporation of decolonized methodologies was accomplished through the inclusion of the Medicine Wheel as a directional approach to the developmental stages of the project. The Medicine Wheel, in alignment with practices of the conversational method, connects Indigenous knowledge to the research. The Anishinabek people of Wikwemikong provided perspectives on communal roles, culture, tradition, language, prayer, the environment and technology through traditional teachings. This research incorporates Indigenous knowledge

through theoretical and methodological perspectives that adhere to guidance provided by the community participants of Wikwemikong, the community researcher and the Community Advisory Group.

2.1 Indigenous Knowledge in Research & Indigenizing Research Perspectives

The presence of Indigenous knowledge in community-based participatory action research ensures that the project is developed and guided by and for the community. This approach respectfully adheres to the culture and traditions of the Wikwemikong Unceded Indian Reserve. The Elders, older adults and youth who have participated in this project embrace varying degrees of understanding, recognition and incorporation of Indigenous knowledge in their daily lives. Each story and thought is shared in a meaningful manner and upholds equal importance in this project.

Indigenous knowledge refers to the experience of local Indigenous people and concerns the everyday realities of maintaining relationships with their traditional lands (Tobias, Richmond, & Luginaah, 2007). Knowledge is dependent upon the location, region, and the groups of people present, making it specific for different groups of Indigenous people. It is for these reasons that Indigenous knowledge is not to be deemed as general or the same for all Indigenous people. Research methodologies, not in alignment with Indigenous knowledge, reflect colonial methods that neglect to bring forth the communal voice and desire for inclusion (Chilisa, 2012 p.98). Western scientific knowledge and Indigenous knowledge systems have been noted as having fundamental differences. Indigenous research methodologies differ from Western approaches to qualitative research in that decolonizing methods are guided by traditional teachings of

Indigenous communities (Smylie et al., 2004).

According to Louise Grenier (1998) Indigenous knowledge is accumulative and is a representation of experiences, careful observations, and trial and error experiments. The knowledge becomes dynamic through trial and error, as new understandings are continuously being added and adapted to suit local communities. Each individual will have different meanings of Indigenous knowledge, represented in various quantities and quality. These variances are due to age, gender, socioeconomic status, daily experiences, roles, responsibilities and the knowledge learnt. Much of the knowledge transferred and learnt comes through the sharing of memories and stories. Such stories can be presented in the form of an activity or expressed through song, dance, myths, cultural teachings, community gatherings, laws, language and means of communal organization. Oral teachings of Indigenous knowledge are accountable and represent Indigenous ways of being and knowing (Grenier, 1998; Partridge, Cote-Meek, Manitowabi, & Mawhiney, 2014; Reynolds, 1997).

When aiming to establish relationships with Indigenous people or communities, recognizing and respecting Indigenous ways of knowing are imperative. Communities may differ in their views and understanding of Indigenous knowledge, making each research relationship and perspective unique to the given community. Dominant societal views may reject the presence of Indigenous knowledge as being central to a qualitative research project. It then becomes essential for the research project to bridge the gap between dominant understandings of qualitative research to Indigenous ways of being and knowing (Smith, 1999; Wilson, 2001, 2008). Bridging the gap through the presence of language, knowledge, stories and cultural experiences helps give voice

to Indigenous communities. These voices become the source of literature that must be relied upon. Through the recognition of Indigenous knowledge in research, opportunities to close the gaps created by colonization are established.

Indigenous research that speaks to Indigenous knowledge can be termed as being Indigenized (Chilisa, 2012, p.101; Chilisa & Tsheko, 2014; Smith, 1999). Knowledge systems that adhere to Indigenous ways of being or perceptions, aid in the process of Indigenizing conventional research practices. Indigenization is a method that involves the critiqued use and resistance to Euro-Western methodological approaches (Chilisa, 2012 p. 101; Chilisa & Tsheko, 2014). Resistance to Western approaches to research have been termed as the process of decolonizing. This process centres the concerns and worldviews of the colonized Other, allowing for self-understanding to occur through their own assumptions and perspectives. The newly framed process of decolonizing cannot be properly engaged with unless the researcher themselves can become relational to the people, and propose an I/We relationship instead of an I/You relationship (Absolon & Willett, 2004; Chilisa, 2012 p 13-18; Hart, 2010). The resistance to Euro-Western approaches to research demonstrates the capability held by Indigenous research, in that it contains the capacity to break the silence, and bring forth Indigenous voices (Braun et al., 2014; Weber-Pillwax, 2004).

It is through my personal understanding for the value for Indigenous knowledge that specific perspectives and methodologies were used in this research. The importance of communal voice and the presence of all relations, aid in connecting the project to Indigenous worldviews. Teachings from the community members of Wikwemikong helped to guide my visions for the

project and their teachings instilled the meaning of community, resilience, determination, awareness and respect. Through this transfer of knowledge and wisdom from the community members, I became aware of my responsibility to collaborate in a respectful and meaningful way.

2.2 Indigenous Research Paradigm

When engaged in academic research, it is imperative to articulate the ontological and epistemological position of the researcher. Furthermore, working within an Indigenous Research Paradigm, axiology and methodology must be acknowledged and integrated. The aspects of this paradigm are reflected as being in relation to one another, where interdependence is present. Therefore, change within one aspect will result in change of the others (Wilson, 2001a, 2001b, 2008). According to Wilson (2008), a paradigm is stated to be "a set of beliefs about the world and about gaining knowledge that goes together to guide people's actions as to how they are going to go about doing their research." Wilson describes *ontology* as the nature of reality. This can also be articulated as a way of being or what is believed to be real in the world. *Epistemology* is how the reality is thought about. *Methodology* is how to use the individual ways of thinking to gain more knowledge about the reality. *Axiology* is the set of morals and ethics when attempting to gain more knowledge about the reality (Wilson, 2008).

Ontology

Ontology incorporates the description of reality and existence (Wilson, 2008). Anishinaabe people encompass the spiritual and physical being, in which both beings are relational to one another. The relationship between the physical and spiritual self are diverging perspectives to dominant understandings and representations of Ontology. Indigenous relations with the physical and spiritual self are guided by Indigenous knowledge (Kovach, 2010; Hart, 2010). The

relationships between the spiritual and physical self are different not only to each Indigenous community, but to each Indigenous person.

Epistemology

Epistemology includes the individual process of defining knowledge and obtaining knowledge. The epistemology of research is to determine how we know what we know. In the Indigenous Research Paradigm, knowing what we know is related to traditional teachings that are specific to each community. Relationships are present in connecting individual thoughts and teachings. It is through knowing what we know that we develop our moral and ethical perspective. These perspectives hold us accountable for our actions and relationships in research (Ermine et al., 2004; Hart, 2010; Shawn Wilson, 2008).

Axiology

Axiology refers to the study of values and ethics. An Indigenous axiology is developed upon the perception of relational accountability between the researcher and the community. The researcher is a part of the project and is therefore, inseparable. The information gathered must be interpreted in a respectful way that aids in the development of the relationship. The researcher is continuously reflecting on their role in the research and how their role engages with the community as well as the voices shared (Chilisa, 2012; Hart, 2010; Wilson, 2008). As a Mi’kmaq First Nation woman, I am held accountable and responsible for ensuring that Indigenous research is collaborative, respectful and meaningful. The perspectives explored in this research, reflect my responsibilities as an Indigenous researcher and my accountability to the communities I collaborate with. The methodological approach to the project is defined in greater detail in the later portion of this chapter.

2.3 Responsibility and Accountability

I acknowledge the colonial impact on the community (Kovach, 2010 p. 80-81) of Wikwemikong and the responsibility I uphold to ensure the community's needs are respected and adhered to. Wikwemikong Unceded Indian Reserve is located in the Georgian Bay, Lake Huron area and is positioned on the eastern part of Manitoulin Island. It is the traditional home of the Odawa, Ojibway and Pottawatomi tribes, which is frequently referred to as the Three Fires Confederacy. The community is comprised of seven villages: Wikwemikong, Rabbit Island, Buzwah, Murray Hill, Kaboni, Wikwemikongsing and South Bay. Historically, settlers approached the land of Manitoulin Island with a proposition to repossess its entirety. The proposition included reclaiming the land, which housed members of the Three Fires Confederacy. The community of Wikwemikong unanimously refused to forfeit their land, resulting in the title 'Unceded Reserve,' which means the land has not been surrendered to any treaty terms or government conditions (Cooper, Maar & Peltier, 2000; Trudeau, 2012).

Following the refusal to surrender, all lands under the domain of Wikwemikong Unceded Indian Reserve were determined to be non-treaty lands. The community of Wikwemikong began to develop sustainable opportunities for self-government and established several community based organizations that would aid in fostering the needs of the community (Cooper, Maar, & Peltier, 2000; Jacklin, 2009; Trudeau, 2012).

In acknowledging Wikwemikong's historical background, I am vigilant to challenges that may still be present in the community. In listening to the stories of community members and their personal histories, I learn about the triumphs and barriers that they may still be confronted with.

Changes sought to overcome personal and intergenerational effects of colonialism are included in the research. The research is not solely based on overcoming the effects of historical and present colonial constructs, but acknowledges how these occurrences may be manifested through the generations.

The inquiry focuses on knowledge as being relational in order to seek ways to promote healthy brain aging opportunities for the Anishinabek community of Wikwemikong. Opportunities sought to promote healthy brain aging were guided by the need for meaningful social interactions across the generations. Engagement in the project by community members of Wikwemikong arose from the voiced need for culturally appropriate tools to promote healthy brain aging. The expressed need includes relational understandings of being Anishinaabe, being First Nation and being a community member of Wikwemikong. Reciprocity and respectful representations (Chilisa, 2012 p. 40-41) of how each individual foresees intergenerational programming in their community are conveyed through the shared knowledge of participants.

In acknowledging the multiple realities of truth in creating opportunities for intergenerational social engagements in Wikwemikong, the research is guided by Indigenous knowledge, aligning with Indigenous ways of being (Kovach, 2010). Each community member's forthcoming truth may vary from the others, giving each voice a unique representation in the project. However, in being guided by Indigenous knowledge and worldviews, perspectives on the research questions will be relatable and relational. Indigenous ways of knowing are presented in a unique manner by each community member, with strengths and weaknesses varying amongst the pathways. These variations include interactions with others and the environment, dreams and visions, cultural and

traditional customs and balance between the emotional, spiritual, physical and emotional self (Getty, 2010). Each pathway reveals an individual journey that a participant may or may not experience barriers or success in.

This project aims to challenge the colonizing, or Western perceptions, of brain aging. The approach centralizes Indigenous views and understandings as valid in attempting to explore and foster traditional roles of older First Nations adults in order to provide healthier opportunities to age. The project's objectives align with reconstructing knowledge on brain aging, in hopes of promoting culturally appropriate ways to address signs and symptoms of brain aging. The project brings forth Indigenous approaches to healthy aging as being valid and unique to the community of Wikwemikong, Ontario. Through the acknowledgment of Wikwemikong's historical past, their present and their future, I hold myself responsible and accountable to the research's success, respect and meaning. I account my relationship and engagement with the community as being imperative to the research's success.

2.4 Theoretical Perspectives

Theoretical perspectives, in research inquiries, are utilized as guiding frameworks to provide complex and comprehensive understandings to impending questions in which researchers seek answers to. The use of theory provides the researcher with different views or lenses through which a question or inquiry can be considered (Reeves, Alberta, Kuper and Hodges, 2008). A combined theoretical perspective guides this research into identifying and promoting opportunities for older First Nations adults to participate in meaningful social interactions. I have situated this research within the Post-Colonial Theory. The theory aids in acknowledging the constructs of colonization that remain present in Indigenous communities (Browne, Smye, &

Varcoe, 2005). Additionally, I draw on the Indigenous Wholistic theory (Absolon, 2010; Bull, 2010; Marsden, 2005) and the Intergenerativity Model (George et al., 2011; George & Whitehouse, 2010; Whitehouse & Bendezu, 2000) to ensure that the analysis embeds Indigenous specific relational theory and provides the possibility of reconstructing previously colonized conceptions of aging in Indigenous communities.

Post-Colonial Theory

Methods of overtaking 'unmarked' or 'unclaimed' lands by European powers was and has continued to be referred to as the process of colonization. Many scholars refer to this overtake as an "annexation of the non-European world" (Childs & Williams, 1997).
The use of post-colonial frameworks in collaborative Indigenous research allows for the consideration and exploration of inequities and imbalances experienced by Indigenous people in all aspects of life (Browne et al., 2005). Indigenous scholars reveal that there is relevance in the use of Post-Colonial Theory for research in Indigenous communities. It is stated that post-colonial perspectives provide direction for research inquiry in Indigenous communities or with Indigenous people in four ways: 1) to infuse partnership and voice in the research process, 2) commit to communal engagement with research inquiry, 3) understand how health contexts are shaped by the past and present, and 4) understand the potential for colonizing research (Browne et al., 2005).

The theory frames the research in recognition of the impacts of colonization on the overall quality of life for Indigenous peoples (Truth and Reconciliation Commission of Canada, 2015; Czyzewski, 2011). Scholars collaborating with Indigenous communities and people, consider the past, the present and the future (Browne et al., 2005) and how this continues to affect the

research, Indigenous communities and its members. In understanding that the past shapes the future, impacts of colonization and the transfer of trauma caused by colonialism provides insight to how relationships, social engagements, traditional roles and overall health can be impacted (Gregory, 2005). Without acknowledging the past being in the living present, research with Indigenous communities and people becomes a 'half-truth,' resulting in only part of the story being shared and a portion of the knowledge being exchanged (Chilisa, 2012; Kovach, 2010).

Conversely, it has been argued that the use of Post-Colonial Theory limits the research inquiry and provides half-truths to the researcher because of its broadness and disregard towards specific aspects of Indigenous culture and traditions (i.e., the importance of relations) (Kovach, 2010). In addition, Browne and colleagues (2005) state that it is difficult to account for Post-Colonialism, as this would imply that society has moved beyond inequality and that new formations of equality have arisen. Smith (1999) gives a brief explanation as to why it is difficult to account for Post-Colonialism: "'Post-Colonial' is, from Indigenous perspectives, to name colonialism as finished business… there is rather compelling evidence that in fact this has not occurred… the institutions and legacy have remained" (p. 98). Browne (2005) and Smith (1999) illustrate a major limitation of Post-Colonial Theory, that is, instead of being in a state of 'post' colonialism society is in a state of neo-colonialism. Its presence is still prominent through various aspects of life in Indigenous communities today such as the dominance and implications of treaties and acts that still hold restrictions on Indigenous populations in Canada (Childs & Williams, 1997). In acknowledging these criticisms, I am aware of the colonial presence that is still in existence for many Indigenous communities today and my responsibility as a researcher to ensure that

decolonizing approaches to research are adhered to.

Recognizing criticisms and limitations to the theory are essential. However, the presence of the theory and its value is noted in my specific research project. The use of the theory in this project is mitigated through the inclusion of the Indigenous Wholistic theory, the Intergenerativity model and Community-Based Participatory Action Research methods. The combined use of these frameworks acknowledges community understandings of the colonial state as well as Indigenous knowledge. The broadness of the theory and its capability to be incorporated in a combined perspective ensures that Indigenous knowledge is at the forefront. The combined lens guides the need for culturally appropriate tools to address brain aging in Wikwemikong while being vigilant to the continued presence of colonial constructs.

Indigenous Wholistic Theory

The Indigenous Wholistic theory is most commonly utilized as a basic foundation for research that collaborates with Indigenous communities and people (Marsden, 2005). Numerous scholars provide reasoning for the use of Indigenous Wholistic theory in research pertaining to Indigenous peoples and communities. Absolon (2010) conveys that the Indigenous Wholistic theory is based on cultural and traditional worldviews and is anti-colonial in its perspectives. Its presence is crucial to ensure that research with Indigenous communities and people are not generalized or grouped within the realm of mainstream research practices. Indigenous Wholistic theory is imbedded within Indigenous cultures, worldviews and traditions as Indigenous knowledge presents itself prominently throughout. It encompasses a multi-layered model of the self that incorporates various entities of the spiritual, emotional, mental and physical elements

(Absolon, 2010).

The theory derives from the traditional teachings of one's surrounding environment, which includes the land, sun, water, sky and all of Creation. The theory's foundation is defined through understanding the processes of ecological change as opposed to a given description of reality (Kenny, 2004). The ideas of traditional knowledge being defined through ecological understandings are key components in approaching the research model. Guidance and insight provided by the theory aids in guiding community-based participatory action research methods and the analysis of qualitative data shared by members of the community (Absolon, 2010). The incorporation and understanding of the Indigenous Wholistic theory is significant for determining cultural blocks that may be experienced by First Nations communities who engage in research. Cultural blocks include research that neglects communal voice, disregards the significance of culture, tradition and language and uses the you/me lens instead of the you/we (Chilisa, 2012; Kovach, 2010; Smith, 1999).

Overcoming cultural blocks through a relational and inclusive lens is guided by the theory. Research is guided in a respectful manner, incorporating Indigenous worldviews that embrace anti-colonial perspectives (Absolon, 2010; Marsden, 2005). Determining cultural blocks allows for an in depth dissemination of barriers hindering traditional roles and in turn aims to improve healthy brain aging.

The Indigenous Wholistic theory promotes the inclusion of culture and tradition as an important role in the exploration and repairing of the self (Absolon, 2010). Approaching research through

the Indigenous Wholistic lens creates opportunity for participants to move from being labeled as participants in research, to voices that are imperative in the process of facilitating change. These opportunities align with characteristics of community-based research (Fletcher, 2003; Tobias et al., 2007).

The communal voice becomes the guiding pathway for change to occur, making the research meaningful. Change guided by community members provides the possibility of repair for pathways that have been disrupted (Fletcher, 2003). The Indigenous Wholistic theory addresses the importance of repairing relationships between all relations as an essential part of one's healing journey (Absolon, 2010). The research then becomes a way for Indigenous knowledge to inform the repairing of relationships and guides the community and its members towards possible healing journeys.

In honouring all relations and interconnectedness of the culture and traditions (Kenny, 2004) of the Anishinaabe people of Wikwemikong, the spiritual, physical, emotional and mental aspects of the self remain nurtured and fostered for those who are seeking self-healing. The continuous influence of colonization has created a disruption in the balance of the self within many Indigenous communities. Personal and community traumas experienced from colonial constraints are continuously manifested in present day. This understanding becomes relevant when determining factors that are important to fostering intergenerational relationships and social engagements. Understanding how trauma can persist through the generations, gives reason to seek opportunities that foster intergenerational relationships and what these relations may signify to the community of Wikwemikong.

It is through understanding the effects of colonization, that pathways towards fostering traditional roles of First Nation older adults can be achieved. The exploration of Wholistic approaches to research provides opportunity for the community of Wikwemikong to address relations and improve healthy brain aging.

Intergenerativity Model

The Model of Intergenerativity, written most prominently about by Dr. Peter and Cathy Whitehouse, seeks to remove age-segregated barriers that are present in communities. The removal of these barriers provides opportunity to foster new ideas, emotions, thought processes and individual achievements that develop through engagement across the generations. The implications of these relationships have noted benefits for all the generations involved. These relationships nourish the developing mind of younger generations and provide meaningful interaction for the aging mind of the older generations. In turn, this provides improved social interactions for both generations (George et al., 2011).

The model provides a foundation for the creation of meaningful relationships between generations in various types of communities (Whitehouse, 2013). The model hypothesizes that increasing meaningful social interactions within the generations will improve brain aging. This theory has led to exploring the model through engagement with individuals experiencing signs and symptoms of aging. Improvement in cognitive decline within the older generations has been linked to the increased presence of social engagements, particularly with the younger generations (George et al., 2011; P. Whitehouse, 2014). The outcomes and benefits of the model are seen in The Intergenerational Schools, developed in 1999 by Dr. Whitehouse and his wife, Dr. Cathy

Whitehouse. The school is a community-based initiative that provides non-medicinal 'treatments', also referred to as opportunities, for those with dementia or those who may be exhibiting varying signs and symptoms of brain aging. The intergenerational school provides new ways for younger children to learn and creates opportunities for older adults to engage in purposeful interactions. Such interactions are created through the contributions made by the sharing of knowledge and wisdom across the generations (Whitehouse & George, 2008, p 143-147).

For foundational purposes of the research, the non-Indigenous model is incorporated as it provides a basis for the importance of intergenerational relationships and is seen as relative to Indigenous perceptions of family, community and health care. The model explores the implications of these relationships and the benefits for individuals experiencing cognitive decline. The model aligns with Indigenous Wholistic views of health and well being in that it focuses on the self and how relationships act as the guiding factor towards improved well-being. Whitehouse (2013) terms the model as a non-pharmaceutical practice that provides healing pathways for individuals faced with cognitive decline. Whitehouse (2013) emphasizes the need for story telling and how these actions define who we are. The foundational basis of the Intergenerativity model being the need to foster relationships and story telling provides reason for a combined perspective with Indigenous Wholistic views.

The use of the intergenerativity model is imperative in finding factors that are considered important to repairing relationships throughout First Nations communities. The model includes a focus on environmental sustainability, which includes reviewing the past, present and future

occurrences in the community that may hinder or alter relationships (Whitehouse, 2013). The model's inclusion of environmental sustainability is relatable to many Indigenous communities and traditional teachings. Environmental sustainability can be contextualized as physical ecological surroundings or the environment in which we each surround ourselves. The inclusion of the environment and the significance this has with all relations is present in many Community-Based research projects (Laveaux & Christopher, 2009). This becomes relevant in the research project as environmental relations, both ecological and personal, are directly linked to traditional roles in First Nation communities (Greenwood, de Leeuw, Lindsay & Reading, 2015; King, Smith & Gracey, 2009; Tobias & Richmond, 2014).

The Intergenerativity model is noted to improve the quality of life for individuals experiencing signs and symptoms of Alzheimer's disease and related dementias (ADRD). Improvements in the quality of life include decreased levels of stress, higher sense of self worth and an enhanced sense of purpose in the community (Whitehouse, 2013). However, the model does not address precursors in determining factors that may be important to understanding how to foster relationships between First Nation youth and older adults in Wikwemikong, Ontario; that is, it has not previously been applied to colonized populations. The combined use of the model with Indigenous Wholistic views accounts for the importance and essential presence of tradition and culture in fostering roles of older First Nation adults as well as promoting intergenerational relationships (Marsden, 2005). The inclusion of the Intergenerativity model in this research inquiry serves as a foundational basis for increasing social interactions and the benefits associated with doing so. The model also guides the research in developing culturally appropriate

opportunities that connect to Indigenous perspectives on relations in order to improve brain aging.

2.5 Connecting Indigenous Knowledge to Methodologies

In alignment with the Indigenous research paradigm, this research incorporates methodologies that encompass Indigenous voice, knowledge, culture and traditions. Historically, research engagement with Indigenous communities received criticism regarding the lack of consultation and partnership with the community (Gone, 2007), neglectful and unpromising 'relationships' (Bull, 2010) and the presence of the I/You title as opposed to the I/We relationship (Chilisa, 2012). Aside from methodological and theoretical alignment, the methodologies employed in this research create pathways for meaningful relationships between the community members of Wikwemikong and me. The methodological design provides opportunities for Indigenous knowledge to guide the research and for Indigenous voice to be privileged (Jacklin & Kinoshameg, 2008). This project incorporates three methodologies that aid in ensuring a meaningful, collaborative, respectful, and an inclusive outcome is developed, nurtured and continuous between the community and me (Braun et al., 2014; Hart, 2010; Jacklin & Kinoshameg, 2008; Sherwood & Edwards, 2006).

The Medicine Wheel

Indigenous worldviews are shaped by a balance and interconnectedness with all relations (Chilisa, 2012; Kovach, 2010; Smith, 1999). The Medicine Wheel, with its circular motion and visible interconnectedness, is one of the basic symbols that depicts the world view for many Indigenous people (Graham & Leeseberg Stamler, 2010). A worldview of the Medicine Wheel includes culture and tradition as a foundational basis, similarly to the Indigenous Wholistic Theory. The Medicine Wheel guides the research project in a way that does not align to the

realm of dominant society (Absolon, 2010). Its circular motion strengthens Indigenous worldviews on relationships and balance within the self. The Wholistic approach and practice of wellbeing is portrayed through the various teachings that are incorporated into the Medicine Wheel (Twigg & Hengen, 2009).

The prominence of the Medicine Wheel in Anishinaabe communities, particularly in Wikwemikong, is different to each community member and is comprised of various teachings about the entities each direction possesses (Absolon, 2010). Similarly to the Indigenous Wholistic theory, the Medicine Wheel embraces a multi-layered view that incorporates many perspectives and teachings. The teachings of each direction do not only vary amongst community members, but they also signify and represent the personal and deepened meanings that come forward throughout the shared voice. However, the presence of difference does not mean ownership, but is instead viewed as a communal gathering of knowledge, in that knowledge is owned by all relations (Graham & Leeseberg Stamler, 2010).

The Medicine Wheel guides two intertwining pathways throughout this project. The first pathway is the relationship as the 'researcher' (Chilisa, 2012) with the community of Wikwemikong. In the East, I acknowledge my connection with the community members and the community of Wikwemikong as a whole. In the South, I acknowledge that I must be emotionally aware in order to speak the truth and to speak from the heart. In the West, I acknowledge that I am on a personal learning journey, and it is through this journey that I discover my relations to the community members, to their stories, to their knowledge, to their heartache and to their joy. The journey helps in discovering my connection not only to the research inquiry, but my

connection to Indigenous ways of knowing. In the North, I acknowledge my education as being insignificant in comparison to the voices, stories and truth spoken by the community members of Wikwemikong. It is through acknowledging the strength of Indigenous worldviews and voice that the research inquiry provides success and meaning to the community of Wikwemikong.

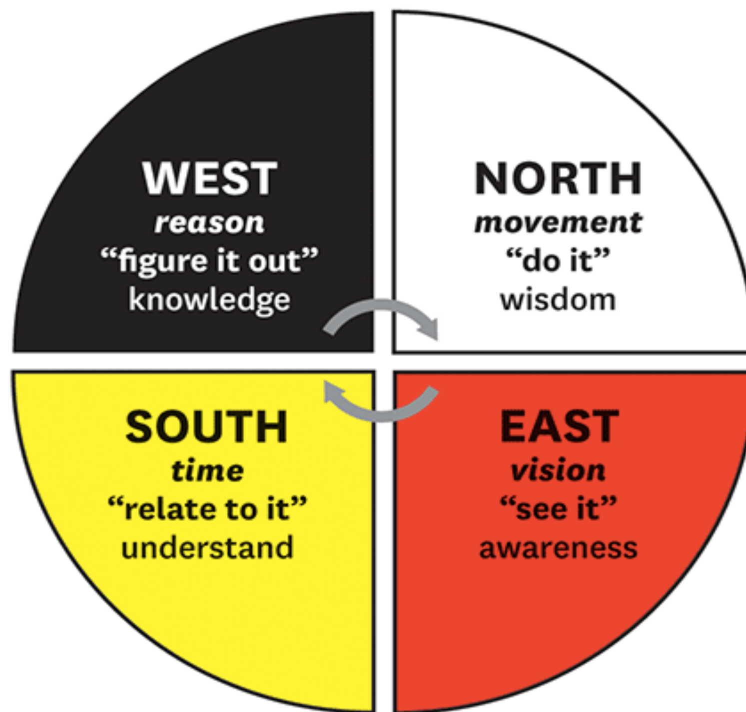

Figure 2 Medicine Wheel Planning Phases (Bell, 2014)

The second pathway led by the Medicine Wheel is the planning phases of the research inquiry, which focuses on what each phase will be comprised of (Figure 2) (Bell, 2014). In the East, there is a vision or inquiry and the self becomes aware of seeing the vision. In the South, there is some time taken to understand what the vision consists of and understanding what it might mean and how it is relatable. In the West, knowledge has been sought and understanding the vision has become possible. In the North, we now possess enough wisdom about the vision or inquiry and all of its entailments that we can act on the need. However, in order to act on the need,

knowledge must have been attained from all the directions (Bell, 2014).

Obtaining knowledge from all the directions is guided by perspectives of the Indigenous Wholistic theory (Absolon, 2010; Marsden, 2005), therefore innovating the use of the Medicine Wheel in the project. Teachings from the Medicine Wheel gives the research inquiry direction (vision, time, reason, movement), the actions that must be taken in order to move in the right direction (see it, relate to it, figure it out, do it) and the learning processes that must occur for action to be taken (awareness, understanding, knowledge, wisdom) (Bell, 2014).

Community Based Participatory Action Research

Community-Based Participatory Action Research (CB-PAR) is an important guiding tool for researchers working with Indigenous communities (Fletcher, 2003), in particular the Anishinaabe communities of Manitoulin Island (Jacklin & Kinoshameg, 2008). Jacklin's proposed research model (Figure 3) for community-based approaches to engaging with Indigenous communities provides a pathway for the progression of this project. The model sheds light on the necessary areas that must be addressed and incorporated throughout this research including the necessary steps to properly plan the research, implement the research, gathering knowledge from the community as well as how to act on the knowledge obtained (Jacklin & Kinoshameg, 2008).

Health research conducted with Indigenous communities has often failed to bridge the health gap experienced between Indigenous and non-Indigenous people in Canada. In order to move past the gap, researchers need not to conduct research 'on' Indigenous communities but instead focus on working 'with' and 'for' the communities (Tobias et al., 2007). The use of CB-PAR when working with Indigenous communities allows for potential empowerment and gives voice to the

community (Petrucka, Bassendowski, Bickford, & Goodfeather, 2012). CB-PAR gives acknowledgement to the various ways of knowing, giving merit to Traditional Ecological Knowledge and the teachings of the Elders (Fletcher, 2003). The engagement of the broader community is important when collaborating with Indigenous communities as it ensures that there is inclusion of all variables a community has belief in. Variables such as cultural beliefs, traditional knowledge and language are included in the duration and outcome of the project. The inclusion of community beliefs and values are made possible through the involvement of community members as meaningful partners in all aspects of the research (Baydala, Saylor, & Ruttan, 2013).

The use of CB-PAR in this project aims to explore and foster traditional roles of older First Nation adults and promote meaningful social interactions. This model ensures that research methods address issues of concern in an acceptable manner, decreases the possibility of resentfulness towards research inquiry, provides community members with the feeling of being a contributor as opposed to a research subject, and creates lifetime partnerships between the community members and me (Fletcher, 2003; Maar, 2004; Minkler, 2005; Tobias et al., 2007).

The nine key principles of Community-Based Participatory Research that aided in the development of this research are:

a) Acknowledge historical negativity of research and overcome past research practices

b) Recognize the existence and importance of tribal governance models

c) See the community as a unit of identity

d) Understand diversity and that Indigenous people are not homogenous groups or communities

e) Invest time in building relationships and trust

f) Collaborate with key individuals including Elders and community leaders

g) Prepare for change in leadership throughout research

h) Inclusion of community members in order to ensure cultural beliefs and traditional ways of knowing are embedded within the research

i) Employ Indigenous Ways of Knowing

(Petrucka et al., 2012)

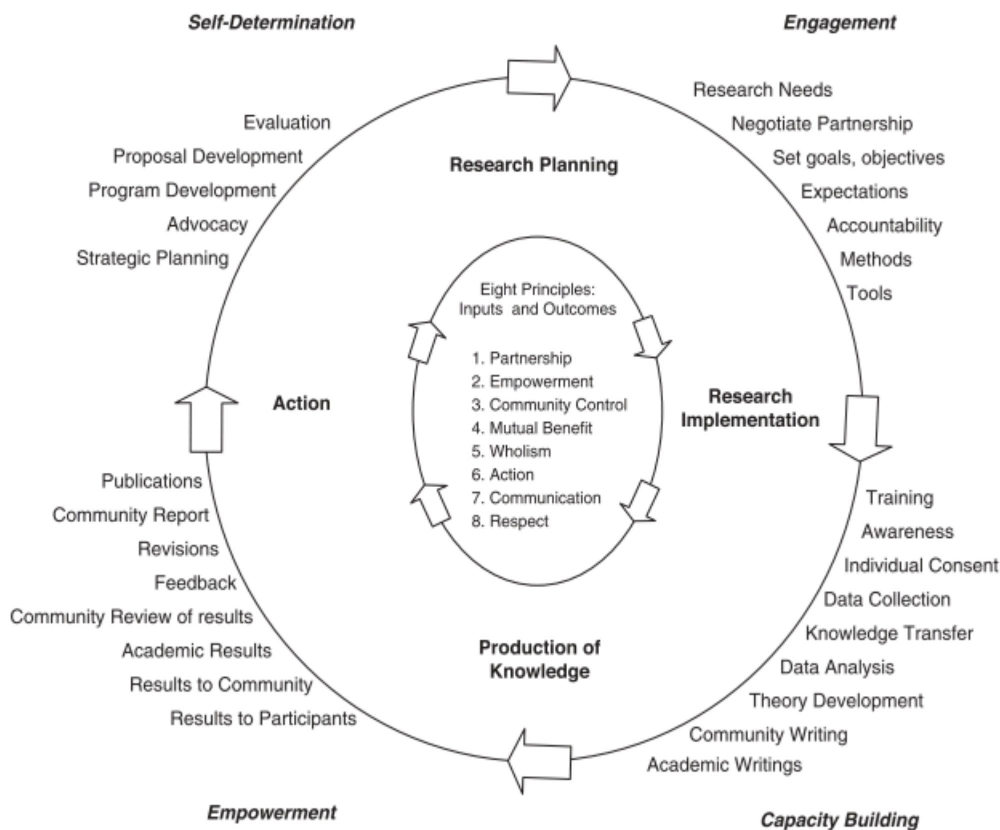

Figure 3 Indigenous Community Based Participatory Action Research Model (Jacklin & Kinoshameg, 2008)

Conversational Method

Indigenous researchers are beginning to move beyond the utilization of non-Indigenous paradigms and explore methods that ensure beneficial outcomes to participating communities. The most prominent difference between the dominant paradigms and emerging Indigenous paradigms are the fundamental beliefs of what knowledge is (Wilson, 2001). An Indigenous paradigm contains the fundamental belief that knowledge is personal and derived from all relations (Kovach, 2010; Wilson, 2001). Wilson (2001) states that knowledge attained through research is not only the idea of the individual but everything that surrounds and encompasses the individual.

The paradigmatic approach to research influences the methods employed and are developed upon core principles (Kovach, 2010). The use of the conversational method for this research inquiry follows the Indigenous paradigmatic view, in the sense that the method (i.e., storytelling, sharing circles, interviews, etc.) has validity from an Indigenous knowledge perspective (Kovach, 2010). The use of this method to translate knowledge is a prominent method of teaching, learning and reviving traditions of Indigenous perspectives. The use of conversations in the research inquiry is appropriate and accepted by the community as it demonstrates the voice of the community (Kovach, 2010). The method aligns with Indigenous worldviews of honouring orality as a way to convey traditional knowledge in a culturally appropriate manner (Kovach, 2010). The model supports the inclusion of Indigeneity throughout the research and acknowledges the project's outcome as being significant (Hart, 2010) to exploring and fostering traditional roles and brain aging, which are determined by and specific to Wikwemikong.

West – Reason and Knowledge “Figure It Out”

Part III Methods

This chapter reviews the approaches and methods employed in order to successfully, meaningfully and respectfully partake in a research relationship with the community of Wikwemikong, Ontario. Insight into the need for culturally appropriate research methods is initially reviewed. Reasoning for the methods used are guided by responsibility, respect and reciprocity, the three R’s of Indigenous research (Kirkness & Barnhardt, 1991; Marsden, 2005; Weber-Pillwax, 2004). Guidance provided by the three R’s gives reasoning for the strong presence of validity and reliability within the project. The study design is broken down into numerous sections including direction provided by the community through communal commitment, participant recruitment and engagement, the consent process and the presentation of incentives/honorariums. Following these descriptions, this chapter illustrates how the information and stories were gathered from the community members. A review of the qualitative thematic analysis approach demonstrates how each story and the knowledge shared aided in addressing the research question. The later portion of the chapter discusses ownership of the research and the community’s involvement as co-authors in published material. The ethics approval process through academic institutions and community agencies is reviewed in greater detail. The community agency ethics approval process brought forth the importance of Indigenous knowledge being the guiding ethical pathway for the project. Teachings and guidance from the Seven Grandfather are also explored in the later portion of this chapter.

3.1 Research Methods and Community Based Participatory Action Relationships

Historically, much of the research done in collaboration with Indigenous people and communities has been referred to as being researcher-driven (Kenny, 2004; Maar & Shawande, 2010). Research inquiries did not align with community values or give merit to the communal voice. This form of research neglected to include insight from community members, included falsifications of Indigenous people and was guided by ideologies that aligned within Western society (Jacklin & Kinoshameg, 2008; Singer, Bennett-Levy, & Rotumah, 2015; Weber-Pillwax, 2004). The shift in research approaches came forth as Indigenous communities and researchers strengthened their voices to ensure that if research collaboration was to occur that it would be meaningful, respectful and trustworthy (Bull, 2010; Ermine et al., 2004; Tobias et al., 2007; Warry, 1990, 1992). These researchers noted the connections between community empowerment in research and community empowerment in health. These realizations began the shift towards participation and action oriented models of research and care. The combined desire for change amongst researchers and Indigenous communities initiated the change in research relationships (Warry, 1990). These relationships became more inclusive and were developed solely on the presence of the communal voice and consultation (Jacklin & Kinoshameg, 2008; Singer et al., 2015; Weber-Pillwax, 2004).

The present research inquiry was led by three R's of Indigenous research (Kirkness & Barnhardt, 1991). As the lead investigator of this project, it was my sole responsibility to ensure that the project met the community's needs and vigilantly listened to their voices. It is through adhering to these responsibilities that the project would have success within the community. I met

regularly with numerous community members to hear their stories and sought guidance when a new idea or question arose. My relationship with community members and participants was respectful in that our association became a We/Us instead of You/I. We shared stories about our families and communities, personal views of health disparities faced by Indigenous people, ideas of how the health of First Nations people can be improved and brainstormed numerous barriers and facilitators of success for programming opportunities in Wikwemikong. It is through open and honest communication that an equal level of relation was developed between the community members of Wikwemikong and me. In establishing this level of relation, pathways for success and honesty were created.

In adherence to the three R's of Indigenous research much consultation, co-learning and discussions occurred between the community of Wikwemikong and me. Three levels of consultation were sought prior to the development of the project as well as throughout the project's duration. Primary consultation occurred with the community members of Wikwemikong Unceded Indian Reserve through the CCNA (Canadian Consortium on Neurodegeneration in Aging) Community Advisory Group, and later included recruited participants. Secondary consultation occurred with a community researcher from the Wikwemikong Long Term Care Facility with additional support from administrative staff. The third level of consultation occurred with the research committee comprised of professors from the Northern Ontario School of Medicine and Laurentian University. Communal collaboration created a co-learning environment for all members involved in developing the project and addressed a common topic of interest; promoting healthy brain aging through intergenerational relationships.

3.2 Validity and Reliability

In the context of this research, validity is signified as trustworthiness. Inquiries built upon relationships and responsibilities to the researched are considered to be the informing pathways that guide every aspect of a postcolonial Indigenous research process, including the dissemination of findings (Chilisa, 2012; Smith, 1999). Postcolonial Indigenous research approaches focus on ensuring the presence of the communal voice. It is through the inclusion of specific research methods that communities engage through their shared voice. Through the selection of conceptual and theoretical frameworks, the methods of data collection and analysis, the researcher's perceptions and Indigenous knowledge must be the voice of reason. This process progresses the development of the research in all aspects. The inclusion of communities and participants in the development of the project is referred to as validity (Chilisa, 2012; Kovach, 2010; Smith, 1999). Validity is described using a wide range of terms in qualitative community based research. The concept of validity is not a single or fixed understanding but instead grounded in the processes and intentions of the research methodologies and project (Golafshani, 2003).

Through discovering barriers and facilitators of success for intergenerational programming, community participants openly share their views, opinions and recommendations for achieving meaningful approaches to address brain aging. It is through the trust that participants have in me, that authentic, meaningful and personal stories guide the project. Similarly, the trust that I have in the participants ensures that my involvement in the project is possible and my presence in the community is welcomed. The development of this trust flourishes on the basis of dependability and reliability. The use of these terms describes the research as well as the relationship between

the community and me.

Dependability and reliability are inherently required in a trusting relationship, and are therefore built into the research's development. Traditional approaches to qualitative research frame dependability and reliability as being descriptors to the project's outcome (Golafshani, 2003). Instead, the current project views these descriptors as creators of the projects success. When I think of validity and reliability, I hear the Community Advisory Group sharing their perspectives of research in the community. I hear the concern in their voices and the hesitation in their thought. I also hear their inspiration and guidance to ensuring that the project is completed in a respectful, meaningful and fun way. As an Elder once told me through this duration of the project, "we don't want to be a piece of paper on a shelf again." The community can rely on me to ensure the honourable sharing of their voices and address the need for increased meaningful social interaction through my dependable and reliable assertiveness to continue working with programming agencies in the community to promote intergenerational inclusion in programs.

3.3 Study Design

Guidance

The research inquiry was guided by community-based participatory action research methods (Petrucka et al., 2012), while incorporating the three R's of Indigenous research (Hart, 2010; Kirkness & Barnhardt, 1991; Weber-Pillwax, 2004). The inquiry adhered to Indigenous health research ethical guidelines demonstrated in the Tri-Council Policy Statement, specifically chapter nine, Research Involving the First Nations, Inuit and Métis Peoples of Canada (Canada, 2014). The presence of the Indigenous Wholistic Theory (Absolon, 2010) in the project ensures that the mental, physical, spiritual and emotional self are respected throughout the research. The

inclusion of the intergenerativity model (Whitehouse, 2013) and the conversational method (Wilson, 2001) provided foundational reasoning for the use of specific methods throughout the research. The direction provided by these methods aids in the explanation for the use of a qualitative thematic analysis in determining the perspectives of participants on exploring and fostering traditional roles in order to improve healthy brain aging.

Community Engagement

The research was carried out with the Health Authorities of the Wikwemikong Unceded Reserve on Manitoulin Island in Northeastern Ontario. My supervisor, Dr. Kristen Jacklin, and the investigators working on the Indigenous projects of Team 20 (Issues in Rural and Indigenous Dementia Care) in the Canadian Consortium on Neurodegeneration of Aging (CCNA) had a pre-established relationship with the First Nations communities and respective Health Authorities on Manitoulin Island. The proposed research matched the Team 20 research goals and this research was included in agreements for CCNA research with the seven First Nations on Manitoulin Island. The inquiry also fell under pre-approved ethical protocols of Laurentian University and the Manitoulin Anishinabek Research Review Committee. However, a separate but connected application was submitted to the Laurentian University Research Ethics Board and a detailed amendment was presented to the Manitoulin Anishinabek Research Review Committee (Appendix A and B). These ethical processes are reviewed later in the chapter.

A Community Advisory Group had been pre-established to guide all of the projects being led by the CCNA's Team 20. Community Advisory Group meetings were held at the Wikwemikong Health Centre with members originating from across the seven First Nation communities on Manitoulin Island. The community advisory meetings involved an opening prayer, a brief

introduction of each member, time to share project updates and seek guidance from the community members, a feasting period and a closing prayer. Guidance by the Community Advisory Group included approval of the research inquiry, participant recruitment through community centres and revision of the qualitative thematic analysis. The community advisory meetings were held monthly, in which the present research inquiry received allotted time every other month, unless immediate guidance and assistance were desired from the advisory group. While in attendance, I provided an update on the projects progression and encouraged suggestions from the group.

Participant Recruitment

All participants were recruited through purposive sampling. The basis of purposive sampling is that the sample selected intentionally includes those who are specified in the proposed research question (Tchacos & Vallance, 2004): First Nations youth and older adults. Participants were recruited with assistance from the Community Advisory Group and their involvement with relevant programming agencies in their communities. The community researcher and the administrative staff of the Long Term Care Facility also played an imperative role in recruiting participants for focus groups and interviews. The community researcher's involvement with the Wikwemikong Health Centre assisted in locating individuals who would provide insight into programming as well as address the needs of their community. The current health director, youth program coordinator and senior centre director of Wikwemikong were approached by the community researcher or myself to assist in recruiting participants. Collaborating with the current health and programming directors ensured that those who will benefit from the outcome of the research inquiry were included in its development.

Individuals who approached members of the Community Advisory Group, local health authorities or me were welcomed to participate in their age-relevant focus groups, demonstrating a snowball effect of participant recruitment. Friends and family members of those asked to participate were encouraged to participate as well. In particular, recruitment for youth differed slightly for two reasons. The first reason was that youth wanted to understand what they were participating in. Members of the Community Advisory Group and health authorities decided that it would be beneficial to create an information poster (Appendix C) to give youth, in order to answer their questions and subside any hesitation that they might be experiencing. Secondly, youth focus groups were held at the Youth Centre in Wikwemikong after school. Many of the youth who decided to participate in either their age-specific or combined age focus group were 'dropping-in' after school and became interested in participating once they were told the detailing of the gathering.

Participant Engagement

Focus groups and key informant interviews have been used in various areas of research with Indigenous communities. The use of such qualitative research methods for this specific research inquiry allowed the research team to obtain information regarding required care for those experiencing ADRD (Jacklin & Kinoshameg, 2008; Jacklin, Pace, & Warry, 2015; Pace et al., 2013). Obtaining information from community members revealed the need for culturally appropriate health care options and the presence of wholistic pathways towards improving healthy brain aging (Gordon, 2012; Jacklin, 2009; Maar & Shawande, 2010).

Knowledge and stories were exchanged and shared by community participants in three different formats. The three formats included: i) Key Informant Interviews, ii) Youth and Older Adult

Focus Groups and iii) Program Observations. Key informant interviews and focus groups were electronically recorded and later transcribed. Initial meetings with community members were led by key informant interviews followed by sequential focus groups with older adults and youth. Program observations were ongoing throughout the research and did not follow a formalized format.

Key informant interviews were carried out with current and previous directors of youth and seniors programs in Wikwemikong to determine programming opportunities that could support a sustained program promoting intergenerational contact. The setting in which the interview took place was decided upon by the interviewee ensuring that the participant was comfortable and relaxed while participating in the interview.

Focus groups were conducted with (a) older First Nations adults, (b) youth (8-14 years of age) and (c) combined age groups, to explore each group's perspectives on how to design a culturally relevant intergenerational program to address role restoration, social interaction and cognitive health. A gender balance was maintained throughout the recruitment process to ensure that both male and female perspectives were demonstrated in the interviews and focus groups. Each individual age-targeted focus group was completed once within close proximity to one another in order to keep participants interested and engaged. Following the individual focus groups a combined focus group was held three days later. The short time period in-between the focus groups kept the conversations vivid in the minds of participants. The combined focus group only occurred once, as an extensive amount of gatherings for the youth age group was not realistic.

The decision to eliminate a duplicate individual focus group with each age group was a reflection of youth participation and commitment.

In order for programming recommendations to be determined, it was imperative to hear the stories of the people living in the Anishinaabe community of Wikwemikong. Hearing people's stories and opinions ensured that the community created programming recommendations. Focus groups allowed participants to engage in a non-structured gathering that was respectful, open and confidential (Kovach, 2010, p 123-125).

Incorporating various opinions regarding the environmental settings for focus groups, aided not only in the comfort level of the participants, but also in recruiting participants, in particular the youth. A repeated focus group with combined age groups provided opportunity for reflection on the previous focus group conversation. A follow up summary was provided to each participant during the combined focus group. The summary encompassed the key thoughts, ideas and opinions shared by all focus group participants. The repetition of the focus groups with older adults and youth participants also served as a member checking purpose. This was completed through the visual use of a word cloud that incorporated key ideas and opinions of participants, which can be viewed in Part IV. Member checking ensured that the information provided is accurate, valid and creditable (Kovach, 2010, p. 131-132) to the participants, which represented a secondary form of analysis.

Program observations were carried out at the youth centre and the local parish community gathering. Observations provided insight into current programming and established rapport with

the community members. Engagement occurred with program participants where opinions and thoughts were shared about the research inquiry. Establishing an understanding for current programming in Wikwemikong elicited positive and negative views that need to be acknowledged prior to providing recommendations for an intergenerational program addressing ADRD.

Consent Process

The consent process began with obtaining informed consent from participating communities, health agencies and current programming directors. Face-to-face contacts with the participating community members helped guide the beginnings of the research process and were one of the most important encounters. The initial conversations established a collaborative working relationship that remained persistent throughout the research inquiry (Fletcher, 2003). An ongoing collaborative relationship with the community of Wikwemikong ensured that consent remained consistent with the progression of the research over an elapsed period of time. The establishment of an open and trusting working environment between the community and myself is important in order for the research inquiry to follow the principles of CB-PAR (Fletcher, 2003).

Prior to engaging in the collection of information from participants, informed consent was given by each participant through the initial conversation. Written consent forms were given to all three groups of participants, which included current program directors, older adults and youth. Consent forms were written in accordance to the specific age group that they were subjected to, meaning consent forms for older adults would differ from consent forms given to youth but contain the same information regarding the proposed research.

However, written consent may not be an appropriate method for all participants. Therefore, any participant who wished to participate without written consent may give verbal or informed consent. As descried in Kovach (2010) many participants in qualitative research sign consents as a formality and engage in this in an autonomic manner. It is the relationship that is established between the researcher and the participant that is of the utmost importance, not the participant's ability to sign consent. All of the participants provided written or verbal consent to participate in the project. However an offering of tobacco would have been given to those who provided informed consent. Research that is conducted within an Indigenous framework still upholds specific ethical complexities, but instead of focusing on concerns of liability, researchers need to focus on the relational aspect of the research (Kovach, 2010, p. 138-147).

A copy of the written consent form was given to each participant at the beginning of the gathering. All relevant consent forms were discussed prior to any interviews and focus groups. Participants were given time to question what they were signing and inquire about the project. Participants had the right to refuse to respond to a question and could reject any further participation in the research at their discretion. All letters of information and appropriate consent forms for each group can be found through appendices D to G.

Incentive/Honorarium

Throughout the focus groups, snacks and refreshments were made available for participants. Variation of the snacks and refreshments were dependent on the age group. The described incentive allowed for participants to engage in an informal setting, where there are no judgements or strict guidelines. The informal setting promoted discussion amongst the

participants, which created an area of trust and nourished relationship building between all the participants and me. Additional incentives in the form of honorariums (valued at $50.00) were given to older adults for their participation in focus groups. Travel costs were covered for participants who had to travel into Wikwemikong in order to participate. Youth received a pizza party to avoid potential conflict in providing a gift card or money. A personal note of appreciation was given to all participants during interviews. Focus group participants were invited to a community gathering, which was held during the summer, where a note of appreciation was given to each individual.

It is important to note that participants did not withdraw from the study in a purposeful manner. Some members of the youth focus group were unable to attend two gatherings due to various obligations, but did not withdraw throughout their initial attendance to the gathering.

3.4 Data Collection

In collaboration with the Community Advisory Group, collecting qualitative data allowed me, the primary researcher, to develop relationships within the community and with the project's participants. The development of authentic research relationships through collaborative methods allowed me to learn, engage and appreciate the Anishinaabe culture in Wikwemikong (Bull, 2010). These relationships allowed me to understand the concerns expressed throughout the research process, ensuring that I responded in a respectful and appropriate manner (Bull, 2010).

Key Informant Interviews

Five key informant interviews began the preliminary gathering of stories. The key informant interviews were approximately forty-five minutes to two and a half hours in length. Each interviewee selected a meeting location and was encouraged to read the conversation guide prior

to meeting. All interviewees were selected through purposive sampling, led by the community researcher. Each participant was initially approached by the community researcher and then later contacted by me, where a more personal introduction was exchanged. Each key informant interviewee is engaged with communal programming through their current or past employment and volunteer opportunities. Key informant interviewees encompassed all aspects of programming in the community either through direct relation or association with agencies responsible for program opportunities. Conversation guides for key informant interviews can be reviewed in appendix H.

Preliminary Actions to Focus Groups

Prior to engaging in focus groups with the youth and older adults, opportunities for socializing amongst the participants were created through icebreaking activities, which were age dependent (Canadian Aboriginal AIDS Network, 2011). Socializing activities, such as icebreakers, conducted prior to the focus groups, encouraged participants to develop a level of comfort with the other participants, establishing an open and accepting environment. An informal activity and gathering allowed participants to ask questions or concerns and develop a level of trust through conversation, not only with other participants, but also with me (Canadian Aboriginal AIDS Network, 2011).

The youth focus group icebreaker encouraged participants to critically think about their fellow peers in the room. The activity required participants to write three things about themselves on a piece of paper. Once completed, participants returned their piece of paper to a bin where it was crumpled and mixed together with other responses from participants. Each participant then picked a note out of the bin and read what the note said. Participants then had to figure out who

wrote the three unique characteristics on the paper. The activity encouraged participation, promoted conversation and evoked laughter from the youth.

The combined age group icebreaker activity encouraged all participants to seek answers from other participants in the room. The activity was referred to as 'people bingo' and required participants to engage in conversation. Each participant was given a piece of paper with a grid on it. Each square had a saying, such as, "Know the Four Sacred Medicines." The participant was responsible for asking another individual in the room if they knew the information being asked from the grid. If so, those two people would exchange names and complete a section of one another's grid. The activity also promoted physical activity, as it was necessary to walk around the room and seek guidance from other participants. Descriptions of ice breaking activities can be located in appendix I.

Older Adult and Youth Focus Groups

The older adult focus group had eight participants and was held at the Wikwemikong health centre. The health centre was a general location that was relatively central for all participants to travel to. The older adult focus group was held first as direction was sought for the youth focus group. Older adults were consulted on where they believed to be the most comfortable and receptive location for the youth to participate in a combined focus group. It was suggested to keep the location the same for the individual youth focus group and the later combined. The focus groups remained relatively small in size, which made the gathering more intimate.

The youth focus group had six participants and was held at the Wasse Naabin Youth Centre in Wikwemikong, Ontario. Youth participants were recruited slightly differently than the older

adults. The community researcher suggested creating an advertisement or reader friendly letter of information regarding the focus group. The community researcher presented this advertisement to encourage participation but to also inform the youths' curiosity (Appendix C). Through collaborating with the youth centre to hold the focus group, participants were also recruited through their own personal interest in what was happening at the centre. After school programs and access to the centre's activities are held daily. Some of the youth participating in both the individual and combined focus groups were drop in participants at the youth centre. The youth centre supported their involvement with program leaders at the centre providing informed consent.

The combined focus group consisted of a majority of the participants from both the older adult and youth focus group gatherings. The combined focus attracted new youth to engage due to its presence being at the youth centre. The combined focus group had a total of 12 participants. Table 1 depicts the final participant count for key informant interviews, individual age segregated and combined focus groups. Conversation guides for the older adult and youth focus groups can be located in appendix J and K.

Table 1: Final Participant Count for Focus Groups and Interviews				
Gathering	Location	Male	Female	Total Participants
Key Informant Interviews [4]	Varied			5
Older Adult Focus Group	Wikwemikong Health Centre	2	6	8
Youth Focus Group[5]	Wasse Naabin Youth Centre			6
Combined Older Adult and Youth Focus Group	Wasse Naabin Youth Centre	5	7	12

Community Program Observations

Community program observations occurred casually throughout my time spent in the community. Programs held through the church and youth centre were the primary programs observed. Through these observations I engaged with many program participants and facilitators. Through informal introductions, I shared my reason for being there and encouraged opportunities for community members to ask questions. Through conversation, many stories were shared and guidance was given to ensure the success of my presence in the community and the outcome of the project. Following my engagement with program participants and various community members, personal journal entries were written. The journal entries included thoughts and opinions of the community members I met, suggestions for adapting current programs to be inclusive to all the generations and any areas of concern that were expressed during the program by either participants or facilitators.

[4] Data has been suppressed for privacy reasons.
[5] Data has been suppressed for privacy reasons.

The journal was also used as a reflection method following program observations, key informant interviews and focus groups.

3.5 Journal Reflections

The journal reflections helped guide the thematic analysis by mitigating any biased thoughts or opinions that may be apparent when thematically analyzing the data. The journals helped in recalling the mood, body language, level of comfort and various personal characteristics that were present during the meeting or gathering, both by participants and me. Personal reflections after each meeting ensured an appropriate interpretation of the qualitative data, before the data were presented to the participants and the Community Advisory Group. The journals helped provide context to the words, as there can be misunderstandings associated to simply reading transcripts. The reflections also allowed me to express my own emotions during these gatherings. The writing created a way for me to share my thoughts while remaining sensitive and sincere to the stories and voices that were shared.

3.6 Potential Risks

With qualitative and community based research relationships, potential risks are always thought of prior to engagement. Due to the nature of the research inquiry regarding traditional roles and intergenerational relationships, potential risks were discussed between the community researcher, the Community Advisory Group and me. Discussions focused around roles of older adults and reasoning behind the gap experienced across the generations raised concern for the potential emergence of emotionally stressful conversations. Interview topics and focus group questions were presented in a manner that promoted the discussion of these subjects in a way that minimized emotional or psychological risk. Consultation with the research supervisor,

community researcher and Community Advisory Group guided the approach to addressing the research topic. An in depth review of the conversation guide was led by the research supervisor, who had previously engaged in numerous focus group which focused around the topic of dementia and brain aging in Indigenous communities.

Program coordinators of the youth and senior centre were vigilant of the content in each focus group, which prompted awareness of potential psychological/emotional changes in participants. The older adults and youth did not express the requirement of any additional supports following the gathering. However, program coordinators at the centres were made available, as well as myself, for one on one discussion if necessary. As the primary investigator, this information was disclosed to all participants prior to engaging in the focus groups.

The participants were provided with information on support services that are available in the community on a copy of the consent form. The community support services did not require referrals and can be accessed directly by participants. Services that participants were made aware of include: Nadmadwin mental health services (located in Wikwemikong) or Noojmowin Teg (Little Current), or Mnaamodzawin mental health services (located in Aundeck Omni Kaning First Nation).

Minimal social risks arose for participants with regards to privacy and reputation. Individuals who participated were informed prior to any data collection that all information and knowledge exchanged through interviews and focus groups would remain confidential with myself, the primary investigator, and encouraged to remain confidential within the focus group gathering.

Anonymity was not guaranteed due to the nature of the focus group methodology and the interview selection process. The main risk throughout the research inquiry was accidental disclosure. In small communities, individual responses are sometimes identifiable by other members of the community, based on their knowledge of the community and community members. For this purpose, participants were not prompted to share stories or knowledge that they were not comfortable with other people knowing.

3.7 Modifications

Throughout the data collection process, minimal modifications were made to the methods used. However, small changes occurred as participants were recruited and focus groups commenced. Conversation guides were given to older adults and youth in advance, if possible, in order to ease their participation in the gathering. Being aware of the questions and topics of discussion prior to meeting helped participants in formulating their responses and stories shared.

During the youth focus group, it was decided by both participants and me that youth would be able to write any thoughts, ideas, opinions and stories down on a piece of paper. This modification allowed the youth to express their voices through writing, which protected their shyness and vulnerability. The option to write gave youth the opportunity to remain anonymous within the group but be outspoken through thought.

Some key informant interviewee participants did not consent to being audio recorded during the interview. In order to ensure that their shared thoughts and ideas were acknowledged, note taking occurred throughout the conversation. Brief notes were made in order to capture the key points and thoughts from the participant. This posed some difficulty in the flow of the interview, as

frequent pausing would occur. However, this paused period gave the participant the opportunity to review questions in the conversation guide, prompting the information that would later be shared. This affected the transcription analysis as notes were not entirely verbatim, but did include actual quotes that were key to the participant's voice.

3.8 Data Analysis

Qualitative Thematic Analysis

A qualitative thematic analysis is a process for encoding qualitative information gathered through various methods, including interviews and focus groups (Saldaña, 2010). This method minimally organizes and describes the data that has been collected by identifying, analysing, interpreting and reporting patterns that are in the information (Sparkes and Smith, 2014). The encoding process gives the information a specific code for that particular portion of the data. The codes may be a list of themes, a model, specific indicators to the research inquiry or be interrelated to one another (Saldaña, 2010). A theme is a pattern that is prominent in the information and can be identified at two levels. The manifest level is directly from the information gathered where as the latent level is derived from an underlying a phenomenon (Boyatzis, 1998).

The research inquiry identified themes at the manifest level as the information directly coded represented the voices of the community of Wikwemikong. This ensured that the communal voice the creation of specific programming recommendations. Qualitative thematic analyses are useful for creating informed developments (Sparkes and Smith, 2014), such as programming opportunities. The use of the thematic analysis in this research inquiry was to gather commonalities across the transcripts that aided in fostering meaningful relationships. The themes

also act as a framework to provide the communities with recommendations regarding intergenerational programming.

The qualitative data gathered from interviews and focus groups were digitally recorded and transcribed verbatim. The transcripts were then thematically analyzed; a qualitative coding process looking for commonalities amongst the responses (Kovach, 2010) derived from focus groups and interviews. The use of a thematic analysis in comparison to a content analysis is due to the attention given to qualitative aspects of the collected material (Joffe & Yardley, 2004). Transcripts and personal reflection notes were printed and reviewed by myself, the primary investigator. The review and analysis of the transcripts focused on (1) opportunities for program implementation as well as barriers and facilitators to success; (2) culturally relevant program components; and, (3) recommendations that can be made for current programs in the community in order to ensure the inclusion of intergenerational approaches.

According to Braun and Clarke (2006) a thematic analysis can be summarized in the following sixe stages presented below. However, due to the nature of the research and the theoretical and methodological foundations, additional steps were included in the thematic analysis that pertained to the community-based approach with Indigenous communities. The additional steps that were included pertained to phase four where potential themes are reviewed. Not only myself, but the Community Advisory Group and participants of the combined focus group, reviewed the initial coding and thematic analysis. During this review process, the advisory group and participants were shown prominent words, themes, ideas, thoughts and opinions pertaining to the discussions held during the gatherings. These words were grouped into generalized themes

and encouraged further discussion and revision, which led to the final themes described in the later portion of this thesis. It is important to note the inclusion of these additional steps, as changes to mainstream methods must occur when collaborating with Indigenous communities. Incorporating additional revisions of themes by community participants and members ensures that the knowledge gathered is being shared in a respectful and appropriate manner that is accepted and approved by the community.

> Phase One: Immersion through listening to audio recordings and transcribing the information into readable transcripts
>
> Phase Two: Familiarizing yourself with the data and generating initial codes
>
> Phase Three: Searching for and identifying themes from the information shared
>
> Phase Four: Reviewing potential themes
>
> Phase Five: Define and name themes, with the inclusion of sub-themes
>
> Phase Six: Writing the report
>
> (Sparkes and Smith, 2014)

Validation of Thematic Analysis

The first level of analysis was completed by myself and then presented to the advisory group for refinement. It was important to ensure that the community advisory council approved the thematic analysis as the results belong to the community participants. Communal involvement in the analysis of the qualitative data ensured that the research was not being conducted on the community, but instead in collaboration with the community. Inclusion of the advisory group ensured that the community is and has remained an equal contributor, developer and validator of the research findings (Tobias et al., 2007).

Upon approval of the thematic analysis by the Community Advisory Group, participants of the interviews and focus groups were invited to participate in a community gathering to discuss their involvement in the project and their thoughts on the determined themes. The community gathering was held outside and began with a feast, again, ensuring that there was an informal environment created. The informality allowed for the development of relationships and a level of trust amongst those in attendance. Participants were encouraged to bring their families and friends to join in on the gathering, feasting and discussion. The community gathering was suggested by a member of the older adult focus group. Following the completion of the community gathering, suggestions and ideas were gathered and noted. The comments would then guide future collaborations with Wikwemikong and their programming agencies to address intergenerational programs and relationships.

3.9 Ownership

The final results and all findings from the research belong to the Anishinaabe community of Wikwemikong and remain an important factor for improving the quality of life for those experiencing signs and symptoms of brain aging. The data will be made readily available to participants and all community members upon request. Through the shared voice and direction provided by the community members of Wikwemikong, joint authorship is offered to the community partners for future publications. Prior to engaging in any future publications regarding the research inquiry guided by the community of Wikwemikong, confirmation and approval will be sought from the Community Advisory Group.

3.10 Ethics Approval

Ethical approvals were sought through three guiding boards for the research inquiry. The research inquiry sought successful approval through the Laurentian University Research Ethics Board, the Manitoulin Anishinaabek Research Review Committee and the Community Advisory Group for CCNA projects in Wikwemikong, Ontario.

3.11 Teachings and Guidance from the Seven Grandfathers

The incorporation of the Seven Grandfather teachings is prominent throughout the research. Ethical approval sought through the Manitoulin Anishinaabe Research Review Committee incorporates fundamental teachings from Indigenous culture and tradition. The Seven Grandfather teachings act as ethical guidelines that must be adhered to when engaging in research relationships with Indigenous communities. The research was approached honouring the teachings and values that inevitably guided the findings of this project. An in depth description of each theme's connection to the Seven Grandfather teachings is described in the following chapter. The guiding pathway of each teaching for the development of the project is highlighted below and aids in understanding the connection between the research findings and the Seven Grandfather teachings.

Respect

Guided by the principle of respect, the research team ensured that participants were informed of the project outcomes through a community gathering. Participants were informed how these findings will be used in the community and for the development of future programs. Open-ended questions were used in focus groups and interviews to ensure that the engagement was respectful of the participant's time and willingness to share. Each participant is respected for his or her own

uniqueness and diversity. Each opportunity that was presented to the participants was provided to expand the concept of Wholistic health and to improve relations with one another.

Wisdom

The project team was guided by the principle of wisdom, learnt from the community Elders, community health workers and all the community members who participated throughout the research. It was understood that participants might need some time to put their thoughts, stories and ideas together. Time was given to each participant to gather their knowledge and share their voices without time constraints. The community researcher provided her wisdom through participant recruitment. The community researcher personally contacted potential participants informing them of the project and that if they were interested the primary researcher for the project would contact them. Upon the initial conversation, information regarding the project, the research question and what would be required of their participation was disclosed. This allowed individuals to prepare for the gathering and collect the knowledge they wished to share regarding meaningful social engagements in the community.

Love

As the primary researcher, my approach to the project was guided by love for the participants and the community; remembering the significance of their story and knowledge shared. Guidance provided by the teaching of love ensured that the needs and benefits for future generations were at the forefront of the research. Conclusions, findings and any written knowledge remain belonging to the community. The love shown for their participation and knowledge shared is reciprocated through the ownership of the research belonging to the community.

Honesty

Throughout the duration of the project and following it's completion, I was dedicated to build and nourish trusting relationships with the community, participants and with the Elders. It was understood that as the primary researcher, I must take the time to establish and build meaningful, honest relationships with the community and the participants of the study. The research was derived from previous community consultation and past research findings. The community's expressed need and concern for meaningful social interaction were honest opinions brought forth by community members. Using these opinions and thoughts as a foundational basis for the development of the project created honest and open pathways for engagement. Through the honesty of community members, the research project was developed.

Humility

The research acknowledges the contributions of every participant and every community member who attended focus groups or interviews. From the participants, to the community members who helped arrange focus group gatherings, to the youth who helped set up the lounge for the gathering, all contributions made the project a successful and meaningful experience. The project was guided through communal understanding and did not interfere with community responsibilities and gatherings. The community researcher shared her expertise of knowing the community and its members through her involvement and dedication to participant recruitment. As the primary researcher for the project, I followed the guidance provided by the community researcher and did not over see my roles in the project and presence in the community.

Truth

In order to be truthful, one must also be wise, respectful and loving. When we love we tend to share our love with all the generations and for the future generations to come. This research

uncovers opportunities for older adults and youth to share their love and wisdom with one another in a wholistic approach to health care and improving brain aging across the generations. During the research, the primary investigator and the research team adhered to confidentiality ensuring participants' right to privacy. This decreased participant hesitation and encouraged participants to speak truthfully without the risk of judgement.

Bravery

The project was guided by a brave heart that seeks to have certain questions answered while keeping compassion and truth at the forefront of the research. The research process upheld the Seven Grandfather teachings as an ethical framework. These teachings continue to be a part of my academic, professional and personal life for many years to come. Participants demonstrated a great level of bravery and a tremendous amount of courage when agreeing to participate in the research, specifically through the sharing of their stories and ideas for intergenerational programs.

It is through the guidance and knowledge provided by the Seven Grandfather teachings that the following findings came through in the research process.

North – Movement and Wisdom "Do It"

Part IV Findings

This chapter reviews the research findings and relates the communal voice to opportunities for improving healthy brain aging. Preliminary findings were presented to participants during the final gathering for the combined focus group. These findings represent data from all focus groups as well as key informant interviews. The preliminary findings were shared during the combined age focus group as a method of member checking and provided the opportunity for participants to discuss, agree, refute, teach or elaborate. Stories shared through the participants voices led the development of the project's themes. The themes provide opportunity for recommendations to be made to current and future programming in the community. In depth descriptions of each recommendation are explored through reviewing the grounding stories and experiences of each theme.

4.1 Findings

Participant voices gathered through interviews and focus groups were audio recorded and transcribed verbatim. I initially reviewed the transcriptions and audio recordings. After re-listening to the audio recordings and reviewing the transcripts from each individual focus group, common words, ideas and themes were distinguished. The prominent words, ideas and themes were placed into a word cloud and presented to the participants of the combined focus group (Figure 4). The word cloud was used to initiate conversations between the older adults, youth and me. The cloud gave participants the opportunity to elaborate on specific thoughts and ideas previously presented in the individual age specific focus groups.

Following the combined focus group, the audio recording was transcribed verbatim and all transcripts were coded following a qualitative thematic analysis approach. The themes were shared with the Community Advisory Group, which was viewed as an additional method for member checking. Discussions with the Community Advisory Group strengthened the thoughts and ideas shared by the communal voices throughout the project. Each of the themes presented represents a general depiction of the topics that came forth in the interviews and focus groups (Figure 4).

Figure 4 World Cloud Presented to the Combined Focus Group to Describe Older Adult and Youth Focus Group Thoughts, Ideas and Common Themes

Each theme is described in greater detail, encompassing specific features about the complexity and significance to those who participated. The themes are presented in a manner that creates opportunity for programming recommendations in the community.

Theme One: Culture and traditional ways of living are weakened and need to be nurtured

For many participants, culture and traditional teachings were prominent in fostering traditional roles of older adults as well as improving social interactions between the generations. Participants emphasized unique perspectives of what culture and tradition signified to them, their families and others in the community. Cultural and traditional practices incorporated teachings from all the generations, spirituality, medicine, storytelling, visiting, living off of the land, prayer, crafts, ceremony and balance with all relations. It is through fostering these understandings that the transfer of knowledge can occur between the generations and preserve culture and tradition in the community.

This key informant interviewee shares an experience of change in traditions and culture from when she was a child to present day. She expresses that teaching is important for maintaining intergenerational relationships and creates opportunity for youth to gain knowledge of how their ancestors lived. It is through the teaching and sharing of knowledge that both generations benefit and acknowledgement is given to this significance:

> "So that might mean storytelling, visiting, speaking the language. And, if we begin to do a lot more of that, not only does it help out that young person, that child ages 8 and up, but it also helps that Elderly, aging person. Again, back to telling those stories. I remember back in the day when… again it is about telling their life story, it is giving those teachings. This is what we did when we were your age, or our way of having fun. I learnt how to sew at this age, I learnt how to cook, I cared for my siblings. I helped mom

> or dad do this, or it could be a great grandparent. And I learnt to go to work at a young age. So you know, those types of jobs opportunities that our relatives may have had back then. So again, it is transferring that knowledge back to our children. And that, learning experience from our Elders, it helps the Elder with the memory, because you are going back to telling those stories. And on the same note, it is giving a teaching on appreciating what you are given today, with regards to food on the table, our relatives had to work really hard to get that food on the table, and how we easy is it now." (KIIP2F)

Another key informant interviewee recognizes the significance of nature in daily life and the importance of living off of the land. She emphasizes what the benefits are for being with the land and acknowledges that not everyone in the community understands this. She attributes this lack of understanding to the barriers presently occurring in Indigenous communities:

> "Success is when you are outside, going for walks and when you are actually in nature. That is when everything comes alive. Of course the Lodge has its place, really important place but it is a whole different level of learning that happens outside. And there is a lot of failures that happen because they didn't understand that or they didn't want to understand that." (KIIP3F)

Many participants talked about the diminishing presence of cultural and traditional ways in the community. Participants also expressed reasons as to why this continues to happen in their community. They discussed the community as having their voices taken away and ultimately living in non-traditional ways. In particular, Elders[6] were seen as community members who have had their voices taken away. Participants discuss the traditional roles of Elder and the importance of their voice in the community. A key informant interviewee explains potential reasons for their voices being diminished:

> "They are not given a voice anymore. Their voice has been taken away. And I don't know, you can blame it on residential schools, you can blame it on anything, but when I was a kid growing up … and I remember that, the seniors were the ones who were

[6] Throughout this thesis, Elder is capitalized when indicating a proper title or signifying honour in the community. Elder is often used to describe Indigenous guides who are culturally and spiritually inclined. These guides have the teachings to pass on the collective wisdom of generations that have passed before their time (Dumont-Smith, 2002). The word is not capitalized when used to represent older generations or seniors (NAHO, 2003). The term 'older adult' will be used to refer to participants who are over the age of fifty-five.

> delegating. Yeah sure you saw a lot of the negativity, of people with the alcoholism because of the residential schools and things like that you know. But the spirit is broken in there some place. And maybe that is what it is all about." (KIIP1F)

Participants discuss fostering traditional ways of life through incorporating activities into their daily lives that pertain to the land. In fostering these activities and ways of living, pathways for knowledge translation occur between the generations. One participant shares that knowledge is not being shared amongst all community members because of the disconnect present between the younger and older generations. She expressed that bringing activities back into daily living can aid in fostering these opportunities for knowledge to be shared and learnt:

> "Even talking about the physical activity, because you have to hunt, fish, harvest, whatever it might be, the food or the animal. So again, transferring that knowledge to our kids. I think that would be something right now that I could say is needed. And I remember talking to [name] about the, you know, we need to start thinking about ways to incorporate activity between our young people and our aging population. Our aging population definitely have the vast amount of knowledge that we are losing. Not only the language but those ways of living. Acknowledging even the way our community is, you know how big has grown. Back then what did it look like? Thinking about who our relatives are and who has passed on." (KIIP2F)

Traditional activities included being on the land, hunting, fishing, beading, quilting and attending ceremonies. These activities were shared as being a part of their ancestry as Anishinaabe people. Participants believed the fading presence of these activities to be attributed to many changes currently happening in their community. Participants expressed that activities were occurring within the community but that there was a lacked presence of culture. Repairing or restoring these traditional activities through the inclusion of culture was deemed as an imperative change that needs to happen. One participant shares an example of culture being successfully woven into sporting activities in the community. She emphasizes that the sports alone do not attract the attention of participants but instead it is the inclusion of culture:

> "They used sports to attract everybody, and they wove culture through that so that they would be impacted. Cause they are not impacted by the sports, they are impacted by the culture. That was really effective." (KIIP3F)

Encouraging the inclusion of culture in activities was deemed as the path that would provide older adults the opportunity to foster their traditional roles as teachers. Many of the participants expressed this as an essential need in the community. Participants expressed the need to share traditional teachings with the youth, in particular language. One key informant interviewee shares that many traditional knowledge keepers are passing on to the spirit world without having shared their teachings. Without encouraging and fostering opportunities for traditional knowledge keepers to teach and share their teachings, the knowledge is being taken in their passing:

> "You can hear the stories from the Elders in the language and it becomes more meaningful, because you are getting the true version. Rather than the English version. Again, we could learn about the medicines, you know we could learn what is out there and we are losing that. Our knowledge keepers have passed on, who may have once picked that medicine and knew exactly where it was, where to harvest it, knew exactly what it was for and then giving it to the people. So you knew which door to knock on. For certain medicines. And to this day you still know who to go to but we are losing that. Because the people are going out to the spirit world with the knowledge. It is not being transferred. Before they leave. But we do have some young people that have either learnt, they have gained that knowledge, so the young people who have that knowledge need to start passing it and sharing the information with their community members. Even the kids! It would be nice for the kids to learn about that. Then again, you are pretty much gifted with that. You are born with that gift to know…" (KIIP2F)

The fostering of culture and tradition was also expressed to include the presence and lack of the language in the community. Community members shared various stories about the need for the language to be present in the community. The presence of language provided opportunities for connections to be made not only between the generations but in teachings as well. One key

informant interviewee shares that learning and speaking the language provides deeper meanings and connections to the knowledge being shared:

> "And our children, it is the same thing, for them to be given that opportunity to learn their language. So when you start learning the language and making those connections, just by the words, and there is more meaning to what you are talking about right?"(KIIP2F)

The participants viewed the presence and use of language in various ways, including how it can be nurtured and the reasons behind why the language is continuously being learnt. A common understanding or appreciation for its presence in the community, in particular for day-to-day living, was eminent. Participants expressed their language to be a form of understanding that cannot be directly translated. When attempting to translate words into other languages, the meaning and significance of the word is altered. Language was spoken of in the highest amount of respect and was sometimes used during conversations throughout the project. Participants expressed the value of the language and its connection to fostering traditional roles, culture and traditional ways of living. An older adult participant from the combined focus group shares her perspective on why speaking the language is important. She expresses speaking English as not being her true self and that the presence of the native language fosters her spirituality:

> "And then from there I made the transition that I would just do Native spirituality…I think when we are just speaking English, we are not really our true selves. So speaking the native language make us true beings and so the spirituality is tied in with that because of what happened historically, we need to pick up our Native spirituality again." (FGC – F)

Language was determined to be a factor that would bridge the gap currently present between many of the generations in the community. Many of the older adults viewed language as an opportunity to speak with younger generations, in particular those who wish to learn to speak it. This participant from the combined focus group shares her perspective on the importance of getting to know the youth and using the desire to learn the language as a basis for interaction:

> "I guess maybe we should think of what ways of getting the young people to engage. Maybe pair up with one and talk. Just talk eh. That way I can, I would know who they are. What they like. Their family. Where they are in school. You know if they want to learn the language. We could teach the language. There are lots of things we can do together you know. If it could go that way, just a thought you know of how we can get together more." (FGC – F)

When inquiring about the entailments of intergenerational programs, all participants touched upon various aspects of culture, tradition and language and how this must be acknowledged. The presence of Anishinaabe culture and tradition was deemed as a requirement in order to foster roles in the community and improve the wellbeing of the community as a whole.

Theme Two: Changes in society, family, community and relations deteriorate social engagements between the generations

Participants discussed change in unique ways that expressed the concept of change as a barrier to fostering intergenerational relationships. Some participants discussed change through a communal lens, which viewed change in relation to society, family and community. Participants reminisced about how the community as a whole endured variation, including the roles of older adults and youth. One key informant interviewee discussed changes that have occurred in the community over time in relation to the roles of the generations. She discusses how these deviations in roles have been primarily with the senior population. She attributes the changes in roles to altered values of people in the community:

> "Things have changed quite a bit in the community, especially with the seniors in our community. I think what happened is the values of people have changed, now they are just like the regular adults. And, uh, it is kind of sad to see, because it is like, hmm, how could I describe that. When I was growing up, the seniors in my day, if my grandma was sitting over here and the kids were running around, (speaking the language) "go play outside." Because back then I was kind of small, and there were kids running around, you played outside. A lot of the times, I spent my time outside. But as adults, you know you come in and my grandparents always had a pot of tea on, or some soup or something –

just to have on hand. Basically what I am doing now." (KIIP1F)

Participants in the older adult focus group talked about societal differences from past to present times and how this created barriers for meaningful social interactions. This participant from the older adult focus group shares the challenges associated with society being faster paced in comparison to when she was a child:

> "Society is so fast paced now eh? Things change constantly, constantly. Like when I look at things like when we were growing up, the things you did. Like, um, society here in [location] anyway didn't move fast. I mean we would be sweating away in the summer dirty face, with mud on them because we had to weed grandparents' garden. There's our friends going by at one o'clock in the afternoon to go swimming. There we are sweating away because we have to do this. It paid off. Because we got a nice big lunch after. Then when we were done we could go swimming. And we could swim until nine o'clock because all of our chores were done." (FGOA – F)

The presence of colonialism and its effects on the generations and the community were attributed to the barriers associated with change in the community. One key informant interviewee discloses the changes that have happened to Indigenous people and their communities as a result of enforced colonialism. She brings forth the idea of changes that are yet to happen in a concerned manner:

> "So much to learn, about ourselves and about other people. Because then you come to realize, it has happened to every culture, not just our culture. Every culture has gone through their changes. I have been taken advantage of…, you can pick our culture out… The Indian agency thought oh these people need government cheques, because they are eating frozen birds. But that is just when they had harvested them. This is how we lost our land, we lost acres upon acres. Because this whole Island of Manitoulin was a reserve once upon a time. This is where all the Indians were shoved. They came from the States, because they were pushed out…I am actually from another tribe and [location] took a bunch of our families in… [language] the fire people/keepers. This is why they call us the three fires, because of the three groups of Indians that live here… So at one time this whole island was what they called Upper Canada. And this is where the government had sent the people. And when they came here to see what it is like they thought wow this is nice. That is why they put us here, that's why they call the reserve [language], meaning 'left overs' or 'the land of no value' but after they put us all here they realized the value….The government had wanted to dig it up years and years ago…They want to

> come here and start digging. The band all said no. Then 10 years down the road, as values are changing, one of these times someone is going to say yeah let's just do it!" (KIIP1F)

A few participants also discussed change from a personal perspective. Fluctuations within the family were determined to be a major contributing factor to the gap experienced between the generations. Changes in the family referred to roles of family members, the home environment and familial relationships. One participant expresses her concern for changes in the family as a result of isolation that has become prominent. Re-establishing relationships in the family was deemed necessary to overcome isolation:

> "Yeah! And I think, "How did we get like that?" How did our families slowly unravel… like move apart and become isolated. In order to, thinking about when I am 55 and over and I would love for my grandchildren to come sit with me when I am 60 years old. And still have that healthy relationship and to continue telling the stories. You know, or when I am 65! And by then they are young adults. So it is a matter of keeping that relationship strong. And now I would say for some families it's re-engaging those relationships." (KIIP2F)

This key informant interviewee explains how many families rely on roles and relationships in the family unit. She associates the changes experienced by these roles and relationships in the family as a result of the way society is now living:

> "Yes, and I believe that as well because I know, traditionally its always been that way we've had - like how you talked about with your family - you had like 10 people and people knew who to rely on and all that kind of stuff but we've gotten away from that– we're not living like that anymore and we have to get back to that because in my family as it was in yours – it worked."(KIIP4F)

Participants shared stories of personal changes and the causation. Personal change was not viewed in a uniformed manner and was directly relational to each participant's own life story. Some participants experienced beneficial life modifications that aided in living 'the good life.' However, not all participants discussed this experience in a similar manner. This key informant interviewee portrays the process of positive change as including all generations in the family, not

only the self. The sharing of knowledge and information was expressed to evoke positive decision making, in turn benefiting one's overall health and wellbeing:

> "I think of several people that I can see right now, I think we are helping make those changes because of, I want to say for myself, some of the changes I have made in my life because the life I live now, I include my grandkids. And it is a healthy activity that we do. Even in those conversations, just sitting around baking, or whatever we are doing, or driving in the vehicle to a hockey tournament singing songs or whatever, just talking about growing up, so it is sharing that information. Sharing the knowledge so that they have that time to process it, "okay, so learning from grandma." And I think giving our young ones as much opportunity to participate in whatever it is, you think about their overall health and wellness, it will make a difference for them as they are growing up! So they are making those choices, I tell them, "Choices, it all falls back on you. Whatever choice you make is what you have to live with."" (KIIP2F)

Unfavourable alterations to the family and communal environment were exhibited throughout participant's stories and attributed to adverse experiences by all the generations. However, adverse experiences endured by youth as a result of changes in the family and communal environment were shared in particular. Concern was articulated around adverse experiences as a result of change in the family environment. One key informant interviewee shares her experience with youth and how variations in the family environment are influential to well-being:

> "Before at the youth centre [they] used to have a hands on food activity, with the kids… made pizza's and stuff. With the kids [they] made food because sometimes they might go home and they might not have food at the house…" (KIIP1F)

A participant from the youth focus group shares a perspective on changes in the community and the repercussions that result from these changes:

> "I think times have changed too eh. With kids. Like uh, I don't know, some kids they don't want to learn… Or just being straight up on their phones all day." (FGY)

One key informant interviewee expresses an altered perspective of youth in the community as a result of familial and societal influences:

> "We don't believe in love. We never see it!" (KIIP5F-Shared Perspective)

Specific recognition was given to the negative influential changes that are present in the community. Negative influential changes included the presence of drugs and their resulting alterations to the community. Stories of peer pressure endured by youth regarding drugs was commonly expressed by participants and relatable to the disconnect present between the generations. Opportunities to overcome negative influence included fostering intergenerational relationships through meaningful social interactions.

One male participant in the older adult focus group shares his concern regarding the presence of drugs in the community. He acknowledges the need for recognition around the severe consequences that accompany drug use:

> "…Get that little scare in there you know. They are gonna find out when they take that little pill, there is no scare in there. There is not scare at all. I mean for that little pill for $5 it could kill you. You know. That's what those drugs do. So this is what we are up against."(FGOA – M)

This female participant in the same older adult focus group continues to give recognition for educating the youth but stresses the challenges associated in doing so. She emphasizes determining common interests as a way to improve the comfort level between the generations, to aid in developing solutions to address negative influences. In recognizing common interests, communication pathways are strengthened and negative influential changes present in the community can be addressed:

> "It is not easy to get down to talk to the kids. You know they'll walk away. If you say they are shy. Especially with older people. But anyway, I am in and out of the youth centre and I think that if they see you enough times, eventually you can sit down and talk with them. Or connect to them. You know you will catch their interest. But I don't think you just walk in there and say oh you know we are going to talk about drugs. I think you have a role to play so that they will talk to you. Listen to you first of all. And you know be able to share with you. But I think they have to be comfortable with you at first. You know, so, that would be my, you know being so close to the youth centre where I see kids coming and going every day… I was just one of them you know. And they would talk, talk to me, you with everybody, I was just a part of them. But that to me would be one thing, just be around them, where they are. Attend games, hockey, ballgames, and just be

> there! So they see you. They know who you are. And when you open your mouth to say something, they will listen, but I think you have to make yourself known at first. So that they will feel comfortable with you. At least that is what I have seen. Or else they will just walk away. They won't just listen to you. They won't just stop and talk to you. I mean there are some who will…be around where the young people are." (FGOA – F)

Societal, familial, communal and relational changes in the community were expressed to be barriers for improving intergenerational relationships. Challenging, educating and sympathizing for such changes were determined to provide opportunities to overcome such alterations present in the community.

Theme Three: Opportunities for intergenerational inclusion encourage equality, community and self-worth

The indication of inclusion came forth in the various discussions with participants. Inclusion was referred to as addressing societal and generational inequalities, feeling safe and belonging to as well as loved and unique. The definitions of inclusion described by participants were relational to feeling wholesome, balanced and wanting to improve self-worth. Many participants expressed the need for inclusion as opposed to exclusion. Exclusion was referred to as segregation that occurs in the community, specifically in programming and communal gatherings. Exclusion was identified as a barrier to bridging the gap between the generations. One participant gives a personal rendition of exclusion amongst the generations that was witnessed through her engagement with communal programs:

> "Well yeah, because it was kind of like these youth need to do hours somewhere…I am going to hook these seniors up with the youth…I know the youth anyways, it is a small community, I know all the kids, so I would say "yeah sure go ahead!" So that's what was happening, the youth were involved in the [program] and um the exchange was happening. The communication you know. So that was wonderful! So anyways, the seniors sat down and…"well the Elders should sit down"…our Elders would say go play outside, go bring in some wood, go get some water, and even tell the adult and children

> what they need to do. You know. Now they have taken that back…They had been happy lining up… because they are able to. They are abled bodies…”(KIIP1F)

This key informant interviewee continues to express her frustration for the segregation amongst the generations, particularly in programs. Identifying opportunities to eliminate segregation were determined to aid in promoting inclusion:

> “I can understand if it is old frail elderly person in a nursing home, then ya! Sure, go serve them. Like if we have a big meal thing going on, and I will make sure that the one with diabetes has their meal, because I know that they need to have their schedule, breakfast, lunch and supper. So those kinds of things, that’s what our community is doing. I find that our community is saying “oh Elders, just sit down, somebody will come serve you!” (KIIP1F)

One participant who acknowledged the significance of engaging with the elderly population addressed the importance of inclusivity. She confirms that the translation of knowledge only occurs when all the generations are in relation to one another:

> “Well yes because right now, the seniors are dying. I can count the seniors who are here. People use to tell us you shouldn’t be hanging out with those old people. Why not? We learnt so much from them! Right now [name] can take your through the bush over there and take you to old homes that are out here. His grandmother showed him that!” (KIIP1F)

A male participant in the older adult focus group expressed similar notions. He shares the benefits of social engagement with the older generation as a way to learn, but addresses the health benefits for older adults in doing so:

> “I use to really enjoy talking to these older people. So, in visiting these older people, you awaken something in them you know. There is no room for dementia in there when they start talking. Because you have awaken something in them. You have awaken the knowledge that has been tested by fire in any different form. You know, you awaken that thing.” (FGOA – M)

Self-worth, to feel belonging to and a sense of community are addressed when inclusion is mandated. Many participants shared the benefits of inclusion for the older population, as well as

the younger, and viewed this obstacle as a main contributor to the gap between the generations. One key informant interviewee shares the joy of seniors at the senior centre when the younger generations are engaged. She acknowledges the benefits for both generations and fosters the idea of self-worth and community:

> "And you see everybody get real happy too! Like when the kids went into Amikook, it was awesome! They came quite a few times too. Which was good! It is good for everybody. Even for the teachers of the class, "I have never seen my kids like this!" So this is good!" (KIIP3F)

Exclusion was determined to have amplified through the introduction of technology into society. Many of the younger generations have exceled at the understanding of technology in comparison to the older generations. However, participants viewed the younger generations understanding of technology as an opportunity for engagement and teaching to occur with the older populations. Typically, youth are taught by the older generations but are now being encouraged to demonstrate their ability to teach. One key informant interviewee shares her perspective on how the older generations view the opportunity of being taught by the younger generations:

> "Yeah, and then again for the elders they have that sense of self-worth because they're like oh I can learn this, right, it's not just me teaching I can still learn at my age, I can still learn and I can learn from this young person." (KIIP4F)

In opposition to the youth being accountable for teaching the older generations, they are frequently being taught simultaneously by the older generations. One key informant interviewee explains the importance of teaching youth basic lessons at a young age. She promotes the concept of investment and the benefits in doing so:

> "That is when you learn! When my nieces and nephews would come over they would help all the time. They liked piling the wood. They were very strong. And that is how we see the kids, you have to invest some time with them when they are small because they become teenagers they are going to go their own way, testing things out. So I don't see them (nieces and nephews) anymore. But, they remember! What they did!" (KIIP1F)

Participants also expressed general understandings for the importance of inclusiveness in the community as a whole. The balance fostered and in some circumstances created through intergenerational social engagements was articulated by participants. One key informant interviewee gives recognition to the idea of learning from one another as opposed to a uni-directional pathway of attaining new knowledge:

> "I think we need to be inclusive. Again, it goes back to learning from each other and supporting one another. It doesn't matter you know, you have a brain injury or you might have that memory loss, or whatever that person is going through. You have your healthier population that can support, and then you would just think, I would not separate it." (KIIP2F)

She continues to emphasize the need for inclusion through intergenerational engagements. It is through these engagements that knowledge is transferred across the generations:

> "Well I guess would just say is that it needs to be inclusive! We need to make sure that those newborns are a part of engaging with the children. You know the children learn, we learn from our little ones all of the time. I do! And visa versa, we can always teach our little ones and they are always teaching us. No matter what age you are! And sometimes those little ones are your Elders. Because they are honest in what they say, right?" (KIIP2F)

Another key informant interviewee continues the discussion around intergenerational learning and elaborates on the concept of balance. Balance is achieved through intergenerational social engagements as the generations become dependent on one another for specific topics of knowledge that may not be known or acknowledged within their own generation:

> "They balance each other – the youth and the elders you bring it together and they will eventually balance themselves, they – the teenagers they'll learn about history they'll learn about that, learning that its okay to change your expectation and that you'll still be successful and it'll give the elders something to do and they will probably learn a lot more about technology and what's going on in the future they'll learn about what's going on in the news, politics, or whatever – whatever the kids are interested – like what is interesting for the kids today they'll learn about that too, so it's like the balance." (KIIP4F)

Uniqueness and safety were also recognized as imperative to promoting inclusion in the community, specifically with programming. When asked to provide insight into what intergenerational programs would resemble, participants prompted the need for uniqueness, as generalized approaches to social engagement do not attract the interest of participants. Participants expressed that the program would encourage involvement and ensure the safety of participants through providing meaningful and inclusive opportunities of engagement. One participant exhibits uniqueness as a facilitator of success when attempting to develop intergenerational engagements:

> "After the 6 weeks, with any program, that is when they kinda got bored or whatever. You would change it up! I would just do it in my work plan for a few times a year. My work plan included activities with the youth. We would go hiking in the spring, summer, winter and fall… Going on these kinds of outings is good for the kids. The adults too! It is good for everybody!" (KIIP1F)

One participant states that it is necessary to be gentle when engaging with the younger generations. Dominance or demonstrating authority will defer engagements and promote exclusion between the generations:

> "And I would just be gentle with talking to them, because that is how my mother was with me. My mom would want to correct me, my mom never blew up at me, nag nag nag, no no no, and she would be gentle with me. And that is what I did with the kids at the youth centre. They actually end up thanking me. It is kind of hilarious."(KIIP1F)

Intergenerational relationships were expressed to increase opportunities to learn new things and feel belonging to. Participants discussed interest in learning new things but opportunities to learn are not prominent. This brought forth the need for commonalities to be recognized amongst community members in order to fill the gap existing between the generations. Participants drew attention to the idea of an apprenticeship to increase opportunities to learn new things. This key

informant interviewee shares her experience with intergenerational communication and the benefits associated with its presence:

> "…having that intergenerational communication really helps with learning and I think that's what happened to me you know I got it all from different places and I – I got the big picture early in my life as opposed to people now who get it later on in life which really helped." (KIIP4F)

Her experience perpetuates the required recognition of commonalities between the generations as a way to create mentorships. The formation of these natural bonds, through sought commonalities, will flourish relations between the generations:

> "…they will form those bonds naturally, right, they will gravitate towards certain people and it will just blossom from there, yeah. It's inevitable that the mentorship will happen… Well you know what they say, spirit guides you, so whatever you're thinking whatever – and I always tell my clients use your gut instinct, if that's what you're feeling and thinking then that's probably what's right." (KIIP4F)

A youth from the individual youth focus group strengthened the concept of mentorships and apprenticeships as a pathway towards improving intergenerational relationships:

> "That'd be really nice if they had some kind of apprenticeship program for youth, like just go, I don't know if you guys are into jobs or something, like mechanics like some apprenticeship like the (inaudible) takes in two apprentices and just they go on their own for a couple hours a day – That's what they should be focusing on." (FGY)

Inclusivity was connected with fostering the model of community. One female participant from the combined focus group depicts the notion of community as being an approach to addressing inclusion. In fostering the model of community, the generations are provided with opportunities to become one through unity:

> "The word is community. Cause at the end the word is unity. So it means like we are all one. So that could help with the feeling of belonging." (FGC – F)

Encouraging opportunities of inclusion through fostering intergenerational relationships also promotes traditional roles of older adults. Such opportunities provide both generations with the ability to learn and teach from one another, through a basis of inclusivity.

Theme Four: The fear felt by youth and older adults towards intergenerational relations perpetuates the hesitation for engagement

Conceptions of fear and hesitation were expressed relatively similar by participants amongst the varied participating generations. Fear towards other generations hindered one's interest in to participating in intergenerational social engagements. One participant from the youth focus group shares a perspective on fear and its association with participation in intergenerational activities:

> "Like, some kids wouldn't want to participate because there's older people and they might feel like, I don't know, like weird just being around them… and they might… they want to be around their own friends and own age group." (FGY)

Notions of fear were not only beheld by youth but similarly voiced by older adults. This key informant interview shares the perspective of seniors in the community through her involvement with programming opportunities:

> "That was a challenge when we first started! The seniors would say, I don't want those teenagers coming over here. They are going to wreck our gardens! This is what they are going to do. And they were just getting a big thumbs down. Oh that garden won't work." (KIIP1F)

Shyness, fear of the unknown, disconnect and judgement were a few of the reasons why both older adult and youth participants were fearful and hesitant about intergenerational relationships. Discomfort and misunderstandings became concerns that participants voiced regarding intergenerational social engagements. Many of the participants admitted to misunderstanding the other generation, and drew on conclusions that were based upon assumptions. These processes

perpetuated the fear of participating in intergenerational programs. In order to overcome the fear and hesitation associated with intergenerational relations, it was stated that all the generations needed to be held responsible in the repairing of relations. One female participant in the combined focus group relates her fear of residential school to fear of the unknown. She reveals that achieving comfort aids in diminishing the fear, which hinders our ability to participate in various activities:

> "Fear keeps us from doing many things. It, I guess it is the same thing as being scared of whatever has to be done. I am scared or I am too shy and I went into I think residential school I, that is one word that I was, afraid. And that was fear of the unknown. But when you get use to what is around you well then you overcome that fear. And I was okay. I learnt many things in residential school. So that is what I will say about fear." (FGC – F)

This male participant, also from the combined focus group, encourages the idea of strength as a way for youth to overcome the fears associated with engaging in opportunities they may not be accustomed to:

> "The desire to want something, the desire to do something about it, so that is what has to be put into the minds of young people it is not so much as, it's not going to be handed to them, or to anybody. There are people that are gifted. But other people really have to learn hard you know, real hard about what you are going to do in life...You have to get passed that role of fear. Once I started learning a little bit of English, I was able to speak for myself. Then I became, a boss all my life, all my work life I should say."(FGC – M)

Overcoming the fear of change, of the generations, of differences, of language barriers, and so forth were noted to potentially create opportunities to foster relations in the community. Language, in particular, was a commonly discussed as being feared amongst both generations. One key informant interviews draws on language as being a barrier between the youth and the older generations. However, opportunities to engage in speaking the language have developed pathways for engagement between the younger generations:

> "…and then of course we still have a lot of elders who speak our language, who are very fluent, so that could be a barrier sometimes between the youth, although that's changing

> because our little, little ones are getting more and more immersed in the language but right now like teens, like probably 13, 14 right now there's still a bit of that gap."(KIIP4F)

Another key informant interviewee reviews the concept of youth fearing engagement with the older populations to the communication barriers created by language. Recognition given to the causation of fear will provide solutions for joining the gap present between the generations:

> "And, also, attempting to talk the language. You know speaking the language. Rather than being afraid. It would open that door. It would also, I could see the relationship more of that connection, because right now we are disconnected. You know from sitting down with our Elderly population, actually to go sit down and have a cup of tea. For some of us we are pretty strong in that in our families we will sit down and visit with our loved ones. Others it is like they are so disconnected but it is their family…" (KIIP2F)

The fear and hesitation associated with intergenerational engagements are noted by participants to have amplified when differences are acknowledged between the generations. Both younger and older participants acknowledged the complications associated with having individual differences and what this might mean in an intergenerational context. The need to achieve a common understanding between the generations aids in dismantling the gap created by the present differences. A participant in the youth focus group acknowledges the need for commonalities to be sought between the youth and older adults in order to improve intergenerational engagements:

> "Yeah, things to like uh, like the older generation and the newer generation they don't have that much in common… So like, I don't know, like all these kids they want to play hockey and stuff, the older generation they don't really want to play hockey, you know what I mean? Like if they found some common ground." (FGY)

Another member of the combined focus group shares her point of view on the presence of fear in her community and how such fears should not be in existence. She elaborates on the need for

people to be receptive as opposed to objective to eliminate the fears present amongst community members:

> "To my point of view, society is like a group of people who like to follow around the lies, and never the truth. They throw rocks at you instead of flowers, they put the negative onto the person who's already going through negative things, and build up problems. I don't know where I'm going with this but the word society scares me, and maybe people need to change their acts and words towards other people, like it's not right and fair to be scared of people and the world, its prolly just me but, I don't know" (FGC –F)

Intergenerational engagements evoke various fears and degrees of hesitation from community members, as expressed by both youth and older adult participants. Addressing the causation of fears and hesitation will aid in developing receptive pathways that foster intergenerational relationships. The establishment of such receptive pathways possess the ability to improve well-being for all the generations engaged.

Theme Five: Policy acts as barrier to facilitating interactions between the generations

The impeding presence of funding and its associated barriers are a dividing wall in programming opportunities for community members of Wikwemikong. Policies regarding funding were also expressed as an obstruction for achieving inclusivity within the community. Overcoming the barriers associated with funding were noted as being beneficial to all the generations. One key informant interviewee shares her perspective on accessible programming in the community. She articulates that programing adheres to the funding it is associated with, as opposed to being guided by meaningful intentions:

> "And all they are doing is running with program dollars for events or for a job basically. They are only doing what they are doing for job security, it isn't in the heart anymore for somebody to go out there and monitor areas." (KIIP1F)

This key informant interview portrays the presence of policy in programming and its association to funding. The structures that are created through funding limit the community's ability to inclusively engage:

> "…and it is the government. But maybe we did that ourselves. But are we accepting of what the government says. "You are funded to do this in this particular program cluster, here, here and here." Even in the 55 plus, you know, that is the adult day program and I am only talking about the federal funding component right now, even provincial we have a few programs that are funded provincially. And they work with a specific group. So it is like, sure give us the money…" (KIIP2F)

Key informant interviewees expressed their personal frustrations with the presence of external government policies and internal governance issues within the community. Constraints associated with funding depicted challenges for programming agencies and promoted exclusiveness. Segregated programming amplified frustrations, as attempts to create intergenerational program opportunities are frequently unsuccessful due to barriers created by policy. Initiating programming and the challenges faced involving local governance were explained by this key informant interviewee:

> "Those kinds of issues that every place has. Those are our big annoying barriers. Even when I want to go into a community and do stuff, they will just sometimes say no. Even though everybody is saying "yes! Come on!" (KIIP3F)

The key informant interviewee continues to share the barriers created by funding policies. Adhering to funding systems that ultimately do not function in the community perpetuates exclusivity. It is through the prolonged presence of exclusivity that systems begin to accommodate funding instead of communal needs and desires:

> "Cause they used a bunch of funding they shouldn't have on me. I know about the funding issue. Yeah you just got to do what they say. But what I found is that, the problems are because we have a whole bunch of systems that don't work. And we, you know, pledge ourselves to these systems, and just follow them." (KIIP3F)

The communal voice has continued to gain strength and strive towards solutions that benefit the community. Participants shared that the community, as a whole, continues to work together to overcome the constructs of funding policy. Working together to overcome these barriers was referred to as being resilient, self-sufficient and determined. Many of the projects participants shared their own ideas of how to overcome insignificant guidelines provided through funding agencies. These actions ensure that the communal voice is at the forefront of all endeavours that pertain to the community and its members. One key informant interview portrays the features of policy and funding as being systemic barriers. She continues by providing insight into how these systemic influences might be eliminated:

> "It's systemic. So when you think of those systemic barriers right, it is set up by the funding source and they accept it and follow within their guidelines. You know we need to break down that barrier and say, "You know what, we are inclusive. We need to include all ages." And this has come out, and has been a part of another conversation in an Advisory group at one time, because we do have an Elder in the community who would say exactly that and I always told him YOU ARE RIGHT. That is so true. And we do, I see it now that is exactly what we do. So that is something that we definitely need to address. Not just because you are funded for this particular age group, we need to get you connected with the older population. And sure you are still meeting that mandate because you are working with that age group, but you are integrating it with the others, you are getting them involved in another program area. It becomes more of learning from each other. We start to share the programming, whatever it might be. It could be a shared cost. But at the end of the day, you are engaging the community to reconnect. Make those reconnections and at the end of the day you are connecting with yourself, because you have learnt more about who you are as a young person or as an Elder, because we learn from each other right? So you are walking away with a little more satisfaction and that wellness." (KIIP2F)

A few participants depicted opportunities and suggestions to overcome the influence of policy in the community. Participants discussed the limitations associated with funding guidelines. Acknowledging these limitations is imperative when aiming to incorporate intergenerational engagement into current programming opportunities. The expressed frustration by participants demonstrated perseverance and the willingness to disregard funding as a barrier. One key

informant interviewee shares her determination in overcoming barriers depicted by policy. Disregarding the systems and funding guidelines provides opportunity for programming to be developed by the community, instead of for the community:

> "I just tried everything, using all of the systems we had available to us, and nothing would work. I just couldn't be employed in a way to be able to pick medicine, learn medicine and give it out. There was nothing available, so I couldn't do it. " (KIIP3F)

Avoiding the systems ensures beneficial outcomes for the community. Individuals willing to persevere and build a resistance to funding and policy create meaningful opportunities that foster the well-being of the community. Creating an understanding for the need to overcome the presence of systems and guidelines was expressed by this key informant interviewee:

> "…they just kept trying and trying and trying and nothing worked. So they said what do we have to do. And they just did it [creating a school to learn the language]. They avoided all the systems to create, revive a whole language and a whole community. They just had to avoid all these systems that we rely on." (KIIP3F)

Guidelines established by funding agencies neglected to include traditional and cultural aspects of the community. One key informant interviewee stresses the need to challenge these guidelines in order to determine whether this program or funding is beneficial to all relations:

> "You have to look at systems and challenge them. Stress them out. See if they can handle it. And if they can't handle it, then there is no need for it, no need to have this here… If it doesn't work, it doesn't work." (KIIP3F)

Rejecting guidelines that do not adhere to the needs of the community is necessary for self-empowerment. This key informant interviewee encourages the acknowledgement of traditional knowledge from the Elders as the voice of reason:

> "Stand on their own two feet and reject what society is saying! Take the knowledge of their Elders!" (KIIP5F)

Barriers created through funding must be eliminated in order to provide solutions for bridging the gap between the generations. Creating ways to bridge the gap through eliminating funding as

a barrier will promote inclusion and foster traditional roles of older adults. Inclusivity ensures the presence of all generations in programming. Through abiding by the communal voice and opposing the inflictions of funding guidelines and barriers associated with policy, opportunities for the development of intergenerational programs are created.

Theme Six: Technology generates communication challenges yet sustains the potential for creating engagement opportunities across the generations

The topic of technology was prominent throughout conversations with participants. The impeding presence of technology in the community was in alignment with gaps present amongst the generations. Technology was determined to be one of the primary reasons for disconnect between the youth and older generations in the community. The frequent use of technology was termed as a less personal way to communicate and promotes exclusion. The dominant existence of technology in the community was initially viewed as a concern by many of the youth and older adult participants. A male participant in the older adult focus group shares his interpretation of technology in relation to the exclusion present in the community:

> " Of all these we are talking about [technology], there is so much activity but there is not interaction like this women mentioned. You can be sitting beside somebody, and they are so much on the machine but no talking. You don't hear that nice voice anymore. You know, it is like in the office where there are these barriers. All you have to do, instead of texting somebody, you just stand up and talk to that person. It doesn't happen." (FGOA – M)

One female participant from the older adult focus group portrays the value of technology in her daily life, which was similarly expressed by many. Intimate conversations with others were preferred over the presence of technology:

> "That's what I tell, to stop buying me these darn gadgets. I am not into technology. So that is the difference between a lot, well I am one of the people that is not up there with technology, I choose not to be, my thing is you want to visit me, then come and see me. Or pick up the phone and call me. But even conversations, everybody has conversations

on Facebook." (FGOA – F)

However, some participants expressed the presence of technology as an opportunity for youth and older adults to connect. Technology provided both generations with opportunities to learn and teach one another. Community programming associated with technology was identified by older adult participants as being successful through its ability to bring the generations together. This common interest in technology amongst both younger and older generations provided the youth with opportunities to be the teacher. This key informant interviewee shared her understanding of teaching opportunities that youth are given in the community with regards to the integration of technology. Interest shown for learning about technology by the seniors provided youth with meaningful engagements and opportunities to address to foster the disconnect:

> "It is causing a disconnect, yeah! There is a big disconnect right now. When I was at the seniors centre, [name] came from the high school… and we fundraised and got some computers for the seniors. Adults were interested. And so [they] started having classes at the Amikook for seniors who wanted to get familiar with Facebook and online banking and all these kinds of things. And it grew! People were interested and it was a program that they looked forward to. Kinda to get back in sync with everybody."(KIIP1F)

Technology also aided in maintaining the connection to family members no longer living in the community. Some older adult participants felt that the presence of technology was acceptable when utilized in moderation. One key informant interviewee shares her use of technology. The beneficial outcomes of engaging with technology in a useful and appropriate manner are conveyed:

> "…well with me yeah I have my cellphone that is about it. But on my cellphone I have face book, but again the cellphone and face time like those are useful tools to have right? And I could speak personally outside of work that that was useful for my dad when he was living, was having Facebook. Because that for him was how he stayed connected not only to his grandchildren but to his great grandchildren too. Because he could go on and see what everybody has been doing. He can go and read all of them comments, I see the pictures. He said, "I stay connected that way." You know, whenever my kids would be

> here or my grandkids would be here that is who they would visit. They would go and knock on the door or call him up and say "come on up and have breakfast or supper, right!" So, to make sure that that connection and that relationship is still strong you know. Because you don't want to loose that right. And just the glow, the look to be happy you know, to me it makes a difference, you could see that bond maintained." (KIIP2F)

It became apparent that technology would not customarily foster traditional roles of older adults, but would create alternate communication pathways amongst community members. Technology allowed family members to stay connected and ultimately pass on their voices to the next generation regardless of their geographical location. The pathways of communication created by technology aids in fostering traditional roles of older adults as opportunities for knowledge translation are nurtured. One participant shares her experience with knowledge translation through the use of technology:

> "So again that's something you can keep in mind with this program is visuals, I know Anishinaabe people are a very visual as well, and I mean it's the 21st century there's a lot of technology, YouTube, I mean I follow this gentleman who is from [location], lives in the states right now and he does – teach language so he has little blogs I guess or whatever on YouTube and every now and again he posts them I just learned last week there's a bunch of ways to say walking like if you're walking towards somebody or someone's walking away from you, if you're walking on the snow there's just like tons of – its just, like oh my gosh." (KIIP4F)

The presence of technology was expressed to have beneficial as well as unfavourable effects to nurturing intergenerational relationships. The use of technology is determined to be inevitable in the community. However, awareness regarding the appropriate use and inclusion in intergenerational programming can provide pathways to bridge the gap between the generations.

Theme Seven: Natural, unique and fun activities empower intergenerational relationships

Participants spoke of barriers and facilitators of success in various contexts throughout the interviews and focus groups. Fun was referred to as a necessity in life, which must also be

forecasted into intergenerational engagements. One male participant in the older adult focus group shares his perspective of fun and its relation to all aspects of life. Approaching intergenerational programming through a natural perspective promotes fun and unique experiences, which aid in the continued development of traditional roles:

> "You have to look at it as fun. So in the community what are the wants, the big want that we have is to have fun doing the things that we need to do. Have fun being a mother. Have fun being a father. A grandfather. Once you become these things you have to act like a father, a grandfather, grandmother or whatever. You have to act those roles. That is the beauty of life." (FGOA – M)

Fun was described as incorporating a relatable and encouraging environment into programming opportunities. Participants expressed fun as a natural entity that is present in the Anishinaabe culture and is specific to each person. Participants expressed forced programming as unsuccessful, deepening the gap between the generations. Instead, participants conveyed approaching intergenerational programming opportunities in a humorous way that makes the engagements natural and fun. One key informant shares how fun can be achieved and re-learnt:

> "So it needs to be across the board no matter what age you are because we know that we learn from one another. We can all re-learn how to have fun in a healthy way, whatever it may be skating on the ice… " (KIIP2F)

A participant from the combined focus group shares how fun and natural engagements are the basic foundations to intergenerational relationships. Unique activities foster the notion of fun as being imperative to bridging the gap between the generations:

> " As long as you make it fun for the child there or youth. As long as there is good vibes and whatever you are teaching them with, if you are real stale with talking to them, telling them how to, I don't know, how to bake a cake or something, I don't know, as long as you make it fun!" (FGC – M)

Some participants referred to fun as a way for the gap to be bridged between the generations. Unique and interesting activities that pertained to youth and older adults in the community would

promote personal levels of relation as opposed to generic gatherings. Inclusion of all the generations in programming was portrayed as fun by one key informant interviewee. Encouraging opportunities for the youth to engage with the older generations furthered success in intergenerational communal gatherings:

> "But, every time I go somewhere I make sure that's always included, that there are always kids. When I am doing like a staff retreat, for like a health centre here or anywhere, I was tell them to bring there kids. For the week or however long we are spending together, because it is always better. Always way better when the kids are there. Or bring your parents! So a lot of them will bring their parents. And you can see that it is way better. But we are just starting to realize that now." (KIIP3F)

The themes presented depict recommendations brought forth by the community participants to address intergenerational relationships in the community. Each theme is discussed from the perspective of the participant. Figure 5 breaks down each of the seven themes and its supporting context.

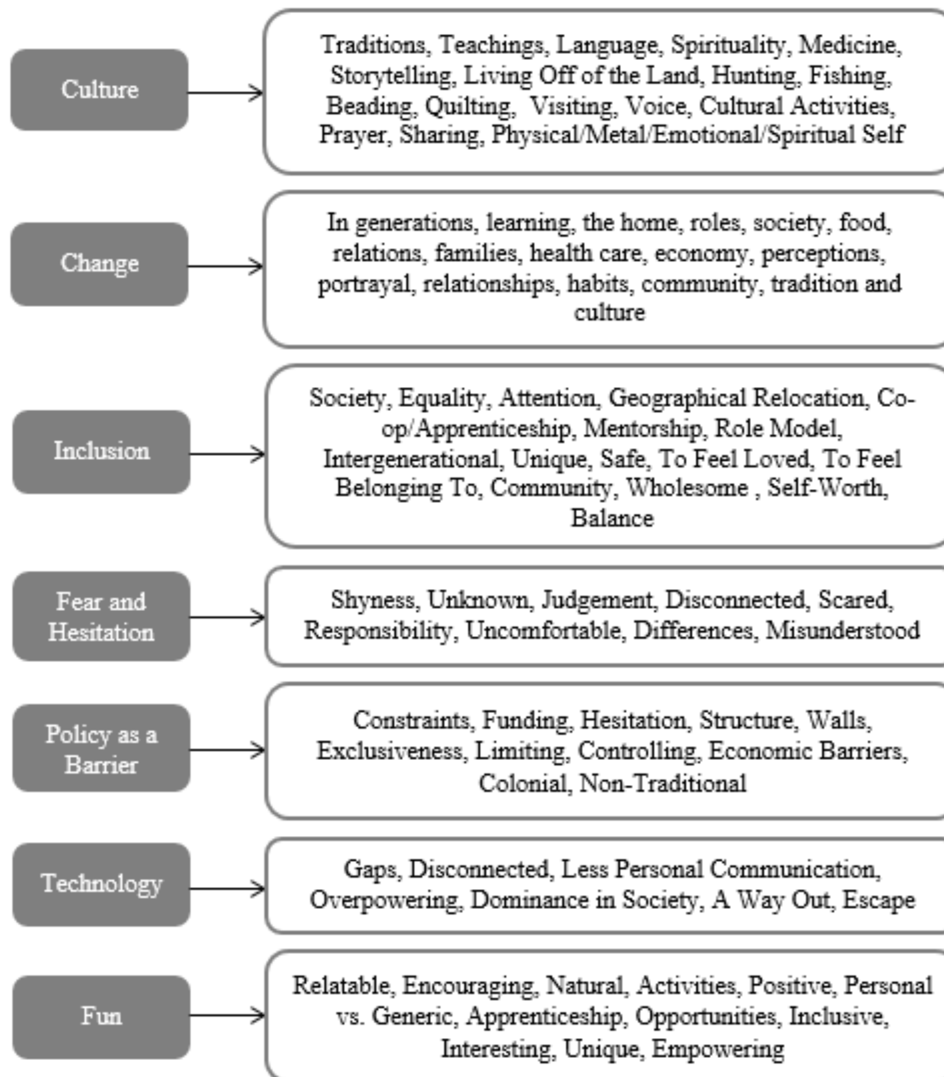

Figure 5 Themes in Fostering Traditional Roles and Promoting Intergenerational Relationships in Wikwemikong, Ontario

Part V Discussion and Limitations

This chapter reviews the role of reflexivity in the research, as well as the connection between the findings, purpose and objectives. In exploring the role of reflexivity in research, the three selves (Chilisa, 2012) are brought forward and the researcher’s voice is understood in the context of the project. Exploring reflexivity in this research project provides an understanding to the

relationships created between the community members of Wikwemikong and me. This section reviews the purpose of the research and its connection to the knowledge learnt through story telling and conversation. This is described through seven complex themes that incorporate various perspectives from each participant pertaining to the need for improved meaningful social interaction as a way to foster unique perceptions of traditional roles, in turn providing health brain aging solutions. The themes are discussed in relation to the importance of Indigenous knowledge, the health gap experienced by Indigenous people, the historical and current presence of colonial constructs, the importance of intergenerational relationships and fostering traditional roles of older adults and the need for culturally appropriate care regarding dementia and brain aging in First Nation communities. Themes are also discussed in relation to the Seven Grandfather Teachings, and their respective role in guiding this research.

Recommendations for future studies are reviewed and related to the discussed themes. Opportunities for knowledge exchange and community ownership are discussed through recommendations and guidance from the community members and Community Advisory Group. Limitations of the research are reviewed from multiple perspectives, adhering to a wholistic and inclusive approach to the research. Participants were encouraged to voice opinions with regards to the projects methods and what they might want to see changed in future projects. Through the development of relationships with community members, my own insight into the relevancy of this project and future intergenerational programs is brought forth.

5.1 The Importance of Reflexivity in Research Findings

Reflexivity has been referred to the way in which participants of the project may or may not be

affected by the researcher throughout the research process (Smith, 1999). Chilisa (2012) elaborates on the concept of reflexivity in Indigenous research and states that three selves are brought forward during community collaboration. The three selves that are brought forth include the research-based self, the brought self (socially and personally created standpoints) and the situational created self. Chilisa states that each of these selves is accompanied by a distinct voice. Through this distinct voice, the researcher must be able to critically reflect on the self and recognize connections between the community, the stories and the relation to the outcomes. In recognizing these connections, the researcher nourishes the 'us/we' relations in collaborative research relationships. Chilisa (2012) gives recognition to the potential for research to continue colonial constructs in communities and suggests the process of reflexivity to be the alleviating method. As a personal reflective note, if your heart is embedded within the project, you are truthful with the community, and the intentions you have with the project are meaningful, regardless of personal self-location, you are engaging in decolonized research and eliminating any potential for perpetuating colonial constructs. It is through this process that judgements are not made upon assumptions and instead knowledge is learnt through respectful relationships. It is in keeping with Indigenous world-views and focusing on decolonized approaches to research that make reflexivity imperative to the project (Russell-Mundine, 2012).

Reflexivity became an important aspect to grouping the thoughts, ideas and stories shared throughout the research. The presence of reflexivity throughout the project created opportunities for participants to elaborate on specific topics and demonstrate their opinions in a safe setting. In the sharing of my own personal thoughts and ideas about communal roles and intergenerational activities in my own community, participants developed a level of comfort in talking about such

topics with me. Continuing with my own personal stories and ideas throughout the research, participants gained insight into why I was doing this research, what I hoped would come of the research and my dedication to improving access to culturally appropriate health care for those experiencing signs and symptoms of brain aging or the medically referred term and diagnosis ADRD. My label of being known as an outsider by the participants slowly diminished the more the participants learnt about me. I believe it is important to disclose the role of reflexivity in this project for numerous reasons. The first reason being that sensitive topics, including perceptions of traditional roles in the community, brain aging, relationships between the generations and the acknowledgement of present barriers if any, were discussed in great detail. Participating in such conversations became emotionally heightened for some participants and myself. Through my ability to connect with the participants and share stories of triumph and heartache created reciprocal support and encouragement through the interviews and focus groups. My ability to be relational and wholesome with the participants and their stories nurtured the presented themes. The role of reflexivity was extremely important in developing themes that would act as guiding recommendations for intergenerational programming. It was important for me to attempt to understand each participant's story and confirm my understanding. Confirming my understanding of their stories was not a way for me to represent their voices. Instead, it became a way to understand what the community and the participants deemed important with respect to exploring traditional roles, improving intergenerational relationships and ultimately address ways to improve health brain aging.

5.2 Relating the Themes

The themes are discussed in relation to the importance of Indigenous knowledge, the health gap experienced by Indigenous people, the historical and current presence of colonial constructs, the

importance of intergenerational relationships and fostering traditional roles of older adults and the need for culturally appropriate care regarding dementia and brain aging in First Nation communities. The seven-presented themes provide a unique perception on how the community of Wikwemikong can create and promote opportunities for intergernational social engagements to address the increased prevalence of brain aging ailments, such as ADRD. The themes elaborated on the barriers and facilitators of success that need to be addressed to foster intergenerational relationships in the community in order to promote health brain aging opportunities.

Participants recognized the importance of Indigenous knowledge as a way for older adults to engage in meaningful social interactions. Many of the participants expressed a lack of meaning and appreciation for Indigenous knowledge in the community and related this to various different causations. The lack of meaning and appreciation was referred to as a repercussion endured by the transfer of trauma experienced because of colonialism. The revelation of these impacts related to the previously discussed topic of colonialism in Indigenous communities. As expressed by Maurice Squires in Bruyere (1999), "all problems must be solved within the context of the culture – otherwise you are just creating another form of assimilation" (Kovach, 2010). Community participants, especially when aiming to address health problems in the community, elaborated upon the idea of assimilation as a continuous cause for the diminishing of culture and tradition. The shared voices of community members elaborated on the presence of change in their community. A majority of the stories focused around change in a negative context and how these changes deepened the exclusion of cultural and traditional ways. These changes were noted to create challenges within the community including the need for cultural appropriateness not

only within health care but within all aspects of the community – including culturally appropriate programming to address brain aging. Incorporating traditional activities and culture into programming, health care, education and so forth was expressed to ensure the presence of meaningful interaction as well as the transfer of knowledge.

Challenges that arose from colonization were determined to be barriers for promoting intergenerational relationships. Referring to survivors of the residential school systems, Brasfield (2001) declared the negative impacts of colonization to have continuous impacts on many generations to follow. The stories shared by participants confirmed this understanding of residential schools and termed this to be a barrier in understanding and fostering traditional roles, which perpetuates the weakening of intergenerational engagement. Participants referred to the effects of residential schools through the numerous changes felt in the community. Some participants spoke of their parents or grandparents attendance at residential schools and how their experiences are still present in the younger generations today. Participants also shared personal reflections on residential school attendance. Their strength and resiliency guided the shared voice and provided insight into the challenges faced by residential school survivors. In particular, participants expressed fading of the language as a blatant repercussion of the residential schools. Participants talked about these repercussions as being a contributing factor to the lacked presence of culture and tradition in the community. Language was intimately tied to identity in the past, present and future. Many of the participants spoke of the language as a guiding factor to success in the community – Language was how culture and tradition were shared, taught and learnt. Older adult participants who spoke the language shared their understanding of language as being a relation and that in order to live in a wholistic manner, the language needed to be present.

Language was also the primary guiding factor behind many of the barriers associated with fostering traditional roles and promoting intergenerational relationships in order to address the increased prevalence of ADRD. Traditional knowledge was referred to as being truthfully expressed through speaking the language. Colonialism and residential schools were noted as being the reasons behind the diminished language, culture, tradition and traditional knowledge (Absolon & Willett, 2004; Chansonneuve, 2005; Gone, 2007; Smith et al., 2005b) in the community. It is through colonialism and residential schools that systemic effects are still present in Indigenous communities, creating and increasing the gaps between the generations.

The presence of culture and tradition in the community is identified to help foster the roles of older adults, as the transfer of knowledge has been recognized as a traditional responsibility of the older generations (Braun et al., 2014). It is through these traditional roles that the older generations engage with the younger generations on a teaching basis. The transfer of knowledge provides opportunities for meaningful social interaction. Without the significant presence of culture and tradition in the community, traditional roles are weakened and isolation between the generations is heightened. This understanding is in alignment with the objectives of the Intergenerational Model (George et al., 2011; Whitehouse, 2013; Whitehouse & Bendezu, 2000). The Intergenerativity Model's ability to adapt to specific cultural and traditional perspectives ensures its success in the Anishinaabe community of Wikwemikong. Participants expressed the traditional foundations of intergenerational engagement in the community, and described the barriers and facilitators of success in order to foster these relations. The model's approach of encouraging meaningful interaction through teaching opportunities supports one perspective of traditional roles of older adults in the community. Incorporating the model to address culturally

appropriate opportunities to improve healthy brain aging in Wikwemikong is supported by the voices of participants. Attention is given to the current barriers associated with the dividing gap between the generations, and is associated with isolation and increased health ailments, including the ways in which the brain is aging. One participant, from a community report completed in Northern Ontario (Pace et al., 2013), shares the idea of needing to appropriately, meaningfully and regularly use your brain in order to prevent losing your brain. His view is similar to the basic foundations of the model, which are focused upon ensuring increased meaningful social interaction. The Intergenerativity Model provides a non-Indigenous approach to fostering meaningful social interactions and encourages the community to foster these interactions in order to address the impeding prevalence of brain aging in the older generations. Through the model's ability to adapt to given contexts, its relevancy in the community of Wikwemikong is significant in addressing brain aging.

Through improving the gaps between the generations, social engagements increase, which ultimately results in creating was to culturally address brain aging in an appropriate manner. With the presence of culture and tradition being weakened in the community through the effects of colonialism, traditional roles of adults are also affected. Community members related traditional roles of the older generations in the community as being the knowledge keepers of cultural and traditional teachings. Members of the older generations regarded the need to foster their culture and tradition, as the newer and younger generations are drifting from learning and engaging. Opportunities to promote engagement were sought through conversations with community members. Community members articulated this disconnect and trauma experienced by the residential school survivors and their generations to follow. The intergenerational transfer

of trauma perpetuates the communal divide, in particular the separation between the generations (Brasfield, 2001; Pace et al., 2013; Sherwood & Edwards, 2006).

In understanding the importance of generational roles and intergenerational relationships in the community, implications of the decreased presence of these roles is endured by every aspect of the community. In particular, community programming and the health status of the community are immensely affected. The health status of Indigenous communities has been noted in relation to the effects of colonialism (Gracey & King, 2009; Greenwood, de Leeuw, Lindsay & Reading, 2015; Raphael, 2009; Smylie & Firestone, 2016). Some members of the community do not seek medical attention because of the memories associated with medical care provided in residential schools (Allan & Smylie, 2015; Goodman et al., 2017). However, the intergenerational transfer of trauma and diminishing of traditional roles in the community has been expressed to increase health ailments, specifically memory loss and cognitive decline. Traditionally, the older generations were seen as the teachers and knowledge keepers in the community. As the roles began to diminish, their teachings and knowledge translation habits also decreased. Throughout the results, the communal voice was strong in expressing this change and attributed health ailments, such as brain aging, to the diminished presence of traditional roles. Specifically for this project, community members described the weakened presence of traditional roles as relational to the reduction of meaningful social interactions. Previous projects with the First Nations communities on Manitoulin Island expressed this loss as a concern for the health of the community (Pace et al., 2013). Community members expressed the need for meaningful social interactions in order to promote traditional roles of older adults as teachers, ultimately keeping them connected to cultural and traditional ways. Decreasing meaningful interactions also

decreased the voices of the older generations and their ability to teach in turn connecting the concern of brain aging in the older generations and the need for improved intergenerational relations.

Fostering traditional roles of older adults in First Nation communities provides benefits to all relations and connections in the community. Through fostering these traditional roles, pathways for knowledge translation (George et al., 2011; Ginn, 2009) are increased in the community. Pathways that promote the inclusion of culture, tradition and language as culturally relevant approaches to health care remain to be significant pillars in the community (Aboriginal Health, 2015). Through communal guidance and consultation it has been recommendation that in order to foster traditional roles of older adults as an approach to address brain aging, values and customs that remain strong to many Anishinaabe communities must be the guiding pathway towards appropriate health care. The following connects the communal voice in the need for fostering traditional roles of older adults to address signs and symptoms of brain aging, while adhering to teachings that are strongly embedded into the cultural and traditional values of the community (Manitowabi & Shawande, 2011; Trudeau, 2012).

5.3 Connection and Guidance from the Seven Grandfather Teachings

In consulting with the community members of Wikwemikong, the Seven Grandfather Teachings were seen as community values that needed to be welcomed, met, appreciated, upheld and incorporated in the research in order to ensure that meaningful, respectful and appropriate approaches were used. I met with individuals from the community who taught me about the sacredness of these teachings and the importance of their value in the community. Community members shared personal experiences with the Seven Grandfather Teachings and encouraged the

development of my own perception and interpretation of their stories. In hearing their stories and voices, the Seven Grandfather Teachings provided a community based ethical approach to developing and engaging in this research. Through my own personal exploration, learning and living of the Seven Grandfather Teachings thus far in my life, I understood why the community insisted the presence of these values while engaging in this research project. Ethical approaches to developing the research in alignment with the Seven Grandfather Teachings are discussed in previous chapters. However, these teachings are also sacred in that they became a connecting pathway for the themes gathered from the communal voice regarding traditional roles and brain aging. Each theme was relational to a teaching that would act as the guiding pathway in order to identify sustainable recommendations for intergenerational programming in the community. Throughout engaging with community participants, various opportunities for the delivery of culturally relevant intergenerational programming were addressed. Participants reviewed current programming options in the community and suggested areas where intergenerational aspects could be incorporated. These included daytime programs between the senior centre and the school to help the youth complete their necessary community service hours, cooking classes, computer classes and outdoor learning activities. Participants also indicated that there was potential for new programs in the community, especially when encouraging the community to voice their opinions. These opportunities were yet to be reviewed but would be an avenue to explore. This section will review a wholistic understanding to the Seven Grandfather Teachings, and their presence in the creation and nurturing of this project.

Theme 1 Culture – Wisdom

"To cherish knowledge is to know wisdom" (Native Women's Centre, 2008)

To have wisdom is to listen and use the knowledge from the elders, spiritual leaders and healers (Native Women's Centre, 2008). The teaching of wisdom aligned with the theme focused upon culture in various ways. Theme one represented disconnections currently experienced in the community with the traditions, language, spirituality, land and prayer. This theme was expressed as imperative in order to foster the traditional roles of the older generations in the community. In order to bridge the gap between these disconnections and develop a culturally appropriate way to improve health brain aging, wisdom must be present and valued. Without wisdom the gaps become deeper and the disconnect strengthened. Wisdom provides the theme of culture with an understanding of how to approach the disconnect that is present. Wisdom teaches us to be receptive of positivity and reject negativity. This teaching provides recommendations for the community to overcome the weakened presence of culture that hinders traditional roles and intergenerational relationships, in turn affecting healthy brain aging.

Theme 2 Change – Love

"The know love is to know peace" (Native Women's Centre, 2008)

To have love is to feel kindness for all the things around you and to be at peace with yourself, the Creator and all relations (Native Women's Centre, 2008). Community members expressed the theme of change in both positive and negative manners. Participants had personal opinions on whether the changes occurring were good or bad, which in turn indicated their receptiveness to the changes. The teaching of love provides guidance for the changes occurring in the community that hinder traditional roles for older adults. Love strengthens peace and provides opportunities for the community to overcome negative changes and experiences. Love teaches us to be forgiving and strive for a peaceful path. It is through the teaching of love that the changes

endured in the community, acting as a barrier to traditional roles and health brain aging opportunities, can be diminished. Qualities that are brought forth to aid in overpowering negative changes include affection for all relations, respect for the knowledge to be learnt, kindness to the generations willing to learn and teach and the concern for improving brain aging for all the generations through intergenerational relationships. Love creates opportunities to accept change and go forward in the pathway to peace.

Theme 3 Inclusion – Respect

"To honor all of Creation is to have respect" (Native Women's Centre, 2008)

Respect is to show honour for the value of all persons and things, to be considerate, to show appreciation and to be polite (Native Women's Centre, 2008). Respect guides the pathway of reconciling the presence of exclusion shared by community members. Exclusion referred to personal exclusion of generations based upon assumptions, fear and disregard as well as political exclusion due to the presence of policy and funding for programming. Community members shared stories of overcoming exclusion and attributed this to breaking apart depictions of generations or refuting the walls developed by policy. These stories were strengthened and guided by the respect individuals shared for ensuring the presence of inclusion in their community. Respect encourages us to be mindful of others and be accepting of their similarities as well as their differences. Respect provides opportunities for community members to disregard exclusiveness and embrace all relations, as spoken of in Anishinaabe culture. Respect provides strength in overcoming the exclusion barriers associated with fostering traditional roles and promotes the opportunity to address brain aging in a culturally specific manner.

Theme 4 Fear and Hesitation – Bravery and Courage

"To face life with courage is to know bravery" (Native Women's Centre, 2008)

Bravery is to stand up to difficulties, obstacles and challenges faced. Courage is to make positive changes and communicate your thoughts, feelings, opinions and ideas (Native Women's Centre, 2008). The teachings of bravery and courage provide positive pathways to the fears and hesitation expressed by participants regarding intergenerational relationships. Many of the participants expressed fear of engaging with other generations and were fearful of being judged. The teachings of bravery and courage provide strengthening pathways to overcome fear and hesitation in order to improve intergenerational social engagements, in turn promoting healthy brain aging. Bravery and courage teach us that we are supported when stepping out of our comfort zone and that it is okay speak from the heart when we feel necessary. Bravery and courage support all voices in this project and encouraged participants to be their true selves, not who everyone else in the room was being. These teachings are valued as vital to overcoming the barriers associated with fear, from the perspective of both the youth and older adults.

Theme 5 Policy as a Barrier – Honesty

"To walk through life with integrity is to know honesty; to be honest in action and character" (Native Women's Centre, 2008)

Honesty is to be truthful, trustworthy and genuine. Honesty is also a reflection of the self and whether you can be honest with yourself, recognize who you are and where you come from (Native Women's Centre, 2008). Honesty rejects the political barriers associated with programming and promotes the nurturing of traditional roles in the community. The teachings of

honesty encourage community members to question the policies present. Community members expressed concern with current policies and termed these opportunities as methods of employment instead of dedication and genuine concern. The teaching of honesty shows us that in order to be content with oneself we need to approach all aspects of life in an honesty way. If all community members approached fostering traditional roles and intergenerational relationships in an honest way, many of the previously discussed themes would be non-existent. Honesty creates opportunity for community members to question policy and ensures that the intent to evoke change specifically approaches that address brain aging, is guided by the heart, dedication and compassion.

Theme 6 Technology – Humility

"To accept yourself as a sacred part of Creation" (Native Women's Centre, 2008)

Humility refers to the balance and equality with all aspects of life. It also encourages us to take pride in what we do, but to share this pride as an accomplishment with others (Native Women's Centre, 2008). Humility guides the theme of technology in the sense that balance must be maintained when introducing or using technology in daily life. Many of the participants discussed technology as a barrier to engaging with the younger generations, increasing the gap in communication and relation. This barrier was primarily associated with the overpowering presence of technology in the everyday life of the youth. The teaching of humility encourages us to use technology in moderation and to incorporate others in the successes that we have with technology. Community members talked about engaging all the generations with technology, in order to benefit from the success that these resources provide. Such engagement would increase relations between the generations and provide a meaningful way to engage, in turn promoting

healthy brain aging opportunities. Humility provides a pathway towards appreciating technology and representing its presence in the community in moderation.

Theme 7 Fun – Truth

"Faithfully follow all of the teachings, be faithful to fact and reality, be true to yourself and fellow man" (Native Women's Centre, 2008)

To be truthful is to be sincere in action and character, to be faithful in fact and reality and to be true in everything that you do (Native Women's Centre, 2008). Fun was regarded as a need when addressing traditional roles and intergenerational relationships, because without it, the true self is not present. Community members instilled the presence of fun as being a foundational aspect to their culture and traditions. The teachings of truth are similar in the way community members talked about fun. Fun was seen as something that needs to be lived by and incorporated to show that we are simply human. The teachings of truth are similar in the sense that these teachings guide who we are and provide pathways for lives to be lived. The teachings of truth are resembled in the community's voices and stories of fun as a requirement in fostering traditional roles and promoting intergenerational relationships, which address the concern for culturally, appropriate approaches to healthy brain aging.

These teachings give guidance, encouragement, strength, perseverance, resilience, determination and possibility to the themes expressed in attempting to foster traditional roles of older adults in order to promote intergenerational programming in the community. The teachings guide the themes in providing a voice of reason to the opinions, fears, doubts and stories that continue to hinder the relationships between the generations. These teachings provide opportunities to shape

program recommendations for intergenerational social engagements in order to encourage healthier brain aging.

5.4 Ownership and Giving Back

All voices, stories, opinions and thoughts used to develop the above themes and discussion belong to the community members of Wikwemikong Unceded Indian Reserve. The themes and recommendations for fostering traditional roles belong to the community and are guided by their desire to promote intergenerational relationships. Throughout the progression of the project, consultation with the community provided insight into the projects approach as well as inquires that arose. Findings from the thematic analysis were presented to the Community Advisory Group, where conversation, inquiry and suggestions were welcomed. On-going conversations with some of the participants created in depth reviews of themes previously discussed, giving a personal community review to the stories shared.

A community gathering was held where all participants were invited to attend. The gathering provided a concluding review of themes and recommendations to address intergenerational relationships as well as foster traditional roles in the community until further research engagements were established. This gathering gave opportunity for the community members to enlighten and critique the themes. Continued collaboration with the projects participants was expressed to each individual during invitations to the gathering.

Future publications were also discussed with the community researcher and community participants. All publications and discussions about this project would seek review from the community researcher and the Community Advisory Group. The Community Advisory Group

would be included in the review of any publications created. In consultation with these groups, publications sought would incorporate the community as a co-author.

5.5 Strengths and Limitations

Strengths and limitations of this project were reviewed from the community's perspective as well as my own. In discussing these strengths and limitations, recommendations from community participants were gathered for future projects.

Strengths of the research are found through the communal voice leading the development of the project. The project findings address the need for increased meaningful interaction in order to provide healthier ways to brain age. The project also aided in the development of relationships between the community and me. My being in the community and meeting with various members was facilitated by the development of these relationships. The project encouraged youth to speak up and share their voices through focus groups. The project shared new ideas with both generations regarding intergenerational relationships and the presence of traditional roles in the community as a way to promote health brain aging. My own personal understanding of gaps experienced between the generations in my own community aided in my considerate view for the need to explore traditional roles in Wikwemikong. The personal connection for this need sparked conversations between the participants and me that may not have flourished without the presence of my own personal understandings.

A major limitation noted by the community was with respect to the participant recruitment process. Members of the community expressed that not all people who could have shared their voice were recruited to participate. Participants shared that incorporating more voices through

other methods of recruitment would have provided deeper understandings as opposed to anything new or different. Participants shared the idea of creating an open-ended questionnaire that allowed participants who were either not recruited through purposive sampling or unable to physically attend the gathering to still participate. The open-ended questionnaires would gather a larger communal voice as it would allow those who do not wish to voice their opinions and thoughts through focus groups and interviews to still participate. Combining the two approaches (questionnaires and face to face communication) were considered to be beneficial for future projects. From a personal stance, there were limited gatherings with the participants, as I did not reside in the community. Being present on a weekly basis or more frequently during programming was a suggestion made as well as a personal observation. Travelling into the community on a scattered basis did not provide me with an in depth or lived experience of the challenges faced by the generations. The ability to reside in or relatively close to the community would promote relations as well as develop my understanding to the voices shared. The limitations are valued, as future gatherings with the community will benefit from the opinions shared.

Part VI Implications and Conclusion

6.1 Conclusion

The aim of this project is to address intergenerational relationships in the community of Wikwemikong as a way to explore and foster traditional roles in order to discover culturally appropriate ways to improving healthy brain aging. Through guidance provided by the Community Advisory Group, the community research team and the project's supervisor, the gathered voices of both older adults and youth developed an understanding to promote

opportunities for older Indigenous adults to participate in intergenerational programs through the themes described in Part IV. The themes were identified as being facilitators and barriers of success for intergenerational programming in the community in order to address healthy brain aging. It is through addressing these themes that the community of Wikwemikong can create and promote opportunities for meaningful social engagement through intergenerational programs. Participants shared the need for increased intergenerational social engagements as a way to nurture, teach and learn traditions and culture. This understanding promoted the inclusion of the Intergenerativity Model in this research, as its foundational basis was in alignment with the expressed communal needs by participants. These revelations provide answers to the research inquiry and create opportunities for further research regarding intergenerational programming as an opportunity to ensure healthy brain aging in older Indigenous generations and well-being in Indigenous youth.

Some of the participant voices expressed the fostering of intergenerational relationships as a pathway towards healing from the present transfer of trauma occurring between the generations. This concept is unique to the community of Wikwemikong and diverges from mainstream concepts of intergenerational relationships due to the continued presence and repercussions endured by colonialism. The notion of intergenerational relationships with respect to the community of Wikwemikong incorporates benefits beyond the need to address brain aging by providing opportunities to address communal concerns, which include the fostering of language, culture and tradition as well as pathways towards reconciliation. Inclusively, participants viewed intergenerational relationships not only as an opportunity to improve healthy brain aging for the older generations but also for the well-being and reconnecting of youth to their traditions and

culture in the community. This component is unique to Indigenous populations and communities in the sense that culture and tradition are historically the foundational basis of the community. In more recent times, culture and tradition remain foundational but experience periods of weakened presence due to influences such as colonialism. The communal voices strengthened the need for reconciliation with Indigenous peoples in Canada, and supported the need for culturally appropriate approaches to health concerns faced by Indigenous communities.

The gathering of communal voices provided an opportunity for the community of Wikwemikong to seek the changes that they wanted to see with respect to traditional roles, intergenerational relationships and culturally appropriate approaches to brain aging. The themes that arose from the gathering of communal voices were also recognized as being recommendations for current and future programs in the community. These recommendations encourage the communal voice to be the guiding pathway for the change they wish to seek. The recommendations represent the gaps experienced in the community when attempting to foster traditional roles as well as intergenerational relationships. Each theme incorporates positive and negative perspectives that need to be equally represented, understood and accepted in order to overcome these gaps and to improve opportunities for healthy brain aging. These recommendations are specific to the community of Wikwemikong and represent their specific needs as a community when attempting to address brain aging. The need for community driven health solutions is present in this project and gives strength to the community to seek culturally appropriate care for all health ailments faced by community members.

6.2 Project Implications

The implications of this project are viewed at an individual and communal context. At an individual level, youth and older adults benefit from this project in a unique manner that pertain to their generational presence in the community. Their combined participation in the research project ensures that guidance from both generations established the recommendations for programming opportunities that promote healthy brain aging in their community. The development of program recommendations through the communal voice increases the level of success for these recommendations since community members have been a primary initiating force in their development. This is evident in research that follows the characteristics of community-based participatory action research (Fletcher, 2003; Jacklin & Kinoshameg, 2008). Participating youth foster their understanding of the roles of older adults in the community, aiding in their involvement in meaningful social interactions. A study completed by Big-Canoe and Richmond (2014), explored the perceptions of youth with regards to social relationships in their community. In the study, youth identify social supports with family members and the community as being important to fostering relationships and roles. This understanding is also evident throughout the shared voice of participants in this project.

Increased awareness on the need, significance and success of intergenerational social engagements by older adults and youth guided the establishment of the previously described themes. The findings suggest, programming opportunities focused upon intergenerational interactions will improve cognitive functioning in older adults and allow youth to reconnect to traditional customs and teachings while learning possible roles they have to fulfill in the future. The research provides teaching and learning opportunities for both generations through the

exploration of traditional roles and intergenerational relationships, overall improving opportunities to increase cognitive functioning.

Influences from this project may also impact programming in the community that focuses upon providing opportunities to improve healthy brain aging for those experiencing signs and symptoms of Alzheimer's disease and related dementias (ADRD). Through exploring traditional roles, opportunities to improve healthy brain aging and pathways towards intergenerational reconciliation are consequentially addressed. The development of culturally appropriate program recommendations to promote intergenerational engagements and healthy brain aging, derived from the qualitative data analysis of key informant interviews, participant observation and focus groups, is the primary knowledge dissemination tool established from this project. Public educational materials including pamphlets and posters can also be created through the research findings. Participants shared modifications that could be implemented for current programming opportunities in the community to foster inclusiveness of all the generations. Recommendations included obtaining the opinions of both generations in order to ensure programming would be receptive. Participants also shared that the program needed to be fun and resemble a mentorship in order to maintain the interest of participants. Educational workshops have the potential to be created and utilized. The educational workshops will disclose findings with practitioners, family caregivers and personal support workers, which may result in modified approaches to addressing health ailments in Indigenous communities.

It is anticipated that, potential outcomes of this project will have impacts over many generations. The project provides reason through communal voice for the fostering of traditional roles,

culture, language, traditional teachings, spirituality, and intergenerational relations. Communal voices give reason to the need for fostering these significant aspects of the community, and the benefits not only to improve brain aging, but for the well being of all engaging generations. Encouraging community empowerment can challenge the presence of current programs and health care opportunities, in turn creating opportunities for the community and future generations to govern their own approaches to health care. Recommendations for current and future programming hold the opportunity to make changes that will not only benefit the aging population or the current members of the community, but the next seven generations to come.

6.3 Closing Thoughts

Exploring and fostering traditional roles of older adults in First Nation communities provides opportunities to improve healthy brain aging through meaningful social interactions with all the generations. Intergenerational approaches to brain aging align with Anishinaabe teachings in that fostering the various traditional roles of older adults provides opportunity for the transfer of knowledge. It is through the transfer of knowledge between the generations that meaningful social interactions occur. The project's outcomes show that there is a need to explore traditional roles and bridge the gap currently present between the generations, in order to improve the health of all generations. Participants note that factors such as the weakened presence of tradition, culture and the ability to teach or share knowledge affects the way the mind ages and ultimately influences the generations that will follow.

Future research on this approach to improving brain aging must recognize the impacts that such interactions will have on all the generations. Ensuring the presence of communal voice when addressing health concerns in Indigenous communities creates culturally appropriate approaches

to health care that nurture the needs of the community. These approaches further develop a community's self-determination and ultimately pave the pathway towards decolonization and resilience. It is through the continued presence of communal voices in health research that change is sought. It is through these changes that Indigenous communities continue to thrive, heal, foster tradition and culture, and maintain balance with all relations, including the physical, mental, emotional and spiritual self. Bridging the gap between the generations through meaningful intergenerational engagement fosters the historical ways in which Indigenous people lived. Empowering Indigenous communities to continue leading health research projects that are inclusive to all the generations ensures that the commonly expressed notion of how we lived flourishes into the present tense of how we are living.

"Wind and storms keep the oak trees strong"

- Community Participant's Recommendation on Addressing Intergenerational Programming

With love and gratitude to all the voices met and stories shared along this journey

References

Aboriginal Health, (2015). Our Health, Our Seventh Generation Our Future: 2015 Aboriginal Health Access Centres Report. Toronto.

Absolon, K. (2010). Indigenous Wholistic Theory: A Knowledge Set for Practice. *First Peoples Child and Family Review*, *5*(2), 74–87. Retrieved from http://journals.sfu.ca/fpcfr/index.php/FPCFR/article/view/95/160

Absolon, K., & Willett, C. (2004). Aboriginal research: Berry picking and hunting in the 21st century. *First Peoples Child & Family Review*, *1*(1), 5–17. Retrieved from http://journals.sfu.ca/fpcfr/index.php/FPCFR/article/view/5

Allan, B., & Smylie, J. (2015). *First Peoples , Second Class Treatment*. Retrieved from http://www.wellesleyinstitute.com/wp-content/uploads/2015/02/Summary-First-Peoples-Second-Class-Treatment-Final.pdf

Baydala, L., Saylor, K., & Ruttan, L. (2013). Meeting Standards for Community-Engaged Aboriginal Health Research. *Paediatrics & Child Health*, *18*(1), 2012–2013. Retrieved from http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3680264/pdf/pch18008.pdf

Bell, N. (2014). Teaching by the Medicine Wheel: An Anishinaabe Framework for Indigenous Education. Canada Education, June 2014

Big-Canoe, K., & Richmond, C. A. M. (2014). Anishinabe youth perceptions about community health: Toward environmental repossession. *Health and Place*, *26*, 127–135. http://doi.org/10.1016/j.healthplace.2013.12.013

Blind, M., Dietrich, D., & Oleson, E. (2015). Understanding the Intergenerational Effects of Colonization : Aboriginal Women with Neurological Conditions — Their Reality and Resilience. *International Journal of Indigenous Health*, *10*(2), 3–20.

Brasfield, C. R. (2001). Residential school syndrome. *BC Medical Journal*, *43*(2), 78–81. Retrieved from http://www.bcmj.org/residential-school-syndrome

Braun, V. & Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*, 77-101.

Braun, K. L., Browne, C. V., Ka'Opua, L. S., Kim, B. J., & Mokuau, N. (2014). Research on Indigenous Elders: From Positivistic to Decolonizing Methodologies. *Gerontologist*, *54*(1). http://doi.org/10.1093/geront/gnt067

Browne, A. J., Smye, V. L., & Varcoe, C. (2005). The Relevance of Postcolonial Theoretical Perspectives to Research in Aboriginal Health. *Canadian Journal of Nursing Research*, *37*(4), 16–37. http://doi.org/Article

Browne, A. J., Varcoe, C., Lavoie, J., Smye, V., Wong, S. T., Krause, M., … Fridkin, A. (2016). Enhancing health care equity with Indigenous populations: evidence-based strategies from an ethnographic study. *BMC Health Services Research*, *16*(1), 544. http://doi.org/10.1186/s12913-016-1707-9

Bull, J. R. (2010). Research with Aboriginal peoples: authentic relationships as a precursor to ethical research. *Journal of Empirical Research on Human Research Ethics : JERHRE*, *5*(4), 13–22. http://doi.org/10.1525/jer.2010.5.4.13

Canada, (2014). *Tri-Council Policy Statement Ethical Conduct Involving humans*. Ottawa. Retrieved from http://www.pre.ethics.gc.ca/pdf/eng/tcps2/TCPS_2_FINAL_Web.pdf

Canadian Aboriginal AIDS Network. (2011). *Young Eagles Challenge*. Ottawa.

Canales, M. (2004). Taking Care of Self: Health Care Decision Making of American Indian Women. *Health Care for Women International*, *25*(5), 411–435.

http://doi.org/10.1080/07399330490438323

Chansonneuve, D. (2005). *Reclaiming Connections: Understanding Residential School Trauma Among Aboriginal People*. Retrieved from http://www.ahf.ca/downloads/healing-trauma-web-eng.pdf

Childs, P., & Williams, R. J. (1997). *An Introduction to Post-Colonial Theory*. *An Introduction to Post-Colonial Theory*. Prentice Hall. http://doi.org/10.1057/9781137012142

Chilisa, B., & Tsheko, G. N. (2014). Mixed Methods in Indigenous Research Building Relationships for Sustainable Intervention Outcomes. *Journal of Mixed Methods Research*, *8*(3), 222–233. http://doi.org/10.1177/1558689814527878

Cooper, S., Maar, M., & Peltier, M. A. J. (2000). A Community Based Approach to Reducing HIV:AIDS Infection in the Wikwemikong Unceded Indian Reserve. *Native Social Work Journal*, *3*(1), 119–126.

Czyzewski, K. (2011). Colonialism as a Broader Social Determinant of Health. *International Indigenous Policy Journal*, *2*(1). http://doi.org/10.18584/iipj.2011.2.1.5

Dilworth-Anderson, P., & Gibson, B. E. (2002). The cultural influence of values, norms, meanings, and perceptions in understanding dementia in ethnic minorities. *Alzheimer Disease and Associated Disorders*, *16 Suppl 2*(1989), S56–S63. http://doi.org/10.1097/01.WAD.0000025541.17499.04

Dumont-Smith, C. (2002). *Aboriginal Elder Abuse in Canada*. Ottawa. Retrieved from http://www.ahf.ca/downloads/ahfresearchelderabuse_eng.pdf

Ermine, W., Sinclair, R., & Jeffery, B. (2004). *The Ethics of Research Involving Indigenous Peoples*. Saskatoon, Canada: Indigenous Peoples' Health Research Centre., Retrieved from http://ahrnets.ca/files/2010/05/ethics_review_iphrc.pdf

Finkelstein, S. A., Forbes, D. A., & Richmond, C. A. M. (2012). Formal Dementia Care among First Nations in Southwestern Ontario. *Canadian Journal on Aging*, *30*(3), 257–270. http://doi.org/10.1017/S0714980812000207

First Nations Regional Health Survey. (2017). First Nation Regional Health Survey National and Regional Reports: Phase I and II. Ottawa, ON: The First Nations Information Governance Centre. Retrieved from: http://fnigc.ca/resources.html

First Nations and Inuit Regional Health Survey. (1997). First Nations and Inuit Regional Health Survey Final Report. Ottawa, ON: The First Nations Information Governance Centre. Retrieved from: http://fnigc.ca/sites/default/files/ENpdf/RHS_1997/rhs_1997_final_report.pdf

Fletcher, C. M. (2003). Community-based participatory research relationships with Aboriginal communities in Canada: An overview of context and process. *Pimatziwin A Journal of Aboriginal and Indigenous Community Health*, *1*(1), 27–62. Retrieved from http://www.pimatisiwin.com/online/?page_id=116

George, D., Whitehouse, C., & Whitehouse, P. (2011). A Model of Intergenerativity: How the Intergenerational School is Bringing the Generations Together to Foster Collective Wisdom and Community Health. *Journal of Intergenerational Relationships*, *9*(1), 389–404. http://doi.org/10.1080/15350770.2011.619922

George, D., & Whitehouse, P. J. (2010). Intergenerational Volunteering and Quality of Life for Persons with Dementia. *Journal of the American Geriatrics Society*, *58*(4), 796–797. http://doi.org/10.1111/j.1532-5415.2010.02790.x

Getty, G. A. (2010). The Journey Between Western and Indigenous Research Paradigms. *Journal of Transcultural Nursing*, *21*(1), 5–14. http://doi.org/10.1177/1043659609349062

Ginn, C. S. (2009). *Urban First Nations Grandmothers: Health Promotion Roles in Family and Community*. University of Lethbridge.
Golafshani, N. (2003). Understanding reliability and validity in qualitative research. *The Qualitative Report*, *8*(4), 4–9. http://doi.org/10.3367/UFNr.0180.201012c.1305
Gone, J. P. (2007). "We never was happy living like a whiteman": Mental health disparities and the postcolonial predicament in American Indian communities. *American Journal of Community Psychology*, *40*(3–4), 290–300. http://doi.org/10.1007/s10464-007-9136-x
Goodman, A., Fleming, K., Markwick, N., Morrison, T., Lagimodiere, L., & Kerr, T. (2017). "They treated me like crap and I know it was because I was Native": The healthcare experiences of Aboriginal peoples living in Vancouver's inner city. *Social Science & Medicine*, *178*, 87–94. http://doi.org/10.1016/j.socscimed.2017.01.053
Gordon, J. (2012). Holistic Medicine And Mental Health Practice: Toward a New Synthesis, *XXXIII*(2), 81–87. http://doi.org/10.1007/s13398-014-0173-7.2
Gracey, M., & King, M. (2009). Indigenous health part 1 : determinants and disease patterns. *The Lancet*, *374*(9683), 65–75. http://doi.org/10.1016/S0140-6736(09)60914-4
Graham, H., & Leeseberg Stamler, L. (2010). Contemporary Perceptions of Health from an Indigenous (Plains Cree) Perspective. *Journal of Aboriginal Health*, *6*(1), 12. Retrieved from http://www.naho.ca/journal/2010/01/15/contemporary-perceptions-of-health-from-an-indigenous-plains-cree-perspective/
Gregory, D. (2005). Aboriginal health and nursing research: Postcolonial theoretical perspectives. *Canadian Journal of Nursing Research*, *37*(4), 11–15. Retrieved from http://www.ingentaconnect.com/content/mcgill/cjnr/2005/00000037/00000004/art00002
Greenwood, M., de Leeuw, S., Lindsay, N. M. and Reading, C. (2015). *Determinants of Indigenous Peoples' Health in Canada*. Toronto: Canadian Scholars' Press.
Grenier, L. (1998). Working with indigenous knowledge: A guide for researchers. IDRC.
Hart, M. A. (2010). Indigenous worldviews, knowledge, and research: The development of an Indigenous research paradigm. *Journal of Indigenous Voices in Social Work*, *1*(1), 1–16. Retrieved from http://scholarspace.manoa.hawaii.edu/bitstream/handle/10125/15117/v1i1_04hart.pdf?sequence=1
Henderson, J. N., & Henderson, L. C. (2002). Cultural construction of disease : A " supernormal " construct of dementia in an American Indian tribe. *Journal of Cross-Cultural Gerontology*, *17*(3), 197–212.
Hulko, W. (2004). *Dementia and Intersectionality : Exploring the experiences of older people with dementia and their significant others*. *University of Stirling*. University of Stirling.
Hulko, W., Camille, E., Antifeau, E., Arnouse, M., Bachynski, N., & Taylor, D. (2010). Views of First Nation Elders on Memory Loss and Memory Care in Later Life. *Journal of Cross-Cultural Gerontology*, *25*(4), 317–342. http://doi.org/10.1007/s10823-010-9123-9
Hunter, L. M., Logan, J. O., & Barton, S. (2006). Aboriginal Healing : Regaining Balance and Culture. *Journal of Transcultural Nursing*, *17*(1), 13–22. http://doi.org/10.1177/1043659605278937
Jacklin, K. (2009). Diversity within: Deconstructing Aboriginal community health in Wikwemikong Unceded Indian Reserve. *Social Science and Medicine*, *68*(5), 980–989. http://doi.org/10.1016/j.socscimed.2008.12.035
Jacklin, K., & Kinoshameg, P. (2008). Developing a Participatory Aboriginal Health Research Project: "Only if it's Going to Mean Something." *Journal of Empirical Research on Human

Research Ethics, *3*(2), 53–67. http://doi.org/10.1525/jer.2008.3.2.53
Jacklin, K. M., Henderson, R., Walker, L. M., Calam, B. & Crowshoe, L. J. (2017). Health care experiences of Indigenous people living with type 2 diabetes in Canada. *Canadian Journal Association Journal*, *189*(3), 106–112. http://doi.org/10.1503/cmaj.161098
Jacklin, K. M., Walker, J. D., & Shawande, M. (2013). The emergence of dementia as a health concern among first nations populations in Alberta, Canada. *Canadian Journal of Public Health*, *104*(1), 39–44. Retrieved from http://journal.cpha.ca/index.php/cjph/article/view/3348
Jacklin, K. M., & Warry, W. (2004). The Indian Health Transfer Policy in Canada: Toward self-determination or cost containment. In *Unhealthy Health Policy: A critical anthropological examionaton*. Walnut Creek, CA: Altamira Press, pp. 215–234.
Jacklin, K., Pace E., J., & Warry, W. (2015). Informal Dementia Caregiving Among Indigenous Communities in Ontario, Canada. *Care Management Journals*, *16*(2), 106–120. http://doi.org/10.1891/1521-0987.16.2.106
Joffe, H. & Yardley, L. (2004) Content and thematic analysis. In D. F. Marks & L. Yardley (Eds), Research methods for clinical and health psychology (pp. 56-68). London: Sage.
Kenny, C. (2004). *A holistic framework for Aboriginal policy research*. *Canadian Cataloguing*. Retrieved from http://www.turtleisland.org/resources/hresearch.pdf
King, M., Smith, A., & Gracey, M. (2009). Indigenous health part 2: the underlying causes of the health gap. *The Lancet*, *374*(9683), 76–85. http://doi.org/10.1016/S0140-6736(09)60827-8
Kirkness, V., & Barnhardt, R. (1991). First Nations and higher education: The four R's—Respect, relevance, reciprocity, responsibility. *Journal of American Indian Education, 30*(3), 1–15.
Kirmayer, L. J., & Valaskakis, G. G. (Eds.). (2009). *Healing traditions: The mental health of Aboriginal peoples in Canada*. UBC press.
Kovach, M. (2010). Conversational Method in Indigenous Research. *First Peoples Child & Family Review*, *5*(1), 40–48. Retrieved from http://journals.sfu.ca/fpcfr/index.php/FPCFR/article/viewFile/172/141
Kovach, M. E. (2010). *Indigenous methodologies: Characteristics, conversations, and contexts*. University of Toronto Press.
Lanting, S., Crossley, M., Morgan, D., & Cammer, A. (2011). Aboriginal Experiences of Aging and Dementia in a Context of Sociocultural Change: Qualitative Analysis of Key Informant Group Interviews with Aboriginal Seniors. *Journal of Cross-Cultural Gerontology*, *26*(1), 103–117. http://doi.org/10.1007/s10823-010-9136-4
Lavallée, L. F. (2009). Practical Application of an Indigenous Research Framework and Two Qualitative Indigenous Research Methods : Sharing Circles and Anishnaabe Symbol-Based Reflection. *International Journal of Qualitative Methods*, *8*, 21–40. http://doi.org/QH 11.0080
Laveaux, D., & Christopher, S. (2009). Contextualizing CBPR: Key Principles of CBPR meet the Indigenous research context. *Pimatisiwin*, *7*(1), 1. http://doi.org/10.1016/j.biotechadv.2011.08.021.Secreted
Lavoie, J. G. (2013). Policy Silences: Why Canada needs a National First Nations, Inuit and Metis health policy. *International Journal of Circumpolar Health*, *72*, 1–7. http://doi.org/http://dx.doi.org/10.3402/ijch.v72i0.22690
Leon, A. M., & Knapp, S. (2008). Involving family systems in critical care nursing: challenges and opportunities. *Dimensions of Critical Care Nursing : DCCN*, *27*(6), 255–62.

http://doi.org/10.1097/01.DCC.0000338866.47164.6d

Lowe, J., & Struthers, R. (2001). A conceptual framework of nursing in Native American culture. *Journal of Nursing Scholarship : An Official Publication of Sigma Theta Tau International Honor Society of Nursing / Sigma Theta Tau*, *33*(3), 279–283. http://doi.org/10.1111/j.1547-5069.2001.00279.x

Ly, A., & Crowshoe, L. (2015). “Stereotypes are reality”: Addressing stereotyping in Canadian Aboriginal medical education. *Medical Education*, *49*(6), 612–622. http://doi.org/10.1111/medu.12725

Maar, M. A. (2004). Clearing the Path for Community Health Empowerment : *Journal of Aboriginal Health*, *1*(1), 54–65. Retrieved from http://search.proquest.com/openview/60ee477dda786f5c72abe1a4a46272ea/1?pq-origsite=gscholar

Maar, M. A., & Shawande, M. (2010). Traditional Anishinabe Healing in a Clinical Setting. *Journal of Aboriginal Health*, *6*, 18–27. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&db=fph&AN=51532485&site=ehost-live

Maar, M. A., Sutherland, M., & McGregir, L. (2013). A Regional Model for Ethical Engagement: The First Nations Research Ethics Committee on Manitoulin Island. (J. White, S. Wingert, D. Beavon, & P. Maxim, Eds.) Aboriginal Policy Research Moving Forward: Making a Difference (Vol. 4). Thompson Educational Publishing.

MacDonald, J. P., B.Sc, Barnes, D. E., PhD., & Middleton, L. E., PhD. (2015). Implications of risk factors for alzheimer's disease in canada's indigenous population. *Canadian Geriatrics Journal, 18*(3), 152-158. Retrieved from https://search-proquest-com.librweb.laurentian.ca/docview/1722885067?accountid=12005

Marsden, D. M. (2005). Indigenous Wholistic Theory for Health: Enhancing Traditional-Based Indigenous Health Services in Vancouver. *The University of British Columbia Thesis and Ph.D Dissertations*. http://doi.org/10.14288/1.0055626

Menzies, P. (2008). Developing an Aboriginal healing model for intergenerational trauma. *International Journal of Health Promotion and …*, *46*(2), 41–48. http://doi.org/10.1080/14635240.2008.10708128

Minkler, M. (2005). Community-based research partnerships: Challenges and opportunities. *Journal of Urban Health*, *82*(SUPPL. 2), 3–12. http://doi.org/10.1093/jurban/jti034

Morita, K., & Kobayashi, M. (2013). Interactive programs with preschool children bring smiles and conversation to older adults: time-sampling study. *BMC Geriatrics*, *13*(1), 111. http://doi.org/10.1186/1471-2318-13-111

Nagel, T., & Thompson, C. (2006). Aboriginal mental health workers and the improving Indigenous mental health service delivery model in the “Top End.” *Australasian Psychiatry*, *14*(3), 291–294. http://doi.org/10.1111/j.1440-1665.2006.02294.x

Native Women’s Centre. (2008). Traditional Teachings Handbook. *Native Women’s Centre, Aboriginal Healing and Outreach Program*. Hamilton: Native Women’s Centre. Retrieved from http://scholar.google.com/scholar?hl=en&btnG=Search&q=intitle:Traditional+Teachings#1%5Cnhttp://www.nativewomenscentre.com/files/Traditional_Teachings_Booklet.pdf

O’Shane, P. (1995). The Psychological Impact of White Colonialism on Aboriginal People. *Australasian Psychiatry*, *3*(3), 149–153.

Pace, J., Jacklin, K., & Warry, W. (2013). Perceptions of Dementia Prevention among

Manitoulin Island First Nations, 1–52.
Park, A.-L. (2014). Is There Anything Special About Intergenerational Approaches to Older People with Dementia? A Review. *Journal of Alzheimer's Disease & Parkinsonism*, *4*(6). http://doi.org/10.4172/2161-0460.1000172
Partridge, C., Cote-Meek, S., Manitowabi, S., & Mawhiney, A. (2014). *Native Social Work Journal* (9th ed.). Sudbury.
Petrucka, P., Bassendowski, S., Bickford, D., & Goodfeather, E. V. (2012). Towards building consensus: Revisiting key principles of CBPR within the First Nations/Aboriginal context. *Open Journal of Nursing*, *2*(2), 143. http://doi.org/10.4236/ojn.2012.22022
Raphael, D. (Ed.). (2009). *Social determinants of health: Canadian perspectives.* Canadian Scholars' Press.
Reading, C., & Wien, F. (2012). *Health Inequalities and Social Determinants of Aboriginal People's Health*. *National Collaborating Centre for Aboriginal Health*. Retrieved from http://www.nccah-ccnsa.ca/Publications/Lists/Publications/Attachments/46/health_inequalities_EN_web.pdf
Reading, J., Kmetic, A., & Gideon, V. (2007). First Nations Wholistic Policy and Planning Model Discussion Paper for the World Health Organization Commission on Social Determinants of Health. *Health (San Francisco)*, (April), 81. Retrieved from http://www.ahrnets.ca/files/2011/02/AFN_Paper_2007.pdf
Reeves, S., Albert, M., Kuper, A., & Hodges, B. D. (2008). Why use theories in qualitative research. Bmj, 337(7670), 631-4.
Reynolds, C. L. (1997). Ways of Knowing about Health : An Aboriginal Perspective. *Advances in Nursing Science*, *19*(3), 28–36.
Richmond, C. A. M., & Ross, N. A. (2009). The determinants of First Nation and Inuit health : A critical population health approach. *Health & Place, 15*, 403–411. http://doi.org/10.1016/j.healthplace.2008.07.004
Russell-Mundine, G. (2012). Reflexivity in Indigenous Research : Reframing and Decolonising Research ? *Journal of Hospitality and Tourism Management*, *19*(1), 85–90. http://doi.org/10.1017/jht.2012.8
Saldaña, J. (2010). *The Coding Manual For Qualitative Researchers* (1st ed.). London, Thousand Oaks, New Delhi, Singapore: Sage Publications LTD.
Sherwood, J., & Edwards, T. (2006). Decolonisation: a critical step for improving Aboriginal health. *Contemporary Nurse : A Journal for the Australian Nursing Profession*, *22*(2), 178. http://doi.org/10.5555/conu.2006.22.2.178
Singer, J., Bennett-Levy, J., & Rotumah, D. (2015). "You didn't just consult community, you invovled us": Transformation of a "top-down" Aboriginal mental health project into a "bottom-up" community-driven process. *Australasian Psychiatry*, *23*(6), 614–619. http://doi.org/10.1177/1039856215614985
Smith, D., Varcoe, C., & Edwards, N. (2005a). pensionnats sur les populations autochtones : implications pour les orientations et les pratiques en matière de santé Turning Around the Intergenerational Impact of Residential Schools on Aboriginal People : Implications for Health Policy and Practice. *Canadian Journal of Nursing Research*, *37*, 38–60.
Smith, D., Varcoe, C., & Edwards, N. (2005b). Turning Around the Intergenerational Impact of Residential Schools on Aboriginal People : Implications for Health Policy and Practice. *Canadian Journal of Nursing Research*, *37*(4), 38–60. Retrieved from http://www.ingentaconnect.com/content/mcgill/cjnr/2005/00000037/00000004/art00004

Smith, K., Flicker, L., Lautenschlager, N. T., Almeida, O. P., Atkinson, D., Dwyer, A., & Logiudice, D. (2008). High prevalence of dementia and cognitive impairment in Indigenous Australians. *Neurology*, *71*(19), 1470–1473. http://doi.org/10.1212/01.wnl.0000320508.11013.4f

Smith, L. T. (1999). *Decolonizing Methodologies*. *New York* (First). London and New York: Zed Books Limited. http://doi.org/10.1097/NAQ.0b013e318258ba14

Smylie, J., & Firestone, M. (2016). The health of indigenous peoples. D. Raphael (3rd ed.) Social determinants of health: Canadian perspective, 434-469.

Smylie, J., Martin, C. M., Kaplan-Myrth, N., Steele, L., Tait, C., & Hogg, W. (2004). Knowledge translation and indigenous knowledge. *International Journal of Circumpolar Health*, *63 Suppl 2*, 139–143. Retrieved from http://journals.co-action.net/index.php/ijch/article/viewFile/17877/20354

Sparkes, A. C., & Smith, B. (2013). *Qualitative research methods in sport, exercise and health: From process to product.* Routledge.

Tang, S. Y., & Browne, A. J. (2008). "Race" matters: racialization and egalitarian discourses involving Aboriginal people in the Canadian health care context. *Ethnicity & Health*, *13*(2), 109–127. http://doi.org/10.1080/13557850701830307

Tchacos, E., & Vallance, R. (2004). Research in Aboriginal communities : cultural sensitivity as a prerequisite Background to the research study. *Australian Association for Research in Education (AARE)*, (November), 1–10.

The Truth and Reconciliation Commission of Canada. (2015). TRC Final Report. Canada.

Thompson, G. E., Cameron, R. E., & Fuller-Thomson, E. (2013). Walking the Red Road: the Role of First Nations Grandparents in Promoting Cultural Well-Being*. *J. Aging and Human Development*, *76*(1), 55–78. http://doi.org/10.2190/AG.76.1.c

Tobias, J., Richmond, C., & Luginaah, I. (2007). Community Based Participatory Research. *Journal of Empirical Research on Human Research Ethics*, *8*(2), 129–140. http://doi.org/10.1525

Tousignant, M., & Sioui, N. (2009). Resilience and Aboriginal Communities. *Journal of Aboriginal Health*, *5*(1), 43–61. Retrieved from http://www.naho.ca/journal/2009/11/10/resilience-and-aboriginal-communities-in-crisis-theory-and-interventions/

Trudeau, P. (2012). *Wikwemikong Unceded Indian Reserve Comprehensive Community Plan*. Wikwemikong, ON.

Twigg, R. C., & Hengen, T. (2009). Going Back to the Roots : Using the Medicine Wheel in the Healing Process. *First Peoples Child Family Review*, *4*(1), 10–19.

Warry, W. (1990). Doing Unto Others - Applied Anthropology, Collaborative Rsearch and Native Self-determination. *Culture*, *10*(1), 61–73.

Warry, W. (1992). The Eleventh Thesis - Applied Anthropology as Praxis. *Human Organization*, *51*(2), 155–163.

Warry, W. (1998).Unfinished dreams: Community healing and the reality of Aboriginal self-government. Toronto: University of Toronto Press. Wesley-Esquimaux,

Weber-Pillwax, C. (2004). Indigenous researchers and Indigenous research methods: Cultural influences or cultural determinants of research methods. *Pimatsiwin: A Journal of Aboriginal and Indigenous Community Health*, *2*(1 (Spring 2004)), 77–90.

Whitehouse, J., & Bendezu, S. (2000). Intergenerational Community Schools: a New Practice for a New Time. *Educational Gerontology*, *26*, 761–770.

http://doi.org/10.1080/036012700300001412
Whitehouse, P. (2013). The challenges of cognitive aging: Integrating approaches from science to intergenerational relationships. *Journal of Alzheimer's Disease*, *36*(2), 225–232. http://doi.org/10.3233/JAD-130116
Whitehouse, P. J. (2014). The end of Alzheimer's disease - From biochemical pharmacology to ecopsychosociology: A personal perspective. *Biochemical Pharmacology*, *88*(4), 677–681. http://doi.org/10.1016/j.bcp.2013.11.017
Williamson, M., & Harrison, L. (2010). Providing culturally appropriate care : A literature review. *International Journal of Nursing Studies*, *47*(6), 761–769. http://doi.org/10.1016/j.ijnurstu.2009.12.012
Wilson, S. (2001). Self-as-relationship in Indigenous research. *Canadian Journal of Native Education*, *25*(2), 91–92.
Wilson, S. (2001a). What is an indigenous research methodology? *Canadian Journal of Native Education*, *25*(2), 166–174. Retrieved from https://www.researchgate.net/profile/Shawn_Wilson2/publication/234754037_What_Is_an_Indigenous_Research_Methodology/links/0a85e5320f48b8d0a3000000.pdf
Wilson, S. (2001). What is indigenous research ? Canadian Journal of Native Education, 25(2), 166–174. Retrieved from https://www.researchgate.net/profile/Shawn_Wilson2/publication/234754037_What_Is_an_Indigenous_Research_Methodology/links/0a85e5320f48b8d0a3000000.pdf
Wilson, S. (2008). *Research is ceremony: Indigenous research methods*. Black Point, Nova Scotia, Canada: Fernwood Publishing. http://doi.org/10.1111/j.1541-0064.2012.00419.x

Appendix A: Laurentian University REB Ethics Approval

APPROVAL FOR CONDUCTING RESEARCH INVOLVING HUMAN SUBJECTS

Research Ethics Board – Laurentian University

This letter confirms that the research project identified below has successfully passed the ethics review by the Laurentian University Research Ethics Board (REB). Your ethics approval date, other milestone dates, and any special conditions for your project are indicated below.

TYPE OF APPROVAL / New X /	Modifications to project X / Time extension
Name of Principal Investigator and school/department	Ashley Cornect-Benoit, MSc candidate, School of Rural & Northern Health, supervisor, Kristen Jacklin, CRaNHR
Title of Project	Fostering Traditional Roles of First Nation Older Adults to Promote the Quality of Life for Those Experiencing Alzheimer's Disease and Related Dementias
REB file number	2016-06-06
Date of original approval of project	August 7, 2016
Date of approval of project modifications or extension *(if applicable)*	September 16, 2016 (youth component)
Final/Interim report due on: *(You may request an extension)*	September, 2017
Conditions placed on project	Oral consents must be documented.

During the course of your research, no deviations from, or changes to, the protocol, recruitment or consent forms may be initiated without prior written approval from the REB. If you wish to modify your research project, please refer to the Research Ethics website to complete the appropriate REB form.

All projects must submit a report to REB at least once per year. If involvement with human participants continues for longer than one year (e.g. you have not completed the objectives of the study and have not yet terminated contact with the participants, except for feedback of final results to participants), you must request an extension using the appropriate LU REB form. In all cases, please ensure that your research complies with Tri-Council Policy Statement (TCPS). Also please quote your REB file number on all future correspondence with the REB office.

Congratulations and best wishes in conducting your research.

Rosanna Langer, PHD, Chair, *Laurentian University Research Ethics Board*

Appendix B: Manitoulin Anishinaabek Research Review Committee Approval

Ethics Review Recommendations

Title of Project: CCNA Focus Area 1: Fostering Traditional Roles of First Nation Older Adults to Promote the Quality of Life for Those Experiencing Alzheimer's Disease and Related Dementias.
Proposal Version:
Date proposal was received: October 5, 2016
Date reviewed: November 17, 2016.

Please note:
This review is an evaluation of research ethics as presented in the research proposal. It is not a guarantee or an endorsement for the proposed research. The committee respects the autonomy of all communities and individuals to make the final decision regarding their willingness to participate in research projects.

Please check all appropriate comments:

☐ Project meets ethical standards

X Project meets ethical standards with minor changes

☐ Project does not meet ethical standards, major changes required as indicated

1. **Research Overview and Summary (section A and B).**

Question #10: It is recommended that you consider financial compensation for youth with a gift card (ie. Chapters, iTunes) with minimum value of $10.00 to recognize their participation and time.

2. **First Nations Community Involvement in the Project (section C)**

Question #16: Based on our experience, it is felt that the budget item for the feast of $200 may not be sufficient for the estimated number of research participants.

3. **Ownership, Control, Access and Possession (section D)**

No comments.

4. **Aboriginal Knowledge (section E)**

No comments.

5. **Risks and Benefits for Participants and Communities (section F)**

No comments.

6. **Free and Informed Consent (section G)**

No comments.

7. **Privacy and Confidentiality (section H)**

No comments.

8. **Dissemination of results and support for community action (section I)**

No comments.

9. **Is the proposed research respectful of the Seven Grandfather Teachings?**

No comments.

Additional remarks:

The project is approved with suggested minor to changes recommended with respect to considerations for compensation to the youth research participants and the budget allocation for the feast.

Appendix C: Youth Recruitment Advertisement

COMMUNITY PROGRAMS AND SOCIAL INTERACTION

Are you between the ages of **8 to 14 years old**, want your **voice to be heard** and enjoy having **pizza and snacks**?

If so, then this gathering might be for you!
Monday, April 3rd at 3:30 pm (to be confirmed - after school)
Health Centre (Multi Purpose Room)

We are looking for youth who actively participate in activities within the community and are willing to meet twice over the next few weeks.

The project aims to learn the opinions and thoughts of youth on community programs and how a community program could incorporate all generations.

If you are interested in attending please contact Rhonda at Long Term Care (705) 859-3098 or Ashley, the organizer of the gathering at ax_cornectbenoit@laurentian.ca

Appendix D: Letter of Information for Key Informant Interviewees

Letter of Information and Consent for Key Informant Interviewees
Project Title: Canadian Consortium in Neurodegeneration in Aging (CCNA) Team 20
Focus 1 – Fostering Traditional Roles of First Nation Older Adults to Promote the Quality of Life for Those Experiencing Alzheimer's disease and Related Dementia's
Project Funder: Canadian Institute for Health Research

Principal Investigator:
Ashley Cornect-Benoit
Master of Science (candidate)
Interdisciplinary Health
School of Rural and Northern Health
ax_cornectbenoit@laurentian.ca

Supervisor:
Kristen Jacklin, PhD
Associate Professor
Human Sciences
Northern Ontario School of Medicine
kjacklin@nosm.ca
(705) 662-7277 1-800-461-8777 ext 7277

Purpose of the Research

This research will examine culturally appropriate opportunities to respond to the need for meaningful social interactions for older adults. We are interested in looking at ways to better include older adults experiencing signs and symptoms of dementia in community activities and interactions. We want to speak with current programming directors, First Nations youth and older adults. We would like to get a deeper understanding of current programming available for youth and older adults in the Anishinaabek communities on Manitoulin Island. We would also like to obtain the perspectives of First Nation older adults and youth in order to distinguish important factors to fostering community roles and social interactions across the generations. Through the exploration of current programming and perspectives from youth and older adults, we hope a framework will be developed in order to create programs that will foster meaningful and appropriate roles for First Nation older adults and promote social interaction across the generations. The information gathered from these interviews and focus groups will be used to develop a culturally appropriate framework for program implementation that is created by First Nation youth and older adults in the community.

What will happen during the study?

You may be contacted to participate in an interview with the primary investigator. We will ask you to share your thoughts about barriers and facilitators of success for current programming available to the youth and older adults in the community. We will ask how do these programs help to foster appropriate and meaningful roles of First Nations older adults and whether or not the programs available promote social interaction across the generations. Over the course of the project, your involvement in developing the disclosed framework will ensure success in creating a program that engages youth and older adults. Upon the completion of our interview, if you wish to strengthen our developing framework of a culturally appropriate program, you are encouraged to do so by contacting the principal investigator or supervisor. We would like to record the shared information in the interview through audio recording and written transcription (if agreed upon by you, the participant). The results will be used to create a culturally appropriate framework for intergenerational programs, which aims to improve healthy brain aging. The results will be shared throughout the community, Alzheimer's advocacy groups, academics, researchers and our funder.

Potential Harms: Will anything bad happen during the study?
It is not likely that there will be any harms or discomforts associated with you participating in the interview. You do not need to answer ANY question that makes you uncomfortable or that you do not want to answer.

If you feel upset about the discussion, the researcher will help make arrangements for you to access mental health services at Nadmadwin (located in the Wikwemikong Health Centre), or Mnaadmodzawin (programs offered through Aundeck Omni Kaning, Sheguiandah, Wheshegwaning, Whitefish River, and Zhiibaahaasing First Nations). Nadmadwin and Mnaadmodzawin both offer counselling and therapeutic services. For participants from M'Chigeeng First Nation, we can put you in touch with mental health services through M'Nendamowin Health Services.

Potential Benefits: what good will this do?
We hope to learn more about current programs available in the communities for youth and older adults and what barriers/facilitators of success need to be discovered in order to encourage social interactions across the generations. We hope to use the knowledge gathered to improve the quality of life for Aboriginal people with dementia and their caregivers through developing a framework for culturally appropriate programs that foster culturally appropriate roles of older adults and promote meaningful social engagement across the generations.

Incentive:
You will be given a personal note of appreciation as an acknowledgment of my gratitude for the time that you have spent providing me with insight into how current programming is established in the given communities. Your expertise and level of administration will be beneficial to the outcome of the project. Your inclusion in disclosing the final thematic analysis may be beneficial to the current programs you are contributing to.

Acknowledgement
Unless directed otherwise, the research team would like to acknowledge your insights and knowledge on the subject of intergenerational social engagement by citing you directly. If you do not wish for your name to be used, all identifying information will be removed from the transcripts and replaced using a code comprised of alphanumeric combinations, which will only be identifiable, by myself, the primary investigator.

( ) Yes, my name and credentials can be used.
( ) No, please keep my identity confidential.

Disclosure: As per your role within the community as a program director, it will be difficult to keep your involvement in the research anonymous as your guidance will provide concrete support and reasoning for the developed program framework. If you do not wish to participate without anonymity, you will remain included in the developing framework (if desired) through the knowledge dissemination feast we will hold following review of the thematic analysis.

Participation

Your participation in this study is voluntary. It is your choice to be part of the study or not. If you decide to participate, you can decide to stop at any time, even after agreeing to participate or even part-way through the study. If you decide to stop participating, there will be no consequences to you. In cases of withdrawal, any data you have provided to that point will be destroyed unless you indicate otherwise. If you do not want to answer some of the questions you do not have to. If you wish to stop your participations in the study, participants will still receive honorariums.

Information about the Study Results:
Research findings will be communicated back to the community through presentations to the health committee, the annual community Research Days, annual written reports, and community newsletter updates. Findings from individuals, who wish to remain anonymous, will remain anonymous. Individual participants can request a copy of the findings directly from the investigator. All information collected will be kept indefinitely in a locked and password protected electronic device. Myself, the primary investigator will keep the collected data and established framework indefinitely. The established framework will remain within the community indefinitely, unless otherwise directed by the Community Advisory Group and health authorities.

If you have questions or require more information about the study itself, please contact the community researcher Karen Pitawanakwat at (705) 859-3098, or by email at kpitawanakwat@wikyhealth.ca. Alternatively, you may contact the research associate at the Centre for Rural and Northern Health Research Centre, Melissa Blind at (705) 675-4883 ext. 7189, or by email at mblind@laurentian.ca; the Principal Investigator from the School of Rural and Northern Health at Laurentian University, Ashley Cornect-Benoit by email at ax_cornectbenoit@laurentian.ca; or the project supervisor from the Northern Ontario School of Medicine, Dr. Kristen Jacklin at (705) 662-7277 (1800-461-8777 ext. 7277), or by email at kjacklin@nosm.ca. You can also call the CRaNHR office toll free at 1-800-461-4030

This research has been reviewed and approved by Laurentian University Research Ethics Board **(LUREB File No. 2016-06-06)** and the Manitoulin Anishinabek Research Review Committee (MARRC). If you have concerns or questions about your rights as a participant or about the way the study is conducted, you may contact:
Research Ethics Officer, Laurentian University Research Office
Telephone: 705-675-1151 ext 2436 or toll free at 1-800-461-4030
Email: ethics@laurentian.ca.

Consent Form

I have read the information presented in the information letter about a study being conducted by Ashley Cornect-Benoit under the supervision of Dr. Kristen Jacklin and her research team. I have had the opportunity to ask questions about my involvement in this study, and to receive any additional details I wanted to know about the study. I understand that I may withdraw from the study at any time, if I choose to not do so, then I agree to participate in this study. I give my permission to use the audio recording in order to collect information. I have been given a copy of this form.

____

Name of Participant Signature Date

Audio recording

I consent to having my interview (please check)

( ) audio recorded

( ) no recording, hand written notes

For participants who choose to give oral consent and not written consent:

In my opinion, the individual ______________________________ is agreeing to participate in this study voluntarily, and understands the nature of the study and the consequences of participation in it.

____

Signature of Researcher Date Location

Appendix E: Letter of Information for Older Adult Focus Group

Letter of information for participants taking part in **Sequential Focus Groups – Older Adults**
Project Title: Canadian Consortium in Neurodegeneration in Aging (CCNA) Team 20
Focus 1 – Fostering Traditional Roles of First Nation Older Adults to Promote the Quality of Life for Those Experiencing Alzheimer's disease and Related Dementia's
Project Funder: Canadian Institute for Health Research

Principal Investigator:
Ashley Cornect-Benoit
Master of Science (candidate)
Interdisciplinary Health
School of Rural and Northern Health
ax_cornectbenoit@laurentian.ca

Supervisor:
Kristen Jacklin, PhD
Associate Professor
Human Sciences
Northern Ontario School of Medicine
kjacklin@nosm.ca
(705) 662-7277 1-800-461-8777 ext 7277

Purpose of the Research

This research will examine culturally appropriate opportunities to respond to the need for meaningful social interactions for older adults experiencing signs and symptoms of dementia. We want to speak with current programming directors, First Nations youth and older adults. We would like to get a deeper understanding of current programming available for youth and older adults in the Anishinaabek communities on Manitoulin Island. We would also like to obtain the perspectives of First Nation older adults and youth in order to distinguish important factors to fostering traditional roles and social interactions across the generations. Through the exploration of current programming and perspectives from youth and older adults, we hope a framework will be developed in order to create programs that will foster traditional roles of First Nation older adults and promote social interaction across the generations. The information gathered from these interviews and focus groups will be used to develop a culturally appropriate framework for program implementation that is created by First Nation youth and older adults in the community.

What will happen during the study?

You may be contacted by a local research assistant to participate in a sequential focus group, where you and the same group of older adults will come together multiple times (maximum of three) to share your thoughts and experiences on a specific discussion topic: Traditional Roles and Social Engagement Across the Generations. We will discuss certain aspects related to Anishinaabe traditional roles – through different cultural activities, traditional teachings about the language, sacred ceremonies and medicines. We will ask if you foresee or have experienced any difficulties engaging in some of these cultural/traditional activities with youth, what are the benefits and challenges associated with taking part in these activities in present day, and what would make an intergenerational program successful in the community. Over the course of the project we will keep in contact with you to ask follow up questions or get your feedback on any new developments or ideas that you may have. We would like to record the information shared in the sequential focus group through audio recording, which will then be transcribed verbatim. Upon the completion of our focus groups, both the youth and older adult focus groups will meet together as one group to give any further ideas or clarification about the themes that have developed from the focus groups. The results will be used to create a culturally appropriate framework that addresses the need for meaningful social interactions across the generations. Any

completed reports and publications to be shared widely with Indigenous communities and organizations, Alzheimer's advocacy groups, academics, researchers and our funder.

Participation:
It is not likely that there will be any harms or discomforts associated with you participating in the focus groups. You do not need to answer ANY question that may make you feel uncomfortable or that you do not want to answer. Your participation in this study is voluntary. It is your choice to be part of the study or not. If you decide to participate, you can decide to stop at any time, even after agreeing to participate or even part-way through the study. If you decide to stop participating, there will be no consequences to you and all participants will still receive their honorarium and personal letter of appreciation.

Everything that is discussed in the sequential focus groups will be kept confidential by the researchers; however, this is an open discussion with other participants. It is expected that all participants will respect each other and not share personal information disclosed in the circle (this will be explained at the start of the discussion). Please keep in mind that the research team cannot guarantee that everything discussed will be kept confidential by the participants involved.

Consent must be given in order to participate in the discussions. Consent can be written or given orally. After the first consent is given to agree to participation, a second consent will be required that asks for permission to audio record the conversation. Recording the conversation helps the primary investigator to acquire every detail that was brought up during the discussion. Since this is a group discussion, consent to audio-record must be unanimous. If one person does not wish to be recorded, then no recording will taking place. The primary investigator will need to take short notes during the conversation. Please see the attached consent form following this information guide.

Potential Harms: Will anything bad happen during the study?
It is not likely that there will be any harms or discomforts associated with you participating in the interview. You do not need to answer ANY question that makes you uncomfortable or that you do not want to answer. We understand that you may feel shy, scared or nervous when you first come to the group. We want you to know that this is going to be a safe environment where you are able to be yourself.

If you do feel upset about the discussion or any of the questions asked/comments made, I, the researcher, will help make arrangements for you to access mental health services at Nadmadwin (located in the Wikwemikong Health Centre), or Mnaadmodzawin (programs offered through Aundeck Omni Kaning, Sheguiandah, Wheshegwaning, Whitefish River, and Zhiibaahaasing First Nations). Nadmadwin and Mnaadmodzawin both offer counselling and therapeutic services. For participants from M'Chigeeng First Nation, we can put you in touch with mental health services through M'Nendamowin Health Services. I can also arrange for you to meet with the program coordinator of the specific community centre that you go to.

Potential Benefits: what good will this do?
We hope to learn more about current programs available in the communities for youth and older adults and what barriers/facilitators of success need to be discovered in order to encourage social

interactions across the generations. We hope to use the knowledge gathered to improve the quality of life for Aboriginal people with dementia and their caregivers through developing a framework for culturally appropriate programs that foster traditional roles of older adults and promote meaningful social engagement across the generations.

Payment or Reimbursement:
Participants in group discussions will be provided a meal and refreshments. Participants will also receive an honorarium of $50.00 as well as personal note of appreciation as an acknowledgment of my gratitude for the time that participants have spent with me.

Confidentiality:
All names will be removed from transcripts and replaced with a alphanumeric code that will only be distinguishable by the primary investigator. The information obtained from the focus groups will be transcribed from audio recordings, if participants give consent. We will use direct quotes but will not attribute them to participants directly. Please keep in mind that the research team cannot guarantee that everything discussed will be kept confidential by the participants involved, as we are meeting in a group setting.

The information obtained will be stored in a secure work space at the Northern Ontario School of Medicine and will only be accessible to the primary investigator. Electronic data will be stored on a secure personal electronic device that is locked on a regular basis.

Requests to keep data locally (at participating Manitoulin First Nations Health Centres) will be accommodated but any identifying information (such as your name) will first be removed from the files. Electronic files stored locally will also be password protected and any paper-based files will be kept in a locked cabinet.

Disclosure:
Information obtained will be kept confidential to the full extent of the law and we will treat all information provided to us as subject to researcher-participant privilege. Unless otherwise specified by the community advisory council, myself and Dr. Jacklin, who is supervising the project, will store the data permanently.

Information about the Study Results:
Research findings will be communicated back to the community through presentations to the health committee, the annual community Research Days, annual written reports, and community newsletter updates. Findings from individuals, who wish to remain anonymous, will remain anonymous. Individual participants can request a copy of the findings directly from the investigators. All information collected will be kept indefinitely in a locked and password protected electronic device. Myself, the primary investigator, will keep the collected data and established framework indefinitely. The established framework will remain within the community indefinitely, unless otherwise directed by the Community Advisory Group and health authorities.

If you have questions or require more information about the study itself, please contact the community researcher Karen Pitawanakwat at (705) 859-3098, or by email at

kpitawanakwat@wikyhealth.ca. Alternatively, you may contact the research associate at the Centre for Rural and Northern Health Research Centre, Melissa Blind at (705) 675-4883 ext. 7189, or by email at mblind@laurentian.ca; the Principal Investigator from the School of Rural and Northern Health at Laurentian University, Ashley Cornect-Benoit by email at ax_cornectbenoit@laurentian.ca; or the project supervisor from the Northern Ontario School of Medicine, Dr. Kristen Jacklin at (705) 662-7277 (1800-461-8777 ext 7277), or by email at kjacklin@nosm.ca. You can also call the CRaNHR office toll free at 1-800-461-4030

This research has been reviewed and approved by Laurentian University Research Ethics Board **(File No. 2016-06-06)** and the Manitoulin Anishinabek Research Review Committee (MARRC). If you have concerns or questions about your rights as a participant or about the way the study is conducted, you may contact:

Research Ethics Officer, Laurentian University Research Office
Telephone: 705-675-1151 ext 2436 or toll free at 1-800-461-4030
Email: ethics@laurentian.ca.

Consent Form

I have read the information presented in the information letter about a study being conducted by Ashley Cornect-Benoit under the supervision of Dr. Kristen Jacklin and her research team. I have had the opportunity to ask questions about my involvement in this study, and to receive any additional details I wanted to know about the study. I understand that I may withdraw from the study at any time, if I choose to not do so, then I agree to participate in this study. I give my permission to use the audio recording in order to collect information. I have been given a copy of this form.

____

Name of Participant Signature Date

Consent to record the conversation:

I ____ agree to have the discussion audio-recorded.

____

Signature Date

For participants who choose to give oral consent and not written consent:

In my opinion, the individual ______________________________is agreeing to participate in this study voluntarily, and understands the nature of the study and the consequences of participation in it.

____

Signature of Researcher Date Location

Appendix F: Letter of Information for Youth Over 12 Years of Age

Letter of information for participants taking part in **Sequential Focus Groups – Youth**
Project Title: Canadian Consortium in Neurodegeneration in Aging (CCNA) Team 20
Focus 1 – Fostering Traditional Roles of First Nation Older Adults to Promote the Quality of Life for Those Experiencing Alzheimer's disease and Related Dementia's
Project Funder: Canadian Institute for Health Research

Principal Investigator:
Ashley Cornect-Benoit
Master of Science (candidate)
Interdisciplinary Health
School of Rural and Northern Health
ax_cornectbenoit@laurentian.ca

Supervisor:
Kristen Jacklin, PhD
Associate Professor
Human Sciences
Northern Ontario School of Medicine
kjacklin@nosm.ca
(705) 662-7277 1-800-461-8777 ext 7277

Purpose of the Research
This project will look for opportunities to respond to the need for meaningful social interactions for older adults experiencing unhealthy brain aging. We want to speak with both First Nations youth and older adults. We would like to get a deeper understanding of what programs are currently available in the communities. We would like to obtain perspectives and ideas from First Nation older adults and youth in order to determine important factors to fostering communal roles of older adults and social interactions between the generations. By getting the perspectives of youth and older adults, we hope a framework will be created to develop programs that will foster roles of First Nation older adults and promote social interaction between the generations. The information gathered from these focus groups will be used to develop a culturally appropriate framework for program implementation that is created by First Nation youth and older adults in the community.

What will happen during the study?
You may be contacted by a local research assistant or a current youth program director to participate in a focus group, where you and the same group of youth will come together multiple times (maximum of three) to share your thoughts and experiences on a specific discussion topic: Traditional Roles and Social Engagement Across the Generations. We will discuss certain aspects related to Anishinaabe traditional roles – through different cultural activities, traditional teachings about the language, sacred ceremonies and medicines. We will ask you to describe your social interactions with older adults and whether you have or have not experienced any difficulties engaging in these social interactions. We will also inquire about what are some of the benefits and challenges experienced when socially engaging with older adults or participating in these cultural activities and what would make an intergenerational program successful in the community. Over the duration of the project we will keep in contact with you to ask follow up questions or get your feedback on any new ideas that you may have. We would like to record the information shared in the focus group through audio recording, which will then be transcribed. Upon the completion of our focus groups, both the youth and older adult focus groups will meet in a combined group setting to give any further ideas or clarification about the themes that have developed from the focus groups. The results will be used to create a culturally appropriate framework that addresses the need for meaningful social interactions across the generations. Any

and all information collected can and will be shared widely with Indigenous communities and organizations, Alzheimer's advocacy groups, academics, researchers and our funder.

Participation:
It is not likely that there will be any harms or discomforts associated with you participating in the focus groups. You do not need to answer ANY questions that may make you feel uncomfortable or that you do not want to answer. Your participation in this study is voluntary. We want you to know that taking part in the group is your decision and no one is forcing you to be involved. Taking part in this group or deciding not to take part in this group, will have no influence on the supports you're receiving from local youth programs. We only want youth in the program who really want to be involved. If you decide to participate, you can decide to stop at any time, even after agreeing to participate or even part-way through the study. If you decide to stop participating, there will be no penalties to you and all participants will still receive a meal and a thank you letter from myself.

Everything that is discussed in the focus groups will be kept confidential by myself, Kristen and any other members of our research team; however, this is an open discussion with other youth, your peers. It is expected that all participants will respect each other and not share personal information talked about in the circle (this will be explained at the start of the discussion). Please keep in mind that the research team cannot promise that everything discussed will be kept confidential by the participants involved.

Consent must be given in order to share in the discussions. Consent can be written or given orally. After the first consent is given to agree to participation, a second consent will be required that asks for permission to audio record your contribution to the circle. Recording the conversation helps the primary investigator, myself, to get every detail that was brought up during the discussion. Since this is a group discussion, consent to audio-record must be agreed upon by all youth. If one person does not wish to be recorded, then no recording will taking place. The primary investigator will need to take short notes during the conversation. Please see the attached consent form following this information guide.

Potential Harms: Will anything bad happen during the study?
During the discussions, we do not expect that you will feel harmed or have anything bad happen to you during your participation. You do not need to answer ANY question that makes you uncomfortable or that you do not want to answer. We understand that you may feel shy, scared or nervous when you first come to the group. We want you to know that this is going to be a safe environment where you are able to be yourself.

If you do feel upset about the discussion or any of the questions asked/comments made, I, the researcher, will help make arrangements for you to access mental health services at Nadmadwin (located in the Wikwemikong Health Centre), or Mnaadmodzawin (programs offered through Aundeck Omni Kaning, Sheguiandah, Wheshegwaning, Whitefish River, and Zhiibaahaasing First Nations). Nadmadwin and Mnaadmodzawin both offer counselling and therapeutic services. For participants from M'Chigeeng First Nation, we can put you in touch with mental health services through M'Nendamowin Health Services. I can also arrange for you to meet with the program coordinator of the specific youth centre that you go to.

Potential Benefits: what good will this do?
We hope to learn more about current programs available in the communities for youth and what obstacles/areas of success need to be talked about in order to encourage social interactions across the generations. We hope to use the knowledge gathered to improve the quality of life for Aboriginal people with dementia and their caregivers through developing a framework for culturally appropriate programs that foster traditional roles of older adults by providing suitable ways for meaning social interactions with youth within the community.

Payment or Reimbursement:
During your participation in the focus groups, you will receive refreshments, snacks, and pizza. I will provide all participants with a personal note of thanks for their help, ideas and thoughts during the focus groups.

Confidentiality:
All names will be removed from transcripts and replaced with a code that will only be distinguishable by the primary investigator. The information obtained from the focus groups will be transcribed from audio recordings, if participants give consent. Please keep in mind that the research team cannot guarantee that everything discussed amongst the participants will be kept confidential, as we are meeting in a group setting. If for any reason, the team believes you may pose a harm to yourself or others, they will have to disclose to relevant services within the community.

The information obtained will be stored in my secure desk at the Northern Ontario School of Medicine and will only be accessible to the primary investigator. Electronic data will be stored on a secure personal electronic device that is locked on a regular basis. Any paper-based files will be kept in a locked cabinet.

Disclosure:
Information will be kept confidential to the full extent of the law and we will treat all information provided to us as a privilege and gift from participants that must be valued. Unless otherwise specified by the community advisory council, myself and Dr. Jacklin, who is supervising the project, will store the data permanently within a locked, personal office.

Information about the Study Results:
Research findings will be given back to the community through presentations to the health committee, the annual community Research Days, annual written reports, and community newsletter updates. Findings from individuals, who wish to remain anonymous, will remain anonymous. You are also able to request a copy of the findings directly from myself and I will ensure that you receive these documents. All information collected will be kept in a locked and password protected electronic device. Myself, the primary investigator will keep the collected data and established framework forever, unless requested by participants or local health authorities to do otherwise. The established framework will remain within the community indefinitely, unless otherwise directed by the Community Advisory Group and health authorities.

If you have questions or require more information about the study itself, please contact the community researcher Karen Pitawanakwat at (705) 859-3098, or by email at kpitawanakwat@wikyhealth.ca. Alternatively, you may contact the research associate at the Centre for Rural and Northern Health Research Centre, Melissa Blind at (705) 675-4883 ext. 7189, or by email at mblind@laurentian.ca; the Principal Investigator from the School of Rural and Northern Health at Laurentian University, Ashley Cornect-Benoit by email at ax_cornectbenoit@laurentian.ca; or the project supervisor from the Northern Ontario School of Medicine, Dr. Kristen Jacklin at (705) 662-7277 (1800-461-8777 ext 7277), or by email at kjacklin@nosm.ca. You can also call the CRaNHR office toll free at 1-800-461-4030

This research has been reviewed and approved by Laurentian University Research Ethics Board **(File No. 2016-06-06)** and the Manitoulin Anishinabek Research Review Committee (MARRC). If you have concerns or questions about your rights as a participant or about the way the study is conducted, you may contact:

Research Ethics Officer, Laurentian University Research Office
Telephone: 705-675-1151 ext 2436 or toll free at 1-800-461-4030
Email: ethics@laurentian.ca.

Consent Form

I have read letter about a study being conducted by Ashley Cornect-Benoit under the supervision of Dr. Kristen Jacklin and her research team. I have had the opportunity to ask questions about my involvement in this study, and to receive any additional details I wanted to know about the study. I understand that I can withdraw from the study at any time, if I choose to not do this, then I agree to participate in this study. I give my permission to use the audio recording in order to collect information. I have been given a copy of this form.

By signing this form, you agree to take part in our program and you're letting us know that you understand everything on this form. You will get a copy of this form that you can keep. Your parent(s) will also be asked to sign this form so that you can take part in the program.

____

Name of Participant Signature Date

____

Name of Parent Signature Date

Consent to record the conversation:

I ____ agree to have the discussion audio-recorded.

____

Signature Date

For participants who choose to give oral consent and not written consent or are unable to obtain parental consent:

In my opinion, the individual _____________________________ is agreeing to participate in this studyvoluntarily, and understands the nature of the study and the consequences of participation in it.

____

Signature of Community Representative Date

Location

Appendix G: Letter of Information for Youth Under 12

Letter of information for parents of youth 12 and younger taking part in **Sequential Focus Groups**
Project Title: Canadian Consortium in Neurodegeneration in Aging (CCNA) Team 20
Focus 1 – Fostering Traditional Roles of First Nation Older Adults to Promote the Quality of Life for Those Experiencing Alzheimer's disease and Related Dementia's
Project Funder: Canadian Institute for Health Research

Principal Investigator:
Ashley Cornect-Benoit
Master of Science (candidate)
Interdisciplinary Health
School of Rural and Northern Health
ax_cornectbenoit@laurentian.ca

Supervisor:
Kristen Jacklin, PhD
Associate Professor
Human Sciences
Northern Ontario School of Medicine
kjacklin@nosm.ca
(705) 662-7277 1-800-461-8777 ext 7277

Purpose of the Research
This project will look for opportunities to respond to the need for meaningful social interactions for older adults experiencing unhealthy brain aging. We want to speak with both First Nations youth and older adults. We would like to get a deeper understanding of what programs are currently available in the communities. We would like to obtain perspectives and ideas from First Nation older adults and youth in order to determine important factors to fostering communal roles of older adults and social interactions between the generations. By getting the perspectives of youth and older adults, we hope a framework will be created to develop programs that will foster roles of First Nation older adults and promote social interaction between the generations. The information gathered from these focus groups will be used to develop a culturally appropriate framework for program implementation that is created by First Nation youth and older adults in the community.

What will happen during the study?
Your child may be contacted by a local research assistant or a current youth program director to participate in a focus group, where your child and the same age group of youth will come together multiple times (maximum of three) to share their thoughts and experiences on a specific discussion topic: Traditional Roles and Social Engagement Across the Generations. We will discuss certain aspects related to Anishinaabe traditional roles – through different cultural activities, traditional teachings about the language, sacred ceremonies and medicines. We will ask your child to describe their social interactions with older adults and whether they have or have not experienced any difficulties engaging in these social interactions. We will also inquire about what are some of the benefits and challenges experienced when socially engaging with older adults or participating in these cultural activities and what would make an intergenerational program successful in the community. Over the duration of the project we will keep in contact with your child to ask follow up questions or get feedback on any new ideas that they might have. We would like to record the information shared in the focus group through audio recording which will then be transcribed. Upon the completion of our focus groups, both the youth and older adult focus groups will meet together to give any further ideas or clarification about the themes that have developed from the focus groups. The results will be used to create a culturally

appropriate framework that addresses the need for meaningful social interactions across the generations. Any and all information collected can and will be shared widely with Indigenous communities and organizations, Alzheimer's advocacy groups, academics, researchers and our funder.

Participation:
It is not likely that there will be any harm or discomfort associated with your child's participation in the focus groups. Your child will not need to answer ANY questions that may make him or her feel uncomfortable or that they do not wish to answer. Your child's participation in this study is voluntary. We want you to know that taking part in the group is your child's decision and no one is forcing your child to be involved. Taking part in this group or deciding not to take part in this group, will have no influence on the supports your child receives from local youth programs. We only want youth in the program who really want to be involved. If your child decides that they wish to participate, they can decide to stop at any time, even part-way through the study. If your child decides to stop participating, there will be no penalties to your child and all participants will still receive their meal and thank you letter.

Myself, Kristen and any other members of our research team will keep everything that is discussed in the focus groups confidential; however, this is an open discussion with other youth. It is expected that all participants will respect each other and not share personal information disclosed in the circle (this will be explained at the start of the discussion). Please keep in mind that the research team cannot guarantee that everything discussed will be kept confidential by the participants involved.

Consent must be given in order to share in the discussions. Consent can be written or given orally. After the first consent is given to agree to participation, a second consent will be required that asks for permission to audio record your contribution to the circle. Recording the conversation helps the primary investigator, myself, to get every detail that was brought up during the discussion. Since this is a group discussion, consent to audio-record must be agreed upon by all youth. If one person does not wish to be recorded, then no recording will taking place. The primary investigator will need to take short notes during the conversation. Please see the attached consent form following this information guide.

Potential Harms: Will anything bad happen during the study?
During the discussions, we do not expect that your child will feel harmed or have anything bad happen to your child during their participation. Your child does not need to answer ANY question that may make them feel uncomfortable or that they do not want to answer. We understand that your child may feel shy, scared or nervous when they first come to the group. We want you to know that this is going to be a safe environment where your child will able to be their self.
If your child does feel upset about the discussion or any of the questions asked/comments made, I, the researcher, will help make arrangements for your child to access mental health services at Nadmadwin (located in the Wikwemikong Health Centre), or Mnaadmodzawin (programs offered through Aundeck Omni Kaning, Sheguiandah, Wheshegwaning, Whitefish River, and Zhiibaahaasing First Nations). Nadmadwin and Mnaadmodzawin both offer counselling and therapeutic services. For participants from M'Chigeeng First Nation, we can put you in touch

with mental health services through M'Nendamowin Health Services. I can also arrange for your child to meet with the program coordinator of the specific youth centre that they go to.

Potential Benefits: what good will this do?
We hope to learn more about current programs available in the communities for youth and what obstacles/facilitators of success need to be talked about in order to encourage social interactions across the generations. We hope to use the knowledge gathered to improve the quality of life for Aboriginal people with dementia and their caregivers through developing a framework for culturally appropriate programs that foster traditional roles of older adults by providing suitable ways for meaning social interactions with youth within the community.

Payment or Reimbursement:
During your child's participation in the focus groups, they will receive refreshments, snacks, and pizza. I will provide all participants with a personal note of thanks for their help, ideas and thoughts during the focus groups.

Confidentiality:
All names will be removed from transcripts and replaced with a code that will only be distinguishable by the primary investigator. The information obtained from the focus groups will be transcribed from audio recordings, if participants give consent. Please keep in mind that the research team cannot guarantee that everything discussed amongst the participants will be kept confidential, as we are meeting in a group setting. If for any reason, the team believes you may pose a harm to yourself or others, they will have to disclose to relevant services within the community.

The information obtained will be stored in my secure desk at the Northern Ontario School of Medicine and will only be accessible to the primary investigator. Electronic data will be stored on a secure personal electronic device that is locked on a regular basis. Any paper-based files will be kept in a locked cabinet.

Disclosure:
Information will be kept confidential to the full extent of the law and we will treat all information provided to us as a privilege and gift from participants that must be valued. Unless otherwise specified by the community advisory council, myself and Dr. Jacklin, who is supervising the project, will store the data permanently

Information about the Study Results:
Research findings will be given back to the community through presentations to the health committee, the annual community Research Days, annual written reports, and community newsletter updates. Findings from individuals, who wish to remain anonymous, will remain anonymous. You and your child are also able to request a copy of the findings directly from myself and I will ensure that you receive these documents. All information collected will be kept in a locked and password protected electronic device. Myself, the primary investigator will keep the collected data and established framework forever, unless requested by participants or local

health authorities to do otherwise. The established framework will remain within the community indefinitely, unless otherwise directed by the Community Advisory Group and health authorities.

If you have questions or require more information about the study itself, please contact the community researcher Karen Pitawanakwat at (705) 859-3098, or by email at kpitawanakwat@wikyhealth.ca. Alternatively, you may contact the research associate at the Centre for Rural and Northern Health Research Centre, Melissa Blind at (705) 675-4883 ext. 7189, or by email at mblind@laurentian.ca; the Principal Investigator from the School of Rural and Northern Health at Laurentian University, Ashley Cornect-Benoit by email at ax_cornectbenoit@laurentian.ca; or the project supervisor from the Northern Ontario School of Medicine, Dr. Kristen Jacklin at (705) 662-7277 (1800-461-8777 ext 7277), or by email at kjacklin@nosm.ca. You can also call the CRaNHR office toll free at 1-800-461-4030

This research has been reviewed and approved by Laurentian University Research Ethics Board **(File No. 2016-06-06)** and the MARRC. If you have concerns or questions about your rights as a participant or about the way the study is conducted, you may contact:

Research Ethics Officer, Laurentian University Research Office
Telephone: 705-675-1151 ext 2436 or toll free at 1-800-461-4030
Email: ethics@laurentian.ca.

Consent Form

I have read letter about a study being conducted by Ashley Cornect-Benoit under the supervision of Dr. Kristen Jacklin and her research team. I have had the opportunity to ask questions about my child's/children's involvement in this study, and to receive any additional details I wanted to know about the study and my child's involvement. I understand that my child can withdraw from the study at any time, if my child does not do this, then we agree that my child will participate in this study. I give my permission to use the audio recording in order to collect information. I have been given a copy of this form.

By signing this form, my child and I agree to take part in the program and I am letting you know that I understand everything on this form. You will get a copy of this form that you can keep.

____

Name of Participant (12 and younger) Signature Date

____

Name of Parent Signature Date

Consent to record the conversation:

I ______________________________ agree to have the discussion my child is participating in audio-recorded.

____

Signature of Parent Date

For participants who choose to give oral consent and not written consent or are unable to obtain parental consent:

In my opinion, the individual ___________________ is agreeing to participate in this study voluntarily, and understands the nature of the study and the consequences of participation in it.

____

Signature of Community Representative Date Location

Appendix H: Key Informant Interview Conversation Guide

One-On-One Key Informant Interview Conversation Guide

We will begin with an informal meeting, which will include a personal introduction of the interviewee and then myself. Following the introduction, I will inform the interviewee my purpose of why I am asking to interview them (i.e., involvement with the CCNA, completion of my master's, my hope to attend medical school and provide culturally appropriate health care to Indigenous communities, traditional approaches to health care, etc.). The interview will take place at a location specified by the interviewee, ensuring that they are as comfortable as possible.

I would like you, the interviewee, to share you thoughts about barriers and facilitators of success for current programming available to youth and older adults in the community.

- How do the available programs in the community help to foster communal roles of First Nation older adults and promote communication across the generations?
- Do these programs promote social interaction across the generations?
- If the programs do not promote social interaction across the generations, what do you think needs to be addressed in order to ensure that meaningful social interactions occur for older adults/youth and encourage social interaction?
- If the programs do not foster communal roles of older adults, what do you believe needs to be different/changed in program implementation? Would it be possible for current programs to be adapted or changed in order to promote intergenerational connections?
- If the programs do promote social interaction across the generations, how do these programs foster social interaction amongst the generations? What are key components of these programs that make social interaction across the generations possible/attainable?
- What are some ways to include older adults experiencing signs and symptoms of dementia in community activities and intergenerational interactions?
- What would an 'intergenerational' program look like to you/in your community in order to foster communal roles of older adults? In your opinion, how would sustainability of these programs be possible in the community?
- How would you make this ideal program, in your opinion, successful while promoting healthy brain aging for older adult experiencing cognitive decline.
- How can we ensure that a program is inclusive to older adults with memory problems or illnesses that might pose challenges to their participation?

Appendix I: Ice Breaking Activities for Focus Groups

ICE BREAKING ACTIVITY FOR YOUTH AND OLDER ADULTS (INDIVIDUAL GATHERING)

Whose Story Is It?

This icebreaker game lets you hear some fun, fascinating, and surprising stories.

1) Pass out paper and pens and have everyone take a few minutes to write a personal experience, the stranger the better.
2) Fold the papers and put them into a bag, basket, or box.
3) Have each person select a piece of paper from the hat, it can not be their own or they must throw it back into the hat
4) Each member of the group reads out the information that is on the paper

The group has to guess who the story belongs to

People Bingo:

Each participant will be given a grid with information written in each square. Participants must locate other individuals in the room who have completed, know the answer to or can assist with the information in the square. If the participant can help then he/she will sign the individuals block with their initials.

For example, a block will say "Know the Four Sacred Medicines." The participant must find someone in the room who knows the Four Sacred Medicines, tell them the medicines and then they can obtain their signature.

People Bingo

Is a pow-wow dancer	Likes Indian Tacos	Can list the 4 sacred medicines	Likes moose meat
Knows the Ojibway word for "water" (must say it)	Has a spirit name (ask them to share)	Owns a pair of moccasins	Has a Dreamcatcher
Has a smudge bowl	Lived on the Rez	Knows the meaning of Shkagamik-Kwe (must say)	Has set up a Tipi
Can name a pow-wow drum group	Has travelled to a pow-wow outside of Canada	Likes Corn Soup	Participated in a sweat lodge

Appendix J: Older Adult Focus Group Conversation Guide

Older Adult Focus Group Conversation Guide

We will begin with an informal ice-breaking activity that is suitable for older adults. Following the ice-breaking activity, I will begin with an introduction of who I am and where I come from and give an explanation about why I am conducting the focus groups and where I hope to go following the completion of my thesis. I will encourage all participants to give an introduction about them including their name, where they come from and any further information that they wish to share with the group. Refreshments and snacks that are suitable to the age group will accompany the focus group.

I would like you, the participants in this circle, to share your thoughts and opinions on what the following comments, topics and questions mean to you.

Day 1

- How would you describe the role of older people like yourselves in the community? What about your role with young people? (probes, leadership, teaching, caring)
- Do you foresee or have you experienced any difficulties engaging in some of the roles you spoke of? How about the ones you mentioned with youth in the community?
- Do you think these roles have changed over time? Are there any previous roles that older people may have held that you think would be beneficial to bring back and support?

Day 2

Last time we met we talked about the roles of older people in the community and talked a lot about this in relation to the youth. Here is a summary of what I heard… Have I missed anything? Does this accurately represent the discussion?

Today we are going to talk more on this topic but mainly around roles and interactions with youth. In the end I am hoping we can spend some time talking about how we use what you've told me to think about community programs that could support you in your role with the youth.

- What are some of the benefits associated with taking part in the roles you've described with the youth? And what are the challenges?
- What importance does social engagement with youth have in your life?
- If we were to create a program that brought youth and older community members together what kinds of activities would you like to see included? How might these change with the seasons? How might they change with different youth or older adult age groups (the very young or the very old)? How can we ensure that a program is inclusive to older adults with memory problems or illnesses that might pose challenges to their participation?
- What would this program mean to you? What would make the program meaningful?

Appendix K: Youth Focus Group Conversation Guide

Youth Focus Group Conversation Guide

We will begin with an informal ice-breaking activity that is suitable for youth. Following the ice-breaking activity, I will begin with an introduction of who I am and where I come from and give an explanation about why I am conducting the focus groups and where I hope to go following the completion of my work. I will encourage all participants to give an introduction about them including their name, where they come from and any further information that they wish to share with the group. Refreshments and snacks that are suitable to the age group will accompany the focus group.

I would like you, the participants in this circle, to share your thoughts and opinions on what the following comments, topics and questions mean to you.

Day 1

- How would you describe the role of older people in the community? How would you describe the role you have as youth in the community?
- Describe what your social interactions are like with older adults whether it be your family members, neighbours, teachers, elders etc.
- Do you find these relationships meaningful? Why or why not? What makes the relationship meaningful to you?
- What are some of the benefits that you have experienced when you speak or socialize with older adults? What are some of the challenges in spending time with or communicating with older adults?
- Do you think it would be a good idea to have a program that both youth and older adults participate in? Why or why not?

Day 2

Last time we met we talked about the roles of older people and yourself as youth in the community. Here is a summary of what I heard… Have I missed anything? Does this represent the discussion that we had?

Today we are going to talk more on this topic but mainly around roles and interactions between the generations. In the end I am hoping we can spend some time talking about how we use what you've told me to think about community programs that could support older adults in the community and provide you, the youth, with opportunities to learn the roles that older adults play in the community which one day you may adhere to.

- What are some benefits to interacting with older adults on a regular basis? What are some problems or challenges that you think may occur?
- What importance does interacting with older adults have in your life?
- If we were to create a program that brought youth and older community members together what kinds of activities would you like to see included? How might these change with the seasons? How might they change with different youth or older adult age groups (the very young or the very old)?
- What would this program mean to you? What would make the program meaningful?