Decolonizing Autism:
An Exploration into the Experiences of First Nations People in Canada

by

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Abstract

In Canada, there is a significant lack of research on the lived experience of autism within First Nations communities. Canada's Human Rights Tribunal found that the Government of Canada was discriminating against First Nations children based on race and national ethnic origin. Systemic barriers exist for First Nations families in receiving adequate services on reserves, including discriminatory policies at the federal and provincial levels. Autism occurs in all populations, including Indigenous populations, but there are minimal supports and services for First Nations families and communities. This research aimed to meaningfully engage with First Nations families and those with the lived experience of autism to better understand their complex realities.

This community-led study was done in partnership with the First Nation communities of Maskwacîs and the Six Nations of the Grand River. The nêhiyaw concept of wâhkôtowin was woven throughout the entire research process. The Sweetgrass analysis method was used for data analysis in the research. A scoping review revealed a dearth of high-quality research on autism among Indigenous people in Canada. The Elders' Study and Caregivers' Study provided insights into autism from a nêhiyaw perspective. Caregivers shared the challenges and opportunities of raising Autistic children, emphasizing the significance of cultural aspects and community support.

The research aimed to address the lack of attention and research on autism within Indigenous populations in Canada through Indigenous-led research methods. Knowledge mobilization efforts included establishing support groups, creating documentaries, and aligning findings with global perspectives on Indigenous autism. Overall, this research obtained its objective and sheds light on the realities of autism in two First Nations communities.

Preface

This thesis is an original work by Grant Bruno. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, Project Name "Experiences of Autism in a First Nations Community", Pro00114136, 2023-07-11.

Chapter 3 has been published "Indigenous Autism in Canada: A Scoping Review" in the Journal or Autism and Developmental Disorders (JADD) (Bruno et al., 2023). I developed the idea, performed literature search and screening, wrote synthesis of results and overall manuscript. T. Chan performed literature search and screening, developed tables and figures, and wrote overall manuscript. L. Zwaigenbaum and D. Nicholas provided input into the idea, and critical input into the initial manuscript and subsequent revisions. E. Coombs revised and provided lived experience on the final drafts of the manuscript. The Indigenous Relations Circle provided community insights on the final version of manuscript. All authors read and approved of the final manuscript and agree to be accountable for all aspects of the work

I was involved in all stages of the research project. This project was done in partnership with Maskwacîs Education School Commission (MESC), specifically with Trina Ertman and Heather Littlechild, and the Six Nations Child and Youth Health Team (SNCYH), Jacqueline Smith and Celina Hill. I was the principal investigator and my supervisory team consisted of Dr. Lonnie Zwaigenbaum and Dr. David Nicholas. My PhD committee consisted of Dr. Sean Lessard (Faculty of Education) and Elder Dr. Francis Whiskeyjack (First Peoples House), and Elder Dr Leona Makokis. The Maskwacîs Autism Advisory Circle consisted of myself, Dr. Lonnie Zwaigenbaum (Dept. of Pediatrics), Dr. David Nicholas (Faculty of Social Work, University of Calgary), Dr. Heather Dreise (Maskwacîs Pediatric Clinic), Elder Cliff Potts

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List of Acronyms

MESC: Maskwacîs Education School Commission
AFN: Assembly of First Nations
INAC: Indigenous and Northern Affairs Canada
FSCD: Family Support for Children with Disabilities
OAP: Ontario Autism Program
ISC: Indigenous Services Canada
CBPR: Community Based Participatory Research
CLR: Community-led Research
JADD: Journal of Autism and Development Disorders
MAAC: Maskwacîs Autism Advisory Circle
SNCYH: Six Nations Child and Youth Health
OCAP©: Ownership, Control, Access, and Privacy
IQAT: Indigenous Quality Assessment Tool
DSM-5: Diagnostic Statistical Manual Fifth Edition
FNCFCS: First Nations Child and Family Caring Society
PRISMA-ScR: Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews
ABA: Applied Behaviour Analysis
OT: Occupational Therapy
SLP: Speech Language Pathology
PT: Physiotherapy
INSAR: International Society of Autism Research
SKIPP: Situated Knowledges of People and Place
WCHRI: Women and Children's Health Research Institute

Glossary of Nêhiyawin (Plains Cree terms)

Kise manitou: the Creator
Kinanâskomitin: I thank you
Mosom: grandfather
Nohkôm: grandmother
Nohkômak: grandmothers
Nikâwiy: my mom
Nohtâwiy: my dad
Nohcâwîs: my uncle
Tansi: Hello
Nitsihkasôn: my name is
Ekwa: and
Ohci niya: I am from
Nêhiyaw: People of the four (sometimes known as Plains Cree)
Nêhiyawin: Plains Cree language
Maskwacîs: Bear Hills
Maskwacîsak: Bear Hills people
Maskekosihk: Enoch Cree Nation (the land of medicine)
Iyinîw Mâmitonehicikan: Be compassionate; recognize one another's diverse experiences, views and voice
Nêhiyaw Pimâtsiwi: Plains Cree way of life
Wâhkôtowin: The state of being related or connected
Neyaskwayak: Ermineskin Cree Nation (the Northern treeline)
Kispahtinaw: Louis Bull Tribe (the end of the hill)
Akamihk: Montana First Nation (across the river)
Nipisihkopahk: Samson Cree Nation (willow meadows)
Napêw: Man
Matô: Cry
Matotisân: sweat lodge or crying lodge
Ospakwân: Ceremonial pipe
Oskâpewis: Ceremony helper
Sewatsiwin: They are sacred
Acahk pimatsiwin: Spiritual way of life
Ka-kamawaci-iyinisit: given a unique quiet spiritual intelligence
pihtos-mânitonihk-iyinisit: given different way of thinking in its own spiritual intelligence
ê-mihkosit pihtos mânitonicihkan: given different way of spiritual thinking
ê-mihkosit pihtos ê-si-waskawiht: given the gift of moving a different way or being (characteristic/behavior)
Awâ: spirit

Awâsis: A child or ‘small travelling spirit’
Mîhkwap: tipi or lodging

Chapter 1: Introduction

1.1 Background

In 2016, Canada's Human Rights Tribunal found that the Government of Canada was discriminating against First Nations children on the basis of race and national ethnic origin (Blackstock, 2011). This ruling solidified what First Nations families have been saying for decades in that there are systemic barriers to receiving adequate services on reserve. These barriers include discriminatory policies at both the federal and provincial levels of governments, and these policies have led to Autistic children and their families experiencing fewer services or no services at all. There are several *Truth and Reconciliation Calls to Action* that address improving the lives of the children with disabilities who are on reserve, which includes the need for increased supports related to autism. This requisite includes the call to action 3 "[w]e call upon all levels of government to fully implement Jordan's Principle"(2015, p. 1)

Autism is characterized by difficulties with communication, social deficits as well as restricted repetitive behaviors and interests (American Psychiatric Association, 2013). It is widely recognized that autism occurs in all populations, including Indigenous populations. Canada's 1982 Constitution recognizes three distinct Indigenous groups, First Nations, Métis, and Inuit. The prevalence of autism in First Nations communities is currently unknown and there is minimal academic literature on the lived experience related to autism in cultural contexts more generally (Lindblom, 2014). Recently a systematic review was done with a focus on autism in Indigenous communities at the international level, and the findings outlined an "urgent need for [autism] research, and [they] express the hope that more government resources can be dedicated to support research for Indigenous and First Nations people across the lifespan with autism and/or other neurodevelopmental disorders" (Shochet et al., 2020, p. 1). This urgent need is further exacerbated by health inequities and limited access to disability services for First Nations families.

1.2 Positionality statement

Tansi, Grant Bruno Nitsihkasôn Maskwacîs ekwa Maskekosihk ohci niya. My name is Grant Bruno, and I'm a registered member of Samson Cree Nation, one of the reserves that makes up Maskwacîs, Alberta; however, I grew up in Enoch Cree Nation with my mom. I am a father to four children, two of whom are on the autism spectrum. I was first introduced to the world of autism when I was 22 years old, when I worked as an educational assistant at a school in Maskwacîs and had the privilege of supporting an Autistic child in a classroom setting. Later my sons were diagnosed at ages 4 and 9 years old respectively and I since have been on a journey learning more about autism. I am also a first-generation residential school survivor as nihkawîy Deborah Cutknife and nohkômak Armine Cutknife and Mariah Lightning all attended the Hobbema Indian residential and Youville residential schools in central Alberta. It is through these identities and experiences that I have dedicated my doctoral work to better understanding the experiences of autism from historical, cultural and social perspectives.

1.3 Maskwacîs

Located on Treaty Six territory, Maskwacîs is made up of four different First Nations and has approximately 25,000 members who live in or around the community. In 1891, Sir William Cornelius Van Horne, then Canadian Pacific Railway president, named a flag station after his favorite Dutch painter, Meinhardt Hobbema, and the name “Hobbema” identified the community for over a hundred years. In 2014, the community of Hobbema restored its traditional name of Maskwacîs which translates to English as ‘Bear Hills’. The name Maskwacîs reflects its unique topography and nêhiyaw culture, both of which are seen as inherent strengths. Maskwacîs is made up of four reserves, neyaskwayak (the Northern treeline) or Ermineskin Cree Nation; kispahtinaw (the end of the hill) or Louis Bull Tribe; akamihk (across the river) or Montana First Nation; and nipisihkopahk (willow meadows) or Samson Cree Nation. (Samsonscree.ca, 2013). Politically, each band has a separate Chief and Councils, and thus four different decision-making bodies and four different sets of agendas. However, education services on the four reserves are somewhat centralized through the Maskwacîs Education School Commission (MESC) which allows for better and more equitable access for students.

Established in 2016 and rooted in the treaty right to education, MESC amalgamated 11 schools from 4 different school authorities in Maskwacîs. It governs on-reserve education services and is separate from Chief and Council. The school system is the only space in the community that provides disability services, and the vision and mission of MESC are as follows,

> To foster competent, confident, and resilient Maskwacîs Cree speaking students who are actualized through the development of a Nêhiyaw Maskwacîs curriculum, which is designed to engage all students through positive, enriched, experiential learning opportunities.
>
> The mission of MESC is to govern an outstanding Maskwacîs education system that ensures students attend respectful and inspiring schools. This includes understandings and respect for the Maskwacîs foundational values of îyinîw Mâmitonehicikan, Nêhiyaw Pimâtsiwin, Nêhiyawewin, and Wâhkôtowin (Maskwacîs Education School Commision, 2019).

There are a total of 2000 MESC students and 500 staff at 11 school in Maskwacîs. Approximately 650 (32.5%) of those students are considered to have complex needs or have a diagnosis of varying conditions. Across those 11 schools there are 5 ‘Interactions’ classes for children with developmental disability (when Measurable IQ <60 plus possible additional physical, sensory, or compounding needs), and 3 Foundations classes for students who need less support (Mild to moderate cognitive disabilities and developmental delays. When measurable IQ <70 (+5)). Occupational therapists, speech language pathologists, and physiotherapists work within the school system. Maskwacîs also has a Head Start program in each of the reserves to support young children as they transition into school. There are no disability supports or services in the community other than those available through the school system. Many students with complex needs who live in Maskwacîs go to school in either the adjacent towns such as Wetaskiwin or Ponoka and cannot access MESC services but would access them if offered in their own school district. Technically families in Maskwacîs can access the Family Support for Children with Disabilities (FSCD), through the Government of Alberta, but these funds are restrictive and if a caregiver wants to access autism-related services, they will likely have to move away from the community and into a city or town.

1.4 Six Nations of the Grand River

The Six Nations of the Grand River are a Haudenosaunee community in Southern Ontario that is located approximately an hour and half drive southwest of Toronto. The Six Nations include the Mohawks, Senecas, Onondagas, Cayuga, Oneidas, and later in 1722 the Tuscarora who all came together to form the Confederacy of the Six Nations (Weaver, 1978).

The Six Nations of the Grand River Health Services mission, which houses the Child and Youth Health team, is below.

> Six Nations of the Grand River Health Services' mission is to provide a holistic system that inspires people to achieve wellness. Our goal is to create a safe environment, to guide, support and care for our community members on their wellness journey. Our wide-ranging services include ambulance services, nutritional and diabetic support, mental and family counselling, maternal support and much more.

The Child and Youth Health Team is responsible for developing and implementing autism services in the community. These services include occupational therapy, physiotherapy, speech language pathology, behaviour analysis, and other family centered supports. They were recently able to add a Caregiver Mediated Early Years Program, Social ABCs and an Entry to School Program under the Ontario Autism Program (OAP). Social ABCs is a twelve-week program where a caregivers work with a trained Social ABCs coach to learn strategies to help their child with social interaction and communication. The Entry to School Program is a six-month group-based program where autistic children learn skills that will help them transition successfully to school. Each cohort runs from March through August prior to their start of school. The group program is followed by up to six months of consultation transition supports in each child's school. OAP enrollment requirements of confirmation of diagnosis and enrollment through Access OAP is a barrier to services for many Six Nations families. As the Child and Youth Health team is committed to providing supports regardless of diagnosis, they leverage other funding resources to be able to provide equivalent programming to children with undiagnosed but suspected autism (Six Nations Health Services, 2022). There are five federal schools in the Six Nations community managed through Indigenous Services Canada (ISC) as well as two private immersion schools which operate independently. Unlike Maskwacis, the bulk of disability supports are provided through the Department of Well-being (previously named Health Services).

It is important to recognize that while each community has some autism-related services and supports, the need greatly outweighs what it offered. The initial research plan was to focus specifically on Maskwacîs, but after being awarded the Data-2-Policy Fellowship through the Autism Alliance of Canada, I felt expanding my research to another large First Nations community would allow for a more dynamic and robust research project. Thus, a relationship was established with the Six Nations. It should also be noted due do a lack of statistical data the prevalence of autism in both communities in currently unknown.

1.5 Autism

Over the past 100 years there has been a substantial shift in how the medical profession has characterized autism. In the early 1900’s, autism was first recognized, with characterization of certain behavioral patterns associated with what we now regard as autism. Swiss psychiatrist Eugen Bleuler, in 1911, coined the term "autism" to describe withdrawal into one's inner world, which he observed in individuals with schizophrenia (Bleuler, 1951), although this not relevant to the modern diagnosis of autism.

It wasn't until several decades later that Dr. Leo Kanner, an Austrian psychiatrist, made a ground-breaking contribution to the field. In 1943, Kanner published a seminal paper titled “Autistic Disturbances of Affective Contact” (Kanner, 1943), describing 11 children who displayed a "profound lack of affective contact" and other distinctive characteristics. This marked the official identification of autism as a separate entity from schizophrenia. Around the same time, another psychiatrist, Hans Asperger, was independently working on similar observations. Asperger’s work outlined a milder form of autism, which later became known as Asperger's syndrome (Tantam, 1988). The 1960s and 1970s witnessed an increased focus on autism research, with professionals recognizing it as a distinct developmental disorder. The third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III) (American Psychiatric Association, 1980) officially introduced the diagnostic category of ‘infantile autism’. This marked a crucial step in standardizing the criteria for diagnosing autism.

In 1994, the DSM-IV (American Psychiatric Association, 2000) expanded the diagnostic criteria and introduced the term "Autistic disorder" to encompass a broader range of symptoms It also included Asperger's syndrome and pervasive developmental disorder-not otherwise specified (PDD-NOS) under the umbrella of pervasive developmental disorders. The most recent major revision, the DSM-5 (American Psychiatric Association, 2013) adopted the term ‘autism spectrum disorder’ to reflect the diverse range of symptoms and severity levels. This shift aimed to address the recognition that autism exists on a spectrum, with individuals displaying varying degrees of social communication challenges and repetitive behaviors. Recently the DSM-5 was revised to the DSM-5-TR (American Psychiatric Association, 2023), with clinical updating based on the literature of the past 10 years.

Throughout this history, societal attitudes about autism have evolved significantly. Early on, individuals with autism often faced stigmatization and institutionalization. In recent years there has been a growing emphasis on understanding and supporting individuals with autism, promoting inclusivity, and recognizing the unique strengths and talents that often accompany this neurodevelopmental condition (Dwyer, 2022; Dwyer et al., 2022). The proposed research aims to create space that recognizes these strengths.

1.6 Terminology

Autism terminology is constantly evolving to keep up with the research and perspectives of those with lived experience, and it is essential to understand the role of language and how it shapes the experiences of, and negatively impacts Autistic people, particularly in research. According to Monk et al (2022) the deficit model associated with the medicalization of autism has caused harm over the decades. Historically the medical model has focussed on the treatment of autism and there has been substantial efforts exerted in ‘curing’ autism which was usually advocated for by parents of Autistic children. In recent years, there has been more representation in the literature by Autistic people, including advocacy for language that respects their dignity and lived experience on the spectrum and this thesis adheres to those wishes throughout. Accordingly, the I employ identity first terms such as ‘Autistic’ rather than ‘person with autism’ and ‘autism’ rather than ‘autism spectrum disorder’ to align and reflect the neurodiversity movement and with many Autistic people’s wishes and reflect their desire to reduce structural stigma (Dwyer, 2022).

Indigenous is a ‘catch all’ term that is appropriate in some cases such as when describing broad concepts or ideas; however, when working with communities it is best to be as specific as possible, such as indicating tribal or community membership. The terms Aboriginal, Native, and Indian are outdated and only used in some instances, such as when exploring historical literature or legal definitions such as ‘Status Indian’ (Vowel, 2016). In this thesis I use the term Indigenous and First Nations interchangeably depending on the context and will use ‘Indian’ when describing identities within the legal context of the *Indian Act.*

1.7 Brief history of colonialism in Canada

Globally, colonialism is inherently violent, and the effect of this violence is still being felt within Indigenous families and communities today. Indigenous peoples in Canada have been subjected to racism and systemic inequities which have resulted in poorer health outcomes, social inequalities, and poorer access to services – lingering and continuing impacts of destructive colonial legislation and policies. Indigenous populations in Canada have significantly higher rates of child mortality, maternal morbidity, infectious disease, shorter life expectancy, malnutrition, substance abuse, lifestyle-related chronic diseases and conditions, accidents, homicide, violence, and suicide compared to the mainstream population (Barnabe, 2021; Gracey & King, 2009; Smylie & Anderson, 2006; Wilson & Young, 2008). Colonial policies have had severe and long-standing impacts. For instance, the *Indian Act* of 1876 outlawed cultural practices, including ceremonies, and enacted the residential school system. Such policy and widespread practices are still being felt in First Nations communities across Canada (Wilk et al., 2017).

Racism is a factor that negatively influences Indigenous health outcomes. This includes discriminatory attitudes and beliefs from medical professionals and other professionals such as social workers and educators (Roach et al., 2023). Furthermore, the *Indian Act* stipulates that the federal health minister has overarching power over 'mentally incompetent Indians' (Bartlett, 1977), which could be extrapolated even today to include Autistic Indigenous people. Such language, perspectives and the principles beneath this terminology raise grave concerns about presumptions, imposed power and potential impacts. Finally, First Nation reserves, all under the *Indian Act* are under federal jurisdiction whereas disability services, including autism services, are a provincial responsibility. Of substantial concern, both levels of government often pass their obligations related to autism support to each other, thus leaving reserves without any services.

1.8 Lack of Indigenous data

In Canada there is a lack of accurate quantitative data on the prevalence of autism and related health indicators in Indigenous communities. There are several key issues related to collecting such data at a national level; for example, in census data collection Indigenous peoples are less likely to participate due to mistrust, frequent mobility among Indigenous people, problems with self-identification. These various issues result in inaccuracies in these datasets as there is a critical lack of comprehensive statistical data on First Nations child and youth health in Canada (Smylie & Anderson, 2006).

The Truth and Reconciliation Commissions Call to Action 19 specifically states,

> [w]e call upon the federal government, in consultation with Aboriginal peoples, to establish measurable goals to identify and close the gaps in health outcomes between Aboriginal and non-Aboriginal communities, and to publish annual progress reports and assess long term trends. Such efforts would focus

> on indicators such as: infant mortality, maternal health, suicide, mental health, addictions, life expectancy, birth rates, infant and child health issues, chronic diseases, illness and injury incidence, and the availability of appropriate health services (2015, p. 2).

Inaccuracies in data contributes to these poor health outcomes by creating systemic barriers to effective policy and program development and data infrastructure deficiencies contribute to hiding health inequities faces by First Nations people (Steffler, 2016). Despite the widespread knowledge that there are health disparities among First Nation child and youth populations, there remains a significant gap in the data. Currently the prevalence of autism in First Nations communities is unknown, and this leads to inequitable autism supports and services.

1.9 Ableism, racism, and Indigenous autism

The intersecting identities of Indigenous Autistic children are heavily influenced by ableism, racism and jurisdiction (Friedman, 2023). Ableism is defined as a set of beliefs and practice that produce a particular understanding of oneself and others based on perceived abilities which in turn leads to labelling and a diminished state of being that is viewed to be lacking ability (Wolbring, 2008). Racism is a worldwide systems of ranking individuals based on perceived levels of superiority and inferiority, which has been established and perpetuated for centuries through political, cultural, and economic means by institutions of capitalist, patriarchal, Western-centric, Christian-centric, modern, and colonial world-system (Grosfoguel, 2016).

Canada has enacted racism against Indigenous peoples since its formation and continues to do so today. Legislation such as the *Indian Act* of 1876 still exists today. The *Indian Act* also implements structural ableism for Autistic people and their families. For example, the *Indian Act* stipulates that reserves are under federal jurisdiction whereas disability supports and services are a provincial responsibility. For many years, this jurisdictional tension has led both the federal and provincial governments to a lack of action on disability support on reserve. This issue that is of great concern resulted in the creation of Jordan's Principle as a legal challenge to the inequitable disability supports First Nations children have if they live on a reserve (Blackstock, 2012):

> Jordan's Principle is a child-first principle intended to resolve jurisdictional disputes within, and between, provincial/territorial and federal governments concerning payment for services to First Nations children when the service is available to all other children. It was named in memory of Jordan River Anderson, a young boy from Norway House Cree Nation, who spent more than two years unnecessarily in hospital while Canada and Manitoba argued over payment for his at-home care. The reason for this is the province normally delivers health care off-reserve, but the federal government funds it on-reserve. In Jordan's case, the two governments could not agree on payment because Jordan was First Nations and, thus, left him in hospital while they argued over payment. Tragically, Jordan died at five years of age after waiting more than two years for both governments to resolve their dispute (p. 368).

Blackstock later (2016) outlines the chronological order where Canada was found guilty of human rights abuse against First Nations children. On February 23, 2007, the First Nations Child and Family Caring Society of Canada and the Assembly of First Nations (AFN) filed a human rights complaint alleging that the federal department of Indigenous and Northern Affairs Canada's (INAC's) flawed and inequitable provision of First Nations Child and Family Services. INAC spent millions of dollars over the next six years, in eight separate attempts, to get the case dismissed on jurisdictional grounds before it finally went to hearing in 2013. In 2016, the Canadian Human Rights Tribunal issued its decision affirming discrimination on the prohibited grounds of race and national ethnic origin and ordering INAC to immediately cease the application of its narrow definition of Jordan's Principle and flawed and inequitable provision of First Nations child and family services. First Nations families and Autistic children living on reserve are still dealing with inequitable access to services today.

1.10 Research question

The research question addressed in this study is ‘what are the experiences of autism in First Nations communities?’. Within this question, several objectives are explored, and activities were performed. The study engaged a culturally rooted multi-methods approach and was built on a community-based participatory research (CBPR) principles, but with the clear goal of establishing community-led research (CLR). Activities consisted of the following:

1. A scoping review of research that has explored First Nations’, or Indigenous experiences of autism and the health system in the context of Canada. This review was published in the *Journal of Autism and Developmental Disorders (JADD)* (Bruno et al., 2023).
2. Using a strength-based decolonizing approach rooted in CBPR principles, meaningful engagement was done with the community of Maskwacîs and Six Nations of the Grand River, including with leadership, community members, Elders, service providers and families to create CLR project. After early community engagement had been done it was decided that I should work with MESC, and the Maskwacîs Autism Advisory Circle (MAAC) was established, and later the Six Nations Child and Youth Health (SNCYH) team was brought on.
3. With the guidance of the MAAC and SNCYH, qualitative exploration has reflected First Nations understandings of autism through an Elder and cultural study and a caregiver and community member study. From this process, community members have been involved in qualitative conversations, interviews, sharing circles, etc., including the active engagement of Autistic individuals and their families regarding their perspectives and experiences.
4. Using an action-oriented approach that benefits the community, sensory friendly opportunities were created including a sensory tipi at local powwows, ceremony, and an

autism support group, for Autistic individuals and their families to participate in First Nations culture.

Ethics review and approval was received by the communities of Maskwacîs (MESC), Six Nations of the Grand River, as well as the Research Ethics Board of the University of Alberta (Pro00114136). Ensuring that this research was conducted in ways that upheld (and continue to uphold) values and ethical principles of these communities was a key priority. Informed consent and informant privacy was and will be honoured, based on the principles of OCAP© (Ownership Control Access Possession).

1.11 Conclusion

The history of Indigenous peoples and Canada has been and continues to be fraught with challenges that include systemic barriers to services. There are multiple studies addressing various facets of lived experience related to autism. However, this study is novel and leading in advancing autism knowledge relative to First Nations communities in Canada. The focus on the lived experience of First Nations families and the realities of autism in Indigenous communities has not been explored in Canada. It is hoped that this study offers informative impact in Canada and internationally, but more importantly, provides value to the community of Maskwacîs and Six Nations of the Grand River. The next chapter discusses the methodologies and methods that have been implemented and practiced in this research.

Chapter 2: Methodologies and Methods

2.0 Study overview

The research methodologies and methods outlined in the following chapter reflect Indigenous ways of knowing and doing, and is rooted in nêhiyaw traditions, concepts, and language. This research is unique in that it has been fully led and established by community members throughout the entire process. Using a decolonizing methodology, the first phase of the research process comprised meaningful and continued community engagement that guided the development of the methodology and methods, co-developed the research questions, supported data collection, analysis, and help plan dissemination activities in the community. There is no unifying theory to decolonizing research, rather it is an intuitive approach and prioritizes the situated knowledges of Indigenous individuals and communities (Kovach, 2010; Simonds & Christopher, 2013; Smith, 2013). The situated knowledges for this research are nêhiyawak teachings, language, and knowledges. Data analysis will also be explored though a decolonized nêhiyaw lens and was developed with community and cultural input.

2.1 Wâhkôtowin research methodology

Indigenous scholars have long recognized the critical need to establish and create their own research paradigms (Ryder et al., 2020; Smith, 2013; S. Wilson, 2008). Specifically, nêhiyaw scholar Margaret Kovach (2010) describes Indigenous research grounded in culture and language as “emancipatory” and “anti-oppressive”. It is critical to think and do research in the communities such as Maskwacîs in a way that reflects the nêhiyaw worldview, language, and cultural concepts. Early in the research journey I recognized the tension between western and Indigenous approaches to research and understood that if I were to conduct meaningful research in Maskwacîs I would be required to develop a research methodology and methods that were rooted in the ancestral knowledge that nêhiyaw people possess and practice. Maskwacîs scholar Dr. Paulina Johnson (2017) describes the power of developing new research methodologies in community with Elder support,

> Nêhiyawak methodologies offer new insights and cultural experiences for researchers and are valuable to [the] growth of Indigenous literature and study. This specific research framework puts the needs of the nêhiyawak in the forefront of the research and allows for them to express how they understand and interact with the world around them. A Nation-specific methodology extends out of Indigenous and decolonizing methodologies but at the same time has distinct goals it aims to achieve. The tensions that exist are those that the nêhiyaw people must forward since it is their way of life being researched, their experiences within the constructs of colonialism, and they know what ideologies and traditions are important for their own resurgence and well-being. Nation methodologies are based on the foundations of creation and incorporate the ontological knowledge linked to philosophies that make each Indigenous Nation distinct" (p. 86).

Throughout my research journey I have consistently engaged with nêhiyaw Elders in Maskwacîs and throughout Treaty Six. Through these conversations the Elders have provided invaluable insight and guidance about the research process. It is imperative that the relationships I find myself in with knowledge keepers and Elders are reflected in the development of these nêhiyaw methodologies and I am grateful for their guidance and support.

Wâhkôtowin is a nêhiyaw concept and is widely considered a part of natural law that governs the relationships around us. According to Maskwacîs scholar, Dr. Matthew Wildcat (2018),

> Wâhkôhtowin directly translates to English as kinship or being related to each other. But the concept encompasses a wider set of ideas about how things are related within Cree worldviews. I break down the meaning of wâhkôtowin into three parts. First, it references the act of being related — to your human and other than human relatives. Second, it is a worldview based on the idea that all of existence is animate and full of spirit. Since everything has spirit it means we are connected to the rest of existence and live in a universe defined by relatedness. Third, there are proper ways to conduct and uphold your relationships with your relatives and other aspects of existence. Thus, wâhkôtowin also includes the obligations and responsibilities people have to maintain good relationships (p. 14).

At its core, wâhkôtowin signifies the interconnected relationships among individuals, communities, and the natural world. This concept emphasizes the idea that all aspects of life are interdependent, forming a complex network of connections. In the context of research, wâhkôtowin as a methodology seeks to honor and acknowledge these relationships, centering the research process on reciprocity, respect, and community engagement.

Wâhkôtowin as a research methodology encourages a holistic and relational approach to inquiry. Researchers adopting this methodology recognize that issues cannot be isolated or studied in isolation; rather, they are interconnected with various factors such as culture, spirituality, and the environment. This holistic lens allows for a comprehensive understanding of the research topic, considering the multifaceted nature of Indigenous knowledge. Wâhkôtowin places a strong emphasis on community involvement throughout the research process. Before initiating a study, researchers employing this methodology actively seek the consent and collaboration of the Indigenous communities with which they are working. This collaborative approach ensured that this research aligned with community needs and priorities, respecting the autonomy and self-determination of Maskwacîsak (Bear Hills People).

Implementing wâhkôtowin as a research methodology is not without challenges. Researchers must navigate power dynamics, address potential conflicts between Indigenous and Western paradigms, and overcome institutional barriers that may prioritize conventional research approaches. Reflecting on these challenges is an integral part of the wâhkôtowin methodology, prompting continuous refinement and improvement. Wâhkôtowin as a research methodology represents a transformative and inclusive approach that goes beyond traditional research paradigms. By embracing interconnectedness, respecting Indigenous knowledge, and prioritizing community involvement, this methodology aims to contribute to a more equitable and just research landscape. As Indigenous voices gain prominence in the research arena, wâhkôtowin serves as a powerful tool for decolonizing methodologies and promoting a research methodology and framework grounded in respect, reciprocity, and relationships. Wâhkôtowin is woven throughout the entire research process right from when I first introduced myself to my supervisors, throughout the community engagements and circles, data collection and analysis, knowledge mobilization and dissemination, and even within publishing. This nêhiyaw concept is foundational to all research activities and key to ensuring accountability throughout the process.

2.2 From community-based to community-led

As noted earlier, this research builds on a community based participatory research (CBPR) approach and has evolved into a community-led research (CLR) project. CBPR is a growing field of research with and within Indigenous communities. CBPR is consistent with critical and constructivist theory but with one main difference being the participation of non-academic researchers in the creation of knowledge (Israel et al., 2013). CBPR is used to identify and address the needs of the community by engaging with community members and stakeholders in ongoing discussions around what are the most pressing issues to the community (Koster et al., 2012). In drawing on these principles, CLR entails research that is fully community-led.

As a community member, I have the unique opportunity to view the research from a perspective that connects me to the community in ways that an outsider could not feel. Whether it is randomly seeing a family member at the store or sharing my family history with some and realize we are related as kin, these interactions allow me to connect and reconnect in ways that go beyond the research. Early in the research process, I realized that this work could potentially have meaningful impacts in the community beyond the health clinic; for example, getting to meet and know families of Autistic children as a parent myself would create a meaningful connection that I did not expect. With every interaction and conversation – whether with a parent to an Autistic child, Elder, or leader in the community – I have taken their guidance and implemented it into the research process. Further, I entered into formal research agreements with both Maskwacîs (MESC) and the Six Nations of the Grand River (see appendices). To obtain these agreements, I presented my research proposal to the MESC board and Six Nations Chief and Council and engaged with them throughout the research process.

A main feature of CLR is to develop and maintain a Maskwacîs Autism Advisory Circle (MAAC). The concept of the circle is fundamental to the nêhiyaw worldview as the circle follows the natural way of being and positions all the members as equal rather than taking a hierarchal approach. The MAAC was integral to the planning, implementation, and overall success of the study. I bring experience in working with a community advisory committee in previous studies in Maskwacîs (Bruno, 2022; Oster et al., 2016; Oster et al., 2018). In these community research experiences, I learned the power of shared decision-making and consensus building, and the expertise of community members and Elders was honored. All decisions in this project were brought to the MAAC for discussion and they will have significant input into the research process. The MAAC is made up of Elders, service providers, educators, and healthcare providers, as well as parents and those with lived experience of autism. There are community members with lived experience and non-community members with experience around (or related to) autism (e.g., a family member with autism). In the spirit of wâhkôtowin all members of the MAAC had a voice and active listening was encouraged. I have also partnered with the Six Nations Child and Youth Health (SNCYH) team and would sometimes combine both groups depending on what stage the research was at.

The concept of the circle is integral to engagement with Indigenous communities as it fits with most Indigenous worldviews (Absolon, 2010). In 2021, I had the opportunity to train with the National Compadres Network and participate in their circle keeper training. In this training, I learned there are many applications of a circle method, including educational circles, healing circles, and sharing circles, each circle having similar yet distinct approaches. The circle creates a space for participants to not only discuss the topic at hand but also encourages active listening. As a circle keeper my role is to guide the conversation while ensuring everyone's perspectives and experiences are respected and acknowledged. Each circle member is given an opportunity to speak. Applying circles in the context of this research, agendas were somewhat formal but if the conversation went in a completely different direction, it was explored by the circle. At the end of the circle there was a 'check in' round to see how all were feeling and then the circle was closed.

In keeping with these concepts, this research notably is in alignment with broader Indigenous community research approaches. For example, Métis scholar Adam Gaudry (2011) outlines what he describes as insurgent research that is a direct challenge to western hegemony:

1. research is grounded in, respects, and ultimately seeks to validate Indigenous world views.
2. research output is geared toward use by Indigenous peoples and in Indigenous communities,
3. research processes and final products are ultimately responsible to Indigenous communities.
4. Indigenous communities are the final judges of the validity and effectiveness of insurgent research, research is action oriented and works as a motivating factor for practical and direct action among Indigenous peoples and in Indigenous communities (p.117).

Using these principles this research aimed to challenge western thought on autism and Indigenous people and to have direct impact in community and with families. Through relational accountability the research is ultimately responsible for contributing to the wellbeing of the communities with whom I work.

2.3 Decolonizing methodologies

Using a decolonizing methodology, this phase of the research process was meaningful and reflective of continued community engagement to guide data collection, analysis, and knowledge dissemination. There were numerous opportunities for community members – whether Autistic people themselves or those with experience working with or caring for Autistic people – to contribute to the development of this research. For example, I chair the Indigenous Relations Circle for the Autism Society of Alberta, which includes Indigenous and non-Indigenous, Autistic individuals, and frontline staff from across the province and would routinely ask them how to meaningful engage with the Autistic community and it is essential to recognize the challenges to community engagement especially when it flows from an academic institution such as the University of Alberta to an Indigenous community. Historically engagement with Indigenous communities in the context of research has been rife with challenges such as being performative, one sided and hindered by miscommunications (Hayward, Sjoblom, et al., 2021). One approach that can address these challenges is what nêhiyaw scholar Willie Ermine defines as Ethical Space of Engagement. According to Ermine (2007) this is

> "the space between the Indigenous and Western worlds, the separation between cultures and worldviews, as the schism of understanding that contributes to the tension riddled enterprise of cross-cultural research involving Indigenous Peoples. These worldviews are each formed and guided by distinct histories, knowledge traditions, values, interests, and social, economic, and political realities that are brought to the encounter of the two solitudes. Creating contrast, by purposefully dislocating and isolating two disparate knowledge systems and cultures represented by the Indigenous and Western worlds is pursued in the interest of identifying and bringing perspective to the current research context. This contrast provides a perspective to a space between entities that lends itself to clarity about the issues and themes of divergence and convergence in the examination of the ethics in research involving Indigenous

> Peoples. With the proposed identification of the contrasting perspectives, the intent is to reconnect the entities with the notion of a bridging concept called the ethical space" (p.19-20).

As a community member and parent, it was and is important for me to remember when engaging with First Nations communities such as Maskwacîs and Six Nations of the Grand River that while these roles provide some expediency to the relationship building process, I regularly reflected on (and must continue to regularly reflect on) these roles and maintain a relational accountability to the community that goes beyond various research conventions (e.g., requisites of the university research ethics board). Accordingly, there is a layer of spiritual accountability that was established and included offering protocol and attending ceremony in the community.

2.4 Ceremony

In conveying the knowledge shared below, I acknowledge that I am nêhiyaw, but I did not grow up with the culture or language. Like many in our communities, I was disconnected from ceremony and cultural practices because of the residential school system. It was only as an adult that I started my ceremonial journey. What I share here is only what I have learned so far and may be different from what others have learned. I also acknowledge that while ceremony may be similar for Indigenous nations, I will be focusing on nêhiyaw traditions and ceremonial processes.

In his seminal book *Research is Ceremony: Indigenous Research Methods*, Opaskwayak First Nation member, and nêhiyaw scholar, Shawn Wilson (2008) shares that for Indigenous scholars, research is deeply connected with ceremony process and protocols. In my current research, one of the first research activities that took place before any community engagement, data collection, or anything else research-related, was to participate in a ceremony. Ceremony can be described as a spiritual space to be able to connect with grandfathers and grandmothers.

Elders would also say that ceremonial spaces are sacred, and it through creating a sacred space that sacred knowledge can be transferred. Protocol, or tobacco, is offered to the Elder or traditional knowledge keeper and from there they will either agree or disagree to conduct the ceremony. There are different types of ceremonies such as a sweat lodge, Sundance, chicken dance, ghost dance, and night lodges. I will not go into the details of these ceremonies as I am aware of my own limitations when discussing sacred spaces and this knowledge should not be publicly available.

The ospakwân or 'pipe' is a fundamental part of the sacred processes of ceremony. According to Waldram (1997), the pipe is a "medium for maintaining the dynamics of reciprocity that sustain the integrity of wholeness of the community, its relationship to the sacred powers of creation, and specific connection to individual gifts and abilities given by those powers". Pipe ceremonies and sweat lodges have complex rights, obligations, and responsibilities. Some of these include the pipe carrier refraining from alcohol or drugs for the rest of their lives as soon as they make the commitment to the pipe. Women are also discouraged from attending sweat lodges during their 'moon' or 'sacred' time, as they are thought to be too powerful since they are the bringers of life into this world. This is not to be misconstrued to mean that they are not welcome in ceremony but rather are honored with the power they carry as life givers. Those participating in the ceremony are encouraged to refrain from substances such as drugs or alcohol for days before a ceremony as these are seen as a negative influence on the person's spirit.

According to Elder Wilfred Buck (2021), the matotisân (sweat lodge) "is a place of healing, where we go for centering ourselves, for finding out who we are, where we belong, where we come from" and "the word sweat lodge comes from the Cree root word, mato, which means ‘to cry’”. I attended several sweat lodges and other ceremonies in Maskwacîs and offered protocol each time for guidance on this project, which included offering tobacco, sweetgrass and prints. By attending these ceremonies, I ensured the project had a ceremonial foundation. I have been attending ceremonies for many years and will continue to do so for my own reasons, but also so that the work I do in community is aligned with the community’s cultural teachings.

A key role during a ceremony is the oskâpewis or ‘ceremony helper’. These helpers support the ceremony by offering their time and energy to what needs to be done. These responsibilities may include keeping the fire, serving food, or cleaning up. I have had the opportunity to be a ceremony helper at several ceremonies and have learned and created an identity through this role. Specific to this research, I attended several sweat lodge ceremonies among other ceremonies in the community and each time offered protocol to ask for guidance and support throughout the research journey. These ceremonies offered a sacred foundation to operate from and require a sacred ethical responsibility that is now connected not only to the community but to my ancestors and kise manitou.

2.5 Scoping review

Guided and inspired by ceremony, it was important to identify published and unpublished information about the complexities of First Nations health and well-being relative to autism, individual and family experiences, and program delivery considerations. To understand the complexities of First Nations health and well-being relative to autism, individual and family experience, and program delivery considerations, a broader understanding of the histories and relationships related to autism in First Nations communities must be established. The first step was to develop a scoping review that synthesizes the existing literature to generate a better understanding of opportunities and challenges/gaps relative to autism research in Indigenous communities in Canada. According to Munn et al (2018), scoping reviews are used to identify and aggregate available evidence in a field. These reviews clarify key concepts and definitions within the field of inquiry, examine how research is conducted, and identify key characteristics or factors related to a concept, and finally analyze knowledge gaps. We implemented Arksey and O'Malley's (2005) five stages in conducting a scoping review: (1) determining the research question, (2) identifying relevant studies, (3) study selection, (4) charting the data, and (5) collating, summarizing and reporting the results. Some reviews assess the quality of the literature and we have adopted this sixth stage. Methodologic/research rigor was analyzed using the Indigenous Quality Assessment Tool (IQAT) (Harfield et al., 2020). Developed and validated by Indigenous scholars in Australia, the IQAT assesses research done on or with Indigenous populations through an Indigenous lens. Most research done on Indigenous peoples has minimal Indigenous leadership or input and through a serious of questions the IQAT can discern whether the research is of good quality from an Indigenous standpoint. This allows for the reader to understand that not all research is beneficial to Indigenous people and adds a layer of actionability and accountability.

2.6 Strength-based research

Currently there is a deficit-based discourse that sustains negative attitudes and beliefs about Indigenous peoples. For instance, Indigenous population health research has historically been and continues to be pathologizing, often framing Indigenous people as a problem to be solved (Bryant et al., 2021). The consequences of this can perpetuate negative attitudes toward Indigenous peoples. Hyett et al describe how,

> Deficit-based research can contribute to stigmatization when problematic health issues are repeatedly characterized in the context of a specific population. Additionally, when any given health deficit is repetitively associated with Indigenous Peoples through research, there is risk of

> stereotyping. Unfortunately, due to a lack of critical exposure in education and media, deficit-based research given without proper framing can perpetuate negative characterizations of Indigenous Peoples (p.104)"

An example of this deficit-based approach is the emphasis researchers have on intergenerational trauma. When exploring the literature on intergenerational trauma, one can find numerous publications on 'ill' or 'sick' Indigenous people and how the trauma that is passed down from one generation to the next is at the root of it. When searching for the intergenerational strengths of Indigenous communities, there is far less literature. In talking with Elders in the community, it was brought up early in my research journey that current research is overly focused on what is wrong in the community, and they emphasized that my research must not follow that path.

I recognize that the wâhkôtowin methodology requires establishing and upholding good relationships. I have also made a conscious decision to implement a strength-based approach within this research. While I acknowledge that there are unmet needs within Indigenous communities, my research is seeking to challenge the deficit-based discourse by sharing the strengths of the community. These strengths include, but are not limited to, kinship, culture, traditional knowledges, inter-connectedness, and unconditional support. These are the strengths we must honor and build from to address the negative health outcomes in the community.

2.7 Data collection

Engaging with, and collecting qualitative data from, individuals, families and professionals associated with autism in the First Nations context, offered unique and informative perspectives on the strengths and challenges of what it means to experience autism within these communities, along with ways to supportively move forward. Learning about the perspectives of families from Indigenous communities is essential to ensuring meaningful and equitable access to supports and services. Similarly important is developing authentic partnerships that emphasize the leadership, expertise, and priorities of the community. Such were priorities in this research.

The first step in data collection explored traditional and cultural understandings of autism. This phase included qualitatively interviewing knowledge keepers in Maskwacîs. It should be noted that there is a certain way to approach traditional knowledge and knowledge keepers. I offered protocol, in this case tobacco, and followed the guidance of the MAAC. With input from the Six Nations of the Grand River Child and Youth Health team, it was decided to not attempt to follow Haudenosaunee as this could be viewed as disrespectful coming from an outsider. This guidance included Elder recruitment and understandings of cultural protocol. Protocol can be described as a spiritual agreement between the one receiving knowledge or guidance, and the one providing knowledge or guidance, usually an Elder or knowledge keeper, with the transfer of tobacco.

The next phase of data collection included interviews at the local level with families with lived experience of autism to gain insights into their experiences, challenges and successes. Consistent with CLR, this project organically evolved to fit and respond to the knowledge advancement priorities of the community as they arose. For example, the research questions were developed in partnership with the MAAC, rather than showing up with pre-determined questions. Our initial idea was to interview Autistic adults, but with community input we quickly learned this would be challenging as many adults did not live in the community anymore due to lack of services. This approach honors decolonizing research methods—a priority of this initiative in working with First Nations communities.

In respect for communities and the priorities of the research, a sampling plan rooted in wâhkôtowin was deemed essential. Sampling was all done on a voluntary basis and potential participants were only contacted once for a possible interview to respect their privacy and preferences to engage or not engage in the research. Moreover, we used a relational sampling method which invited maximal diversity and opportunities for inclusion in sampling and processes for participant recruitment (Moser & Korstjens, 2018). Relational sampling adheres to the principles of wâhkôtowin by allowing for the researcher to build and maintain relationships with participants that go beyond the conventional interviewer/interviewee praxis by allowing for back-and-forth dialogue and possible follow up engagements. Along with relational sampling, we used snowball sampling. Snowball sampling is when participants are asked to identify other potential participants (Parker et al., 2019).

Relational sampling requires access to information rich informants, in this instance, with lived experience of autism. It was seen that the relational approach was well-suited to our aim of exploratory inquiry and engaging key stakeholders. The MAAC identified key informants relative to the focus of the research (Ghaljaie, Naderifar, & Goli, 2017). For the Elders study recruitment was done primarily through word of mouth. Elders were asked about their connection to autism to gauge if they were a good fit for interviews. Not all Elders who were asked agreed to participate but would often identify another potential Elder to interview. For the caregiver study there was greater need to place more effort into recruitment; hence, the development of a community-based social media campaign. For the caregiver study social media channels local to both communities were used for recruitment, but with commenting turned off to adhere to and honour confidentiality of participants (see appendices). Due to social media bots and fake accounts all participants who were interested in conducting an interview were screened for eligibility, which included asking community specific questions to indicate if they were genuinely from the community or just a bot. After it was ascertained, the participant was interested an interview was set up.

In partnership with MAAC we developed semi-structured interview guides for the Elders study and for the Caregivers. In developing the guides, I engaged both with the MAAC and SNCYH to have the interview guides reflect the wants and needs of the community (see appendices). Their feedback provided valuable feedback and ensured any ableist language and beliefs were worked through and taken out of the guide. Data collected first with the Elders study starting in Summer 2022 and the caregiver's data started in Winter 2023. We felt the Elders study could inform the caregiver study and should be done first. Data analysis was done concurrently as data collection to validate the interview guides and so we could focus in on certain topics if need be.

Semi-structured interviews enable reciprocity for a rich discussion and flexibility, allowing the researcher and participants to improvise during the interview process (Kallio et al., 2016). All interviews were audio recorded**,** transcribed verbatim and coded/managed with the support of ATLAS.Ti data management and analysis software. I conducted the analysis and used the Sweetgrass Method which relationally brings together knowledges, experiences, and stories. This analysis of the qualitative data in each arm of the study was done with the research aims and questions in mind. The research process was iterative to allow for a flexible and community-mediated approach in the aim of community-relevant, yet also robust approaches and results deeply reflected in the data. As a means of enhancing rigor, the MAAC and participants were given an opportunity to provide feedback on emerging learnings from the study, during the analysis phase. Analysis included perspectives from the nêhiyaw worldview and language, reflecting the cultural background and context of these communities, including the development of the Sweetgrass Method of data collection and analysis outlined below. The sweetgrass analysis method was developed with community and specifically for this thesis. Early in the research process I recognized that western data analysis methods are not sufficient or appropriate and after some reflection and numerous conversations with knowledge keepers in the community, the concept of sweetgrass data analysis method was developed.

2.8 Indigenous qualitative analysis methods

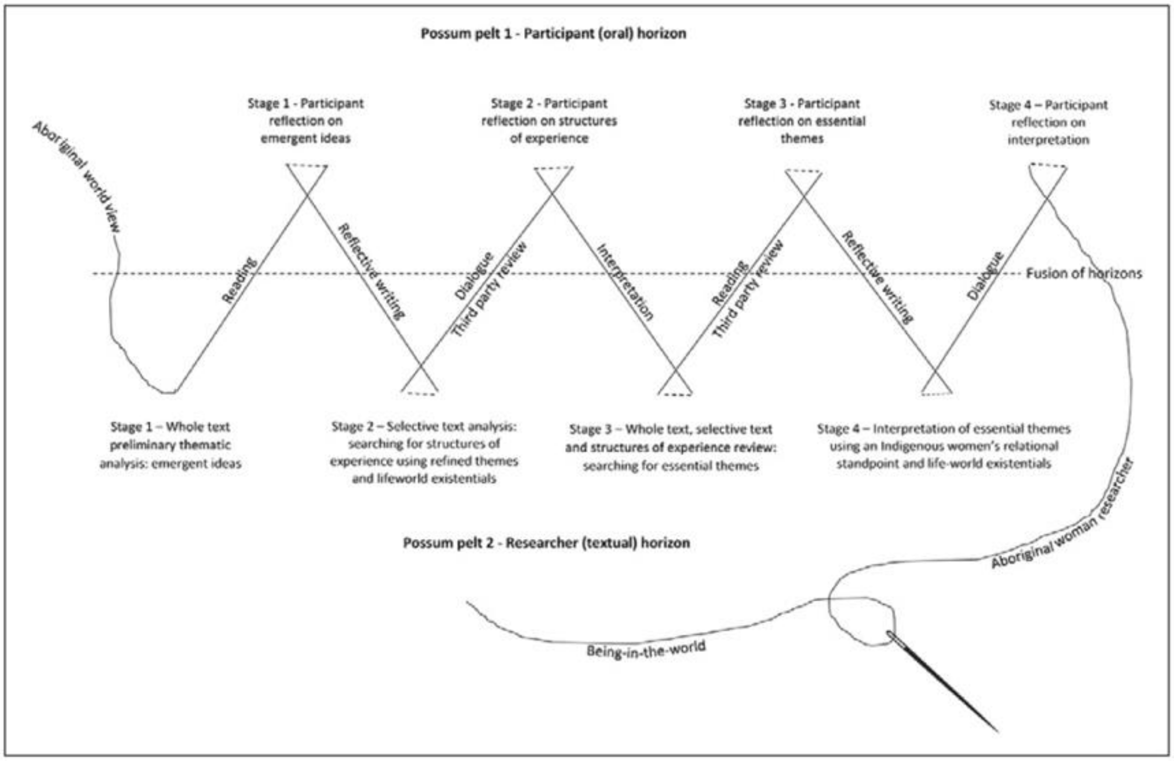
The academic literature on Indigenous data analysis techniques is limited. Indigenous scholars often grapple with having to analyze their research via western research tools and approaches which do not align with Indigenous ways of knowing or doing. The last three decades have seen a shift among Indigenous researchers from all over the world developing research methodologies and methods that are rooted in their own Indigenous cultures, values, and belief systems (Smith, 2013). Indigenous academics have continually sought to define research and look for new ways to approach research that is not only able to interface with western research paradigms but that can also standalone without the problematic Eurocentric research approaches which are seen as extractive and harmful (Smith, 2013). Western qualitative analysis often fails to adequately represent Indigenous worldviews and can further marginalize Indigenous voices by forcing Indigenous data into western paradigms. Decolonizing qualitative data analysis methods, as an ongoing work, has challenged and will continue to challenge colonial structures and provide space for Indigenous scholars by centering Indigenous ways of knowing and wisdom seeking (Thambinathan & Kinsella, 2021).

Several key elements are needed when approaching data collection and analysis from an Indigenous worldview. Indigenous knowledge encompasses three separate but connected processes: empirical observation, traditional teaching, and revelation (Castellano, 2000).

Empirical observation is the convergence of perspectives and knowledges over time, for example, on Indigenous medicines such as sweetgrass. Traditional teaching is the ancestral knowledges that have been, are and will be passed down from one generation to the next such as the medicinal properties of sweetgrass and the sacred story of how sweetgrass was gifted to humans. Revelation encompasses the belief that all things are interconnected in research including the physical, emotional, mental and spiritual dimensions (Castellano, 2000).

Indigenous scholars recognize the lack of qualitative research methods that represent culturally-specific Indigenous worldviews (Simonds & Christopher, 2013), and it is also argued that some Indigenous knowledges are generalizable and can be used with other knowledge systems (Agrawal, 1995). An example of such a qualitative research method is that developed by Indigenous scholar Shawana Andrews (2021) who is from the Palawa Trawlwoolway clan in Tasmania. Andrews recognizes the secular and linear nature of western methods and how Indigenous research methods are interconnected, spiritual, and operate at the dimensions of space and time. It is through this understanding that Andrews offers the Herringbone stitch model as Andrews describes and illustrates (see figure 2), “Herringbone stitch model employs the material practice as a metaphor for knowledge generation and negotiation through several hermeneutic key concepts: ‘being-in-the-world’, ‘fore-structure’, ‘life-world existential themes’, the ‘hermeneutic cycle’ and ‘fusion of horizons’” (p, 943).

Figure 1. Herringbone stitch model



Andrews demonstrates how this model is interfaced with western methods and explains the approach through the Cloaked in Strength study. This study explores Indigenous women's experiences with family violence. The Herringbone stitch's three main parts are the twine, the stitch, and the pelt. The twine is the standpoint from which the researcher is situated, the stitch outlines the cyclical and iterative process of the research, and the pelt is when the research comes together, and new knowledge is created.

Andrews situates the Herringbone stitch model and connects it to a western method and describes the "research interface as that in which to establish new and innovative constructs about, and relationships with, knowledge and research" (p. 942). The interface here connects this method to a western method and the Herringbone stitch model is used for the qualitative analysis. Andrews outlines the challenges and successes of implementing an Indigenous data analysis method and how it is critical to account for the inherent contradictions between Indigenous and Western research paradigms that require meaningful and careful dialogue. While the Herringbone stitch model is an effective qualitative analysis method in the context of Andrews' cultural protocols it would not align with nêhiyaw protocols. I personally have not heard of or used anything from a herring and when I brought this to the Elders in my community they shared the same sentiment. Ultimately this model outlines the successful application of an Indigenous qualitative analysis method and how the results generated are reflective of Indigenous ways of knowing and being and shows the appropriateness of using an Indigenous method for Indigenous qualitative data. While the Herringbone stitch model is an appropriate data analysis technique in the context of the Indigenous worldview in Tasmania, its application in the context of nêhiyaw culture would not be suitable, rather it serves as a good example of how to develop a decolonized data analysis technique in the context of localized Indigenous knowledges and traditions.

As a nêhiyaw person, I am mindful that the data I am collecting goes beyond western reductionist approaches to research that aims to take data and pull it apart to make sense of it; rather, in an Indigenous worldview, it is important to build connections between the data, the participants, and the community. The participants are gifting me their knowledges and expertise as a community. I must carry these stories with the utmost respect. There is also the responsibility of recognizing the interconnectedness of the participants and community.

In the nêhiyaw worldview sweetgrass is one of the four sacred medicines (see figure 2), which also includes tobacco, sage, and cedar. These medicines are used in ceremonies and have healing properties that go beyond the physical realm. There are nêhiyaw specific stories that are told of how kise manitou (the gentle Creator) gifted sweetgrass to the people. Sweetgrass has a sweet aroma to it hence its name. I will not be sharing these stories here as they are sacred and certain protocols are to be followed, but what I can say is that I was gifted the sweetgrass story by an Elder in Maskwacîs and it is powerful. Sweetgrass is considered medicinal and has healing properties both physically and spiritually. Within this context, the potentially healing nature of research in the context of the sweetgrass approach has not been explored adequately in the literature but happens in several key areas during the sweetgrass method process. Picking sweetgrass symbolizes or metaphorically depicts elements of the research process. These will be further described below.

Figure 2. Sweetgrass photo

2.9 Sweetgrass Method phases

To more fully comprehend the Sweetgrass Method to data analysis, the researcher must accept Indigenous knowledge as valid and resist the positivist belief that research is objective and neutral (Lincoln, 2000). While it is also argued that western methods are sometimes incompatible with Indigenous ways of being and knowing, they may be woven in as long as they fit the axiology, ontology, and axiology of the Indigenous paradigm (S. Wilson, 2008). These commitments were sought in the attempt to develop an Indigenous qualitative data analysis method and adhere to Western standards of qualitative research within this research.

The Sweetgrass Method goes beyond mere analysis and recognizes the interconnectedness of the data collection, analysis, and dissemination, and how each phase of the research informs the others. In this section the process of sweetgrass picking and ceremonial use will be symbolized through various research processes outlined above. The Sweetgrass Method honours the sacred knowledge that is being gifted through research.

The first phase of this approach is to set an intention and to smudge to cleanse your spirit of negative energy before you go sweetgrass picking. Smudging is usually done with one of the four sacred medicines, but there are other medicinal smudges as well. When you smudge you usually offer a prayer or meditation and give thanks to the Creator or universe, and it is through this appreciation that the researcher grounds themselves to bring balance to their physical, emotional, mental, and spiritual dimensions. Before any data collection I would smudge and make sure I set a positive intent through prayer and meditation. This phase would also include identifying and reaching out to potential participants through the appropriate channels. In our research we relied on the MAAC and SNCYHT to ascertain families in each community respectively to volunteer and conduct an interview.

The second phase involves offering protocol or tobacco to participants for their knowledge. In this cases protocol could also be monetary, such as gift cards. It is important to keep in mind that not everyone practices these traditions so this would need to be determined on a case-by-case basis. Tobacco could be offered directly to the participant or offered at ceremony such as a sweat lodge on behalf of the participants. When picking sweetgrass you would give thanks to the sweetgrass for offering its life and allowing you to use the sweetgrass later for medicinal and ceremonial purposes. Then you would put the tobacco on the ground to reciprocate and bring balance to the environment. In my case, and in the context of research, I shared my own experiences as a participant and as a father, community member, and researcher. This allows the researcher to connect with the participant and honor the relationship between them.

The third phase is to gather the sweetgrass, or in applying this to research contexts, conduct the qualitative interview. When gathering sweetgrass you need to be mindful and seek to not be distracted. The ability to stay present while picking sweetgrass is essential to staying in balance within the ceremony. You must also be gentle when picking sweetgrass and pick from the root while being sure to leave the base of the sweetgrass intact so that it may grow in future seasons. While conducting interviews, every story, experience, and perspective that is shared is considered a blade of sweetgrass. Once you have a bundle of sweetgrass, or reach data saturation, you can stop picking or stop interviewing, usually when there is no new information being give or now new participants volunteering. During the interview the researcher must be reflexive and conduct themself in the spirit of wâhkôtowin. This means prioritizing the relationship of the participant over the research. If they are uncomfortable or non-responsive, then the researcher must respect that and not be pushy or forceful. It is important to honor the participant and allow them to share their knowledge on their own terms.

The fourth phase is to clean and separate the blades sweetgrass or transcribe the interviews and start to see connections within the data. Data collection and analysis is done concurrently, thus allowing the researcher to stay flexible on what needs to be explored through the interviews. Interview transcription is done by hand and transcribed verbatim which provides the researcher an intimate understanding of the data. The sweetgrass or data must also be cleaned at this phase. Not all strands of sweetgrass will be a part of the braid, but you would keep all the sweetgrass and use it for other purposes. This phase would be considered when the sweetgrass is brought together, but not yet braided. The researcher should be able to see broad connections within the sweetgrass bundle or data.

The fifth phase is the braiding of sweetgrass or the data analysis phase. The first time you try to braid sweetgrass you are not going to have a straight or tight braid, and it might take several attempts. The researcher must be rigorous and will have to go over the interviews more than once and re-braid the sweetgrass multiple times, akin to how the researcher repeatedly goes through the data through data collection, transcribing and analysis. In this phase the researcher will notice that there are three distinct strands in the braid and each of these strands represents a collection of similar stories or experiences. Each strand is a different but connected theme and when braided together becomes a sweetgrass braid or the results of the qualitative data. Another dynamic that happens within the braid is a collection of stories and experiences reflective of what participants have shared or touched on as the most important topics discussed. These would constitute another layer of connectedness between participants and their knowledge, and these would be woven throughout the braid. Ultimately these blades of sweetgrass or experiences are woven throughout the entire braid and further reinforce the connections within the data.

The sixth phase is the bring the braid together and share the braid or knowledge back with the participants and stakeholders for feedback. In this phase the stakeholders such as the MAAC and SNCYH were given the opportunity to provide their perspectives on the findings. This opportunity for community feedback and sharing can be done in several ways including a presentation or a written document. Obtaining feedback from stakeholders should also be done more than once. Broader community feedback is also important, and this can be done by sharing the results with the broader community. The community will have the final say on whether the sweetgrass braid, or results of the research, is deemed shareable or publishable. This is a key to step in practicing wâhkôtowin and adds to the methodological rigor.

Sweetgrass picking is often done in groups and there are those with more experience who give guidance to those with less experience. Throughout the data collection process the researcher will ask for guidance from their mentors or supervisor throughout the process. There were several opportunities for academic supervisors and community advisors to give feedback throughout the entire process including on the interview guide, analysis, and sharing of results. Sweetgrass is much stronger as a braid than as one blade of grass; the strength of the braid comes from the interconnectedness of the grass, much like the strength of the stories when they are brought together. When stories and experiences are brought together and can find connection, they are formidable. As noted, sweetgrass is also medicinal and has healing properties. The researcher may go through their own healing process when following this method.

Sweetgrass is used by many Indigenous peoples and therefore this data analysis method can potentially be used by Indigenous researchers from different nations. The method could also be used by non-Indigenous researchers who are open to Indigenous ways of being and doing as well as if they have earned the right to use Indigenous methods. The Sweetgrass Method has some similarities to other qualitative analysis methods. As an example, thematic analysis is a six-step iterative process and includes familiarization, creating codes, constructing themes, reviewing themes, describing themes and subthemes, and producing a report (Braun & Clarke, 2012). While these steps may include complementary components to the ones outlined in sweetgrass method there are some key differences. The Sweetgrass Method is comprehensive and includes additional stages before and after data collection and analysis. This can be attributed to adhering the wâhkôtowin and acknowledging all parts of the research process as interconnected and building off each other.

There is also the medicinal or healing element of the sweetgrass method that provides space for everyone involved in the research to learn from and connect with one another. For example, the interviews created a space of connection between researcher and participant that allowed for reciprocation of experiences and knowledge which could be of benefits to both parties. Sharing this knowledge with the community can act as a healing opportunity through knowledge mobilization and dissemination. Teachings on the knowledges emerging from the research may contribute to a family's overall wellbeing by creating cultural and social connections and they may feel less alone and empowered. Knowledge sharing and mobilization are important features of the Sweetgrass Method. Knowledge sharing is akin to lighting sweetgrass with a match. The smoke or smudge represents when the research is disseminated more broadly to families and community, and this will be outlined below.

2.10 Relational knowledge mobilization strategy

An integrated knowledge mobilization strategy was used throughout the research process including active involvement of key community members and leaders in all phases of the research. Some community members such as the MAAC were more involved than others, for example, during autism-related knowledge mobilization activities such as a monthly autism support groups where the attendees were engaged less formally. Accordingly, early in the research process community members were informed of the research and invited to convey priorities and processes that would advance knowledge about autism and its application in the community and beyond. I had numerous discussions with key members of the community to plan and reflect on each part of the study. We will also share key learnings with other Indigenous communities that may be grappling with similar issues related to autism in their own community and social contexts.

I engaged with health and other service providers in the health care region (including at the Glenrose Rehabilitation Hospital and the regional diagnostic centre) and with Autism Edmonton, Autism Society of Alberta, and the Canadian Autism Alliance to ensure that the research was led with the expertise of those with a lived experience of autism and their families. These engagements were critical in that they reinforced the need for research on autism in First Nations communities. We have presented these learnings as capacity-building for key groups across Canada, such as autism organizations. This teaching has taken place from the beginning of the research and as more knowledge has been generated. There were also opportunities to engage with multiple levels of government at the band, federal, provincial, and municipal levels including with Members of Parliament, Members of the Legislative Assembly, and Chief and Councils.

One of the main strengths of this research is having the ability to reciprocate what is being shared by the community, such as data for Indigenous communities' traditional knowledge and experiences. Historically, the relationship between Indigenous communities and outsiders has been one sided, with the researcher reaping the benefits of the research such as funding, publications and career promotion, without substantial benefits experienced by the community (Minkler, 2005). Commonly, there is also a dubious lack of sustainable relationship building in such research due to the funding mechanisms within institutional models which leads to a power imbalance by prioritizing the researchers' time and deadlines over community priorities (Duke, 2020). These power imbalances create an environment that is not conducive to relationship sustainability that goes beyond the research project. In contrast, activities supporting the community that were implemented as a part of this research included a monthly autism support group, a sensory friendly ceremony, a sensory teepee at a powwow, and two documentaries which will be examined in the discussion chapter.

As a community member who has relations with others in the community, spanning multiple generations, I feel that I am accountable to the community in ways that outside researchers cannot comprehend. As a nêhiyaw, I understand how we are relational people and there are responsibilities I carry to ensure I am upholding these relationships in respectful and appropriate ways. Throughout the PhD journey I have looked for opportunities to give back. It is through these opportunities I have consistently taken guidance from the community and applied it to the work.

2.11 Conclusion

Weaving wâhkôtowin throughout all facets of this research is essential to building a research project that is reflective of the nêhiyaw worldview. The weaving takes place with and within the ethical space of engagement, CBPR and CLR principles, decolonized methods such as the Sweetgrass Method, and reciprocal knowledge mobilization. Wâhkôtowin acknowledges all the relationships in the research journey and in this research, has laid the foundation for a project that is relational and reflective of the communities and families. Ultimately, I set out to address the tension between western methodologies and Indigenous ways of being and knowing. This research has aimed, and continues to aim, to address these challenges and adhere to the nêhiyaw worldview throughout the entire process by connecting with nêhiyaw concepts such as wâhkôtowin. The next chapter discusses the scoping review, referred to earlier, that collated and explored literature on Indigenous people and autism in the context of Canada. Note that these chapters are developed to be stand-alone papers; hence, there may be some repetition of introductory ideas and definitions.

Chapter 3: Scoping Review

3.1 Introduction

The DSM-5 characterizes autism as having difficulties with communication, social deficits, and restricted, repetitive behaviors and interests (American Psychiatric Association, 2013). It is widely recognized that autism occurs in all populations, including Indigenous populations. The prevalence of autism in Indigenous communities in Canada is currently unknown and there is minimal academic literature on lived experience related to autism in cultural contexts within Canada (Lindblom, 2014). Globally, autism research has disproportionately focussed on the biomedical and clinical aspects of autism rather than public health or social aspects (Pellicano & den Houting, 2022).

Canada's Constitution recognizes three distinct Indigenous groups, First Nations, Métis, and Inuit. There are 1.8 million Indigenous people, accounting for 5.0% of the total population in Canada (Stats Canada, 2021), including 600 First Nations and 70 different languages, numerous Métis groups, and 50 Inuit groups. The experiences of Indigenous peoples are complex, distinct and unique. The experiences of Indigenous people in Canada are further influenced by Section 35 of *Canada's Constitution,* geography, legal status, and other colonial experiences including systems such as child welfare, education, and the justice system.

Indigenous peoples in Canada have poorer health outcomes, social inequalities, and reduced access to services all of which reflect destructive colonial legislation and policies. Relative to the mainstream Canadian population, Indigenous populations have significantly higher rates of child mortality, maternal morbidity, infectious disease burdens, higher rates of malnutrition, substance abuse, lifestyle-related chronic diseases and conditions, accidents, homicide, violence and suicide, and have a shorter life expectancy (Barnabe, 2021; Gracey &

King, 2009; Smylie & Anderson, 2006; Wilson & Young, 2008). Colonial policies such as the *Indian Act* of 1876, which outlawed cultural practices, including ceremonies, and enacted the residential school system, are still being felt in First Nations communities across Canada. Specifically, the *Indian Act* stipulates that the federal health minister has overarching power over 'mentally incompetent Indians' (Bartlett, 1977), which today includes Autistic Indigenous people.

3.2 Terminology

Terminology in both Indigenous and Autistic communities is constantly evolving and dynamic. *Indigenous* is a catch-all term that is appropriate in some cases such as when describing broad concepts or ideas; however, when working with Indigenous communities it is best to be specific, such as using tribal or community membership. The terms 'Aboriginal', 'Native' and 'Indian' are outdated and only used in some instances, such as when exploring historical literature or legal definitions such as 'Status Indian'.

Autism also has an evolving terminology (Monk et al., 2022b), and for this review we will be using identity first language such as 'Autistic person' rather than 'person with autism'. We will also be using the term 'autism' rather than 'autism spectrum disorder' or ASD.

3.3 Research Questions

1. What is known about autism in Indigenous communities in Canada in the literature?
2. What are the areas of focus of published research on autism and Indigenous peoples in Canada?
3. What is the quality of research on autism in Indigenous communities in Canada?

3.4 Methods

Scoping reviews are used to identify the types of available evidence in a given field; to clarify key concepts or definitions in the literature; to examine how research is conducted on a certain topic or field; to identify key characteristics or factors related to a concept; to serve as a precursor to a systematic review; and to identify and analyze knowledge gaps (Munn et al., 2018). According to Arksey and O'Malley (2005) there are 4 stages in scoping review: Stage 1: identifying the research question; Stage 2: identifying relevant studies; Stage 3: study selection; Stage 4: charting the data; and Stage 5: collating, summarizing and reporting the results. Some reviews assess quality and we have adapted this sixth stage of analyzing quality, using the Indigenous Quality Assessment Tool (IQAT) (Harfield et al., 2020). For this review, we will be using the PRISMA Extension for Scoping Reviews (PRISMA-ScR) through Covidence (Tricco et al., 2018).

3.5 Protocol and registration

A scoping review protocol was developed and registered with the Open Science Framework in April 2022. The title was "Indigenous Autism in Canada: A Scoping Review" (Bruno, 2022).

3.6 Inclusion and exclusion criteria

We included records that have a component specific to Indigenous peoples (First Nations, Métis, Inuit) and disability, with some focus on autism. Records had to be in Canada or have a significant component about the Canadian context. Records relating to Indigenous people in Canada and disability more generally, that mentioned autism in one or more sections, were also included. Theses and dissertations were included, given the dearth of information on our research topic in the conventional literature.

Records that did not have a primary or substantial focus on autism (e.g., studies of other developmental disabilities in Indigenous peoples) were not included. Records that studied autism but without a substantial focus on Indigenous populations were also excluded. Records in which non-Indigenous and Indigenous Autistic participants could not be differentiated were removed. Publications that mentioned Indigenous populations in Canada and autism but did not detail the context were excluded. The context here includes demographic factors such as what Indigenous populations were studied (e.g. First Nations, Métis, or Inuit). Publications such as conference abstracts, book reviews, and news media were also screened out. Study inclusion was decided by the two reviewers and if there were any discrepancies, both reviewers met and reached consensus on whether to include or exclude the article.

3.7 Information sources & article search/retrieval

A health sciences librarian was consulted to assist in developing a search strategy and identify keywords and databases relevant to our research question. As suggested by Arksey and O'Malley (2005), we were flexible and iterative in using search terms and in creating our final search strategy. The aim was to capture the broadest possible selection of papers in this area of study. The search terms represent associated keyword combinations of autism, Indigenous communities, and Canada (see Table 1). Two authors, GB and TC, performed an extensive systematic search to find articles within the specified criteria. Databases searched were: MEDLINE, CINAHL, ERIC, PsycINFO, Web of Science, Cochrane Library, PubMed, and Google Scholar. Additionally, the authors included North American Indigenous research databases: iPortal (Indigenous Studies Portal - University of Saskatchewan), Circumpolar Health Bibliographic Database, Bibliography of Native North Americans, and Native Health Database. Each database was queried using Boolean or database-specific operators. Database searches were limited to articles published in English between 2000 and 2022.

Table 1. Search terms used for the database searches

Concept	Keywords Used

Autism	Autis*, Asperge*, ASD, PDD, PDD-NOS, pervasive development disorder, childhood disintegrative disorder, Autistic disorder, Kanner
Indigenous	Indigenous, Aboriginal, Premières Nations, First Nations, Metis, on-reserve, off-reserve, Athapaskan, Saulteaux, Wakashan, Cree, Dene, Inuit, Inuk, Inuvialuit, Haida, Ktunaxa, Tsimshian, Gitsxan, Nisga'a, Haisla, Heiltsuk, Oweenkeno, Kwakwaka'wakw, Nuu chah nulth, Tsilhqot'in, Dakelh, Wet'suwet'en, Sekani, Dunne-za, Dene, Tahltan, Kaska, Tagish, Tutchone, Nuxalk, Salish, Stl'atlimc, Nlaka'pamux, Okanagan, Secwépemc, Tlingit, Anishinaabe, Blackfoot, Nakoda, Tasttine, Tsuu T'inia, Gwich'in, Hän, Tagish, Tutchone, Algonquin, Nipissing, Ojibwa, Potawatomi, Innu, Maliseet, Mi'kmaq, Micmac, Passamaquoddy, Haudenosaunee, Cayuga, Mohawk, Oneida, Onodaga, Seneca, Tuscarora, Wyandot
Canada	Canad*, North Americ*, British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, Quebec, Nova Scotia, New Brunswick, Newfoundland, Labrador, Prince Edward Island, Yukon Territory, NWT, Northwest Territories, Nunavut, Nunavik, Nunatsiavut, NunatuKavu

*Denotes truncation/stemming

3.8 The selection of sources of evidence

Study selection process was based on the strategy outlined by Arksey and O'Malley (2005) and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) framework (Tricco et al., 2018).

All references and abstracts were imported and screened using Covidence, a web-based software for systematic and scoping reviews. Both authors independently reviewed all sources in two stages (title and abstract review followed by full-text review) for inclusion based on the content matter of articles and their relevance to the research questions and inclusion/exclusion criteria. Covidence automatically generated Cohen's kappa coefficients (κ) to determine interrater agreement. Proportional agreement, the rate at which both reviewers voted the same way, was also recorded by Covidence. Any discrepancies between authors on the eligibility of articles for inclusion were discussed and resolved through consensus.

3.9 Data charting process

With initial guidance from a librarian for the search strategy, data was compiled and charted for synthesis by GB and TC through Covidence. Covidence is an online tool that supports and organizes reviews for better research outcomes. Through the data charting process, the authors met regularly to discuss the findings and maintained constant contact. Finally, between the two authors, a data extraction template was created and implemented to chart the following categories of data: author(s) name, year of publication, type of publication, was the article peer-reviewed, Indigenous authorship, Indigenous involvement, situatedness of the work within colonialism, study focus, study design, study funding, recommendations to move forward, was the article strength or deficit-based. Specific data on socioeconomic status and educational attainment levels was not recorded.

3.10 Indigenous Quality Assessment Tool

The Aboriginal and Torres Strait Islander Quality Assessment Tool is a research instrument that allows for a standardized approach to examine research pertaining to Indigenous peoples (Hartfield et al., 2020). Fourteen questions are used to appraise quality–from an Aboriginal and Torres Strait Islander perspective–with respect to research governance, community engagement, regard for cultural and intellectual property, and capacity building. For this review, the IQAT was adapted from ‘Aboriginal and Torres Strait’ to ‘Indigenous’ to fit the context within Canada. It was integrated as a part of the review process to measure and assess how Indigenous people have been engaged and included in the research. While the Indigenous Quality Assessment Tool (IQAT) is a relatively new research instrument, it provides valuable insight into the quality and process of research that has taken place. Two reviewers (GB and TC) independently appraised each article using the adapted IQAT and resolved any disagreements through consensus. Studies were assessed as high quality if they met at least 10 out of the 14 appraisal questions, moderate quality for 6 to 9, and low quality at 5 or less, based on previous uses of the IQAT in literature (Christidis et al., 2021).

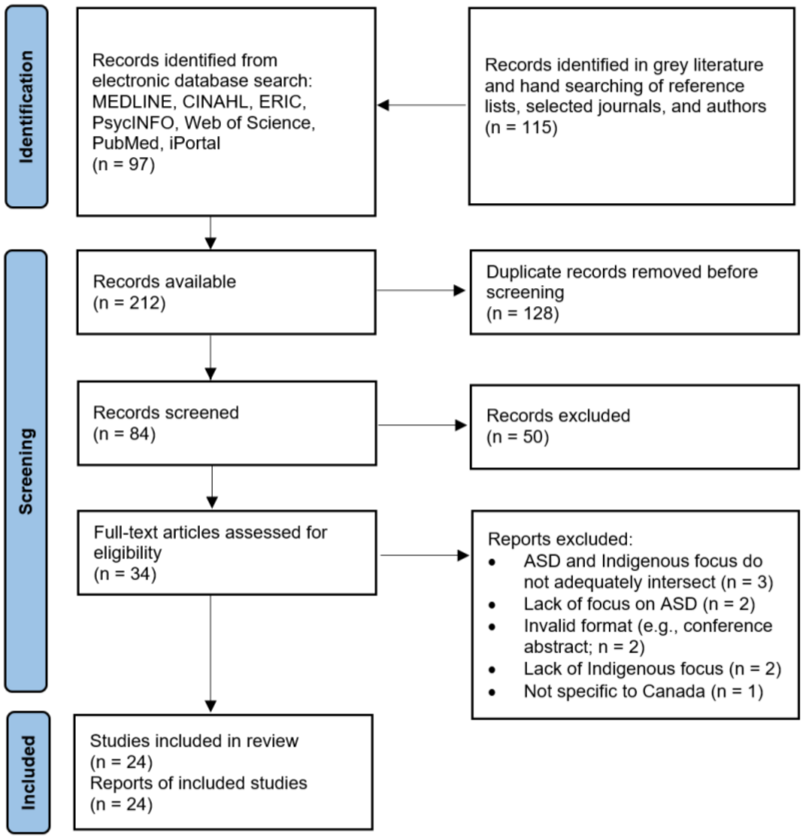
3.11 Community involvement

The lead author GB is nêhiyaw (Plains Cree), a registered member of Samson Cree Nation, and a parent to Autistic children. TC is a non-Indigenous settler, with experience as a researcher and registered social worker with family caregivers. This review was also brought to the Autism Society of Alberta's Indigenous Relations Circle for their feedback and guidance. This circle is made up of Indigenous Autistics, parents to Autistic children, autism service providers, autism researchers, and those with an interest, professional or personal or both, in autism. The Circle meets monthly to discuss autism in Indigenous communities and uses those learnings to advocate as well as plan cultural events for Indigenous Autistics and their families.

3.12 Selection of sources of evidence

The initial database search yielded 212 articles; after removing 128 duplicates, 84 articles remained. Both authors independently screened out 50 articles through title and abstract review. From the remaining sources ($n = 34$), the authors excluded 10 through full-text review as they did not meet the inclusion criteria (e.g., irrelevant study, lack of Canadian context). A total sample of 24 articles met the criteria for this scoping review (see Fig. 1: PRISMA flowchart). There was a substantial interrater agreement ($\kappa = 0.633$) and high proportional agreement (81.81%) observed during the initial title and abstract screening. This level of concordance was sustained during the full-text review ($\kappa = 0.655$; 84.38% proportional agreement). Aggregate summaries of study characteristics (see table 2) and quality (see table 3) were generated in tabular format. Any disagreements on inclusion were resolved by consulting with one of the other authors.

Figure 3. PRISMA flow diagram showing document retrieval and selection process



3.13 Characteristics of sources of evidence

Table 2. Characteristics of selected articles.

Characteristic	Studies *n (%)*
Year of Publication	
2006-2010	4 (16.67)
2011-2015	4 (16.67)
2016-2020	10 (41.67)
2021-2022	6 (25.00)
Peer-Reviewed	
Yes	15 (62.50)
No	9 (37.50)
Type of Publication	

Academic Journal Article	14 (58.33)
Peer-Reviewed Research Methods Case Report	1 (4.17)
Grey Literature: Dissertation	1 (4.17)
Grey Literature: Policy, Planning, or Commentary	2 (8.34)
Grey Literature: Program Evaluation or Engagement Summary	5 (20.83)
Grey Literature: Research Poster	1 (4.17)
Research Methodology Type	
Peer-Reviewed	
Qualitative Research	4 (16.67)
Quantitative Research	2 (8.33)
Literature Reviews	6 (25.00)
Unapplicable (Commentary & Theory Article)	3 (12.50)
Grey Literature	
Qualitative Project	3 (12.50)
Quantitative Project	1 (4.17)
Mixed Methods Project	3 (12.50)
Unapplicable (Literature search & Program/Resource Guide)	2 (8.33)
Location of Interest in Article	
Canada	22 (91.67)
International (including Canada)	2 (8.33)
Indigenous Focus (FNMI)	
All (First Nations, Metis, Inuit)	14 (58.33)
First Nations	9 (37.50)
First Nations & Metis	1 (4.17)
Self-Identified Indigenous Authorship	
Yes	7 (29.17)
No	17 (70.83)
Indigenous Involvement in Developing & Implementing Study	
Full Involvement	3 (12.50)
Substantial Involvement	7 (29.17)
No Involvement	10 (41.67)
Uncertain	4 (16.67)
Research Situated Within Context of Colonialism	
Yes	13 (54.17)
No	11 (45.83)
Discussion Included Strengths-Based Insights	
Yes	12 (50.00)
No	10 (41.67)
Unsure	2 (8.33)

Table 3. Quality Assessment Tool results from selected articles

	Response Type

Questions	*Yes (%)*	*Partially (%)*	*No (%)*	*Unclear (%)*
1. Did the research respond to a need or priority determined by the community?	7 (29.17)	10 (41.67)	3 (12.5)	4 (16.67)
2. Was community consultation and engagement appropriately inclusive?	5 (20.83)	3 (12.5)	13 (54.17)	3 (12.5)
3. Did the research have Indigenous research leadership?	4 (16.67)	5 (20.83)	12 (50.00)	3 (12.5)
4. Did the research have Indigenous governance?	3 (12.5)	0 (0.00)	20 (83.33)	1 (4.17)
5. Were local community protocols respected and followed?	4 (16.67)	1 (4.17)	14 (58.33)	5 (20.83)
6. Did the researchers negotiate agreements with regards to rights of access to Indigenous peoples existing intellectual and cultural property?	0 (0.00)	1 (4.17)	16 (66.67)	7 (29.17)
7. Did the researchers negotiate agreements to protect Indigenous ownership of intellectual and cultural property created through the research?	1 (4.17)	1 (4.17)	17 (70.83)	5 (20.83)
8. Did Indigenous peoples and communities have control over the collection and management of research materials?	1 (4.17)	3 (12.5)	18 (75.00)	2 (8.33)
9. Was the research guided by an Indigenous research paradigm?	4 (16.67)	1 (4.17)	18 (75.00)	1 (4.17)
10. Does the research take a strengths-based approach, acknowledging and moving beyond practices that have harmed Indigenous peoples in the past?	7 (29.17)	5 (20.83)	11 (45.83)	1 (4.17)

11. Did the researchers plan and translate the findings into sustainable changes in policy and/or practice?	6 (25.00)	9 (37.50)	8 (33.33)	1 (4.17)
12. Did the research benefit the participants and Indigenous communities?	3 (12.5)	4 (16.67)	5 (20.83)	12 (50.00)
13. Did the research demonstrate capacity strengthening for Indigenous individuals?	2 (8.33)	7 (29.17)	15 (62.50)	0 (0.00)
14. Did everyone involved in the research have opportunities to learn from each other?	8 (33.33)	3 (12.5)	9 (37.50)	4 (16.67)

3.14 General characteristics

Overall, most articles focused solely on Indigenous peoples and autism specific to Canada, with only 2 (Shochet et al., 2020; Simpson, 2021) taking an international focus. Within Canada, the majority had a pan Indigenous focus (Antony et al., 2022; Burstyn et al., 2010; Canadian Academy of Health Sciences, 2022; Canadian Autism Partnership Project, 2017; Coo et al., 2012; Di Pietro & Illes, 2014; Di Pietro & Illes, 2016; El-Hayek, 2007; Gerlach et al., 2022; Inman, 2019; Shochet et al., 2020; Simpson, 2021; Stavropoulou-Kampoukou, 2019; Virginia Lane, 2022), with some focusing strictly on First Nations (Auerbach, 2007; Cowessess First Nation, 2021; Lindblom, 2014, 2016, 2017a, 2017b; Manitoba First Nations Child and Family Services, 2017; Woodgate et al., 2013), and one with a Métis focus (which also included First Nations) (Thompson, 2012). No articles focused on Inuit populations. Of the 24 articles, 7 included self-identified Indigenous authorship or co-authorship and none self-identified Autistic authors.

Of the 24 articles, 15 were peer reviewed (Antony et al., 2022; Burstyn et al., 2010; Canadian Academy of Health Sciences, 2022; Di Pietro & Illes, 2014; Di Pietro & Illes, 2016; El-Hayek, 2007; Gerlach et al., 2022; Inman, 2019; Lindblom, 2014, 2017a, 2017b; Ouellette-Kuntz et al., 2006; Shochet et al., 2020; Simpson, 2021; Thompson, 2012) and 9 were either unclear (Lindblom, 2016, 2017c) or considered grey literature (Auerbach, 2007; Canadian Autism Partnership Project, 2017; Cowessess First Nation, 2021; Manitoba First Nations Child and Family Services, 2017; Stavropoulou-Kampoukou, 2019; Virginia Lane, 2022; Woodgate et al., 2013). None of the articles had Autistic authorship, or any Autistic persons identified as partners.

The aim was to answer the following research questions; 1. What is known about autism in Indigenous communities in Canada from the literature?; 2. What are the areas of focus of published research on autism and Indigenous peoples in Canada?; 3.What is the quality of research on autism in Indigenous communities in Canada?

3.15 Research question 1

Overall, there was limited literature on autism and Indigenous peoples in Canada. The main theme that was identified was that there is a severe gap in the literature on autism and Indigenous peoples specific to Canada. Several articles pointed toward the need for data and research to be done on autism in Indigenous communities, but it was not clear who should, or how that research was to be conducted.

Only 3 articles were considered to have full involvement in the planning and execution of the research with Indigenous peoples (Cowessess First Nation, 2021; Gerlach et al., 2022; Manitoba First Nations Child and Family Services, 2017). Of these three articles two were community reports (Cowessess First Nation, 2021; Manitoba First Nations Child and Family Services, 2017).

Most of the focus in this literature was on all Indigenous peoples, First Nations were noted second most frequently. No literature exclusively focused on Inuit people. When using a pan Indigenous approach, caution is needed as not all research findings can be applied broadly. Indigenous peoples across Canada have distinct historical and cultural differences that may be influenced by language, legislation and geography, just to name a few. For example, in Inman's (Inman, 2019) article on FASD there are statements that generalize Indigenous populations. While it is understood that FASD does affect Indigenous populations at a higher level, Indigenous people are not a monolith and FASD may present, or be misdiagnosed, at varying rates among the different First Nations, Métis, or Inuit populations.

There were a total of five reports with two of them being community reports (Cowessess First Nation, 2021; Manitoba First Nations Child and Family Services, 2017) and three having a national focus (Canadian Academy of Health Sciences, 2022; Canadian Autism Partnership Project, 2017; Virginia Lane, 2022). These reports provided valuable insights about the experiences of autism in Indigenous communities. For example, the Cowessess First Nation community report (2021) qualitatively explored community experiences of autism and outlined the nêhiyaw (Plains Cree) cultural understanding of autism. Although the community report was not peer reviewed it provides important insights into an Indigenous, specifically nêhiyaw, worldview on autism. The report explores several definitions of autism outlined below,

- ka-kamawaci-iyinisit: given a unique quiet spiritual intelligence
- pihtos-mânitonihk-iyinisit: given different way of thinking in its own spiritual intelligent
- ê-mihkosit pihtos mânitonicihkan: given different way of spiritual thinking

- ê-mihkosit pihtos ê-si-waskawiht: given the gift of moving a different way or being (characteristic/behavior) (p. 3)

3.16 Research question 2

All but two articles had some focus on program delivery. The programs described in the literature addressed special education (Auerbach, 2007; Manitoba First Nations Child and Family Services, 2017), barriers to diagnoses, early diagnosis, and misdiagnosis (Burstyn et al., 2010; Canadian Academy of Health Sciences, 2022; Canadian Autism Partnership Project, 2017; Inman, 2019; Lindblom, 2014; Ouellette-Kuntz et al., 2006), lack of culturally informed services and cultural understandings of autism (Antony et al., 2022; Lindblom, 2017a; Shochet et al., 2020; Thompson, 2012), negative systemic impacts and stereotyping (Gerlach et al., 2022), and considerations related to reduced access to services and funding (Lindblom, 2017b; Simpson, 2021).

A key finding being explored is that there are discrepancies as to whether Indigenous children have inequitable access to services such as diagnostic assessment, intervention supports, and the influence of geography and legal status. Specifically, Lindblom (2017c) argues that First Nations children who live on reserve have less access to resources and support than those who do not live on reserve. There are several reasons for the lack of services on reserves, but Lindblom (2017) argues the primary barrier is the jurisdictional disputes between the provincial and federal government related to service access.

The majority of the literature had some focus on the experiences of autism with the exception of five articles (Burstyn et al., 2010; Di Pietro & Illes, 2014; El-Hayek, 2007; Ouellette-Kuntz et al., 2006; Stavropoulou-Kampoukou, 2019). Di Pietro's & Illes (2016) noted the realities of being a member of the Autistic community, but also outlined a way to move forward: "all participants affirmed that engagement in autism spectrum disorder health research can only take place if the outcomes of research directly benefit the communities. Such outcomes must be focused on improving access to health care and services. Under these circumstances, they predicted that trust in non-Aboriginal neurodevelopmental disorder researchers would follow" (p. 246). Lindblom's (2017b) article also explored the negative experiences of raising an Autistic child on a reserve and how some families traveled upwards of 300 km to access diagnostic services. However, the author also highlighted how incorporating First Nations culture, such as drumming, into the child's life promoted better overall wellbeing and provided a space for the family to feel connected.

3.17 Research question 3

Indeed, a dearth of research reports that included primary data were observed in this review, with just under half of all included articles (n = 11) being a review, report, or commentary. Of the remaining articles which reported primary research, six were not led by Indigenous people. Primary research identified in this review, such as community reports, tended to use relationship-based methodologies and frameworks that were culturally responsive to Indigenous communities. Examples included ethnography (Lindblom, 2014; Lindblom, 2017) and *Touchstones of Hope* (Manitoba First Nations Child and Family Services, 2017) which include a set of principles guiding reconciliation, fostering relationships, and facilitating conversations on systems reform.

None of the articles met all the criteria for the IQAT, with the majority of the articles scoring in the low range. The highest scoring article achieved "yes" in 11 out of the 14 categories (Manitoba First Nations Child and Family Services, 2017), followed by 10 out of 14 (Cowessess First Nation, 2021), and then 7 out of 14 (Lindblom, 2017a; Woodgate et al., 2013). Overall, 2 studies were assessed as high quality, 3 as moderate quality, and 19 as low quality. Two criteria that were met more consistently were ‘responding to the need or priority by the community’ (yes = 7, partially = 10), and whether the researchers planned on translating the findings into sustainable changes in policy and practice (yes = 6, partially = 9). In most articles, it was unclear whether there was information relevant to scoring the IQAT that was left out during the peer review process. Criteria 6 (yes = 0, partially = 1), 7 (yes = 0, partially = 1) and 8 (yes = 1, partially = 3), which focused on Indigenous research and data ownership, consistently scored poorly during this review. Questions focusing on the inclusion of governance (no = 20) and use of an Indigenous research paradigm (no = 18) scored the lowest. Lastly, the criteria on whether the research directly benefitted Indigenous communities scored as the most challenging to appraise (unclear = 12) during this review.

3.18 Discussion

Our aim was to explore, gather, collate, and analyze all the known literature on autism in Indigenous communities specific to Canada. Overall, we found that not only is there a severe gap in the literature on autism and Indigenous communities, but the quality of the literature would also be considered low from an Indigenous standpoint, based on the IQAT. When examining the literature, it is important to maintain a critical lens and recognize that findings may not be truly representative of what is happening in Indigenous communities. This review also amplifies a critical need for Indigenous community-led research to be established with a focus on autism. Indigenous Autistics and communities are largely being left out of the research process and thus the results of current research can be problematic. Funding organizations and researchers will need to rethink their approaches to be more inclusive, with the aim of results that are reflective of Autistic Indigenous peoples’ wants and needs. It is not surprising that the community or

Indigenous-led literature scored better on the IQAT, and this can be attributed to communities being able to lead the research and generate results that reflect the true wants and needs of the community.

Our findings are like another scoping review done recently in the context of Indigenous autism and Canada. Although Gerlach et al's (2022) scoping review examined the same literature in a similar context, the results of that review and the current review have some key differences. Gerlach's review explored Indigenous autism from a social work perspective with the following research questions; "what is known about autism diagnosis and prevalence in Indigenous communities in Canada?; What is known about how autism is perceived by Indigenous peoples in Canada?; What is known about the intersections of autism, the child protection system in Canada and Indigenous communities?" (p. 7). While these research questions were like those in our scoping review and the two reviews included much of the same literature, the two reviews produced different results. Whereas the current review covered both the findings and the quality of the research, Gerlach's review explored content with little examination on the quality. This is an important distinction because when those making decisions for Autistic Indigenous children and families such as government, policy makers, service providers or other supports, this current review, and through the application of IQAT, cautions against using the current Indigenous autism literature in Canada as a reliable source. Rather the gaps identified in this review argue for more Indigenous-led and high-quality research into autism. It is not surprising that each of the IQAT criteria were aligned with research agreements, ownership, and control of the research as western research often has power imbalances that benefit the researcher and not the researched.

The poor scores of reviewed studies on the IQAT highlights a critical need for Indigenous-led research in autism in Canada. As Indigenous autism research moves forward, institutions and research communities must provide equitable opportunities to Indigenous peoples and specially, Indigenous Autistics to lead the research or engage as full partners. The lack of Indigenous input can be attributed to many factors including the lack of awareness about autism in First Nations communities, lack of research capacity for Indigenous people, or ongoing mistrust Indigenous peoples of research institutions (Blanchet Garneau et al., 2021). While Gerlach et al's review provides important insights into the themes of the literature, an additional review is important for corroborating and ensuring reliability of current knowledge in this area.

Canada has a history of human rights abuses against Indigenous children including children with disabilities. In 2007 the First Nations Child and Family Caring Society (FNCFCS) of Canada and the Assembly of First Nations (AFN) brought forward allegations that the federal government had discriminated against First Nations children under the *Canadian Human Rights Act* (Blackstock, 2016). The FNCFCS and AFN successfully argued that the crown discriminated against First Nations children in a flawed child welfare system, which includes disability services and supports. In 2016 the Human Rights Tribunal agreed that Canada was indeed discriminating based on race, yet until recently the federal government ignored this ruling. As Canada attempts to move forward in reconciliation with Indigenous peoples it is important to recognize the historical and contemporary injustices Indigenous children continue to face.

There have been similar reviews done in other countries with the two most notable being Australia and New Zealand. In Bailey & Arciuli's (2020) scoping review the authors explored the existing and emerging themes of autism in Indigenous communities in Australia. They identified similar barriers that Autistic families face in Canada such as no access to diagnostic services, misdiagnoses, lack of autism data, and recommendations to improve the lives of Indigenous Autistics in Australia. Moreover, in Tupou et al's (2021) scoping review on autism in Māori communities in New Zealand, their findings determine differences cultural understandings, similar to what the Cowessess community report explored. This scoping review also observed the need for better diagnostic services and supports.

These reports exemplify what can be done when the community is able to take the lead on their own research interests. The community reports represented the communities in a way that traditional peer reviewed articles could not. When contrasting the findings of this scoping review with the others done in Canada, Australia, and New Zealand, the findings, i.e., emergent themes, were similar, which included challenges to diagnosis, different understandings of autism, and lack of research in this area. All the scoping reviews highlighted the critical need for culturally informed services and supports for Indigenous Autistics.

Despite the challenges outlined earlier, Indigenous communities and families in Canada demonstrate strength and resilience in supporting Autistic family members. Indigenous communities are impacted by centuries of ongoing destruction that has its roots in colonialism, yet they are also the result of generational resiliency that has been passed down. Amidst systemic and day to day problems, Indigenous people practice their culture, speak their languages, and stay connected through kinship. These strengths offer important pathways by which Indigenous families can support Autistic relatives.

3.19 Limitations

Scoping reviews are used to capture the breadth of a body of literature. In this review, despite an extensive and thorough search strategy, much of what emerged was grey literature. We further acknowledge that we could have missed research that was not properly indexed or easily identifiable. The adapted Indigenous IQAT was specifically developed to apply to studies about Indigenous peoples; however, we recognize it emerged from another part of the world. Despite this potential limitation, the IQAT exceeds what is typical of a scoping review and appeared to add important study evaluation. Notably, the IQAT only considers what is put into the manuscript at the time of publication and some details may be left out due to word limits or journal submission requirements. Due to the limited amount of available literature, this review used a pan Indigenous approach and we recognize the limitations of doing so.

3.20 Recommendations

Key findings emerging from this review were that Indigenous autism research is currently limited as a whole and that there is a lack of Indigenous-led peer reviewed autism research based in Indigenous communities. While these findings are concerning, there is also a unique opportunity to prioritize community research capacity. Indigenous communities have often been on the receiving end of research. Conversely, creating space for Indigenous people and communities to lead their own research is an area that should be prioritized moving forward. Building meaningful partnerships with Indigenous communities and providing opportunities for community members to lead and guide this research in meaningful ways will provide much needed literature that truly reflects the wants and needs of Indigenous communities.

The community report done by Cowessess First Nation provides powerful insights into cultural understandings of autism. Moving forward, there will need to be more opportunities to explore different understandings of autism that may challenge the western biomedical model. Autism is often framed as a deficit or in negative terms; in some cases, as something to be solved or fixed. The Cowessess report offered an Indigenous approach that is more inclusive and less ‘othering’. Accordingly, an Indigenous approach may be critically useful in addressing the stigma associated with autism and that currently imposes barriers that might potentially challenge an individual or family to pursue an autism diagnosis.

Antony et al's (2022) recent article outlines five actionable items for improving the lives of Autistic Indigenous people: 1. Develop an Indigenous autism engagement framework that recognizes and honors the diversity of Indigenous peoples across Canada; 2. Assess the barriers to healthcare including diagnostic assessment, services provision, socioeconomic considerations, and overall mistrust of the health care system; 3. Partner with Indigenous communities and organizations to collect data and evidence to understand autism prevalence and the lived experience of autism in Indigenous communities; 4. Explore what Indigenous-led and culturally safe services, assessments, and interventions would look like; and 5. Provide equitable funding across Canada for Indigenous communities and organizations to provide culturally safe autism services, appropriate autism assessments, autism awareness and education (p. 08). If implemented, these recommendations would contribute to more equitable opportunities for Indigenous Autistic people and their families and potentially ameliorate some of the challenges Indigenous communities and families face.

3.21 Conclusions

To our knowledge, this is the first scoping review on autism and Indigenous people in Canada that is fully led by Indigenous people and has been brought back to the community for them to offer their perspectives. We also used the IQAT to evaluate the literature from an Indigenous perspective. Future research in the area of Indigenous peoples and autism in Canada must have substantial Indigenous input that respects their worldviews, rights, and knowledges. While shifts are occurring in western views of autism, this work amplifies differences in how autism is perceived in western and Indigenous lenses. Finally, this review shows that there is an urgent and critical need for Indigenous-led and high-quality research that explores both the prevalence and lived experiences of autism in Indigenous communities across Canada.

Chapter 4: Elders Study

4.1 Introduction and overview

This study offers Elders' perspective on autism. All data collection was done in the spirit of wâhkôtowin. Persons in the community are an Elder when they reach the age of 65 years or when the community accepts them as an Elder. Our aim was to gain qualitative insights of autism from an Elder and nêhiyaw perspective. This study focussed on nêhiyaw understandings of autism, so the participants had to identify as such. All interviews were done in person and the interview guide was developed in partnership with the MAAC, although it was used sparingly as the Elders preferred a more conversational style of interview that allowed for rich and organic discussion. Recruitment was done through a relational, purposeful and snowball approach.

Analysis was done with the Sweetgrass Method. As discussed in chapter 2, this method consists of six phases: 1) set an intent and smudge, 2) offer protocol or tobacco to participants for their knowledge, 3) gather the sweetgrass or conduct the qualitative interview, 4) transcribe the interviews and start to see connections between the data or blades of sweetgrass, 5) braid the sweetgrass or analyze the data, 6) bring the braid together and share the braid or knowledge back with the participants and stakeholders for feedback.

The Elders study was an exploration of their knowledges and perspectives of autism from a nêhiyaw perspective. All participants were considered Elders by the community and while some were not from the community, they all had some connection to Maskwacîs or were nêhiyaw. They each had a connection to autism whether it was having a child or family member who was on the spectrum, working with Autistic people, or knowing of autism in the community. A total of 13 Elders participated in interviews, and one interview was done with an Elder and their Autistic adult child. The average age of the Elders was 64.8 years and most (n = 8) lived on reserve whereas some (n = 5) lived off reserve. but due to the small population size of Maskwacîs there was no other demographic information collected for confidentiality reasons. The Elders talked about their historical experiences with autism, current realities of autism, and ways forward, and every Elder touched on acceptance, the importance of language, children as gifts, and autism as a gift.

4.2 Historical experiences with autism

4.2.1 Impact of colonialism

The Elders talked about how colonialism brought many things to the community such as "illness", "loss of language and culture", and how "colonization killed many medicine people." The destructive policies of colonialism included "the introduction of organized religion" and it was later noted that "Christianity took [our teachings] away from us…and your ways are no longer relevant". An Elder also spoke about how they remember that their "mother was in the Charles Camsell Indian Hospital right from start" and how they were brought up by their grandparents and raised in a traditional way and learned the language. The Charles Camsell Indian Hospital was a segregated hospital located in Edmonton, Alberta, and many children from all over western and northern Canada were admitted to that hospital, sometimes never to be heard from or seen again.

The Elders also felt it was important to understand the impact of colonialism, and specifically, the impact of residential schools in Maskwacîs and how people in the community "are products of the residential school. So, keep in mind what that institution did, to change the psyche, to change the nature of the mind, as the creator had intended it you know, it's broken, so now that must be fixed."

An Elder talked about the roles of men in the community and how in “the old days our young men would go fast for their wives, so they'd have good births. And that was part of who we were [relative to] the child even before the child came into this earth; we would do that. So, there was many things we did that were taken away from us or pushed away and told that we weren't allowed to do these things because of Christianity”. While it is important to acknowledge the harm that colonialism has brought to Maskwacîs there are still Elders in the community who bring traditional teachings to their homes and families, and still “speak their language” and “maintain tradition”.

4.2.2 Residential school experiences

As mentioned in the introductory chapter, Maskwacîs used to be home to the Hobbema Residential School, and the community is still dealing with the negative impacts today. Elders often talked about their childhood experiences at the residential school, and one explained “how can people be so cruel, but during that era, in the 1940’s and 50’s, it was much different with the introduction of Christianity, our way was the way of the devil, that’s how everything was taught to us. The language we speak was from the devil”, and this was often used as a justification from the priests and nuns to abuse children in residential schools.

An Elder discussed how Autistic children were taken from the schools and the community and how “those kids were not acceptable to the school; they were all sent away. Where? I don’t really know, and half the time I don’t believe the parents knew”. Later in the interview the Elder further explained, “[Indian Affairs] decided if your child was in good shape, you can keep the child, but if there was a malfunction or handicap in one way or another, Indian Affairs would take that child”. Another Elder talked about the abuse and mistreatment an Autistic child would face,

> If you think about it, in residential schools, Autistic behaviour was frowned upon. It was so bad, if you are left-handed then you were serving the devil, so they made you right-handed, like that kind of medieval thinking, but could you imagine how an Autistic child who was in residential school and how they would look at that child and how he or she was treated?
>
> - Elder 3

Elders spoke about how residential school experiences were a traumatic for all children, but for those with disabilities such as autism, it would most likely have been a death sentence, as one Elder explains "how many children have been buried or have been murdered because they were 'different'". Children who were sent away and not heard from again — speaks to the horrific policies and actions toward Autistic children in residential schools and how, if the child was "handicapped" in any way then "Indian Affairs would take [that] child". Despite experiencing abuse and cruelty, students still managed to support each other including children who may have been Autistic,

> We were all one big family in that school, we all took care of each other. So, some [children] did not speak right, but we took those kids. I had a friend, he was about 10 or 11, and I helped him right along, you know, because I was raised that way.
>
> - Elder 3

The stories of Autistic children in residential school have not been shared or explored in a meaningful way, and this can be attributed to these children not surviving or simply disappearing without a trace, as well as there being minimal diagnostic access and assessment in that era. Despite the challenges that the Elders faced in residential schools, they were able to provide their powerful stories and share their painful experiences with the belief that we can better support Autistic people in the community.

4.2.3 Autism historically

Elders often spoke about autism in a historical context and reflected on whether they have noticed a rise in autism prevalence. One Elder shared, “do I see a rise in autism? I don’t think so. I think that we are being assessed, that’s why I see a rise, we weren’t being assessed otherwise. I think autism was always there, but we just didn’t know”. The same Elder also reflected on how they felt they were being stereotyped as being an alcoholic, during a development assessment on their child, done in the 1980’s, and how powerless they felt in these situations, with the added risk of their children being misdiagnosed due these negative stereotypes,

> The questionnaire I filled out was about my parenting and my history, but when I read the assessment, it indicated that I had a trouble with alcohol, and I was an alcoholic. And I told them, that's not true. I don't drink. So, I don't consume alcohol, but they wouldn't change it. So, I just said, "well, I know it's not true. So, I'm just gonna let it go". Because, you know, I can’t fight this system of people of psychologists back then.
>
> - Elder 4

Another Elder stated that if children with disabilities were supported properly, their quality of life could be improved. They reflected that “[we] had a mute boy who could not hear, but we all helped him with writing, we had no sign language, but we helped him and he’s still living today and he’s thriving. He had a good life”. The support that Elders in the community gave each other during the residential school era was key to them living a good quality of life later on, and they felt Autistic people should receive that same strong level of support.

4.2.4 Traditional parenting

The role and impact of traditional parenting was often discussed by Elders. One Elder talked about how traditionally, the entire community would have been involved with parenting a child, but due to the influence of colonialism, this parenting approach has been lost, “it was the whole kinship, the wâhkôtowin…and I still maintain that tradition, and as far as parenting, everybody used to be involved. Nowadays there's a lot of single parent homes.” Another Elder explains because of residential schools, many of these teachings have been lost and a new dysfunctional approach was established and now “[they] spoil their grandchildren, now watch what she created because they became alcoholics, they didn’t have to go to school, she did everything”, and the spoiling and not allowing for her grandchildren to work made them “emotional cripples”. Later in the interview, they reflected on the importance of ceremony in traditional parenting,

> I had the honor to be there when they were born to see them. But what I did prior to that is I went and fasted in the mountains for them. And for four days and four nights. And that was a really difficult, that's probably one of the most difficult fasts I ever had in my life.
>
> - Elder 11

The Elders identified different activities such as the importance of “play” and traditionally, there would have been specific activities for the boys and girls that would have supported their development. Elders also raised the importance of moss bags, with one Elder stating,

> the reason we put them in a moss bag is that they were in the belly so long and they were secure. Their world was complete. After they're born, they leave that environment and they come to us. So, then we put on the moss bag, and it is to continue the experience that is familiar to the child in the belly. So, you try and continue that. So, the child continues to develop.
>
> - Elder 2

Finally, the Elders emphasized the importance of the Nehiyawin language as a foundation to traditional teachings as one Elder describes,

> I think the language is really important and like I said, when I'm around others, I really feel like I should be speaking the language because I owe it to them. My ancestors, my grandparents, everyone, because a long time ago, we weren't

> allowed to speak it. So, I speak it at every opportunity. I pray and pray with my grandkids, and they repeat what I say.
>
> - Elder 9

An Elder further explained “we had an obligation to raise our children together and to teach them how to work and to teach them how to listen. To teach them manners, to teach them boundaries. And all these teachings are in the Cree language.” These teachings were often focused on neurotypical children but Elder felt if applied to Autistic children they would have the same positive effect.

Elders felt that despite their experiences in residential school there were still opportunities to raise Autistic children in the community with traditional Cree values, but they also felt that the culture was being lost due to the language not being taught enough in schools or at home. They also recognized that not all people in the community had access to an Elder or culture and there should be more community focus on rebuilding this connection.

4.3 Current realities of autism in First Nations communities

4.3.1 Experiences with autism

Elders often spoke about their personal experiences with autism in the community — as with their own children, grandchildren, or other families, as well in their place of employment. An Elder felt they still need to learn more about autism, stating,

> I'm not sure that I can make sense out of autism. Like I'm still in that stage where I'm trying to find out what is this? What effect does it have on children? What are the facts? What are what is the effect on parents? What are the different things that you need to know about communication?
>
> - Elder 5

Another Elder reflected that through their own grandchild, “what I've seen in Autistic children, is that they're super intelligent. And they're very capable once they master something. They're very good at what they do like my grandson does. He's a gamer, he develops games. He makes money from it and so long as he keeps doing that, I guess he's going to be kind of self-sufficient.” The Elder also recognized that Autistic people were often “loners” or “did not fit in anywhere”, and that “society does not have the configurations to provide for neurodivergent people”.

One Elder explained that their grandchild is “just a child that wants be loved and he wants to play”. These experiences are important as they provide a basis for coming to understand and accept autism in the community. Elders often talked about the need for more opportunities for children, and especially Autistic children, to be able to connect with Elders in the community for better cultural transmission.

4.3.2 Jurisdiction

The jurisdictional divide between the province and federal governments in service provision as well as the jurisdictions of the four nations in Maskwacîs was noted to create “barriers” such that families feel like they just get “turned away” when attempting to access services or supports. One Elder explained “[t]here's a lot of discrimination and I was even shocked to hear that there's a difference or discrepancy between the ability to access these things based on where, or whether you're on reserve or not, I didn't know, that sounds discriminatory in principle”. Elders also faced negative attitudes from government and described how legislation such as the *Indian Act* and the assimilationist policies that were implemented encourages these attitudes, “[t]he minute you’re one foot off the reserve, to the province, you have provincial dollars. The federal government is trying to push us off the reserves. They don't want reserves.” These types of racist beliefs and attitudes toward First Nations are entrenched in colonialism. Another Elder echoes this sentiment when they shared, “but once you take your child off the rez, you have access to provincial services and all that.” The Elders felt that there should be equal services for families living on reserve but the way the system is set up creates legislative barriers for those services to be established or maintained.

4.3.3 On and off reserve challenges

Building off the jurisdictional challenges, the Elders spoke about the challenges of living on reserve. One of the main challenges was the lack of services on reserve, as exemplified by an Elder who had heard of an Autistic child who was “a runner,” she started running away. They had to tie her around her waist with a rope and tie her to like a doorway, to make sure that she didn't go far. “Like I literally cried when they said that” and how the family shared “they had nobody.” Stories like this are common and expose the lack of community or social supports families face in First Nations communities and the desperate attempts to keep their children safe with makeshift or even harmful solutions.

Leaving the reserve for better access to clinical supports such as occupational therapists or speech language pathologists is common for families, but it often comes at the cost of leaving kinship and cultural supports. For example, an Elder illustrated the difficult choice (or rather, lack of choice) between staying or leaving the reserve in an anecdote about their own child and grandchild, “[they] thought about moving to [the city], because she said the resources there are better and I was kind a like, but we're all here, your support is all here”. Another difficult choice and dilemma for parents is whether to give up their child to the child welfare system because of the challenges families face with an Autistic child as one Elder explained,

> And those are the families that give up the children to child welfare and look at the family dynamics, which a couple that have special needs children and you look at the dynamics and the relationship between a man and a woman. It's strange because of finances because emotional stuff going on. And so how many families break up because a child is special needs and so they can't cope because they don't have the tools. They don't have the support. They don't have the resources on the reserve.

- Elder 13

4.3.4 Kinship support

Elders also share that one of the many strengths of living in a First Nations community is access to meaningful kinship supports, as one Elder explained relative to their life: “I know that sometimes my relatives would come and they'll stay a week or so, they'll pitch up a tent, and they'll just stay and visit and they'll do mutual things like gardening or berry picking, or other things as such,” and this shows that family is welcome to stay over and they were welcomed. Another Elder spoke about the kinship support they received and how “everybody was there to help my son, help me, give me a break, aunties took him home, friends took him home, to go and spend time with them. He went to visit his friends and sleepovers were common among our group, we all took turns having each other's boys over.” Elders often spoke about how important family support is as well as how we should “appreciate” and “learn to love one another” and how these relationships are key to supporting Autistic people in the community.

4.4 Ways Forward

4.4.1 Community Solutions

The Elders frequently talked about the importance of community supports and solutions and how we need “to go back to supporting families in our communities.” An Elder spoke about how we cannot wait for the federal, provincial, or Chief and Council levels of government to start working toward community solutions, and stated,

> we have to create it ourselves. We can't wait for Chief and Council to do it. We can't wait for other people to do it, and like I said, it always comes back to us as we want change, it always comes back to us. We have to look for funding to create a place for these children and to be able to accept that we have to do it ourselves.
>
> - Elder 5

Elders spoke about resources that are already established in the community such as the Maskwacîs Parents Place and how it was created “to address some of these community members whose children have a disability” and how they appreciated it was a grassroots initiative. Another community support that was identified was the MESC (Maskwacîs Education School Commission) and how it is a “place that parents could start”. MESC notably houses autism supports in the community and families whose children attend school on reserve have access to these services.

Elders often spoke about how community members support one other already – whether it is with transportation or childcare, and it is important to acknowledge this support and how “our people are good people that way. They look after one another and I just think it's beautiful — that it's a blessing to be born into an Indigenous community where we can focus on the language and culture and ceremony to help our children, so they feel valued and important.” The community support is essential for families to be able to raise their children, and while raising a family on the reserve does present some challenges, it is important to recognize the strengths in the community such as community supports.

4.4.2 Advice for parents

Elders often offered advice for families with Autistic children such as making “an effort to understand, not just to hear people talk, but to understand what it is they're talking about. Very important, because a lot of people sit there and listen, but as the old saying goes — in this ear and out the other ear”. When it comes to understanding autism and embracing autism, the Elders conveyed that the first step is learning how to listen and sit in that discomfort so that the parent can learn to be a parent to their child. An Elder explained that there is no cure for autism and to “quit trying to fix them because I thought to myself ‘is there a cure out there? Is there a medicine out there?'" and later the Elder explained "they just learned how to manage" and there was a shift from thinking that autism could be cured or fixed and how acceptance is the most important part. Trauma was often discussed by the Elders. They spoke about how due to trauma, one can find addiction and other types of dysfunctional of behaviors, but it is key for parents and caregivers to "sober up and take care of themselves" to be fully present with their families and this was especially important for caregivers of Autistic children as their children could have more complex needs.

4.4.3 Ceremony and culture

Ceremony and culture were frequently addressed by the Elders. They noted that ceremony and culture are key to the health and healing of community members. An Elder talked about raising a child and how "we know that many of our children are underdeveloped individuals because they never got a chance from the day they were born, to be welcomed in their language, to be welcomed in a teepee, to be born on the land." Ceremonies are powerful ways to establish family connections in the community, and one Elder reflected on a ceremony they participated in,

> There's also a ceremony and what I want to share, that just reminded me, it's called the circle of life. We take the baby, and we invite everybody to come in. The people that are hosting the ceremony will invite a traditional person to come and pray for this baby. There they'll bath the baby in cedar water or sweetgrass water depending on what you have, and invite the baby and Elder, the grandfather, will pray for this child and they will ask him "can you name this child?" and he will name this child. Here's how powerful the ceremony is. You invite people that you want in his child's life into the circle, and they make a circle, and they pass the child and say, "I'm going to teach you how to be a good student". The next one "I'm going to teach you how to hunt". So, they make these commitments to this child, everyone makes a commitment to this child as it goes around the circle and it's so powerful. I remember I was doing the ceremony and these two little boys said, "I'm going to be your protector", and he started crying and then the other little boy said the same thing. "I'm going to be your protector when you grow up". And he started crying, they felt

> that emotion. This is a ceremony of emotion and commitment to this child to bring this child up to be strong.
>
> - Elder 3

Protecting Autistic children was also brought up by an Elder who talked about how "we need to go back to traditional way of thinking and doing and protecting the children and also embracing the child's special needs". Culture and ceremony are viewed as the foundation from which we should develop supports and services in the community and this can be a powerful approach to creating a more inclusive community. An Elder shared that they were taught "we believe that the people with autism have, you're part of them as in the spirit world and I like to think of it as one foot in the spirit world and one foot in this world", and how Autistic people are here to teach us about the spiritual dimension of life if we are open minded and willing to accept that.

4.5 Braided throughout.

All of the Elders discussed the following themes, which were considered important enough to be highlighted as individual topics. When examining the braid of sweetgrass, these experiences, knowledges, and perspectives were braided throughout and are connected to all the other themes. The following themes are braided throughout the entire sweetgrass braid.

4.5.1 Acceptance

The Elders spoke about seeing and practicing acceptance of autism in the community and the Autistic person because "the child is a gift from the Creator" and "the Creator has given them those behaviours…I tell people in the western world that we're more accepting of Autistic people". This sentiment was echoed by another Elder who shared how they believe "if you're looking at special needs, and you look at [that] as a negative, that's going to flow in the way of the everyday life of how that child is going to live in this world. And so, if it's negative, then they're going to feel negative" and how if we shifted our perspective to a more "positive" view such as acceptance, the child is going to feel that as well. The Elder also spoke about how the Creator made these children the way they are, and they are here to teach us and show us their gifts,

> So, I think that we are so accepting. I never see children or people with disabilities as such, I see them as human beings first, I think that's the way we are because you've got to look back at creation, when the Creator gives us life, our creation stories. Where do they start? Where do we come from once, we're conceived? And how, what are we bestowed with to become a human being on this earth? Well, we're given gifts. We're given gifts by the ancestors — our Creator to come onto this earth and all elements of the earth participate. So, when you look at the child, you hear the Elders say, these are gifts loaned to us. So, I think that's how we see our children as gifts.
>
> - Elder 3

4.5.2 Language

The Elder felt that something that is missing and should be revitalized is nêhiyawin or the Cree language. The Elders often spoke about how nêhiyawin was missing despite it being taught in schools because "when they go home everyone speaks English" but "every child has a right to learn the language". An Elder also shared that the language is the "foundation from [which] everything works from", and another Elder spoke about how they speak the language at home "I owe it to my ancestors because they weren't allowed to speak it. So, I speak it at every opportunity, and I pray with my grandkids". Another Elder discussed how the "language is the spiritual base because it's the language the Creator gave us".

Language was seen as the foundation from which our culture and ceremonies start. It was viewed as the "spiritual door", and as such, it is critical for Autistic children to learn the language. One Elder shared "I started speaking Cree. I said [to my grandchild], let's say our prayers in Cree and so he's got his prayers down in Cree. And even now when I'm not there, he says his prayers in Cree. It's awesome.” Finally, the Elder also translated what it means to be a child in Cree and gave a Cree definition of autism, “our language is so key like I said, 'awâsis' is a child right. But 'awa' when we talk about something 'awa', it's spirit. Awa is well, it’s obvious, those are animate. 'Sis' at the end of a word makes a diminutive, like small. So 'awa' spirit 'sis' is little. So, a child is a little spirit,” then they shared “acahk is spirit. Yeah. I would think it would be how I would describe autism in terms of the 'acahk pimatsiwin', they live more in spirit."

4.5.3 Children as gifts

Elders often spoke about how children are closer to the Creator than adults, and how “the Creator has made them come into this world with such innocence, the viewpoint that they have. It's amazing how they look at the world through their eyes,” and having the ability to learn from children was key to learning about the world as children’s knowledges needs to be acknowledged and respected. The Elders also shared cultural teachings on children: “we need to learn how precious this spirit child is that is being on loan to us” and that our approach to children must be rooted in unconditional love and acceptance because we never know when the Creator may call the child home.

4.5.4 Autism as a gift

An Elder also spoke about how all children are “gifts” and “sacred” and how we must protect all children, but when it comes to Autistic children, we must be willing to “learn from them” as they have “gifts” other children do not have. All the Elders touched on the cultural knowledge that Autistic children were gifted in some way or another, and that these gifts need to be celebrated at home, in classrooms, at clinics, and in the community. One Elder shared that they appreciate the “idea of really looking at the spiritual aspect and the specialness, the giftedness that these children and adults bring to community. And like with my [grandchild], he's very spiritual and I support that.” The spiritual aspect of autism was common in the interviews and provides a foundation for families to understand autism in a way that is not stigmatizing. Ceremony was also brought up and as one Elder talked about a time when they participated in ceremony with an Autistic child: “ceremonies are based on spirit, so I knew he was going to be fine, Autistic children are sacred, and they know, and they can feel they know what's real.” The Elder felt that the Autistic child was more connected to the spirit world and when in ceremony, could feel or recognize spirits. Elders also spoke about how sometimes the gift is about what the parents are going to learn,

> [The parent] has been given a gift. This little boy has chosen the parents and has a spirit. He's been chosen with a gift and he himself is a spirit, has chosen to live on this earth as an Autistic person, because he's got something to give [them]. He's got something to teach us, and we are to learn from that, figure out what his gift is. What really made a difference was that his spirit chose us, his family, his parents, and that he chose to live as an Autistic person, because I got something to learn myself. At the same time, he's got something to teach the rest of the world and our job is to nurture that.
>
> - Elder 8

An Elder shared that they remember growing up as a child and their grandparents shared with them that “those [Autistic] kids were gifted…and told that their spirit is that gift within that spirit”. This cultural transmission from one generation to the next illustrates that autism was not seen as negative, and acceptance has been practiced for hundreds of years. But due to colonialism, these teaching have been lost or disrupted, yet despite this imposed disruption, long-held values related to autism nêhiyaw people have prevailed and continue to enrich their understanding of autism.

4.6 Discussion

The wisdom shared by the Elders provides valuable insights into the historical, social, and cultural dimensions of autism for nêhiyaw people. Themes reflected on historical experiences with autism, current realities of autism, and ways forward. Every Elder touched on acceptance, the importance of language, children as gifts, and autism as a gift. I am deeply grateful for this teaching and how these themes were so generously and thoroughly explored by the Elders.

Chapter 5: Caregivers Study

5.1 Introduction and overview

The caregivers study explored the experiences of caregivers in Maskwacîs and the Six Nations of the Grand River. Wâhkôtowin was woven throughout the data collection phase. Our aim was to gather and analyze the experiences of family caregivers of Autistic children. Interviews were done via phone, in person, or on Zoom depending on what the caregiver preferred. Recruitment was done through a relational purposeful and snowball sampling. This initial approach did not yield enough participants; hence we implemented a social media campaign via a poster distributed to local social media pages for both Maskwacîs and the Six Nations (see appendices).

All the participants were considered caregivers, but not all were biological parents. The participants included grandparents, kinship foster and adoptive parents, and biological parents. All caregivers were registered to either one of the four reserves in Maskwacîs or a member of the Six Nations of the Grand River. Due to the relatively small sizes of Maskwacîs and Six Nations limited demographic information is recorded (see table 4). A total of 14 interviews took place. All the caregivers' children had a diagnosis or were on the waitlist to be assessed.

Analysis was done using the Sweetgrass Method. As discussed in chapter 2 this method consists of six phases 1) set an intent and smudge, 2) offer protocol or tobacco to participants for their knowledge, 3) gather the sweetgrass or conduct the qualitative interview, 4) transcribe the interviews and look for connections between the data or blades of sweetgrass, 5) braid the sweetgrass or analysis of data, 6) bring the braid together and share the braid or knowledge back with the participants and stakeholders for feedback.

Caregivers from both communities shared both the challenges and opportunities of raising an Autistic child. The main themes that emerged were caregiver experiences, caregiver perspectives on their child, growth transformation, and ways forward. All the participating caregivers discussed these themes which are braided throughout school experiences, service access/lack of access, ableism, culture, language, and ceremony. Caregivers frequently shared the challenges and strengths of raising Autistic children. Although they felt more should be done to better ensure autism supports and services, caregivers also strongly recognized the gifts their children bring, and often talked about the cultural and community dynamics of autism.

Caregivers often reflected on the acceptance of autism that they have experienced in the community but felt there is more that could be done particularly around schooling and addressing ableism in the community. Further, there are also some key similarities and differences between caregiver experience in both communities which will be explored below.

Table 4. Caregiver demographics

Caregivers	Maskwacîs (n = 8), Six Nations (n = 6)
Age of Child	1 - 6 (n = 4), 7 – 12 (n = 8), 13 – 17 (n – 2)
Caregiver Gender	Women (n = 13), men (n = 1)
Sex of Child	Girl (n = 0), boy (n = 14)
Relationship Status	Married/common law (n = 4), single (n = 10)
Residence	On reserve (n = 9), off reserve (n = 5)

5.2 Caregiver experiences

5.2.1 Lack of understanding

Caregivers often talked about a lack of understanding about autism. Such gaps were described to be experienced in both communities. They expressed the need for more awareness of autism in the educational and healthcare systems and in the community overall. One caregiver who had a background as a healthcare professional, discussed how they "had very little training in autism and when my son was showing signs, like, I would go to my colleagues and say, you know, do you think this is autism? My son is doing this, and there was a very stereotypical view of it still, where it was like, "oh, does he hug you? Oh, no, he doesn't have autism. If he hugs you, he doesn't have autism." Caregivers felt that such stereotypes often create barriers for Autistic children to participate fully in society and reflect the presumptions among those who do not understand autism. These misjudgments are based on stereotypical behaviors such as being disruptive or the inability to listen or take direction.

Caregivers called for training about autism particularly for first responders, aiming for greater understanding and increased safety for the Autistic persons. A caregiver spoke about an incident where their child "took off" and how the "the attitude they got from the police officers was not understanding" and how they felt the police blamed them for their child's behavior. Caregivers further stated that in trying to make sense of was going on with their child, they experienced a sense relief when someone, including healthcare professionals, would simply listen to them or validate how they felt. One caregiver commented, "it was the first time the psychiatrist acknowledged our struggles" and the caregiver told them, "thank you for acknowledging it."

5.2.2 Exhaustion and burnout

Caregivers shared their experiences on how challenging providing care to an Autistic child can be felt strongly and unless you have experience with providing care to an Autistic child, you would have a difficult time fully understanding their experience,

> it's hard for people to kind of understand, and I've experienced it myself going from a parent, like parenting a neurotypical child, and parenting a child with autism. I see the difference, and I see, like the challenges, and I fully believe that you will not understand what it's like to parent a child with autism until you're parenting a child with autism.
>
> - Caregiver 8

Later in the interview that caregiver described what it is like to care for a child with extensive support needs, with implications for supporting the caregiver,

> Like, imagine that these parents, and these families that you're treating are almost in like a newborn stage of life. That's what it feels like to me is I feel like I'm constantly in that newborn bubble. That tired, hungry, like how do you help a parent of a newborn child? You take care of them, you let them rest, you, you know, offer them social support, you check in with them, ask them how they're doing, you know, you bring them a gift to let them know that you thought of them, you. You know, like all of those things. When I explain what my life looks like to people that don't have a child with high support needs. I say, imagine that day that you first brought your baby home, and you look at your life and you're like, oh my gosh, I don't know what I'm doing and every day, I wake up, and it's like, okay, I don't know what I'm doing because I don't know what today is going to entail and every day is a new day, and every day is a new blessing and a new challenge.
>
> - Caregiver 8

Caregivers further spoke about how their mental health had suffered and they may access “counselling” but still experience “depression”. They reflected on the support system or lack thereof. One caregiver shared that because they do not live on reserve, their “family supports are limited” and they “have been doing this challenge on their own.” Another caregiver talked about how their “family support has been wonderful; they have been the foundation of support since the beginning.” Kinship support seemed to be integral to caregivers’ ability to navigate what was described as an overwhelming experience of autism-based caregiving. This demonstrates that when such support is lacking, caregiving an Autistic child is much more challenging.

5.2.3 Day-to-day challenges

Caregivers often cited some of the day-to-day challenges they faced. One caregiver spoke about the challenges of getting their child to school every day and keeping them motivated to keep attending, stating, “where I'm struggling is, he doesn't want to go to school? I don't know, I don't know what other stops to pull out to try and get him back into school.” One caregiver talked about their child’s restrictive eating, and how “food is something else too. He's super, super, super fussy and he will not eat. It's very hard for us to find something that he would eat like, soups or something he can eat, but some of the other stuff he just can't eat or won't eat.” Sometimes caregivers felt like they could not do important activities such as grocery shopping or going to public parks because their child’s behavior,

> I still have a hard time taking them into public places like a park, a grocery store. I just kind of like to stay home, like if I did take them to a park, I take them to a park where there's nobody around. When I do take them to the grocery store, he likes to grab everything and put it in the car. And if something doesn’t go his way, he starts throwing tantrums and everybody's just looking at me. And half the time, I will just drop everything and put them in the car and go home and go grocery shopping another day.
>
> - Caregiver 2

5.2.4 Embracing the journey

The ability of caregivers to fully embrace what was happening in their lives was a key characteristic of being able to support their children through their developmental journey. A caregiver illustrated this perspective,

> …in the very early stages of this journey, I think there was a pivotal shift that happened to both me and [my partner], immediately after we received the

> diagnosis, because I remember very specifically we left the [assessment clinic] and it was, I guess, a shock once you receive that label, and I remember, we sat in the car, and we cried about it and I remember telling [my partner], I said, "you know, this is the last time we're going to cry about this, because I don't ever want [our child] to feel sorry for [themselves] and we're never going to feel sorry for ourselves, we got to figure out where do we go from here." And so, I think, to me, that was kind of the shift that happened with us internally.
>
> - Caregiver 3

Kinship support was raised as an important means to embrace the journey as a caregiver. A participant shared, "just by having that acceptance that came from us and came from our family, like, I feel like that really did kind of help us to remove that stigma that we were talking about before, you know, and really kind of let go and just accept who he is and like, he was the person before the diagnosis that didn't change anything right." When going through the diagnostic journey caregivers also felt there was a "grieving process" that happened, but after the grieving took place, they were able to fully accept their child's diagnosis. Caregivers also shared they "accepted their children no matter what and the diagnosis was only a small part of the autism journey.

5.2.5 Diagnosis experiences

Caregivers conveyed what they viewed as the importance of an autism assessment and getting a formal diagnosis not only so that their child can access services, but also to better understand their child. Caregivers spoke about how they "want to know every diagnosis…so they can help them," and while the diagnosis helped caregivers make sense of their child's behaviours, it also created more questions such as "what does the future hold for her/him? What does it hold for me as a parent? How involved am I going to have to be in his life? Will they ever live independently?" Caregivers also felt that the professionals who were responsible for the diagnosis could be a barrier. A caregiver shared,

> Our family doctor at the time, told us to wait. [They] said, “you know, basically, that autism doesn't really present until preschool” and I'm like, “no, it's presenting now. Like I need to get him a sense that we can do what we need to do for him.” And thankfully, she agreed with me. She gave me the referral over to [the assessment clinic] and he was assessed and diagnosed I want to say in like, maybe 20 minutes with [the pediatrician], like it didn't take long at all.
>
> - Caregiver 9

Another caregiver shared how grateful they were to a daycare worker who spent time with their child and subsequently had a discussion with the caregiver regarding their concern that the child was not hitting certain milestones. They further encouraged the caregiver to get an assessment done which was appreciated. The caregiver noted, “we appreciate her [the daycare worker’s] courage to be able to do that, because we can imagine that it probably wasn’t easy for her to approach any parent.” Finally, another caregiver discussed the mixed feeling they encountered after the diagnosis including being “overwhelmed”, “caught off guard”, and “ill informed”, but at the same time they also felt “validated” and were now able to make sense of their child’s behaviour and start applying for the services needed.

5.3 Caregiver perspectives on their child

5.3.1 Perspective on sensory experiences

Caregivers frequently shared the unique sensory experiences their child seemed to have, which ranged from smell, taste, sound, visuals, and touch. A caregiver explained that their child has outbursts behaviorally and would yell if there was a “loud sound” that “it would trigger them.” Another caregiver shared similar sentiment stating, “he doesn’t do well with loud noises”. Seeking to ensure the child is not exposed to loud or intense environments emerged as key to supporting a calm state for the child. A caregiver shared a story about when they brought their child to an exhibition with rides, and how “he only went on one ride, and he was freaking out and it was like he was in pain, and he just started crying.” Another caregiver discussed the impact of lights. The caregiver stated, “I couldn’t take him with us to Costco. Costco used to have those lights, a certain type of light and he used to hide his eyes, and he closed his eyes when we go to Costco.”

Caregivers also spoke about how certain sensory experiences could be calming or grounding for the child. A caregiver described the experience of when their child was in their autism assessment, and the assessor, “pulled out like the sensory type toys. And as soon as he grabbed one, he like instantly calmed down. And it was the only time through that entire assessment that she could get him to sit down and so that was super interesting.” Creating sensory-friendly spaces for children to self-regulate was described to be beneficial for Autistic children. A caregiver reflected,

> the school actually has a sensory room, which is awesome. So, they are doing a really good job with working with him rather than against him. So, they give them lots of breaks throughout the day, that he'll go hang out in the principal's office to play a game with her just to regulate himself and then go back.
>
> - Caregiver 7

Caregivers further discussed a range of supports to address sensory challenges including “ear protection”, “sensory toys”, “weighted blankets”, and “exercise balls.” Such sensory solutions were thought to provide children the space and opportunities to self-regulate when they otherwise may feel overwhelmed or stressed.

5.3.2 Unique approaches

Caregivers often shared unique approaches they implemented with their children, and how they felt the need to be creative when interacting or attempting to get them more involved with school or family. One caregiver shared a story about their child joining a drama class in junior high, and the way he learned how to approach social situations reflected lessons learned from “drama class because he learned somehow being in another character took all those fears away. He could be a different person, and he learned a lot about communication and relationships through drama in junior high school.” Communication was another key area in which caregivers felt the need to be creative in their approaches. For example, a caregiver describes how their child would not answer questions but rather would use a proxy item to communicate,

> He couldn't answer questions or tell me about things. But one day, he was walking around with, he was about three, a coffee cup that he turned into a horse, and he had it on his hand, like a Styrofoam coffee cup and I thought, “I wonder about puppets? And if the puppet can answer the questions that he won't answer.” So, I asked him, “so what did you have for lunch at daycare today?” And the horse told me, but [my child] would not answer that question until the next day, but the horse got it right away and so I had a really good conversation with the horse. So, it's that that protective barrier between them and the and the outer world.
>
> - Caregiver 10

Other strategies/tools used by caregivers to engage their child’s communications included “playdough”, a “whiteboard”, and an “iPad”. Caregivers also spoke about the importance of service providers’ approach, with one caregiver appreciating that their service providers did not get, “caught up in medical practices or theories,” but rather used a “simple authentic type of approach.” This approach created what was described to be a space for the child to feel more connected.

Another caregiver talked about the challenges for their child of “transitions” and specifically starting school but appreciated the school staff and how “if I just pull into the parking lot, and the teacher comes out to the vehicle and gets him, it's a lot better for him.” These adjustments were described to address barriers and difficulties some Autistic children face in their day-to-day lives. Caregivers were often grateful for the small wins which they felt were important to being able to provide consistent and meaningful care.

5.3.3 Caregiver interpretations of Autistic behaviour

Caregivers frequently shared what they viewed were behaviours that were directly related to autism. They described social situations such as a child who did not "read social cues" or "understand social situations" and this was thought to lead to the child feeling left out or isolated. Another caregiver described a similar challenge:

> he (the child) needs to know every square inch of the space he's in, which can be challenging sometimes, like an example: I took him to the doctor and when we went through the autism assessment, it was a new building, and he was trying to open every door, just to see the space. And then they took him into the room he was going to be in and had to go through a big, like shelving room, like cupboards, and all this stuff and he had to open every one of them just to examine the space.
>
> - Caregiver 5

Caregivers often reflected on special interests of their children, how committed they were to those areas of interest.

Other types of Autistic behaviours that were discussed, reflected how dysregulated their children would become and in turn, how they would self-regulate. Anger was also brought up and a caregiver understood it as the "trauma that affects him" and later explained that "he blows up easily, he does not know how to control his anger," and later this caregiver explained their child "experiences a lot of anxiety". Another caregiver also shared that their child, "doesn't get angry spells like that too often. He has had them but they're few and far between." While emotions such as anger and anxiety were described as common, some caregivers also shared about other emotional states their children would experience, as one caregiver explained, "he is the most, kind, gentle, caring kid that we've seen."

Caregivers felt it is important to recognize when Autistic children are in an elevated emotional state and have a plan or strategy to regulate that child. They shared moments when their children would “rock”, “grimace” or “cringe” which seemed to occur when they were not enjoying a sensory experience. Caregivers shared ways they would support their children toward self-regulation by creating spaces for them as one caregiver shared a strategy of just allowing their child to come home after school and regulate before anything else,

> So, he doesn't have outbursts or stuff like that at school among his social peers, but you know, things are bothering him, and he gets home. And then he's got to really decompress.
>
> - Caregiver 12

Caregivers frequently shared activities that their children enjoyed and in turn, supported self-regulation. Outdoors was brought up a few times as one caregiver’s experience exemplified, “he likes active outdoors, swimming, walking, playing on the dirt, swinging, the trampoline, climbing.” Another caregiver talked about how their child, “is obsessed with hockey.” Caregivers would often allow their child to try different activities and would not let stereotypes of autism become a barrier. Finally, a caregiver spoke about technology and how, if used appropriately, could support their child’s wellbeing and educational journey.

Managing, or reflecting on technology in the sense of what was helpful, versus what was problematic, emerged as an important consideration for caregivers. As an example of negative risks of technology, a caregiver shared, “one counselor [said my child] lives in a virtual world, that's the reality of everyday life. So, if we can get him out of that virtual world back into, you know, our world, then he would [be better at] attending to school.” The virtual world here was being on a computer and their child did not want to do anything else but stay online. Yet, while caregivers felt that technology was a challenge, sometimes it was viewed to be the only way to get their child to “calm down” or “communicate.”

5.3.4 Autism as a gift

Despite challenges and concerns related to care for the Autistic children, caregivers described a diverse understanding of autism that included the cultural belief that autism is a gift. A caregiver shared “there's understanding of special needs, they’re very special children, they've been gifted, these are special children from the Creator. They're more special than us. And they will just tell me that I should be thankful and grateful for these special children to be in my life.” Another caregiver discussed the “idea of really looking at the spiritual aspect and the specialness, the giftedness that these children and adults bring to community. And like with my son, he's very spiritual and I support that.” Another caregiver shared “[w]hen our kids are small, we're told that they're still connected to the Creator, and so everything that they say is really profound and should be taken seriously, because they have more wisdom [while we] have kind of lost that connection.” Although not all caregivers were aware of cultural understandings of autism from First Nations people, they viewed autism as something to be “embraced” and “a learning opportunity.”

Beyond the cultural aspect of autism as a gift, caregivers shared some of the personal gifts their children brought. As an example, a caregiver told a story about their child’s creative gift “anything you ask him to go create, let's say the Eiffel Tower, he'll come back and have created the Eiffel Tower, whether it be out of his connects, his Legos, paper that he's cut up and glued back together, like he can do it. He's very visionary.” Another caregiver shared

> On his first day of school, they said “oh, he did some artwork” and they didn't know what it was. I took one look at it. And I said, “it's an aerial view of his classroom.” I said, “can't you see it?” [and] said it shows me right there, where he sits where he's sitting right now, look that's your table. That's the drawer, and he had a detailed overview of this classroom. They said it was artwork. I say there's artwork, but it’s also his aerial view.
>
> - Caregiver 6

5.4 Growth, transformation, and ways forward

5.4.1 Caregiver expertise

Caregivers often felt that their experiences would be useful to share with other caregivers. They frequently shared advice or practical tips such as “don’t stress the small stuff” and be “patient”. A caregiver shared “the last thing you want as a parent of a child with autism is to burn out, you can’t burn out on your own kids” and they felt that “self-care” is key to being able to provide quality care for their children. Another caregiver talked about “taking it one day a time” and not imposing too much pressure on themselves. Caregivers felt that parenting an Autistic child does come with many challenges, but it is important to know when you become overwhelmed and reach out for help. Learning about autism was deemed to be important for caregivers, as an example, a caregiver suggested “do… much research [and] ask many questions.”.

At the same time, caregivers recognized that not all experiences with autism are the same. As one caregiver put it, “autism isn’t [a] cookie cutter sort of situation, it’s every kid is different” so getting to know a particular child’s behaviors, triggers, and patterns was deemed important to being able to better support that child. Following this up, a caregiver shared,

> I would say, to really take the time to get to know your child. Like, don't listen to what everybody else's perspective is of autism, but look at your child for who they are. Because the spectrum is so vast that no two people with autism are the same. So, in order to really meet your child's needs, and connect with your child, you have to focus on getting to know them for who they are.
>
> - Caregiver 13

Caregivers’ attitudes towards autism, positive or negative, were described as an opportunity to meaningfully support their Autistic child especially when caregivers begin to feel “hopeless” or “overwhelmed”. One caregiver shared their approach that helps them support their child,

> not looking at challenges as obstacles, but almost like steppingstones to learn from. And that's kind of part of the journey that sometimes is scary is you see progress and the biggest fear is regression. But sometimes in the regression, it's almost like a steppingstone for a bigger breakthrough.
>
> - Caregiver 6

Caregivers suggested embracing "those fears and saying, ‘this is not the end’ because I think that what I’ve personally encountered is sometime those fears can become overwhelming.” Overall, caregivers felt that despite all the challenges they encounter, they love that they still get to raise their children because “they know their children best” but would still like more support in the community. Addressing this understanding and balancing love for, and appreciation of, caring for their child, yet also needing supports due to caregiving challenges — emerged as important in moving toward better and more accessible service access.

5.4.2 Potential services

Caregivers reflected on the type of services in the community that are needed. These services include access to “respite”, more “OT and speech professionals”, and “parent support groups”. Having day-to-day support such as respite was described as essential to being able to provide care for their children. A caregiver talked about the challenges accessing the community without support and they felt if they had access to respite, they could be a better caregiver,

> Like when parent helpers are well, we can take care of our kids. I think that's one thing. That's really important is the parent’s house. Because I mean, this is a lifelong thing. It's not going to go away; it's not going to be cured. There are things that are very difficult. There are some very beautiful things about parenting our kids, don't get me wrong. But there are some things that are very difficult, like lack of sleep, not being able to eat, not being able to access the community.
>
> - Caregiver 5

Other types of events or supports were recommended. For instance, caregivers advised the development of a place where “parents can get together and support each other so that they know someone else who has been through this.” Caregivers felt that if they could connect with other caregivers, then they would feel less isolated and could learn from each other,

> Yes, I would love that. That's what I was trying to like to recommend, we need to have a group or somewhere parents can get together and talk and help each other out. Like someone might know how to deal with, I don't know, like a tantrum. And one parent might not be good to talk and that parent that doesn't really know what to do can get tips on how to handle their own child. I thought that would just be awesome to have down here.
>
> - Caregiver 14

Caregivers reflected on the need for service providers or anyone working with Autistic children to have formal training such as an “8-week program dealing specifically with behavioral and Autistic kids because it seems to be becoming more frequent here.” It was thought that potential services and supports in the community would offer the potential to support not only the children but also the caregivers as well.

5.4.3 Acceptance

Acceptance of autism was discussed frequently, and caregivers recognized the importance of acceptance when it comes to feeling supported in the community and by their families. A caregiver pointed out the difference of attitudes they feel happens in, and out of, the community: “I feel like in the community, we have a lot of acceptance, but outside of the community, like I've had people say stuff to me in the grocery store or stare at him.” Caregivers felt like their communities were more “open and understanding” compared to outside of the communities. They also felt that there was more acceptance based on a cultural difference as one caregiver put it, “I find that Cree, that my people are way more open and accepting” and how they were “welcomed with such open arms.” Another caregiver touched on the cultural differences and how because autism is viewed as a gift, acceptance is encouraged:

> I have heard different perspectives in terms of like, being gifted, stuff like that. So, I think from a cultural perspective, there's how would you say? What, I appreciate it's viewed in a more positive light than it is negative and there's more of an acceptance to that difference, if you will, versus stigmatizing it in a negative way. To me, it's been more of like an acceptance.
>
> - Caregiver 7

Family acceptance was discussed. A caregiver shared, “my sisters, my mother-in-law didn’t treat him any different than anybody else,” and when a child is seen as the same as the other kids in the family, it can create a space for them to be accepted in the family. Caregivers also felt their family’s acceptance of their child allowed them to accept their child as well and “that acceptance that came from our family, I feel like that really did kind of help us remove that stigma.” Caregivers frequently discussed the importance of unconditional acceptance and how if their child was fully accepted by their families and communities, it made their lives more manageable and less isolated.

5.4.4 Advocacy

Caregivers understood the importance of advocating on behalf of their Autistic children. A caregiver described having to become “the biggest advocate because nobody else will be. Nobody knows my child like I do.” Another caregiver reflected on a time when they were advocating for their child with a teacher who had a loud voice when teaching, but refused to change their approach and they explained to the teacher “you might be an expert in education, but I am an expert on him and he can’t handle when you raise your voice, it makes him nervous, so we ended up talking to the principal about [the situation].” The belief that the caregiver knows best was brought up again by another caregiver,

> [Don't] give up. Fight the good fight. Advocate. Like I, the one thing I will say is, you know your child best as a parent. So, someone's telling you something, and it's not sitting right, then it's okay to advocate and get a second opinion.
>
> - Caregiver 7

Some of the caregivers were dealing with child and family services. This was described as adding to the challenges and barriers experienced by the family,

> I feel like we've been doing nothing but advocating for him for the last five years — with the ministry, because trying to get this adoption through, it was really challenging. So I feel like any decision we had to make, we had to go through a lot of red tape with the ministry. Like even to get them into like, when I was talking about the occupational therapist, it was a lot of advocating a lot of what seemed like arguing or me being mad, which in a sense I was but I know we're his parents, we know what he needs. So, we just wanted someone to listen to us. So, I feel like that piece trying to get him resources, we've had to advocate quite hard for.
>
> - Caregiver 10

Caregivers noted that those working with Autistic children sometimes do not have enough knowledge of autism and this created a barrier for them. A caregiver shared that they had "to be the biggest advocate and had to push for school testing" because the school wanted to start him at a grade level, he was not ready for. While advocacy was acknowledged as important, some caregivers felt that they were too "overwhelmed" or "exhausted" to fight anymore and without proper supports they could not advocate effectively on behalf of their children.

5.5 Braided throughout

The following themes were touched on by all the caregivers, whereas the themes above were intermittently described. I felt it is important to dedicate the following section to its own focus, given such strong agreement, for example, the unanimous endorsement for the following considerations. When braiding the sweetgrass, these would be connected to the rest of the strands and the blades would be seen in each strand, but for the thesis I felt they were important enough be explored in their own section.

5.5.1 School experiences

Schooling was discussed by all the caregivers at some point in their interviews. These discussions included topics such as interactions with teachers and administrative staff, learning challenges and strengths, and concerns with bullying. Caregivers spoke often about the challenges they faced when their children started school. For instance, a caregiver shared, "The first week was kind of difficult for him…he was only there for three days, he had a hard time transitioning to the school environment." Caregivers also talked about some of the solutions that had worked when transitioning such as "talking about when things are going to change" or "if the teacher comes out and gets him it is a lot better." Caregivers also felt that open lines of communication between themselves and educators are essential to making sure their children can more fully embrace their educational journeys,

> I think the way I can see the school helping families is through communication. I feel like there has to be like a consistent form of communication, that can be updated frequently. So, meaning that if there's something going on at home, that's going to affect the child in the school, that there's a way for the parent to communicate that in a timely, manner, to be able to help support the school and the same thing with the school to have like regular updates for the family, so they know what's going on.
>
> - Caregiver 1

Caregivers felt that there is no consistency between teachers' attitudes and beliefs on autism and depending on the year/class of their child, could have a positive or negative experience in the school setting. A caregiver shared,

> like you're going to have different personalities, teachers have different personalities, and you have some who are so willing to learn new things, when their students might have different challenges like with autism, but then you're going to have some who just have a way of doing things and have always done

> things and might not be so open to it. It's like, this is how I run and manage my classroom.
>
> - Caregiver 2

Caregivers reflected on special education classrooms and the role of these spaces in transitioning their children to school environments. A caregiver explained that special education has supported their children by allowing them to attend “half a day,” and this approach “lets them get used to the environment” with the intention of eventually attending “full time.”

Caregivers also spoke about their experiences with other supports in the classroom such as educational assistants (EAs), with one parent reflecting that they were not “there one day, and I guess he had a really bad day at school as a result. So, he obviously needs a full-time one-on-one EA, which right now, I think the EA he has, she has like five other kids. So, you know, it's not ideal.” Caregivers felt that for their children to be able to participate in class they needed support.

A key concern brought up by the caregivers was bullying in schools. Caregivers were often “worried” or “concerned” that their child would be bullied. A caregiver reflected on their own childhood experience and remembered, “watching [another student] get so severely bullied in school for his difference that other kids just wouldn’t have empathy.” Caregivers expressed that the school environment can be the difference between their children living (or not living) a good quality of life and how important it is for the teachers and classmates to “understand them enough” and “have the supports” to be able to be included fully. Caregivers offered some practical tips to school staff to support Autistic students and encouraged “letting them learn at their own pace” and having more “on the land learning” opportunities.

Caregivers in the Six Nations shared their experiences with the language immersion program in the schools in the community. Caregivers felt that the school staff did not know enough about autism and discussed their interactions when wanting to put their child into the immersion program and how “administrators and teachers try to tell me not to put a kid in immersion who can't talk, or who has language difficulties. That happens every year. They're like, “are you sure? Are you sure this is a good idea?” And like, yeah, it's also like his right to like, learn his language.” As mentioned earlier caregivers often had to advocate for their child to be able to participate in the school setting.

Yet such engagement, safety and opportunity for learning was important and a basic right. As an example, a caregiver talked about how their child was in “immersion their whole life and took 11 years of immersion” and now can now speak the language at home. Caregivers further noted a difference in how their children were treated in the immersion school and English-speaking schools,

> So, in English schools, what you see in a lot of the classrooms here is like a real serious lack of compassion, empathy, there's a lot of bullying, there's a lot of harassment. There's a lot of hierarchical attitudes from the staff to the kids, which is really disrespectful. But in the immersion classrooms, they kind of operate on a more traditional mindset. And that is like the idea that these kids are also your equal, and they're probably smarter than me and so, and they have a gift, and they have a purpose.
>
> - Caregiver 11

While there were a lot of concerns overall in that caregivers knew that schools were going to be a challenge at times, they also viewed school as offering opportunities for growth and social connection for their children. Caregivers touched on the fact that children in the immersion school were being raised in a traditional way with traditional values such as honesty, humility, courage, and respect. These principles and processes of education offer important and instructive guidance in considering education delivery.

5.5.2 Access to services

Caregivers all spoke about their experiences with applying to and accessing various services and supports in their respective communities. They often shared the specifics of what they have access to such as “Applied Behavioural Analysis (ABA) therapy”, “occupational therapy”, and “speech pathology” and “behavioural therapy.” Caregivers often expressed appreciation for these service providers, stating “they gave us a lot of really good strategies and techniques.” They described that sometimes they would be referred to other providers, for example, being “recommend[ed} because of [the child’s] noise sensitivities that [they] take them to an OT.” Another positive example shared by a caregiver was with a speech therapist and how they “did a really good job of teaching him to communicate without words…through alternative ways of communicating.” Yet not all experiences were positive as a caregiver shared, “I don’t access ABA anymore because it was too oppressive”. She later shared “I feel like the way they talk in ABA therapy is rude. They talk condescendingly and they talk down to the kid in [a] very commanding way.”

The caregivers identified racism from service providers. For instance, a caregiver reflected on an experience in which a service provider was “freaked out coming here [to the reserve], just from probably the stereotypes”. Caregivers shared how important it is to have Indigenous service providers in the community and one reflected on how Indigenous teachings and cultural knowledge can be beneficial to the children,

> Both [the service providers] parents are Indigenous, and she was so respectful to him. I told her like our teachings about kids and how I expect him to be treated. Like he's in charge of his own life. And he has a right to like his comfortability and his stress level and so I would tell her that I want you to teach him within his limits. I want you to be respectful to him, and for a year he had her and he just did so good. He learned so much in that year.
>
> - Caregiver 14

Applying for funding was frequently identified as leaving caregivers feeling "overwhelmed" with the process, as illustrated by a caregiver's story,

> They gave me a stack of papers. And they're like, if you fill these out, you'll get this money and I was like, "okay", and then I was like, "when are we gonna do this?" And they're like, "no, just bring them back filled out." So, I took them home, like the first line I couldn't answer. Second question I couldn't answer. Didn't even know what the words were. And I have a master's and I was like, if I have a master's degree, I can't fill this paper out, how many people have they done this to?
>
> - Caregiver 2

Transportation was brought up as a key challenge to accessing service. A caregiver brought up her experience that "transportation became an issue" and without reliable transportation some caregivers would try "cab rides" but could not sustain it without sufficient funding. They also spoke about the challenges of driving into the city for services and how they would need to plan "childcare" and "miss work" to accommodate service providers' schedules. Caregivers knew they could receive services in the city but without proper transportation and support at home, access was a formidable challenge.

Jordan's Principle was discussed frequently, and caregivers shared how much of a "blessing" this policy has been. But at the same time, they brought up concerns and critical gaps such as "a worker quit because she didn't get paid for two months" from Jordan's Principle. Another caregiver talked about the support they received in school from a Jordan's Principal worker yet intermittent access to this resource,

> I did apply for him to have a Jordan's Principle worker again. He thought he could do without one, but he hasn't been to school. So obviously, I think he needs a worker that's going to keep motivating him at school and he did like it when she drove him to school, they went for their lunch, and they went back to school.

- Caregiver 4

A caregiver conveyed their view that the application process to this resource needs to be re-examined because they had "put an application in for Jordan's Principle, and somehow the application disappeared" and they had to "jump through a bunch of hoops" to get their application resubmitted. Another caregiver shared about a crisis they experienced when their basement flooded in their children's rooms and "Jordan's Principle got them new bedding and clothes, and I just put an application in to get the foundation repaired." Overall, despite challenges with Jordan's Principle caregivers viewed it as a beneficial funding mechanism for their families.

Finally, caregivers discussed the differences in services on and off reserve and how government policies are often barriers to getting support in the community. A caregiver shared that since "we moved to the city; we are able get all kinds of services she wouldn't have been able to get if they were living on reserve." Another caregiver shared the same sentiment, "We have never had any programs down here on our reserve for him." Yet caregivers felt that that living in the city for support requires them to leave kinship supports and "our family supports in [the] city is limited. So, we don't have a lot of family supports, and I feel like for the last five years, we have been kind of doing this challenge on our own." Caregivers who live off the reserve and receive adequate support recognized the challenges of living on reserve. A caregiver reflected, "our journey happened off reserve and we do see the gaps that exist on reserve and the limitations."

Caregivers further felt getting service providers to the community was challenging such that finding a "worker was hard because people didn't want to come to the rez." There were many challenges related to the lack of services in the community. For caregivers who had the resources to support their children, more services were available. Conversely though, other caregivers felt guilty for not being able to get their children the support they know they need.

5.5.3 Stigma and discrimination

Caregivers brought up numerous experiences in which they felt they were being discriminated against. A caregiver shared how they are followed around [the grocery store] due to the fact they are “visibly Indigenous” and was told to “watch their children” by security. Another caregiver shared that at a [large department store] they catch people “staring” at their children and how uncomfortable it makes them. Another caregiver shared a story when they went to eat supper at [a restaurant] and there was a table “of Caucasian people and they’re glaring at us like we don’t belong here.”

Caregivers also spoke about the stigma they anticipated once they got a diagnosis and how “when we first got the diagnosis, we were scared and I think we were probably really kind of letting our past experience or what society says autism is, kind of fuel what our fear was, like how we were afraid of the diagnosis,” and also “if autism is something to be afraid of, then it is going to negatively impact the family.” A caregiver also shared how they were misinformed and as such, used to believe “if I just get him help, he won’t be Autistic forever.” These types of ableist beliefs were identified as present in the community as well. A caregiver shared “unfortunately, like, as accepting as our people are, I do see some ableism in our communities that we can address as well. You know, around not only just autism, but disabilities in general, where people aren't thinking like that quite yet.” When it comes to attitudes and beliefs toward autism in the community, the caregivers indicated that if we can teach children at a young age what autism is and why Autistic individuals sometimes need extra support then they will “be fine with it.”

Finally, how to address stigma was talked about frequently. A caregiver shared what they believe is a fundamental problem many people carry relative to the beliefs society carries and perpetuates about Autistic people. The caregiver stated,

> I think really dramatic misconceptions for Autistic people is that they aren't able to do a lot of things, when really, it's probably the way that we present the demand that creates a barrier for them and so we have to address the way we communicate.
>
> - Caregiver 13

As illustrated above, caregivers conveyed the need for a shift in how society perceives autism. They further suggested that if we can teach the public more about autism, it would help take the “stigma away and replace it with a different view.” Another caregiver added that more awareness would be beneficial as “I think it's more than just breaking down stigma, I think it’s because you meet one child with autism, you meet one child with autism. Each child with autism is going to be completely different.”

5.5.4 Culture, language, and ceremony

The importance of culture, language, and ceremony was commonly raised by the caregivers. Caregivers wanted to keep their children connected to the culture and in community despite being on the autism spectrum, but they described many challenges in doing so,

> I go to longhouse. I only took him and it is very overwhelming for him. To sit there and to be around all these people, you know, and the singing and dancing was too much for him. Like I had to leave halfway through the ceremony with him because there's too much for him. He's very sensitive to loud noises. He'll cover his ears and get mad. So, it was so hard, but I do plan on taking him to the next ceremony.
>
> - Caregiver 11

A caregiver also shared that they would like to attend other cultural events such as powwows, but their children simply did not want to go or were “overwhelmed with the sounds and crowds." Caregivers conveyed the importance of taking into consideration their children's sensory challenges when planning on attending ceremony or cultural events. Unfortunately, caregivers often would not attend due to those challenges being prohibitive.

Caregivers also noticed that there were certain cultural activities their children like to do. A caregiver shared, "He loves hunting, and he loves being an oskâpewis (ceremony helper) for different things." Another caregiver talked about how their child "loves the drum, and he loves dancing." Smudging was also brought up, and several caregivers spoke about how their children "like the smell of sweetgrass."

Cultural activities were described to meaningfully engage Autistic children in the school setting: "he loves drumming at school…I make sure I get to school before 8:30 am because that's when he has a good day is when he gets to be with the drum." A caregiver shares their idea about what they would like to see in the community with creating cultural connections,

> I think that we need like a language and culture school for kids with disabilities, to like, meet them where they're at, and to kind of give them teachings like to have teachers who have teachings, to be able to support them and who they are, and their gifts and what they bring here, rather than trying to force them into who we think they should be.
>
> - Caregiver 2

Language was identified relative to schooling as there were many challenges identified in ensuring children have opportunities to learn their Indigenous language. A caregiver in Maskwacîs talked about how their child wants to "learn his own language and he likes the syllabics and that type of thing." A caregiver in Six Nations discussed how their child "loves to do socials where they sing, and everybody dances" and the singing portion was an opportunity to hear ceremony songs. Another caregiver shared that they "didn't know [their child] was fluent in Mohawk, but he knows it quite well." Overall caregivers shared the importance of keeping their children connected to the culture and language but due to some of the behavioral and sensory challenges, and some of the potential negative experiences they may face at cultural events some decided not to participate.

5.6 Similarities and differences between caregiving experiences in the two communities

Maskwacîs and the Six Nation of the Grand River are both considered large First Nations with populations that exceed 15,000. Caregivers in each community spoke about similar and sometimes different perspectives. One of the main similarities they discussed was around the barriers to culture. These barriers came in the form of caregiver's lack of connection to culture and them being unsure if they would be accepted at different cultural events or not, but also some of the caregivers who attended cultural events at the longhouse in Six Nations or ceremony in Maskwacîs knew that the way these cultural activities are set up would not be inclusive of Autistic children as they can be sitting for long periods of time, there are loud noises, and times where the families are expected to be quiet. Caregivers also frequently talked about the various forms of discrimination they faced in both communities. They discussed legal forms of discrimination, such as jurisdiction and how if they had an address that was off the reserve, then they could access more services. Caregivers often brought up the ableism they still experience both on, and off, reserve on top of the racism they may face as well and how these two forms of discrimination make it even more difficult as a caregiver. Another similarity that caregivers spoke about was their experiences within the school system and they had concerns with bullying and some of the negative attitudes with school staff, but they also talked about the positives that came with schooling such as having an understanding teacher and how their child excelled in some programs.

Some of the key differences between caregivers from each community included the types of services they were expected to access. In Ontario, where the Six Nations is located, most of the caregivers had accessed ABA therapy whereas there were zero caregivers who access ABA in Maskwacîs which is in Alberta. This can be attributed to ABA therapy being a provincial mandate of the Ontario government. Overall, caregivers in the Six Nations mentioned they had accessed, or were currently accessing services whereas Maskwacîs caregivers had talked about wanting to access services but had more barriers due to being in a rural location. Maskwacîs caregivers (n = 4) also spoke about how they were providing foster care for their children, whereas, in the case of the Six Nations caregivers, none were care providers, meaning they were the biological parents. There were also differences between the communities when examining Haudenosaunee and nêhiyaw understandings of autism. Maskwacîs parents often talked about cultural understandings such as autism as gift, whereas these understanding were spoken about less in Six Nations.

5.7 Conclusion

Caregivers commonly discussed the difficulties and positive experiences of raising Autistic children. While acknowledging the need for enhanced support and services for individuals with autism, caregivers also highlighted the positive attributes their children possess. They frequently engaged in discussions regarding the cultural and communal aspects of autism. Caregivers often contemplated the level of acceptance of autism within their communities, noting both positive experiences and areas where further improvements could be made.

Chapter 6: Discussion

6.1 Summary of findings

This research addressed the critical gap on the dearth of autism research with First Nation communities in Canada. The lack of attention to, and research on, autism within Indigenous populations in Canada served as the starting point for this thesis. The absence of data regarding Indigenous individuals and autism in Canada represents a notable gap that necessitates Indigenous-led research, as is demonstrated in this thesis. In this way, this thesis can make a meaningful contribution to the existing literature and to reciprocally support the two communities. The objectives of this work, established by the Maskwacîs Autism Advisory Circle (MAAC) and Six Nations Child and Youth Health have been successfully attained, stemming from research conducted in accordance with the spirit and principles of wâhkôtowin. My personal experiences as a parent, community member, and researcher have provided invaluable opportunities to establish connections with families. These connections have had a significant impact on the research process, resulting in a multi-faceted intercommunity research project that I believe accurately represents the community and families involved.

The findings from these studies offer significant insights into the realities of autism in the context of Indigenous communities. The introduction established the background information on the history of Indigenous peoples and autism. The scoping review provided a foundation from which to build the other two studies and offered critical insights on the lack of research in this area. The scoping review highlighted not only minimal literature in this area, but also showed that the research that has been done is of low quality from an Indigenous perspective, as assessed through the Indigenous Quality Assessment Tool. The Elders study contributed to our knowledge by offering the first of its kind globally, by engaging with Elders on an Indigenous cultural understanding of autism. Specifically, the study highlighted autism in historical contexts such as in residential schools, which is an experience and context that has received little if any attention in academia. There was also knowledge conveyed on cultural understandings of autism and Elders shared the nêhiyaw perspective that the child is viewed traditionally as a sacred gift. This study shed much needed light on traditional understandings of autism and what we can do to support families of Autistic children. The caregiver study was the first study in Canada to solely focus on the experiences of First Nations caregivers in the context of autism. This study highlighted the many challenges caregivers face when navigating diagnostic services, government funding, schooling, and various forms of discrimination including ableism and racism. Caregivers also shared the strength and resilience of their families and often spoke about how they came to embrace the autism journey. It is through these three studies that the families and communities I work with have come to a better understanding of autism and potential pathways to move forward. This knowledge was the basis for the action that took place throughout this PhD research journey. Overall, I feel that this thesis reflects the expertise in the community and relational approach we implemented in all areas of the research project.

6.2 Personal reflections on insider-insider research

As a father, community member, and graduate student, I acknowledge this research and resulting thesis is the outcome of these three intersecting identities. When first introduced by Kimberlé Crenshaw (1989), intersectionality was first described as the interconnectedness of identities between race and gender. Since then, intersectionality has evolved and now includes identities such as disability, sexual orientation and so on. Intersectionality also aligns with wâhkôtowin which was discussed in the earlier chapters. Both intersectionality and wâhkôtowin position the individual to recognize and acknowledge the connectedness of their identities and how those identities influence their place in the world and vice versa.

For myself, I identify as a nêhiyaw napêw (Plains Cree man), father and husband, the son of a residential school survivor, neurotypical, and Maskwacîs community member. While other identities may be present, these are the ones that have had the most impact on who I am today. It is through these identities I consider myself an insider-insider researcher which is a role I take with the utmost responsibility. Insider research can be described as when an investigator researches themselves, their family or their community (Wilkinson & Kitzinger, 2013). Another layer to this is that my role as a father to Autistic children provides me with insider-insider research privilege. The autism community in Maskwacîs is small and my role as an autism parent allowed me to connect with and learn from the autism community in meaningful and sometimes intimate ways. The challenges and opportunities of conducting insider-insider research from such a position has been discussed within the literature. Opportunities may include a deeper and more meaningful understanding of the challenges and strengths of the families or community, better understanding of the complexity of the social and legal order of the community, more expediency to identify research participants, and more connection to the families and community and thus better lines of communication. Some of the challenges may include inherent biases of the insider-insider researcher and subjectivity which may result in knowledge distortion, and what is referred to as a “monolithic insider view” which is argued to be that the research becomes filtered by the researcher and thus can lose meaning (Taylor, 2011). I would argue that while these challenges may be present in insider-insider research, they would also be challenges for an outsider researcher.

One of the ways to address the challenges of insider-insider research is to practice ongoing reflexivity. When examining the success of insider-insider research, one of the main indicators includes the ability of the researcher to be reflective on an ongoing basis (Smith, 2013). According to Mariam Attia (2017) there are two types of reflexivity—prospective and retrospective—of which, "prospective reflexivity concerns itself with the effect of the whole person-researcher on the research. Retrospective reflexivity concerns itself with the effect of the research on the researcher." (p. 34). Reflexivity was practiced in several ways. Firstly, I kept research notes and reflected after each research-related activity. The MAAC was also a space where I could look back at the research and discuss past conversations and activities with circle members. Finally, I had monthly meetings with my supervisors Drs. Lonnie Zwaigenbaum and David Nicholas where we would plan future research but would also talk about what has happened specifically in this research. During these engagements, I would frequently discuss my role in the community with the MAAC, my supervisors, and community members at large. With each iterative conversation and reflection, new ideas and concepts were fleshed out and I had the opportunity to instill these learnings in the research. There were also discussions with my supervisors on the scope of the research, how to navigate the university systems, and how to ensure community perspectives were interwoven within the thesis.

As I reflect on my role as a parent to atypical and neurotypical children, I am reminded of how this journey began—specifically, with those uncomfortable conversations with educators and healthcare professionals. While these conversations were not the ones a parent would want to have, I am grateful for their candid yet gentle approach in guiding me through the early stages of the autism journey which included assessments and diagnoses at both the Camrose and Glenrose Rehabilitation Hospitals' autism assessments clinics. Yet there was a lack of cultural responsiveness and no follow up to the diagnosis, which is a common concern among caregivers. These experiences greatly influenced my perspective on the process which I have learned many other caregivers have variably faced when going through a diagnostic assessment. After the diagnosis I was left to navigate the complex and often frustrating world of disability funding.

Over the course of my PhD, my perspectives on autism and research have greatly shifted. Early in the research journey, I did not know about the cultural dimensions of autism and disability, and I am honoured to have been gifted this knowledge. As mentioned in the introduction chapter, I am a registered member of Samson Cree Nation, but I did not grow up in Maskwacîs, rather I grew up in Enoch Cree Nation where my mom is a registered member. This dynamic gave me unique insights into the particular social and political aspects of each community. I recognize and understand all the support and opportunities Maskwacîsak have gifted me. I have had the opportunity to travel nationally and internationally to share the findings of this research, including at the International Society for Autism Research (INSAR) meetings in Stockholm, Sweden (2023) and in Melbourne, Australia (2024). At the same time, I know my research should be accessible to Maskwacîs and other First Nations communities. Over the past year I have presented in communities including Maskwacis several times, Enoch Cree Nation, Sturgeon Cree First Nation, Six Nations of the Grand River, and to the Kenora Chiefs Assembly as well as numerous Indigenous child family service organizations and to academic Indigenous focussed classrooms at various universities. I also planned the Maskwacîs Autism Awareness Walk and Gathering where I brought together Elders, community members, autism related professionals, and vendors, to share my results and have other autism experts share their knowledge, this will be described in detail below.

6.3 Indigenous-led research

I would consider the research in this thesis to be fully community-led research (CLR) and built on community-based participatory research (CBPR). CBPR is usually conducted by an outsider researcher who often does not have a deep connection to the community. CBPR in Indigenous communities has been done in numerous ways and LaVeaux and Christopher (2009) present Indigenous specific CBPR principles. These are:

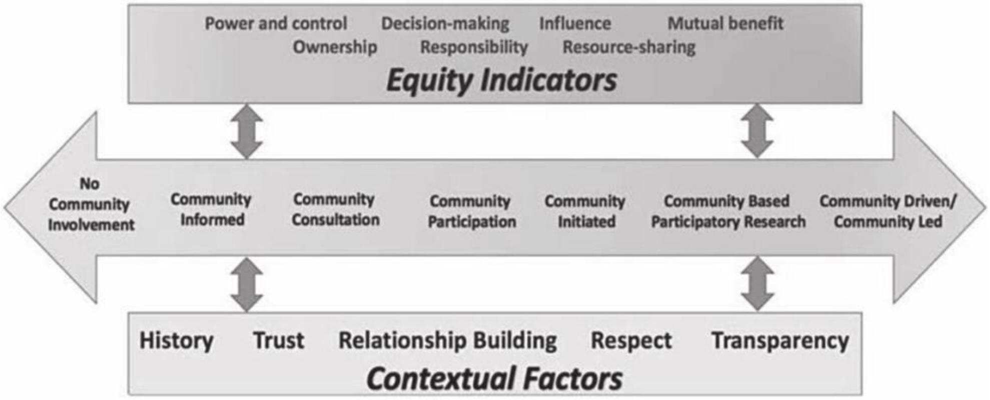
1. acknowledge historical experiences with research and with health issues and work to overcome the negative image of research;
2. recognize tribal sovereignty;
3. differentiate between tribal and community memberships;
4. understand tribal diversity and its implications;
5. plan for extended timelines;
6. recognize and engage key gatekeepers;
7. prepare for leadership turnover;
8. interpret data within the cultural context;
9. use and respect Indigenous or local ways of knowing.

As a community member, I have a first-hand understanding of the negative image of research and how it causes harm. I can recognize tribal sovereignty, can differentiate between tribal and community memberships, recognize why time is thought of differently in First Nations, have identified key members included those on the MAAC as key gatekeepers, understand the *Indian Act* political climate, have used nêhiyaw concepts in my research with respect Indigenous ways of knowing and being. Overall, this research adhered to, and built on, each of these principles and created a CLR research project. By adopting these principles, there were connections made in the community and through these connections, community representation was created in the research.

The lack of connection is problematic as researchers often come from privileged backgrounds and thus may not understand community priorities (Minkler, 2005). Another key research challenge is how funding mechanisms are structured. Often, when there are no further incentives for the researcher to stay, following a research initiative, they simply leave. When examining how much engagement has been done throughout this PhD, I would argue that this research is fully community-led, and I recognize my own accountability to the community. As someone who has deep ties to the community, the principle of 'do no harm' takes on new and profound meaning, and the research I conduct in any First Nation must have continuity and ongoing community empowerment. As I plan the next stage of my career, I often reflect on what a community research project might fully entail, particularly working through all the institutional barriers to doing good work in community. As I move forward, I will continue to advocate for, and push through, these barriers so others who are doing community work can do so without so many restraints.

Key et al. (2019) provide a framework (see figure 1) on the layers and levels of what community-engaged research looks like. They also highlight equity indicators such as power and control, decision making, influence, mutual benefit, ownership, responsibility, and resource-sharing, all which were addressed in this research. The other areas that are addressed are the contextual factors including history, trust, relationship-building, respect, and transparency.

Figure 4. Continuum of Community Engagement in Research.



As a community member, I am ultimately accountable to the community and this accountability is one of the many strengths of this work. Accountability was established and continued in many ways. As mentioned in the introduction chapter, this research started in ceremony, and I consistently attended ceremony throughout this PhD. Another form of accountability that was established was the creation and integration of the MAAC in this work. The implementation of the MAAC has been critical to the success of the research. Circles are a fundamental concept in many Indigenous cultures and are used particularly in the data collection process (Hunt & Young, 2021; Tachine et al., 2016).

There is minimal literature on how to implement a circle method for advising a research project. Most of the written work has been on advisory committees or councils which are hierarchal in nature (Oldfield et al., 2019; Strauss et al., 2001), and do not align with Indigenous ways of knowing or being. Early in the research journey, I was given the opportunity to receive circle keeper training through the National Compadrés Network. I was taught that there are several types of circles including teaching circles, healing circles, and sharing circles. While each circle is conducted in a similar way, each has a distinct structure that serves a different purpose. With this training and knowledge, I implemented the MAAC. When planning to create the MAAC I knew the success of the research was reflective of who would be in the circle.

The MAAC met monthly, both in-person and virtually, to discuss and learn about autism in the community and how we could best approach the research. Later in the research journey, the Six Nations child and youth team were eventually brought into the circle to provide guidance on how to engage and work with their community. The MAAC was made up of educators, community members, researchers, and those with lived experience as caregivers of Autistic people. The group advised the research from the beginning and continued throughout and included discussions around the research questions, data collection, participant recruitment, and opportunities to give back to the community. The circles always started with a smudge to cleanse the spiritual energy of the space, and each circle participant was given an opportunity to share their perspective on the topic at hand. The guidance and support from the MAAC were essential to the overall success of the research and allowed for the research to be representative of the community.

6.4 Nêhiyaw methodologies

Ceremony is the foundation from which this research operates. As someone who was raised in community but did not grow up with culture, language, or ceremony, I understand the importance of ceremony. The research outlined in this thesis is rooted in ceremony and from the beginning, I have continued to attend ceremony. These ceremonies provide a layer of accountability from me to the community that is rooted in the connections to ancestors and for those who come after us. Nêhiyaw scholar Shawn Wilson (2001) describes this as relational accountability and it is an essential feature for researchers as we are “answering for all of [our] relations” (p. 177) when doing research. I was gifted this knowledge, but I do not own it, therefore I must share so that others may learn from it as well.

Wâhkôtowin as a research methodology has been explored in previous research contexts. In the article “Pathways to understanding: ‘Wâhkôtowin’ as a research methodology” (O’Reilly-Scanlon et al., 2004) incorporate the nêhiyaw concept into their educational research. They outline how they participated in ceremony for guidance on how to implement wâhkôtowin as a research methodology and describe it is a “cross-cultural research paradigm that may be useful for others interested in bridging the gap between Indigenous and non-Indigenous research methodologies” (p. 31). They then integrate what they call “narrative and memory-work” methods for “pathways to understanding” (p. 33). With this method, they engaged with education students, asking them a series of questions and inviting them to critically reflect on their memories. They then discussed how wâhkôtowin guided their research by “allowing [them] to form relationships based on trust, flexibility, humour, and a willingness to move beyond our personal comfort levels to a place of shared understanding and experience” (p. 41).

This article shows that wâhkôtowin, as a methodology, is versatile and flexible enough to be utilized with various methods, much as this thesis has worked to apply methodologies and principles of community-based participatory research and wâhkôtowin that are woven together to provide a holistic and interconnected research project that illuminates and meets the needs of community, such as the Sweetgrass Method for qualitative data analysis.

When exploring the idea of wâhkôtowin as a research methodology, I had various conversations with Elders and community members. Through these conversations, I brought together the idea of establishing the fundamental nêhiyaw cultural concept of wâhkôtowin and research. As mentioned in the methods chapter, wâhkôtowin is an all-encompassing term that acknowledges the interconnectedness of all living things. A fundamental feature of wahkôtowin as a research methodology, is that is it not reductionist like many forms of western research, but rather builds connection between all the different parts of the research.

I would argue wahkôtowin is less of a methodology and more of an orientation toward research that prioritizes the relationships that develop during the research journey. These include the easier to identify relationships between a researcher and participant, researcher and community, and organizations, researcher and other researchers, and researcher and the academic institution, but they also include the less acknowledged relationships such as researcher to themselves, researcher to their ancestors, researcher to the land, and researcher to the reader. It is important to understand that I am centering the researcher in these relationships as they are accountable to all these relationships and this accountability must go beyond the research and looks to establish and maintain healthy relationships throughout. The accountability of the research outlined in this thesis will be discussed later in the reciprocal research section.

There have been other Indigenous scholars who have developed their own culturally rooted research methodologies. For example, Māori scholar Kiri Dell (2021) offers a methodology she terms rongomātau, or 'sensing the knowing'. This cultural methodology "involves the collection and analysis of data through a frame of three dimensions: connecting in (self-inner world), connecting out (external world) and connecting the whole (higher/spiritual consciousness), to achieve holistic ways of theorising" (p. 1). Like the wahkôtowin methodology, the rongomātau methodology recognizes there is an interconnectedness between the researcher and all the other aspects surrounding the research. There is also an emphasis on the dual nature of the researcher as they navigate and connect western and Indigenous worldviews. Overall, the rongomātau methodology is rooted in Māori ways of knowing, notably as the wahkôtowin is rooted in nêhiyaw ways of knowing and being.

Furthering the conceptualization of nêhiyaw ways of doing research that are rooted in nêhiyaw culture, was the use of Sweetgrass Method. The Sweetgrass Method is a way to approach qualitative research from a nêhiyaw worldview. Western qualitative analytic methods such as thematic analysis aims to categorize and separate the data based on themes that emerge (Castleberry & Nolen, 2018). While this approach is effective for certain types of qualitative inquiry, I felt it did not align with the nêhiyaw worldview of building connection and examining relationships. While there may be some similarities between Indigenous qualitative analysis methods and western methods, there are some key differences. One of the key differences and contribution of the Sweetgrass Method is its focus on the spiritual and healing nature of the research. When working with Elders and community members I understood that they were gifting me knowledge. Although used in the context analysis, the Sweetgrass Method acknowledges the interconnectedness of all the research process including research planning, data collection, and dissemination and encourages healing throughout. The knowledge that was gifted was spiritual and therefore I was responsible for it, but I do not own it. It is my responsibility to share the results of these studies with families as it may have a positive impact and provide support in their own healing.

Sweetgrass is a medicinal plant used by many tribes across Turtle Island (North America). Thus, the Sweetgrass Method potentially can be utilized by other Indigenous and non-Indigenous academics who are working with Indigenous knowledges and data. When gathering data, or in this case sweetgrass, it is important to acknowledge the interconnectedness of the data and interpret the data from a cultural standpoint. One of the main differences of the Sweetgrass Method from western methods is not only the connection that is being established, but also the healing or medicinal properties of sweetgrass and how it creates an environment for the research to be healing. Healing in this case happens in several ways, the first way is for the researcher themselves, in this case, me. Early in the PhD journey, and while I was connecting with data, I did not realize how this research would have such a positive impact on my spiritual, physical, mental, and emotional wellbeing. This connection allowed me to grapple with the challenges of being a parent to Autistic children and come to a healthier understanding of what autism is and how I can better support my family and community.

Another way this research was healing, was for families and the community. After I would finish up interviews with both Elders and caregivers, they would often thank me for the work I was doing. Specifically, the caregivers told me that the interview I did with them was the first time anyone had sat down with them and listened to their story. I would use a conversational approach to allow for meaningful discussion and I would often share my own experiences as a caregiver, with the goal of making the interviewee feel less disconnected or isolated.

6.5 Scoping Review

The scoping review was a research exercise that gathered and collated all the known literature as it pertains to Indigenous peoples and autism, with a focus on Canada. The review was a critical starting point for this thesis and provided insights into the research gaps we could potentially address. The results of the scoping review align with other scoping reviews done globally. Much like our scoping review in which we found a low number of records and articles, reviews done in New Zealand Māori (Tupou et al., 2021) and Australian Aboriginal and Torres Strait Islander (Bailey & Arciuli, 2020) contexts yielded minimal academic literature on autism and Indigenous peoples – 13 records and 17 records respectively. These reviews underscore the lack of resources and research done in Indigenous communities. Globally the articles also outlined ways forward, discussed cultural differences in how autism is culturally viewed, and explored experiences of Indigenous Autistic people in the medical, educational, and child family services sectors.

The scoping review revealed many gaps in Indigenous research on autism in Canada. These gaps include the lack of primary quantitative data resulting in not knowing the prevalence of autism in Indigenous communities. There is also minimal qualitative research done on the lived experience of autism from the perspectives of Indigenous families. The scoping review, community engagements, and information obtained during the research process have revealed a significant gap in current research and practice. This gap pertains to the failure to address the wants and needs of the Indigenous people with whom I collaborated.

6.6 Elders study

The Elders study explored autism in a nêhiyaw cultural and social context. When asked if there are any words that translate directly as autism from a nêhiyaw perspective, the Elders said ‘no’, although a few Elders conveyed a few nêhiyawin (Plains Cree words) that may be a fit. The first word is sewatsiwin which roughly translates as ‘they are sacred’. This word generally translates as people with disabilities as shown in the following quote “they're sacred children, all children are sacred. But the ones that come out with disabilities are even more sacred because they come out with a different view on life” (shared by an Elder in the community). Another word that was given was acahk pimatsiwin which roughly translates to “spiritual way of being”. The Elder that gave this word emphasized the spiritual gifts that these children bring, and they also spoke about these children living more in spirit. An example they gave was what is widely known as stimming. Stimming is often viewed as an involuntary movement done by an Autistic person and is considered disruptive or something to be ‘fixed’ (McCarty & Brumback, 2021). Stimming behaviour can be seen as hand flapping, rocking back and forth, and verbal noises. A study done on Autistic adults explored the experiences of stimming and found that stimming has a net positive affect for sensory regulation but is also potentially detrimental relative to the Autistic individual ‘fitting in’ (Charlton et al., 2021). The Elder who gave the nêhiyaw word acahk pimatsiwin also talked about stimming as when Autistic people are in their ‘spirit space’; that is, when they are most connected to the spiritual dimension. This strengths-based perspective is rooted in culture and provides a perspective on autism that goes beyond acceptance and actively views autism as a strength. Elders provided knowledge on the cultural understandings of autism and these knowledges have been outlined here so that this research may have the opportunity to positively benefit Indigenous families and Autistic children and adults.

There have been studies that explore cultural understandings of autism, but minimal attention has been given to Indigenous beliefs and approaches. A study done with caregivers in Indonesia touches on cultural beliefs of autism and discusses how some parents believed it was karma and autism was a curse, while others felt it was God's plan to make their child Autistic and they would have to accept it (Riany et al., 2016). Another qualitative study conducted in Saudi Arabia revealed similar results and parents felt autism was the result of black magic and was a curse (Alqahtani, 2012). In another study in Africa they found many of the mothers would ask tribal traditional doctors for an explanation and believed they may be bewitched (Manono & Clasquin-Johnson, 2023). The idea that autism was something supernatural is common around the globe, but generally with negative implications, which is the opposite of what was found in our Elders study.

While there has been minimal literature in Indigenous contexts that has explored the colonial and cultural experiences of autism, Steven Kapp, who is an Autistic non-Indigenous researcher wrote the chapter "Navajo and Autism: the beauty and harmony" (2013) in the book *Moving Beyond Boundaries in Disability Studies*. This chapter looks primarily at secondary sources and explores both the cultural and colonized understandings of autism and disability among the Navajo, an Indigenous tribe located in southwest United States. The chapter offers many similarities to the work that is outlined in this thesis. First Kapp outlines the historical underpinnings and negative impacts of colonial policies such as forced relocation, boarding schools, and loss of language and culture. Kapp also shares the Navajo cultural concept of Hozho. Like wâhkôtowin, hozho is a philosophy that upholds the view that "everything has a spirit, is interconnected, and thus merits equal respect. In addition, it appreciates the mystery of life rather than absolute knowledge, thereby enabling flexibility to multiple truths" (p. 584). It is through the concept of Hozho that the Navajo people embrace and accept autism, and this has positive implications on the wellbeing of Autistic people as well as their caregivers. Acknowledging the similarities between Indigenous tribes is a powerful step to being able to accept and support the autism community in meaningful ways, and by rooting our understandings of autism back into cultural concepts of wâhkôtowin and hozho we can address the harmful stigma experienced by the Indigenous Autistic community, and hopefully, move forward in a good way. These cultural teachings offer important lessons in dispelling the stigma many Indigenous families experience when it comes to autism and can act as a roadmap to ensuring families are able to fully embrace the autism journey.

Globally, Indigenous understandings of autism are similar with tribes practicing acceptance through cultural teachings. There are also connections that can be identified between nêhiyaw and Māori understandings of autism. Māori scholar Jessica Tupou is a researcher who has written several research articles on the cultural and the lived experience of autism specific to the Māori people in New Zealand. According to Tupou, the Māori word for autism is takiwātanga, which translates as 'in his or her own time and space' (Tupou et al., 2023). Tupou attributes this word to another Māori person, Keri Opai, where the Māori people are described to have a "view of autism at its core and seeks to recognise and honour the view that autism is intrinsically personal for every individual and whānau" (p. 5). The name is derived from the whakataukī, Ā te tau tītoki which means, "when the tītoki fruits". The valued tītoki tree does not fruit regularly but does it in its own time, an allusion to Autistic people blooming in their own time and space" (p. 5, Te Pou o te Whakaaro Nui., 2019). Much like nêhiyaw and Navajo understandings of autism, Māori people view Autistic individuals as distinct and capable, not as people with ‘something having to be solved or cured’. Globally, Indigenous knowledges and wisdom related to autism offers a powerful opportunity to shift from the deficit-based narrative that was established in the western medical model.

6.7 Caregivers study

Overall, the caregivers study aligns with research that has been conducted with caregivers from other ethnic and socioeconomic backgrounds. Caregivers in our study often spoke about how important it is to connect their children with the culture. A study done on language immersion in another Indigenous community showed the positive effects of students learning their language and how it has a positive impact on wellbeing (Whalen et al., 2016). Another quantitative study showed that cultural continuity, such as identity, spirituality, and traditions were all factors for resiliency of First Nation youth (Snowshoe et al., 2017). Caregivers knew that connecting their Autistic children to their culture would have a positive effect on their health and learning outcomes. They also understood how cultural dynamics constitute one of the main reasons for the acceptance they have seen in the community. When a child is raised with traditional values, they grow up with a traditional mindset and behave in a traditional way. Caregivers often looked for opportunities for their children to practice their culture, whether it was attending a powwow or going to ceremony, as they knew it was vital for children’s health and wellbeing.

The findings from this study align with other Indigenous caregiving contexts such as a study on New Zealand caregivers. Tupou et al (2023) explored the experiences of whānau (family) Māori caregivers and Autistic children and identified several themes including (1) daily activities, (2) social interactions, (3) communication goals, (4) cultural goals, (5) social goals and values, (6) early childhood education, (7) whānau support, and (8) understanding and attitudes. These themes align with emergent themes from our caregiver study and further reinforce the similarities between Indigenous peoples across the globe. When examining the results of Tupou's study, a common perspective of the caregivers is their goal to have their children grow up around their culture, in this case te reo Māori and tikanga Māori, while also perceiving that learning English may have benefits for their children. Caregivers often shared the frustration they had with government policies and services, including long wait times for diagnosis and autism services. Tupou outlined future recommendations which include better access to culturally informed services for caregivers and Autistic people. Tupou also emphasized the importance of relationships when it comes to working with Māori people.

The experiences of caregivers in this study can also be seen in other contexts based on the literature. For example, themes such as exhaustion and burnout (Fong et al., 2023), autism as a gift (Cook, 2019), advocacy (Stahmer et al., 2019), ableism (Furr, 2023), and school experiences (Martin-Denham, 2022) have been addressed within the broader literature. Caregivers brought up many experiences and perspectives like those of caregivers in other cultural and social contexts. One of the main findings from our research was the challenge for caregivers to access services.

In contrasting our research with other studies, a qualitative study done on cross cultural understandings of improving access to autism services explored the experiences of caregivers across three groups: Black, Korean, and Hispanic (Stahmer et al., 2019). Like our study results, the main challenges caregivers faced in that study were around diagnosis, autism service provision, geographic location, transportation, stigma, system navigation, and ways forward — including as facilitators of participation. This study presented caregiver experiences across race, ethnicity, and socio-economic factors and many of the findings align with our research. The main difference between those studies and ours was that Indigenous caregivers often talked about cultural understandings of autism and how culture is seen as a way forward to accepting and embracing an autism diagnosis.

Both studies offered powerful insights into the realities of autism in First Nations communities and how to better support First Nations Autistic children and their families. The main take away from each study was the importance of culture and how Autistic children deserve to be immersed in their culture and have the same opportunities as other children in the community. Particularly, the Elders study is an opportunity for First Nations caregivers to obtain cultural knowledge around autism and apply it to their own lives.

6.8 IQAT assessment

Reflecting on this research overall, ensuring that my research and the scoping review adhered to Indigenous-approved approaches to research was critical to the success of the research. I applied the Indigenous Quality Assessment Tool (IQAT) to this thesis. As mentioned earlier, the IQAT is an evaluation instrument and was developed by Indigenous people to assess the quality of research done on Indigenous populations. The results show that the research presented scored a 16/16 on the IQAT which is substantially more than what the articles in the scoping review scored. This shows that when research is led by Indigenous peoples it has the potential to have more meaningful impact.

Table 5. Indigenous Quality Assessment Tool application on thesis

Questions	Yes	Partially	No	Unclear
1. Did the research respond to a need or priority determined by the community?	x			
2. Was community consultation and engagement appropriately inclusive?	x			

3. Did the research have Indigenous research leadership?	x			
4. Did the research have Indigenous governance?	x			
5. Were local community protocols respected and followed?	x			
6. Did the researchers negotiate agreements with regards to rights of access to Indigenous peoples existing intellectual and cultural property?	x			
7. Did the researchers negotiate agreements to protect Indigenous ownership of intellectual and cultural property created through the research?	x			
8. Did Indigenous peoples and communities have control over the collection and management of research materials?	x			
9. Was the research guided by an Indigenous research paradigm?	x			
10. Does the research take a strengths-based approach, acknowledging and moving beyond practices that have harmed Indigenous peoples in the past?	x			
11. Did the researchers plan and translate the findings into sustainable changes in policy and/or practice?	x			
12. Did the research benefit the participants and Indigenous communities?	x			
13. Did the research demonstrate capacity strengthening for Indigenous individuals?	x			
14. Did everyone involved in the research have opportunities to learn from each other?	x			

6.9 Relational knowledge mobilization

As mentioned earlier, there has been an emphasis on reciprocating back to the community. Whether or not the research has given back to the community, is an important factor in measuring if the research is successful or not. As mentioned in the introduction, ‘research’ is often seen as a ‘dirty word’ in Indigenous communities due to its extractive nature (Smith, 2013). Identifying opportunities to give and to implement relational and reciprocal research is seen as an opportunity to address the negative attitudes Indigenous communities have about research (Tsosie et al., 2022). Over the course of my PhD, and through numerous community engagements, several ideas emerged on how to give back to the community in meaningful ways. These events and activities are outlined below.

Implementing inclusive sensory spaces is a way to improve the wellbeing of Autistic people (Atmodiwirjo, 2014). One of the challenges families face in the community, was the lack of cultural participation in cultural events. Indigenous spaces often embody a rich sensory environment deeply intertwined with cultural practices, traditions, and beliefs. These spaces may include natural landscapes like forests, rivers, or mountains, as well as communal gathering areas such as powwow grounds, traditional dwellings, or ceremonial sites. Within these spaces, sensory stimuli are abundant and diverse, ranging from the rustle of leaves in the wind to the rhythmic beat of drums during ceremonies. An example of an Indigenous sensory space that was implemented in community was a sensory mîhkwap (tipi) both at the Maskwacîs Education School Commission powwow and the Samson Cree Nation and Ermineskin powwows (see figure 5). This was done in partnership with the Maskwacîs Parents Place, Autism Edmonton, and by the MAAC.

Powwows are often loud with large crowds and can be overwhelming for people on the autism spectrum. The sensory teepee was set up near the periphery of the powwow grounds and was a cultural space for families to be part of this experience even if they felt their children were becoming overstimulated. The teepee was outfitted with a buffalo hide and other sensory toys. The buffalo hide was important as it represents the cultural aspect of the community. The kids appreciated the hide because it was soft, and they could lay down on it. Smell was also a part of the sensory experience as the hide was tanned and the kids could feel connected to the culture visually, with touch, and smell. The sensory tipi was well received by the community and families. The tipi also raised autism awareness the community and gave parents an opportunity to ask questions about the diagnostic process or how to access autism related supports.

Figure 5. Sensory mîhkwap (tipi)

Another opportunity to give back was through supporting the Maskwacîs Autism Support Group. While this group was already underway and being led by Carmella Cutknife at the Maskwacîs Parents Place, I felt it was a good opportunity to connect with, learn from, and support those with the lived experience of autism in the community. I applied for, and was awarded, a small operational grant through the Situated Knowledges of People and Place (SKIPP) from the University of Alberta Indigenous Initiatives office and was able to redirect those funds toward the support group. Over the years, Carmella and I planned and executed several events for the group. These included sharing circles, renting out the local movie theatre to watch a Mario Bros movie with families, a back-to-school barbeque, a Halloween event and a Valentine’s Day event. Participation ranged from 5 to 15 families, depending on the event. I understand there are many challenges for Indigenous families directly impacted by autism to participate in these kinds of events. Barriers to participation include transportation, food insecurity, and childcare. We offered the families a ride, fed them, and had childcare onsite to address those challenges, and after each event, we gave the families a $50 dollar gift card for attending. Overall, the autism support group has established itself as a consistent and supportive space for parents to connect and for their children to feel included.

Early in my research career, an Elder sat me down and explained that when conducting research and gathering wisdom, that the knowledge that is gifted to me does not belong to me, and I have a responsibility to share that knowledge with those I feel it may help. Over the four years of the research, I have had numerous opportunities to present locally, regionally, nationally, and internationally. These include keynotes at conferences such as the Canadian Autism Leadership Summit, the Kenora Chiefs Assembly, and the Alberta Council on Disability Services IMPACT Conference. The presentations I would like to highlight include community presentations at MESC, the Six Nations of the Grand River, and Maskwacîs Autism Awareness Gathering. The MESC keynote presentation was attended by approximately 500 MESC leadership, educators and support staff. I presented some of the early findings of my research as well as my own personal experiences as a community member and parent to Autistic children. I used the presentation to build awareness on the cultural dimensions of autism to address the stigma that can still happen in the community. I also wanted to share possible autism-related opportunities the community can start to work toward. Overall, the presentation was well received, and multiple attendees approached me afterward and thanked me for the work I am doing.

I had the opportunity to visit the Six Nations of the Grand River four times in 2023 thru 2024. The March 2023 visit was my first in person introduction to the community, Jacqueline Smith and the rest of the Child and Youth Health Team. At this visit, I received a tour of the community, and an overview of autism services in the community, and met key stakeholders. From there, I crafted a community-specific research proposal and presented it virtually to Chief and Council where it was passed unanimously. In August 2023, I visited again and began creating new connections in the community, including with community autism coordinator Celina Hill. Based on these connections, I was able to do a presentation to caregivers and support staff in the community. I also went back to the community in November 2023, building on the past two visits and again presenting to the community on the Elder study findings, as well as conducting some interviews with caregivers in the community. Finally, I visited again in March 2024 to present on the caregivers' study findings at the Six Nation Community Conference on Autism. Over the course of the year, I established relationships in the community, all of which have provided invaluable insights and knowledges on the experiences of autism in the community. I am grateful for these relationships and honoured to have been able to conduct meaningful and critical research on autism in the community.

Early in the PhD I recognized the need for a Maskwacîs community event that focussed on autism, but without the proper resources or personnel support I knew I could not properly plan or execute an event like that. It was not until I partnered with the Women and Children's Health Research Institute (WCHRI) that I had both the financial resources and support to create an autism event in community. I also knew I had to present my findings back to the community and this event would allow me to do so. On May 7th, 2024, we hosted the first annual Maskwacîs Autism Awareness Gathering and Walk (see figure 6). This event was in the community and included transportation for community members. We had 72 people attend and 6 vendors. Attendees included caregivers, support staff, educators, Elders, Autistic children, and autism-related organizations. The day started with a prayer by an Elder where they gave a blessing and shared cultural knowledge on how nêhiyaw people view children and autism. I then presented on my PhD findings titled "Decolonizing Autism: Insights from a Community-Led Research Study" and my supervisor Dr. Lonnie Zwaigenbaum presented on "Autism and Healthcare". After lunch, I facilitated a community caregiver panel that was supported by the Canadian Caregiving Center for Excellence. Unfortunately, due to rain, we had the cancel the awareness walk. Overall, the day was well received, and I had numerous attendees thank me for planning the day.

Figure 6. Maskwacîs Autism Gathering and Awareness Walk

Finally, over the course of my PhD, my family and I were asked to participate in two separate documentaries. The first documentary, *The Gift of Being Different,* was filmed in late

2022 and early 2023 and was released in April 2023. This film was done in partnership with Autism and/or Intellectual Disability Knowledge Exchange Network (AIDE) Canada, directed by Conor McNally. The film was relatively short at 18 minutes and included an opportunity for viewers to get to know my son Anders and me. The film also had a tea dance ceremony which included drumming and a feast. The purpose of the film was to be a resource for families who did not have much experience with autism. The film was well received and is available on YouTube and Vimeo.

The second film, which just wrapped up filming in April of 2024, is a full-length feature about my research journey and the autism related community. This film is done in partnership with Abenaki director Kim O'Bomsawin, and her film company Terre Innu. The film goes into much more in depth than the previous documentary and includes scenes of a hunting trip, a sweat lodge ceremony, the sensory teepee at the Samson Cree Nation powwow and various interviews with community members. This film is set to be released in Spring 2024.

6.10 Strength-based Indigenous autism

Globally, there is a growing shift in how society views autism. Traditionally, the medical model sees autism as a disorder or something to be cured or treated, whereas the social model of disability views autism as a 'way-of-being' (Anderson-Chavarria, 2022). Neurodiversity complements the social model of disability by understanding we are all neurologically built differently, and that difference is something to be celebrated. The term, 'neurodiversity', was first credited to Judy Singer in 1999, but recently has been found to have been discussed among an online Autistic community years earlier (Botha et al., 2024). Simply, "neurodiversity can simply refer to the reality that diverse minds and brains exist, just as 'biodiversity' refers to the factual reality of biological diversity. In this factual sense, even groups of neurotypical people are neurodiverse, as no two individuals have exactly the same mind or brain" (Dwyer, 2022, p. 71) whereas neurodivergence is seen as a term of exclusion that describes those who diverge from the inclusivity of neurodiversity, for example, Autistic people (Legault et al., 2021).

Cultural models of autism are also contributing factors to how autism is perceived both at the societal and familial levels (de Leeuw et al., 2020). It is through a cultural model that this thesis aims to transcend the neurodiversity model. Through numerous engagements and through this thesis, I have concluded that Indigenous peoples have been practicing neurodiversity and celebrating neurodivergence for millennia. The societal framework that promotes inclusivity and celebrates neurological differences constructed through our culture, languages, and traditions. Unfortunately, a significant portion of this knowledge has been eroded because of colonialism, particularly due to the establishment of residential schools in Canada. It is crucial to disseminate the insights gained from this research to Indigenous families, with the goal fostering a positive influence with, and for, Indigenous families.

6.11 Recommendations and next steps

The main strength of this research is that it is fully community-led. As mentioned in the methods chapter, having the opportunity to do insider-insider research was a unique and meaningful process. As I continue my academic journey, I am going to create and implement continuing community-led research projects. For example, I am leading the Ispimihk Awasisak, program, which translates as Sky Children, in partnership with the Women and Children's Health Research Institute (WCHRI). The name was gifted in ceremony and the program is guided by and is responsible for Indigenous children in Maskwacîs and beyond. Indigenous children have been, and continue to be, significantly impacted by settler colonialism with detrimental effects on their health and wellbeing. To make changes that can tangibly improve these circumstances for Indigenous children, WCHRI will partner with, and learn from, Indigenous and non-Indigenous researchers, clinicians, and community members to generate new knowledge and initiatives through the Indigenous children's health program. This program has a five-year term and will use a community-led research approach to improve the health and well-being of Indigenous children and their families at the community level. This program is a direct response to the pressing need for targeted program development and research to address health disparities among Indigenous children.

The need for culturally informed autism assessments has also been discussed in the community, with an aim of creating spaces for First Nation families to receive a diagnosis that is rooted in their culture. In March 2024, through the leadership of my supervisor Dr. Lonnie Zwaigenbaum, we were awarded a 'One Child, Every Child' Catalyst Grant to explore the experiences of autism diagnosis in Maskwacîs and use that information to develop assessments that reflect the culture and the wants and needs of families in the community. That work will also be informed by findings from this study in terms of how to meaningfully engage with Indigenous communities to inform other diagnostic services.

I would also recommend more Indigenous communities across Canada and around the world begin to explore their own cultural understandings of autism. It is important to acknowledge the diversity Indigenous peoples have and that the teachings of each community and tribe may be different. While there may be similarities across Indigenous groups, learnings from each group are critical for families to learn from as they will provide much more meaningfully impact if they are able to connect with the teachings on a cultural level.

Another critical piece that is missing, is a prevalence study on Autistic Indigenous peoples in Canada. Prevalence of autism and other disabilities is currently unknown in

Maskwacîs and other First Nations communities. Current data on Indigenous health is flawed and often inaccurate resulting in an inability to comprehensively understand Indigenous health outcomes (Botha et al., 2024). Indigenous health data inaccuracies are the result of a flawed data collection system that does not collect information on how Indigenous peoples want to identify themselves and is often not led by Indigenous peoples (Hayward, Wodtke, et al., 2021). These inaccuracies and gaps often have led to health policies and programs that do not reflect the realities of Indigenous peoples (Smylie & Anderson, 2006). Current national data on autism prevalence gathered by the Public Health Agency of Canada (2019) estimates 1 in 50 in Canada, but excludes Indigenous communities and specifically, families living on reserve. The lack of prevalence data makes creating policies and programs on reserve challenging and must be addressed with future research.

6.12 Limitations

While I would consider using wâhkôtowin as a methodology as a strength of this research it does have a limitation. While wâhkôtowin as a research methodology was done in consultation with four nêhiyaw Elders and through various conversations with community members and academics, I feel there is still more work to be done to refine it so other nêhiyaw academics may be able to implement the methodology in their own research. The same can be said for the Sweetgrass Method. While this method worked effectively for this thesis, more engagement is needed, specifically with knowledge keepers and Indigenous methodological experts so that other Indigenous qualitative researchers can apply this method in their own work. Overall, more applications of these culturally rooted approaches and thus more detail for application in future research would be beneficial.

This research was done in the context of nêhiyaw culture and more culturally rooted research can also be done with tribes such as the Haudenosaunee, Anishinaabe, Blackfoot, Mi'kmaq, Coast Salish, Dene, Inuit, and Métis and other Indigenous groups as their understandings may differ from ours. It is important to not pan Indigenize teachings and work must be led by each group. For families to come to an understanding and acceptance of autism, these teachings must be rooted within their own cultural contexts. While there are some important teachings that all families can learn from, it is important to recognize the limitations of these teachings as well.

Although we did our best to address the power imbalances that are inherent with community research projects through principles such as OCAP© and the establishment of the MAAC, I recognize that even though I am community member, I am still bound by university regulations and procedures. Being a graduate student also creates limitations to doing community work including an inability to apply for, and hold your own funding, lack of experience navigating university structures, and adhering to departmental deadlines all of which can get in the way of getting the work that needs to be done in community. I also understood that the professionals I worked with are busy and I knew early in the research process I would have to balance their time commitment and the pressure of doing research and not wanting them to have to take on any extra work on top of their already hectic schedules. As the research moved forward, I did my best to accommodate the wants and needs of the community while also adhering to institutional expectations and procedures.

Finally, another perceived limitation is the low number of participants for each study, ($n = 13$) for the Elders and caregivers ($n = 14$) respectively. While we did our best to recruit and accommodate participants in each community and had quite bit of interest in the research from the initial conversations with potential participants there was less interest once the interviews started to take place. There are still many fears community members face when to research and these are exacerbated when autism is the topic of research. Stigma, fear of child family services, and misunderstandings could have all contributed to the low level of recruitment.

6.13 Conclusion

The three studies outlined in this thesis are the outcome of an Indigenous-led research project focused on autism. All research objectives were met, and the results yielded critical knowledges on the experiences of autism in Indigenous communities. The scoping review, Elders and caregiver studies provided valuable insights into the experiences of autism from an Indigenous lens. The nêhiyaw methodology and methods offered a unique perspective on how community research can be done. Overall, this research adhered to community principles and addressed a critical gap in the literature and offers insights into the needs and priorities of Maskwacîs and will guide future work in this important area.

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Appendices

MEMORANDUM OF UNDERSTANDING

between

MASKWACIS EDUCATION SCHOOLS COMMISSION
PO Box 2415, Maskwacis AB, T0C 1N0

AND

Grant Bruno
PhD Medical Sciences Student
Faculty of Medicine and Dentistry
Department of Pediatrics
University of Alberta

on

“Redefining autism through a Nehiyawak (Plains Cree) lens”

This Memorandum of Understanding (MOU) is made between **MASKWACIS EDUCATION SCHOOLS COMMISSION** (hereinafter referred to as the “MESC”), a First Nations education authority located in Maskwacis, AB, and **GRANT BRUNO** (hereinafter referred to as the “researcher”), a PhD Medical Sciences student out of the University of Alberta.

Purpose

The purpose of this MOU is to define the areas for fundamental, academic research in which the Parties desire to work together. The Parties have common research interests and will cooperate in performing the activities stated below.

GENERAL COUNCIL
MOTION MEMORANDUM

TO:	File
Cc:	Renay Ross, Executive Assistant to Chief Executive Officer Tammy Martin, Chief of Staff Rebecca McComber, Admin. Assistant to Director of Finance
FROM:	Brooke Froman, Executive Coordinator
DATE:	**June 27, 2023**
MEETING DATE:	June 28, 2023
RESOLUTION NO:	**GC#839/06/27/2023 and GC#840/06/27/2023**

GC#839/06/27/2023

Moved by Nathan Wright and seconded by Michelle Bomberry that the Six Nations of the Grand River Elected Council accept the recommendation from the Ethics Committee and approve Grant Bruno's Ethics application titled "Autism in First Nations Communities".

ALL IN FAVOUR CARRIED.

GC#840/06/27/2023

Moved by Nathan Wright and seconded by Michelle Bomberry that the Six Nations of the Grand River Elected Council to waive second reading on **GC#839/06/27/2023**.

ALL IN FAVOUR CARRIED.

SIX NATIONS OF THE GRAND RIVER ELECTED COUNCIL

Brooke Froman

Brooke Froman, Executive Coordinator, Central Administration Office

Elder Interview Guide

Preamble

The purpose of this interview is to learn from your cultural perspective and traditional knowledge about autism. The information gathered from this interview will be used to help people understand autism and provide better support to individuals with autism in your community.

1. Tell me a bit about yourself, where are you from etc?
2. Cree understandings of parenting?
3. How important is culture?
4. Can you tell me about your understanding of autism?
    - Supports in community?
5. Have you or anyone you know had experience with someone who has autism? Can you share with me what that experience was like?
6. What do you think are some of the challenges that individuals with autism face in your community?
7. In your opinion, what can be done to better support autistic individuals your community?
8. How does your community support individuals with disabilities in general?
9. Are there any traditional practices or beliefs that can be helpful in supporting individuals with autism?
10. Can you share any stories or teachings from Cree culture that may be relevant to understanding and supporting autistic children?
11. What advice would you give to non-indigenous people who are trying to learn about autism from a Cree cultural perspective?
12. Is there anything else you would like to share about autism and how it relates to your community and culture?
13. Disability services as a treaty right?
14. Cree word for autism?
15. Jurisdiction challenges?
16. Diagnosis challenges?
17. One piece of advice?
18. How to build awareness?

19. Thank you for your time today, is it possible to follow up with you in the future?

Caregiver Interview Guide

Preamble

The purpose of the interview with a parent of an autistic child is to gain a better understanding of the experiences, challenges, and needs of First Nations families who have an autistic child. The information gathered from this interview can help inform the development of culturally appropriate support services and interventions that meet the unique needs of First Nations families and their autistic children. Specifically, the interview aims to:

1. Understand the family's experience in raising an autistic child within the context of their First Nations culture and community.
2. Identify the challenges and barriers that the family has encountered in accessing support services and interventions for their child.
3. Gain insight into the family's perspectives on how autism is perceived and understood within their First Nations community.
4. Explore the family's beliefs and values regarding disability and traditional healing practices that may inform their approach to raising an autistic child.
5. Gather recommendations from the family on how support services and interventions can be better tailored to meet the needs of First Nations families and their autistic children.

Overall, the purpose of the interview is to honor the unique experiences and perspectives of First Nations families who have an autistic child and to use their input to inform the development of more culturally appropriate support services and interventions.

Introduction

1. Tell me about yourself?
    - Where you are you from? Family?

2. Tell me about your child/ren?
    - What activities does your child enjoy doing?
    - With whom?
    - Are there any sensory challenges?

3. When did you first learn about autism?

4. When did you first suspect that you child had different abilities?
    - What were some of the earlier signs?
    - Did anyone approach you specifically talk about autism?

5. Can you tell me a little bit about your child and their diagnosis process?

6. What are your thoughts on the thoughts on the stigma?

7. Challenges of living on/off reserve?

8. Is there more acceptance in your community?

Support and services

9. Do you currently access any disability resources/services?
   - If yes, which one would be the most beneficial?
   - What do you know about Jordans Principle?

10. Is there anyone or any place you find support for you child/ren?
    - Are they close with their siblings? Cousins? Aunts/uncles? Mosom or kokom?

11. As a parent who supports you?

12. If there was one support/service for autistic children, you would like to see on reserve, what would that be?

School:

13. How does your child manage in school or daycare?
    - Do they require extra supports? Please explain?
    - What accommodations and supports does your child receive in school?
      - OT, SLP, Physio?

14. Have you faced any challenges in getting appropriate services or accommodations for your child in school?

15. What are your child's strengths when it comes to learning?

16. What are you child's coping mechanisms?

17. How does your child interact with their siblings and other family members?
    - Do you find they are closer with some family? Please explain.

Cultural Connection

18. Do you know anything about cultural understandings of autism?
    - Children are gifted.

19. Do you practice your culture in your home?
    - If yes, please explain.
    - If not, is this something you would be interested in?

20. Do you feel cultural events such as powwows, ceremonies, etc are inclusive of autistic people?
    - If there was opportunity to attend cultural events in the future

21. Can you think of other ways your keep your child connected to the culture?

Wrapping up

23. Can you give an example of one example of advocacy you have done for your child?

1. If there was one piece of advice you would give to another parent to an autistic child, what would that be?

24. Is there anything else you would like to add to our conversation today? Something I have missed?

RESEARCH STUDY: LIVED EXPERIENCE OF AUTISM IN FIRST NATIONS COMMUNITIES: A QUALITATIVE STUDY

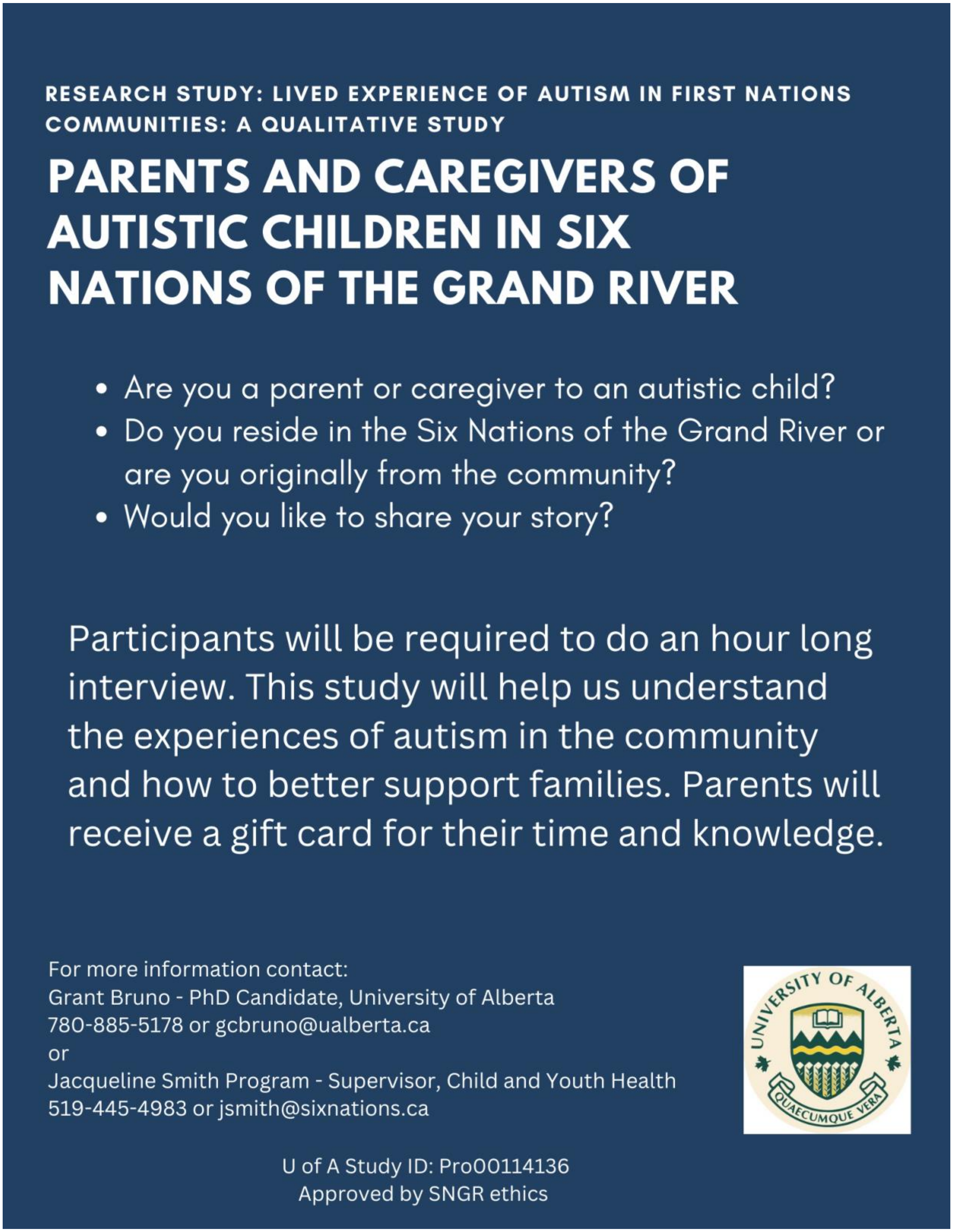
PARENTS AND CAREGIVERS OF AUTISTIC CHILDREN IN MASKWACIS

- Are you a parent or caregiver to an autistic child?
- Do you reside in Maskwacis or are you originally from the community?
- Would you like to share your story?

Participants will be required to do an hour long interview. This study will help us understand the experiences of autism in the community and how to better support families. Parents will receive a gift card for their time and knowledge.

For more information contact:
Grant Bruno - PhD Candidate, University of Alberta
780-885-5178 or gcbruno@ualberta.ca

U of A Study ID: Pro00114136



RESEARCH STUDY: LIVED EXPERIENCE OF AUTISM IN FIRST NATIONS COMMUNITIES: A QUALITATIVE STUDY

PARENTS AND CAREGIVERS OF AUTISTIC CHILDREN IN SIX NATIONS OF THE GRAND RIVER

- Are you a parent or caregiver to an autistic child?
- Do you reside in the Six Nations of the Grand River or are you originally from the community?
- Would you like to share your story?

Participants will be required to do an hour long interview. This study will help us understand the experiences of autism in the community and how to better support families. Parents will receive a gift card for their time and knowledge.

For more information contact:
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U of A Study ID: Pro00114136
Approved by SNGR ethics