

EXAMINING ADVERSE CHILDHOOD EXPERIENCES IN A FIRST NATIONS  
TREATMENT-SEEKING POPULATION

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### Abstract

Experiencing adversity during childhood can disrupt typical developmental pathways and consequently affect health outcomes throughout the lifespan (Norman et al., 2012), particularly for Indigenous populations in Canada as they tend to experience greater health disparities when compared to non-Indigenous populations (Statistics Canada, 2018a). To better understand these relationships within Indigenous populations, the *First Nations ACE* study examined Adverse Childhood Experiences (ACEs) in a First Nations population seeking substance use treatment, including participant-reported ACEs and health outcomes of parents and grandparents using a community-based participatory approach. Regression models assessed the relationship among ACE scores and subsequent health outcomes reported by 141 individuals in an on-reserve residential treatment program. Higher reported ACE scores were significantly associated with an increased number of health concerns. Some study hypotheses were not supported despite being supported with prior literature. Odds ratios of increased prevalence of specific diseases were not significant, however trended in expected directions. Parent and grandparent ACEs and residential school attendance were not significantly related to increased health concerns by participants, although were associated with parenting difficulties. Future research with a larger sample size may increase the power of analyses to detect clinically and statistically-relevant relationships among these groups. When participant and staff experiences with *First Nations ACE Study* were examined, participants generally reported positive experiences with the study, and staff members reporting satisfaction with the CBPR practices embedded within the study.

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## Chapter 1: Introduction

Health disparities among Indigenous<sup>1</sup> populations when compared to non-Indigenous populations in Canada are well documented (Cooke et al., 2007; Public Health Agency of Canada, 2018; Reading & Wein, 2009; Truth and Reconciliation Commission of Canada [TRCC], 2015), yet recent literature has only begun to explore specific mechanisms of why such gaps exist. In Canada, despite many health outcomes increasing for national samples (Bushnick et al., 2018), such gains do not extend to many Indigenous populations, as they tend to experience lower life expectancies, higher rates of chronic disease, and poorer mental health outcomes. Such differences have been attributed to systemic racism and colonialization (Allan & Smylie, 2015; TRCC, 2015), geographic challenges related to health care accessibility (Chambers & Burnett, 2017; Harasemiw et al., 2018), intergenerational transmission of health concerns through lingering effects of residential schools and increased child welfare involvement (Bombay et al., 2011; Elias et al., 2012; McQuaid et al., 2017; Wilk et al., 2017), socioeconomic disparities (Hajizadeh et al., 2018), difficulty accessing environmental factors that promote social determinants of health (Bethune et al., 2019) including access to clean drinking water (Baijius & Patrick, 2019), housing stability (Alberton et al., 2020), and nutrition (Levkoe et al., 2019). Understanding how mental and physical health concerns are experienced across a lifespan is paramount to preventing and reducing disease prevalence for future generations.

Given the multi-faceted mechanisms for how disease is propagated within Indigenous communities, addressing such health disparities, particularly those that show an intergenerational transmission from parent to offspring, is challenging. Existing prevention and treatment

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<sup>1</sup> For the purposes of this document, the terminology used to describe Indigenous populations reflects the terminology used in the literature that has been cited. Various terms are not interchangeable. The term “Indigenous” in Canada represents distinct groups of people including First Nations, Métis, and Inuit populations.

initiatives continue to target a range of interdisciplinary health indicators across a lifespan, in attempts to improve the overall health of Indigenous people. Such strategies require finite understanding of both biological and environmental effects of systemic disparities, to conceptualize how such relationships can be exerted at an individual level to bolster and balance physical, emotional, spiritual, and mental health and wellbeing. Health and wellbeing approaches among Indigenous peoples must be as diverse as the needs faced within these communities, incorporating two-eyed seeing approaches prioritizing multiple knowledge systems and models of health and wellbeing across generations.

### **Adverse Childhood Experiences (ACEs)**

Over twenty years ago, the Adverse Childhood Experience (ACE) study conducted at the Kaiser Institute by Felitti and colleagues (1998) was the first study to describe concrete longitudinal health consequences within a population that had experienced adverse events during childhood. Authors identified ten ACEs that were directly associated with increased risk of chronic disease. The ten ACEs identified to affect later in life health outcomes experienced by an individual prior to age 18 were the experience of emotional, physical, or sexual abuse, emotional or physical neglect, having a family member who had been incarcerated, having a family member with substance use or addiction concerns, parental separation or divorce, having a family member with a history of mental illness, or having a mother who was treated violently (Felitti et al., 1998).

These ACEs have been associated with increased risk for health concerns later in life. For all children, experiencing 4 or more ACEs was associated with detrimental health outcomes across a lifespan (Bellis et al., 2013). This dose-response relationship has been associated with several life-threatening medical conditions, including ischemic heart disease, lung disease,

cancer, and skeletal fractures (Bellis et al., 2013; Kalmakis & Chandler, 2015). The cumulative effect of an increased number of ACEs demonstrated that as the number of ACEs increases, so does the risk for various health concerns.

In Canada, studies have examined multiple ACEs in relation to community health outcomes (Afifi et al., 2016; Chartier et al., 2010; Fuller-Thompson et al., 2016; McDonald et al., 2015). Data from the Ontario Health Survey was used to examine 6 ACE variables, in addition to poor parent-child relationship quality, and low parental education outcomes (Chartier et al., 2010). Of provincial population-based samples, mean ACE scores of 1.31 (Alberta Centre for Child, Family, and Community Research, 2014; McDonald et al., 2015) and 1.23 (Chartier et al., 2010) using six ACEs from the Ontario Health Survey have been documented. Of these studies, results were similar to those described within other populations, with most individuals (72%) reporting at least one ACE, and 37% reporting two or more. Three ACEs (childhood sexual abuse, physical abuse, and parental domestic violence) were found in a general Canadian community sample to be associated with increased odds (OR= 2.52-34.42) of lifetime suicide attempts (Fuller-Thompson et al., 2016). These three variables were examined in a Canadian military sample, and found to also be significantly associated with increased odds of suicide ideation (Afifi et al., 2016).

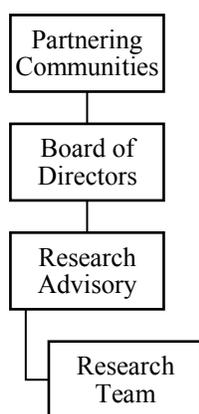
### **Description of the *First Nations ACE Study***

To date, the majority of literature examining ACE scores and longitudinal health outcomes has been completed with non-Indigenous populations. The current study is the first attempt to understand how early life experiences may affect later life health outcomes for Indigenous individuals seeking residential substance use treatment. This community-based participatory research partnership, entitled the *First Nations ACE Study*, was established within

an Indigenous mental health organization, and guided the development and implementation of this study through a four-tiered Research Advisory. The Research Advisory (Figure 1) was structured to seek consultation and expertise from local First Nation communities, the service organization board of directors, the Research Advisory, and the research team. Ethical approval for this study was obtained from both the Research Advisory of the partnering mental health organization and the Lakehead University Research Ethics Board (protocol number: 1466763).

### Figure 1

*Structure of Research Advisory Partnership*



The *First Nations ACE Study* partnered with communities in the Robinson Superior Treaty Area, who expressed research related queries through communication with the Board of Directors. This board formally represents members from these partnering communities, many of whom are band counsellors or chiefs in their communities. The Research Advisory regularly reports to and receives approval from the Board of Directors regarding all research activities. Through the Research Advisory, organizational leadership within this level of the partnership determines current project initiatives, specific project activities, and study directions that are deemed to best meet the needs of the partnering communities. The research team meets with this

organizational leadership as necessary, and performs project duties as required. Ongoing communication about research activities occurs between all levels of this partnership.

### **Goals of the *First Nations ACE Study***

The goal of the *First Nations ACE Study* was to document the general prevalence of ACEs for clients of an adult addiction treatment facility, examine relationships between ACEs and client health outcomes, and collect information about client-reported intergenerational familial ACEs and health. We hoped these endeavors could inform how viable it is to scientifically assess these relationships on-site at an Indigenous led treatment facility with an Indigenous population. Chapter 2 begins this process by describing results of a systematic review of ACE health outcomes specifically related to Indigenous populations within North America. This synthesis of literature allowed us to generate an accurate range of ACE scores for various Indigenous populations, which was used as a comparative benchmark to contextualize Chapter 3 results. Further to describing the prevalence of ACEs, Chapter 3 examines intergenerational ACEs for parents and grandparents, contrasting these relationships to parenting difficulties, health outcomes, and individual participant ACEs. Chapter 4 extends these findings to future assessment of ACEs with Indigenous populations, and provides five recommendations to guide this process.

Development of sustainable data collection processes can ensure future exploration of ACE scores with First Nations individuals. Chapter 5 describes the development and implementation of ongoing inter-agency data collection and documentation processes of ACEs within a residential substance use treatment facility. Through authentic adherence to community-based research principles, partnership experiences with the *First Nations ACE Study* were generally positive, indicating a high likelihood that the study will continue past the completion of

this dissertation. Finally, my perspectives and personal experiences of completing Indigenous community-based participatory research are described in Chapter 6. This chapter also provides a scoping review of global Indigenous research guidelines, and situates the methods used in the *First Nations ACE Study* within a general synthesis of research values within this body of literature.

## **Chapter 2: Adverse Childhood Experiences and Indigenous Populations<sup>2</sup>**

Indigenous populations are more likely to report poorer physical and mental health outcomes compared to non-Indigenous populations in Canada (Statistics Canada, 2018a). Rates of chronic physical conditions such as obesity, diabetes, arthritis, high blood pressure, and heart disease are higher among Indigenous people than non-Indigenous people (Statistics Canada, 2018a). Similarly, Indigenous populations in Canada report higher levels of anxiety and depressive symptoms (First Nations Information Governance Centre [FNIGC], 2018; Kumar & Tjepkema, 2019). Many of these reported health difficulties appear to be stable over time, despite similar health trajectories improving for non-Indigenous populations in recent decades. Disproportionately high rates of intimate partner violence, child welfare intervention, abuse, and neglect within some communities can also affect the longitudinal wellbeing for a new generation of Indigenous children (Statistics Canada, 2018a). These factors can affect the prevalence of ACEs in Indigenous communities, and thus contribute to higher prevalence chronic health conditions for these populations. Examining dose-response relationships of ACEs within an Indigenous population may predict later in life health outcomes for Indigenous children.

### **Outcomes Associated with Increased ACEs**

The initial ACE study by Felitti et al. (1998) examined physical health indicators that had been identified previously to be leading causes of death in association individual experiences of both child maltreatment (physical, sexual, and emotional abuse) and household dysfunction (violence against mother, household substance use, or a household member who is mentally ill or suicidal). Since this time, Dube et al. (2001) expanded this classification to include three

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<sup>2</sup> Adapted from Radford, A., Toombs, E., Zugic, K., Boles, K., Lund, L., & Mushquash, C. J. (submitted). Examining Adverse Childhood Experiences (ACEs) within Indigenous populations: A systematic review. As corresponding author and supervisor of Ms. Radford on this paper, I contributed to all aspects of this manuscript.

additional ACEs, emotional neglect, physical neglect, and parental divorce, creating the categorization of 10 ACEs that remain most frequently measured within subsequent literature.

Numerous studies have examined the influence of ACEs on a range of both physical and psychological adult health outcomes (see Table 1 for a brief review). A bibliometric analysis of recent ACE literature found that from 1998 to 2018, published scientific studies relating to ACEs examining these outcomes across various health, education, and justice disciplines have almost doubled since 2016 (Struck et al., 2021). As interest in ACEs grows, so does the diversity of publications, including those which describe individual-level relationships among mental health, physical, health, and substance use, community level outcomes (related to education, various socio-demographic characteristics, and health care use), and systemic level outcomes (related to intervention, treatment, screening, and measurement). The range of mental health consequences associated with ACEs described at an individual level have included depression, anxiety, substance use, diagnoses of Post-Traumatic Stress Disorder, and increased suicide attempts. Increased health-risk behaviours, or behaviours that increase the likelihood of developing further health concerns, were also identified. Such behaviours associated with ACEs were increased to include binge drinking, tobacco use, sexually risky behaviour, and early adolescent substance use.

**Table 1**

*Study Outcomes Related to ACE Exposure*

Outcome Variable	Relevant Citation
Attachment Difficulties	Choi et al., 2020; Cooke et al., 2019; Thomson et al., 2017
Crime Involvement and Recidivism	Baglivio et al., 2020; Bonner et al., 2020; Brown et al., 2015; Craig & Zettler, 2021; Drury et al., 2019; Dudeck et al., 2016; Wolff et al., 2020;
Educational Attainment	Houtepen et al., 2020; Metzler et al., 2017

Executive Functioning		Espeleta et al., 2018; Lund et al., 2020; Poole et al., 2018; Shim et al., 2018; Treat et al., 2019
General Mental Health Difficulties		Afifi et al., 2017; Bowen et al., 2018; Burke et al., 2011; Chartier et al., 2010; Dobson et al., 2021; Fuller-Thomson & Lewis, 2015; Grigsby et al., 2020; Houtepen et al., 2020; Liu et al., 2020; McCabe et al., 2020; McElroy & Hevey, 2014; Poole et al., 2018; Rhee et al., 2019; Riedl et al., 2020; Schalinski et al., 2016; Strine et al., 2012; Villodas et al., 2016
Specific Mental Health Difficulties	Depression	Afifi et al., 2017; Elmore & Crouch, 2020; Kelifa et al., 2020; Merrick et al., 2017
	Post-Traumatic Stress	Elkins et al., 2019; Frewan et al., 2019; Kalmakis et al., 2020;
	Suicide Ideation, Self-Harm, and Attempts	Afifi et al., 2017; Almuneef et al., 2016; Baiden et al., 2017; Choi et al., 2017; Merrick et al., 2017; Ryttilä-Manninen et al., 2018; Thompson et al., 2018
General Physical Health Difficulties		Anderson et al., 2018; Almuneef et al., 2016; Bryant et al., 2020; Burke et al., 2011; Font & Maguire-Jack, 2016; Felitti et al., 1998; Felitti et al., 2019; Grey et al., 2019; Godoy et al., 2020; Jakubowski et al., 2018; Merskey et al., 2017; Petrucci et al., 2019; Raffaelli et al., 2018; Riedl et al., 2020; Thompson et al., 2020
Specific Physical Health Difficulties	Sleep Disruption	Chapman et al., 2011; Kajeepeeta et al., 2015; Sullivan et al., 2019
	Obesity	Burke et al., 2011; Danese & Tan, 2014; Davis et al., 2019; Elsenburg et al., 2017; Wiss et al., 2020
Health Care Utilization		Hargreaves et al., 2019; Kobal et al., 2021; Schickedanz et al., 2019
Sexual Violence		Ports et al., 2016
General Substance Use		Afifi et al., 2020; Brown & Shillington, 2017; Choi et al., 2017; Raffaelli et al., 2018
Specific Substance Use Concerns	Alcohol Use	Afifi et al., 2017; Almuneef et al., 2016; Loudermilk et al., 2018; Merrick et al., 2017; Strine et al., 2012
	Opioid Use	Derefinko et al., 2019; Merrick et al., 2020; Stein et al., 2017; Swedo et al., 2020;

Some studies examining individual level and community factors suggest that ACEs are more prevalent in populations that may be more susceptible to increased health concerns, such as those who were incarcerated, homeless, engaging in heavy substance use, or living in poverty (Kalmakis & Chandler, 2015). Research has examined racial, gender, and geographical differences among individuals reporting high ACE scores. Racial minorities in North America, including Black, Hispanic, and Indigenous populations report higher exposure to ACEs when compared to White populations (Giano et al., 2020; Maguire-Jack et al., 2020; Richards et al., 2020), particularly when experiencing socio-economic challenges (Goldstein et al., 2020). When gender differences were examined, some studies found women and gender minorities were significantly more likely to report higher ACE scores (Goldstein et al., 2020; Schnarrs et al., 2020; Winstanley et al., 2020), although these relationships with physical and mental health outcomes among genders are mixed (Gallo et al., 2018; Cunradi et al., 2020; Hodes & Peerson, 2019). When ACEs were examined by geographical location of participants, individuals living in rural communities (Crouch et al., 2020) and communities with high rates of crime (Wang et al., 2020) reported higher ACE scores. Such variations among race, gender, income, and geographical location indicate that relationships of ACEs and physical and mental health outcomes can be experienced differently among various populations.

### **Prevalence of ACEs within Indigenous Populations in Canada**

Recent research has attempted to describe prevalence of ACEs experienced by Indigenous people in Canada. Descriptive statistics of health outcomes for Indigenous populations demonstrate that many indicators of wellness are less likely to occur for Indigenous children in Canada. Within many Indigenous communities, the lack of or reduced access to social determinants of health, long-term housing instability, food insecurity, and addictions

within communities depict detrimental outcomes for Indigenous families in Canada when compared to non-Indigenous families (Carrière et al., 2018; Statistics Canada, 2018a; 2018b).

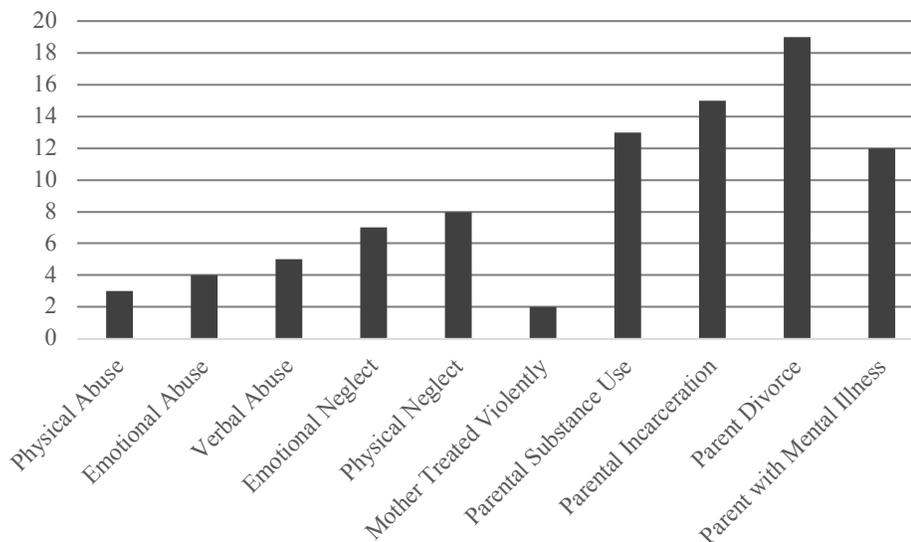
A systematic review by Radford and colleagues (under review) completed in 2019 explored and organized available ACE literature pertaining to Indigenous populations. Studies were included if they (a) were comprised of participants who identified as Indigenous, (b) identified any type of formally classified ACEs relating to physical or mental health outcomes (c) were written in English language, (d) were peer-reviewed, and (e) were published since 2000. Twenty-one publications (Appendix A) described ACE outcomes relating to Indigenous populations. Of these studies, all reported that increased ACEs were associated with detrimental health outcomes. Four studies reported that participant ACE scores were related to self-reported physical health outcomes (Brockie et al., 2018; Moon et al., 2015; Remigio-Baker et al., 2017; Twizeyemariya et al., 2017). One study reported ACEs associated with sleep problems (Klest et al., 2013), and another study examined ACEs and parenting satisfaction (Libby et al., 2008).

### **Reporting of ACEs Across Studies**

In studies that examined nine to ten ACEs (Brockie et al., 2018; Burnette et al., 2017; Moon et al., 2015; Moon et al., 2018; Roh et al., 2015; Roh et al., 2019), the mean number of ACE scores for non-clinical sample Indigenous populations ranged from 2.5 to 3.05, higher than a large-sample population ACE mean of 1.36 collected from 2011 to 2014 in 23 American States (Merrick et al., 2018). In Canada, large population-based ACE data, such as the Ontario Health Survey, has typically excluded Indigenous people living on reserve, and has not described all ACEs, making it not feasible to compare the prevalence of ACEs (Chartier et al., 2010). Figure 2 describes the number of studies retrieved that examined specific ACE variables.

**Figure 2**

*Number of Retrieved Studies that Examined Each ACE within Indigenous-Specific Populations*



One study found that American Indian (AI) children were two to three times more likely to have multiple ACEs than non-Indigenous children (Kenney et al., 2016). When Aboriginal and non-Aboriginal women reported similar rates of childhood sexual abuse, both groups also reported high rates of other ACEs as well, highlighting a cumulative effect of ACE scores across demographics (Hamdullahpur et al., 2018). This may indicate that detrimental health outcomes are similar across ACE exposures, regardless of population group. Prevalence of ACEs may be higher in some populations due to higher risks of exposure. For example, AI children were more likely to have a parent incarcerated, witness and/or be victim to violence, and live with an individual who was abusing substances compared to non-Indigenous children (Kenney et al., 2016). Similarly, Australian Indigenous children had a higher risk of child welfare intervention compared to non-Indigenous samples (Basu et al., 2019). Continuous discrepancies in these types of prevalence statistics may influence current ACE prevalence within Indigenous populations.

### **Examination of Individual ACEs within Indigenous Populations**

Some studies have described relationships between each individual ACE variable experienced by Indigenous children in Canada and detrimental health outcomes experienced during adulthood. Overall, research has suggested that First Nations populations are more likely to report lower health outcomes compared to non-Indigenous populations (Carrière et al., 2018; Statistics Canada, 2018a). Aboriginal people also have higher rates of obesity and tobacco use (Statistics Canada, 2018a). Additional major health problems for Indigenous people have been related to high infant and child mortality, increased risk for infectious diseases, malnutrition and delayed development, shortened life expectancies, increased substance-used related health concerns, increased prevalence of lifestyle diseases (including diabetes, hypertension, cardiovascular diseases, and chronic renal diseases), and increased risk of accidental death (Gracey & King, 2009). Adverse experiences during childhood have been associated with some of these health indicators for Indigenous people, and individual ACE variables have been examined.

Recent data examining recent trends of ACEs within United States has found that overall, incidence rates of ACEs are declining (Finkelhor, 2020). Specifically, national population data depicting rates of parental illness, sibling death, intimate partner violence, family poverty, parental divorce, physical and sexual abuse, physical bullying, and exposure to community violence all have declined since 2000 (Finkelhor, 2020). Only parental substance use (alcohol and drug use) increased from 2000. As results were derived from national samples, it was not feasible within this study to examine specific population trends for race or gender. Table 2 describes similar trends derived from Canadian national censuses and surveys, contrasted with various trends for Indigenous samples in Canada. Although this table is not directly comparable

to the method used by Finkelhor (2020), it does describe national increases in family violence, and mental health difficulties in Canada. For all ACE variables examined, comparisons among Indigenous and non-Indigenous populations suggest that Indigenous populations experience all ACEs examined at higher rates than non-Indigenous people in Canada.

**Table 2**

*Trends of Reported ACEs in National and Indigenous-Specific Population Data*

ACE (measured variable)	National Trend	Relevant Population Differences
Family violence experienced by children and youth (Rate reported to police in 2018)	7% increase from 2017 to 2018 <sup>1</sup> ; Previously stable from 2009 to 2017 <sup>1</sup>	1.6x higher rates of childhood physical and sexual abuse reported for Indigenous people in 2015 <sup>2</sup>
Intimate partner violence <sup>1</sup> (Rate of intimate partner violence reported to police in 2018)	2% increase from 2017 to 2018; Decreased by 12% from 2012 to 2017 <sup>1</sup>	2 to 5x higher rates of IPV for Indigenous people <sup>3,4</sup> ; 6.5x higher rate of homicide for Indigenous people, 73% of Indigenous female victims killed by an intimate partner or family member <sup>5</sup>
Divorce (Estimate of divorce in 2020)	Remaining stable (~1% decrease from 2019 to 2020); Previous decrease of 2% from 2016 to 2019 <sup>6</sup>	2x higher rate of living in single parent household for Indigenous children aged 14 and under in 2016 <sup>7</sup>
Mental health (Prevalence of mood disorders 2018 and 2019)	2% increase from 2018 to 2019; 8% increase from 2016 to 2018 <sup>8</sup>	2x higher rate of mood disorders for Indigenous people in 2011/2014 (2.5x higher in 2007/2012 data) <sup>9</sup>

Mental health (Prevalence of reported suicidal thoughts 2015-2019)	7% increase from 2015 to 2019 <sup>10</sup> ; Remained stable 2002 to 2012 (~.2% change) <sup>11</sup>	3x higher rate of suicide in Indigenous populations in 2012 <sup>12</sup>
Problematic substance use (Heavy alcohol use reported 2018 to 2019)	Remained stable (~1% decrease from 2018 to 2019) <sup>13</sup> ; Remained stable from 2016 to 2019 (~0.5% change) <sup>13</sup>	1.2x higher rates of heavy alcohol use for Indigenous people in 2012 <sup>14</sup>
Incarceration <sup>7</sup> (Adult incarcerations rates 2018/2019 in all jurisdictions)	4% decrease from 2017/2018 to 2016/2017 <sup>15</sup>	In 2018/2019, 30% of incarcerated population identified as Aboriginal <sup>16</sup> ; Increase of 4% from 2014/2015 data <sup>16</sup>

<sup>1</sup>(Statistics Canada, 2019a); <sup>2</sup>(Statistics Canada, 2017); <sup>3</sup>(Burczycka, 2013); <sup>4</sup>(Brownridge, 2013); <sup>5</sup>(Moreau, Jaffray, & Armstrong, 2020); <sup>6</sup>(Statistics Canada, 2020a); <sup>7</sup>(Turner, 2016); <sup>8</sup>(Statistics Canada, 2020b); <sup>9</sup>(Statistics Canada, 2015); <sup>10</sup>(Statistics Canada, 2020c); <sup>11</sup>(Statistics Canada, 2013); <sup>12</sup>(Kumar & Nahwegahbow, 2016); <sup>13</sup>(Statistics Canada, 2019b); <sup>14</sup>(Kelly-Scott & Smith, 2015); <sup>15</sup>(Statistics Canada, 2020d); <sup>16</sup>(Statistics Canada, 2020e)

### Childhood Maltreatment

Child experiences of physical, emotional, or sexual abuse, as well as physical or emotional neglect have each been conceptualized as distinct ACE variables. Many studies that examined these ACE variables within an Indigenous population do so in the context of examining consequences associated with attending a residential school (Bombay et al., 2014; Dion et al., 2015; Hackett et al., 2016; Ross et al., 2015). Attending a residential school has been significantly correlated with reported abuse in an on-reserve First Nations population, with 39% of all participants ( $N= 2935$ ) reporting a history of abuse (Elias et al., 2012). Having a parent or grandparent who attended residential school has been associated with a history of both suicidal

attempts and ideation (Bombay et al., 2014). For those individuals who reported they were negatively affected by their residential school experience, they were 4 times more likely to report a history of abuse (Elias et al., 2012).

Few studies report specific experiences of one form of abuse, but rather have examined the effect of compounding experience of multiple forms of abuse for a child. Literature pertaining to distinct experiences of emotional or physical neglect for Indigenous people is particularly sparse, partially due to how frequently such experiences co-occur with various forms of child abuse (Fernandez et al., 2017). An American study that examined 6 ACE prevalence scores in a population of 288 Native Americans found that 48% of participants reported emotional abuse, 30% reported physical abuse, 20% sexual abuse, 42% emotional neglect, and 40% physical neglect (Brockie et al., 2015). For Indigenous participants that have reported sexual abuse, they were three times more likely to be at risk for pathological gambling (Dion et al., 2015). To date, no studies have specifically described results for Indigenous populations in Canada.

Early experiences of emotional and physical neglect can disrupt child mental and physical developmental processes (Leeb et al., 2011; Norman et al., 2012). Such research may generalize to Indigenous populations in Canada, although to date no studies have specifically been completed within Indigenous communities. Specifically, for First Nations children, early life adversity has been associated with increased depressive symptoms (McQuaid et al., 2013).

Child experiences of physical and emotional neglect can have secondary consequences on day to day life for that child. Children involved with the Canadian child welfare system are primarily placed due to experiences of neglect (Sinha et al., 2011). Structural factors, such as poverty, housing instability, and parental mental health concerns, all of which are statistically

more pervasive for Indigenous families (Statistics Canada, 2018a), can be more likely to perpetuate child neglect. Given that Indigenous families are also more likely to be monitored for childhood maltreatment (Lindstrom & Choate, 2016), and less likely to be reunified with families after placement within the child welfare system (Fernandez et al., 2017), there remains a disproportionate number of Indigenous children in care in Canada (Ma et al., 2019; Statistics Canada, 2018a). Consequences of child neglect can result in subsequent experiences within the child welfare system. Removal of children from family and home communities, and increased inaccessibility to cultural practices, may reduce potential protective factors for these children (Toombs et al., 2018). For non-Indigenous adults who were previously involved with the child welfare system, increased ACE scores have been associated with increased psychological distress (Bruskas & Tessin, 2013).

Identification of child neglect is culturally contextualized (Ma et al., 2019) and disparities between parenting practices can result in over-identification of Indigenous children by child welfare systems. For example, when responding to child aggression, Indigenous mothers were less anxious, and did not enforce punishment strategies to reduce child behaviour as did non-Indigenous mothers (Cheah & Sheperd, 2011). An emphasis on child autonomy (Muir & Bohr, 2014) may result in deliberate non-intervention by Indigenous parents, which without cultural contextualization, may be inappropriately perceived as permissiveness at best, and at worst, neglect. Although research indicates that positive punishment strategies such as spanking are harmful for children (Gershoff & Grogan-Kaylor, 2016), non-intervention may be viewed as parental absence by child welfare systems, particularly if additional factors (such as poverty or housing instability) that may warrant investigation are present (Ma et al., 2019). Measurement of

neglect remains challenging due to overlapping conceptualizations of physical abuse and neglect, context-specific differences, and legislative policies and procedures.

Broad definitions of child neglect have typically described how parental omission to engage in necessary child caregiving, such as failure to provide adequate safety or nutrition, creates endangerment of children (Putman-Horstein et al., 2013). One definition of child neglect proposed by Straus and Kantor (2005) has contextualized neglectful caregiver behaviours, and stated that it is, “behaviour by a caregiver that constitutes a failure to act in ways that are presumed by the culture of a society to be necessary to meet the developmental needs of a child and which are the responsibility of a caregiver to provide” (p. 20). Parenting norms and behaviours are inherently influenced by culture, and therefore, the absence or presence of particular parenting behaviours may reflect cultural values rather than neglect. Given that cultural beliefs may influence parental behaviour, parents may feel they are acting in a child’s best interest, when in another context, such behaviours may be considered to be neglectful. Further, overlapping definitions of physical abuse and neglect may reduce contextualization of cultural parenting practices. Some authors consider neglect to be a form of physical abuse, and research examining these behaviours often combines these terms (Gershoff & Grogan-Kaylor, 2016). These types of expansive definitions may reduce the likelihood culture is considered within child intervention needs, as the definition of what is considered neglect becomes too broad to be consistently enforced in light of complex cultural considerations. The presence of objectifiable harm to a child, and the severity of that harm, must also be considered contextually. Straus and Kantor (2005) argue that dichotomous parallel assessment of both neglectful behaviours and actual harm to the child must be completed in a culturally-useful assessment of neglect. Such procedures serve to separate behaviours from both the causes and motives of the

parent, and contextualizes parental behaviours in a more meaningful way. Chronicity of the behaviour can be a useful measure of neglect, given that it can increase the relative risk of harm to a child (Straus & Kantor, 2005).

Clear definitions and subsequently, standardized assessment of child abuse and neglect remains challenging, as culture continues to influence national and international legislation. For example, internationally, through the Convention of Rights on the Child, the United Nations has stated that corporal punishment or spanking, constitutes as physical abuse (Durant, 2018). Within Canada, spanking remains legal (Durant, 2018), despite it being considered an adverse childhood experience, as it is associated with subsequent child developmental disruptions (Afifi et al., 2017). A distinct definition between physical abuse and neglect is required to ensure that legal conceptualizations of abuse align with child welfare policies, cultural and contextual parenting practices, and best reflect child development research. Until then, it will continue to be challenging to assess and incorporate changing definitions of abuse across contexts and assess the relevance of these interpretations across cultural groups.

### **Mother Treated Violently in the Home**

The definition of Intimate Partner Violence (IPV) commonly refers to verbal aggression, physical and sexual violence, verbal abuse, threats, indirect violence, and violence experienced during pregnancy to an individual by their intimate partner (Garcia et al., 2006). Although IPV can occur by male or female partners within a relationship, studies show that women are overwhelming more likely to report experiences of IPV, particularly when in a relationship with a male partner (Garcia et al., 2006). Rates of self-reported IPV for Indigenous women in Canada when compared to non-Indigenous women have ranged to be approximately 2 times (Burczycka,

2013) to 5 times higher (Brownridge, 2013). For Indigenous men, IPV rates were 2.5 to 3.5 higher than non-Indigenous men (Brownridge, 2010).

Few studies have explored the relationship between IPV and longitudinal health outcomes for Indigenous women in Canada. When Indigenous and non-Indigenous experiences of IPV in Canada were compared, Indigenous women reporting IPV were more likely to have experienced abuse as a child (Tutty et al., 2020). Within this sample, the most common reported mental health concerns were depression, PTSD, anxiety, and addiction, with no significant differences among groups. Of the international studies that have quantitatively examined IPV experienced by Indigenous women, Indigenous women with prior experiences of IPV were three times more likely to be diagnosed with PTSD. The reported odds of being diagnosed with a mental health disorder were three times higher for women with IPV and a family history of substance abuse (Duran et al., 2009). Of Indigenous women reporting experiences of IPV, they were also likely to report witnessing IPV as a child (Burnette & Cannon, 2014).

When effects of exposure to IPV for Indigenous children were explored, childhood maltreatment predicted later in life IPV for Indigenous adults (Brownridge et al., 2017). One study of women reporting IPV found those who remained with their partners were more likely to have children under care of child welfare services, particularly if they experienced physical abuse. Of these groups of both Indigenous and non-Indigenous women experiencing IPV, significantly more of the women with children in care reported an Indigenous partner and being in care as a child themselves (Tutty & Nixon, 2020). When Indigenous female participants from the United States were asked how their experiences of IPV have affected their children, 64% ( $n=16$ ) of women said there were negative consequences to this experience for their children. Women reported child self-harm, ongoing mental health concerns such as depression and

suicidal ideation, and increased aggressive and disruptive behaviours following witnessing IPV (Burnette & Cannon, 2014). For perpetrators of IPV residing in a small community, personal relationships with authority figures may create conflicts of interest that reduce the likelihood of receiving appropriate responses to IPV, thus potentially increasing the likelihood of re-offending (Burnette, 2014).

### **Incarcerated Family Member**

Within Canada in 2018 to 2019, Indigenous adults represented 30% of admissions to federal criminal justice correctional facilities despite only representing 4% of the Canadian population (Statistics Canada, 2020e). In 2015, analyses revealed that 38% of females and 26% of males in provincial or territorial custody identified as Aboriginal. For federal custody, 31% of females receiving sentenced custody and 23% of males were Aboriginal (Reitano, 2017). Given that Aboriginal women in Canada are more likely to be mothers, and have more children than non-Aboriginal women (National Household Survey, 2011), the number of Aboriginal children affected by maternal incarceration is likely disproportionately higher than the general Canadian population.

When Aboriginal and non-Aboriginal inmate familial experiences were compared, children of Aboriginal inmates were significantly more likely to be placed in care than non-Aboriginal children, with a placement rate of 41% as compared to 19% (Trevethan et al., 2001). A qualitative study of 20 First Nations individuals living in Saskatchewan examined community perspectives of Indigenous incarceration in Canada (Jones et al., 2016). Lack of stability, including regular enforcement of household rules was attributed to long term effects on children (Jones et al., 2016).

Additionally, Indigenous fathers have reported increased difficulty parenting their children while incarcerated, and less than half of study participants (41%,  $n= 17$ ) stated they were not currently involved in parenting any of their children. About one fourth of fathers (22%,  $n= 9$ ) indicated that a child visited them at least one time while they were incarcerated and 24% indicated that they did not have direct contact with their children or caregiver (Dennison et al., 2014). Children of incarcerated parents were more likely to engage in delinquent behaviours and externalizing concerns, such as anti-social behavior (Murray et al., 2012), however child educational attainment, mental health concerns, and substance use, were not significantly associated with parental incarceration (Murray et al., 2012).

### **Parental Separation or Divorce**

In 2016, Aboriginal children in Canada aged 14 and under were two times more likely to live in a single-parent household, and two times more likely to live with their grandparents than non-Aboriginal children (Turner, 2016). Among single-parent households, rates remained the same across age categories, with 34 to 35% of Aboriginal children living with a lone parent, as compared to 19% of non-Aboriginal children. Within these households, 15% of Aboriginal children were living with four or more children. Aboriginal children were also less likely to live with married parents (49.6%) than non-Aboriginal children (76%) and more likely to be step-children (9%, as compared to 6% of non-Aboriginal counterparts (Turner, 2016).

The majority of single-parent households raising Aboriginal children are headed by Aboriginal women (Turner, 2016). Single-parent families have been hypothesized to contribute to increased housing and food instability for Indigenous children as increased caregiver responsibilities may be a barrier to parent employment (Kolahdoz et al., 2015). Research with non-Indigenous children raised by single-parents, step-parents, or a blended family has reported

that they children experience significantly more mental health concerns when compared to nuclear families (Perales et al., 2016). Children of single-parent families scored higher on all types of disorders examined (anxiety, behavioural, and total) than all other family structures. Such results indicated that being raised by a single-parent may contribute to detrimental health outcomes for Aboriginal children as well, particularly as single parents are more likely to be living in poverty and experiencing increased parenting demands when compared to two-parent households.

### **Family Member with Problematic Substance Use or Addiction**

Maternal substance use during pregnancy has been associated with increased risk of birth complications (Kelly et al., 2011). For example, narcotic use during pregnancy by First Nations mothers has been associated with premature births, and longer hospital stays (Kelly et al., 2011). For all children, substance use during pregnancy has been associated with slower attainment of developmental milestones, and increased likelihood of deficits in cognitive, physical, and psychosocial development (Forray, 2016). Aboriginal children are more likely to have lower birth weights and birth complications when compared to non-Aboriginal children (Gracey & King, 2009).

Research with non-Indigenous children has indicated that children of parents currently diagnosed with a Substance Use Disorder (SUD) had an elevated risk for the development of externalizing and internalizing concerns (Bountress & Chassin, 2015). This relationship was mediated by consistency of parental support. Children with parents with a prior history, but not current diagnosis of SUD, were at increased risk for externalizing disorders (Bountress & Chassin, 2015). A history of parental substance use has been correlated with increased substance use for their adolescent children, some of which has been related to the interaction of both

genetic and environmental risk factors (Bountress & Chassin, 2017). Parental substance use can also disrupt positive parenting practices that can influence child development, and is associated with greater likelihood of a child being placed in care (Smith et al., 2007).

### **Family Member with a Mental Illness**

When controlled for age, hospitalization rates for mental or behavioural disorders for First Nations people living on reserve were more than twice the rate than non-Aboriginal people in Canada (Carrière et al., 2018). The primary reason for hospitalization for First Nations people (living on or off reserve) with mental health concerns was related to substance-related disorders. Nearly half of those hospitalized were seeking treatment for substance use, and rates of substance related disorders were seven times higher for First Nations people living on reserve than for non-Aboriginal Canadians. For First Nations people living off reserve, rates were 4.3 times higher. Secondary to substance use, mood disorders and psychotic disorders were the next leading reasons for hospitalization. Although non-Aboriginal populations were hospitalized due to similar mental health concerns, the primary reason for hospitalization was for mood disorders, followed by psychotic disorders, and then substance use disorders (Carrière et al., 2018). First Nations people in Canada have reported increased mental health difficulties, particularly those related to suicidal ideation and completion. Although suicide completion rates are non-existent in some First Nations communities, in others, they can be seven times higher than non-Aboriginal communities (Statistics Canada, 2016).

High rates of mental health concerns of a family member can affect later health outcomes for the child. Increased mental health changes for offspring of parents affected by mental health concerns have been noted in parents diagnosed with schizophrenia (Keshavan et al., 2008), depression and bi-polar disorders (Bould et al., 2015; Propper et al., 2017), and personality

disorders (Eyden et al., 2016). Parents experiencing mental health concerns were less likely to monitor their children, and adolescents have reported the parent-adolescent relationship as strained when compared to parents without mental health concerns (Van Loon et al., 2014).

### **Future ACE Research Directions with Indigenous Populations**

Documentation of ACEs within Indigenous populations can be valuable to determine how early life experiences can affect longitudinal health outcomes. When models robustly explain relationships of health disparities experienced within Indigenous communities, prevention and treatment efforts may be improved. Literature describing ACEs specific to Indigenous health outcomes is relatively new, with the earliest study retrieved in the Radford and colleagues (submitted for review) systematic review was published in 2006. Although these relationships may be newly conceptualized, potential pathways for treatment of individual ACEs are well-established, particularly those related to trauma, depression, and anxiety.

Such gold-standard interventions may require modification to meet the complexity of need within some Indigenous communities, but may be a useful initial approach dependent on community need. Any research or treatment process must reflect approaches requested and approved by communities, and address the explicit needs within each region. The usefulness of cultural approaches for both prevention and treatment of health concerns could be examined in relation to ACE relationships. Examination of ACEs within Indigenous communities is a viable endeavor, and can inform existing health approaches to potentially generate novel, culturally-relevant treatment and prevention strategies. When developing treatment models are amended to include both contextual and cultural considerations related to the presence of ACEs, better health outcomes may be promoted for First Nations communities (Marsh et al., 2015).

ACE research is not meant to be a comprehensive review of all developmental experiences that can affect adult health outcomes, nor is experiencing ACEs synonymous with development of trauma for an individual. As a result, screening for ACEs in relation to understanding current symptoms of trauma has been cautioned (Finkelhor, 2018). Considerations for severity, complexity, age of occurrence, and duration of ACEs, and potential trauma that may result, can contextualize an individual's response to such experiences. Previous literature has explored the possibility of additional ACEs that describe how other early childhood experiences may contribute to specific health outcomes (Afifi et al., 2017; Cronholm et al., 2015; Finkelhor et al., 2013; Ford et al., 2014; Mersky et al., 2017). Specific research has attempted to describe how current and expanded ACEs may be useful for culturally-diverse populations. In Philadelphia, Cronholm and colleagues (2015) proposed five expanded ACEs including living in an unsafe neighborhood, history of placement in foster care, experiencing bullying, witnessing violence, and experiencing racism. Authors noted participants in conventional ACE research studies tended to be mostly white, insured, and well-educated, thus creating a potential sampling bias. Given that experiences in childhood for non-majority populations may differ from those of majority populations, it is possible that different ACEs may also contribute to the presence or absence of health concerns. As such, high participant endorsement of Cronholm et al.'s (2015) proposed ACEs were more predictive of belonging to a non-White racial group, being male, and having an income below the poverty line. Within this study, these expanded ACEs were not associated with health outcomes data, however it remains possible that when the measurement of ACEs is contextualized, understanding of diverse experiences of health can be increased.

For Indigenous people in Canada, exploration of alternative ACEs may increase the relevance and predictability of ACEs influence on health outcomes. When Indigenous health

outcomes are compared to non-Indigenous ones, many Indigenous health outcomes are lower (Statistics Canada, 2018a). Given these chronic health disparities, including inaccessibility to health services, housing stability, poverty, inability to access clean drinking water, and additional disparities related to social determinants of health, it is possible that the mechanisms that predict the health of Indigenous peoples may be different. Two potential ACEs for Indigenous communities may be attendance at a residential school and involvement with the child welfare system.

A strength of ACE research is that such results can be situated within models of Indigenous wellness, such as the First Nations Mental Wellness Continuum Framework (FNMWCF). At the centre of the FNMWCF, the model has situated hope, belonging, meaning, and purpose as indicators that promote wellbeing for Indigenous individuals, families, and communities (Assembly of First Nations & Health Canada, 2015). Specific components of these models have aligned with other indicators of Indigenous wellbeing, such as the medicine wheel, which promotes a balance between physical, emotional, mental, and spiritual wellbeing (King et al., 2009). These models can address health concerns both proximal to an individual and in conjunction with broader contextual or cultural concerns experienced by First Nations communities. Individual developmental trajectories associated with ACEs can be contextualized within broader models of wellness to provide further support for Indigenous models. If clear relationships between ACEs and health outcomes can be established, the role of protective factors (including hope, belonging, meaning, and purpose, as described in the FNMWCF) and the promotion of resilience can be better understood. Unfortunately, of the studies completed with Indigenous populations to date (Brockie et al., 2015; De Ravello et al., 2008; Koss et al.,

2015; Roh et al., 2015; Warne et al., 2016), few results have been incorporated into existing models that address Indigenous wellbeing, particularly in a Canadian context.

It is essential that ACE research, like all Indigenous research, be completed with consideration of both cultural and contextual Indigenous knowledge. Many First Nations conceptualize good health as the promotion of wellbeing rather than non-Indigenous disease-based models (King et al., 2009), and such frameworks can provide unique perspectives to promote Indigenous health outcomes. ACE research has led to alternative strength-based research approaches, including those that focus on Benevolent Childhood Experiences (BCEs). A scale of ten BCEs has been developed and piloted with lower socio-economic status pregnant women (Narayan et al., 2018). BCEs have tended to focus on positive aspects of school, care-giver support, peer-support, predictable routines, and positive self-identity. These indicators have been used to assess the predictive validity of how positive experiences can predict health outcomes or mitigate experiences of adversity. BCEs were found to significantly predict low levels of PTSD symptoms and perceived stress of mothers (Narayan et al., 2018). Such constructs were meant to conceptualize how the presence of factors may mitigate lower health outcomes. Table 2 describes commonly referenced ACEs and newly conceptualized BCEs, and demonstrates how the constructs of each measure are relevant to overall well-being research.

Subsequent ACE and BCE measures are likely not intended to be dichotomous assessment of factors that strictly either promote or prevent positive health outcomes, and the continuation of both research streams is required to understand such complex relationships. The use of either measure does not negate nor replace the use of the other. A holistic perspective is required to contextualize both negative and developmentally appropriate positive experiences in childhood. For example, a recent study by Kowatch and colleagues (unpublished master's thesis)

examined First Nations child psychopathology in relation to parental reported mental health intervention needs. Improved child functioning, higher reported strengths of the child, and higher reported caregiver strengths predicted lower mental health intervention needs. The linear relationship between increased reported psychopathological concerns and subsequent symptoms can also identify the presence or promotion of strengths moderated effects. Despite the presence of new strength-based measures such as the BCE, understanding relationships between ACEs and health outcomes remain useful to conceptualize health outcome base-rates within various contexts.

**Table 3***Adverse and Benevolent Childhood Experiences*

Adverse Childhood Experiences	Benevolent Childhood Experiences
Physical abuse	One caregiver present with whom child felt safe
Sexual abuse	Presence of one good friend
Emotional abuse	Beliefs that gave you comfort
Physical neglect	School enjoyment
Emotional neglect	Presence of teacher that cared about child
Mother treated violently in the home	Presence of good neighbours
Family member substance use	Presence of an adult (non-caregiver) who provided
Family member with mental health issues	support
Parental separation or divorce	Opportunities to have a good time
Parental incarceration	Liking self or feeling comfortable with self
	Predictable home routine

Wellbeing can be promoted through examination of individual ACEs as understanding such relationships can aid in development of tailored interventions. Conceptualizing (or potentially reframing) how early childhood experiences have affected current health outcomes may have a therapeutic effect for an individual, in a way that traditional, present-focused

Cognitive-Behavioural Therapy (CBT) approaches would not typically incorporate. For Indigenous individuals, it is possible that a holistic approach to treatment that incorporates discussion of such experiences throughout the lifespan may align with cultural beliefs of healing.

### **Conclusion**

The limited literature pertaining to Indigenous health outcomes, particularly when contrasted to the availability of non-Indigenous health outcome research in Canada, means that various bodies of knowledge still need to be documented. Although ACE research has existed for over 20 years, such concepts have infrequently been adapted for Canadian Indigenous populations. To further existing knowledge, it may be useful to first describe how such indicators may lead to longitudinal health concerns across a lifespan, before incorporating how various protective factors may affect these relationships. It is likely that the promotion of wellbeing through the reduction of the likelihood of ACE occurrence for a child can promote overall health outcomes. Ongoing research is required to determine how to contextualize previously described ACE frameworks in culturally meaningful ways for Indigenous populations in Canada.

### **Chapter 3: Examining the Prevalence of ACEs within a First Nations Treatment Seeking Population**

Indigenous people in Canada have experienced an intergenerational transmission detrimental physical and mental health concerns which have been partially attributed to ongoing experiences of systemic discrimination, colonization, and cultural genocide. These intergenerational experiences of trauma have disrupted parenting practices, exacerbated untreated mental and physical health difficulties of prior generations, and contributed to disparities in Indigenous health outcomes when compared to non-Indigenous people (Sinclair, 2016; Tam, 2015). Canada continues to attempt to reconcile ongoing ramifications of systemic inequalities perpetuated by federal and provincial legislation, including those that have reduced wellness and autonomy of Indigenous communities. The Truth and Reconciliation Commission of Canada (TRCC) has published 94 Calls to Action, directed to improving child welfare, health, justice, and education systems for Indigenous people. One of these Calls is to have understand and implemented methods to promote long-term health trends for Indigenous people, by gathering relevant data of factors that affect life expectancy within Indigenous communities, such as the presence of chronic disease (TRCC, 2015).

Intergenerational trauma, first academically conceptualized by Vivian Rakoff (1966) in relation to high levels of psychological distress among offspring of Holocaust survivors, describes the preliminary theories that later informed current understandings of genetic and epigenetic transmission of health outcomes between generations. Research has since been extended globally to genocides (Mangassarian, 2016), famines (Bezo & Maggi, 2015), slavery (Graff, 2014), and refugee experiences (Sangalang & Vang, 2017) influencing large populations of people. Research with Indigenous populations in Canada has associated prior experiences of

residential schools and previous child welfare involvement by families with intergenerational transmission of mental and physical health disparities.

Residential school attendance (either familial or personal) has been associated with depressive symptoms, suicidal ideation, a history of abuse, sex work involvement, and problematic substance use (Gone et al., 2019). The residential school program in Canada, lasting from the early 1800's to 1996, which removed children from their families and forced children to adopt non-Indigenous identities, is an example of such a practice (TRCC, 2015). By prohibiting the use of traditional language and cultural practices, and removing children from their communities, often where cultural practices were taught, many children grew up not knowing their cultural identity or how cultural practices were embedded in daily life (TRCC, 2015). The effects of these experiences are long-lasting. Indigenous attendance at residential schools have increased rates of transmission of trauma effects across generations, contributed to ongoing experiences of colonization and cultural assimilation, decreased the transfer of culturally-useful parenting practices, and affected outstanding parent-child relationships in present day (Gone et al., 2019). A study of 80 Indigenous fathers found that 82 percent of participants referred to intergenerational trauma contributing to existing parenting difficulties (Ball, 2010). These related to lower emotional warmth or expressiveness by parents, increased substance abuse, and experiences of abuse or neglect by parents resulting in challenging relationships with their children and influencing the way that they parented (Ball, 2010).

The relationship between residential school attendance and lower health outcomes for Indigenous peoples across generations remains clearly predicted. Bombay and colleagues (2011; 2014) found that family experiences of residential school attendance predict lower health outcomes, including mental health and suicide ideation across generations. Such indicators,

although not a proxy of intergenerational trauma, are relevant of their own accord, and therefore, may be a specific indicator of health. Given that the vast majority of residential schools in Canada were largely attended by Indigenous populations (TRCC, 2015), residential school attendance may be a unique predictor of poor health for Indigenous populations in Canada.

A second potential predictor of Indigenous health outcomes is involvement in the child welfare system. Aboriginal children were more likely to be placed in out of home care than non-Aboriginal children when under review by a child welfare system (Fallon et al., 2013). In 2011, although Aboriginal children aged 14 and under consisted of 7% of the total children in Canada, they accounted for almost half (48%) of the children in foster care (Turner, 2016). When provincial and territorial statistics were examined, rates of Aboriginal children in care were as high as 85% of the total number of children in foster care, with less than half of these children living with an Indigenous foster parent. These statistics varied significantly by province or territory, with percentages of children placed with an Aboriginal parent ranging from 29% in Alberta to 88% in Nunavut (Turner, 2016). Historically, the Sixties Scoop, named for the high apprehension rates of Indigenous children by largely non-Indigenous child welfare organizations, has contributed to a reduction of shared cultural knowledge in Indigenous communities (Fallon et al., 2013).

Experiencing both or either of these variables has previously predicted lower mental health scores for Indigenous individuals, with intergenerational effects of parental experiences on offspring also documented. Despite knowing some effects of such historical experiences, understanding the mechanisms of actions for the translation of such effects across generations remains limited. Epigenetic theories have focused on environmental mechanisms (including disrupted parenting, attachment, and social learning) and biological mechanisms (including

changes to typical neuroanatomical and neuroendocrine functioning and structures). For example, disruption of typical patterns of stress responses, including cortisol secretion, can create lasting influences on offspring of parents exposed to trauma (Bowers & Yehuda, 2019).

Multifaceted theories have incorporated such bio-psycho-social models of the influence of intergenerational stress and examined broader predictors of mental health functioning affiliated with substance use. Intergenerational transference of problematic substance use at a one to one ratio of disease transference is documented among parents and grandparents (Escario & Wiklinson, 2015; Henry & Augustyn, 2017; Hill et al., 2018). Recent research has begun to explore commonly co-occurring disorders affiliated with problematic substance use, including mental health disorders and chronic diseases. For Indigenous populations, contextualizing high rates of problematic substance use in a way that better reflects the needs of these individuals can better inform understanding of high rates of chronic physical and mental health concerns.

### **Adverse Childhood Experiences within Indigenous Populations**

The ACE model (first described by Felitti et al., 1998) provides a useful framework that can quantify complex relationships of intergenerational experiences of adversity for Indigenous people. Experiencing four or more of the ten ACEs prior to the age of 18 is affiliated with increased rates of chronic disease and lower mental health functioning. For potentially vulnerable populations, including Indigenous people actively engaging in problematic substance use, understanding relationships of early childhood experiences, adult substance use, and current health outcomes can provide understanding of how developmental trajectories can differ across a lifespan. Although there are many pathways to the development of a substance use disorder, it is possible that intergenerational experiences of abuse, neglect, and increased exposure to maladaptive environments during childhood directly affect an individual's current mental and

physical health outcomes as an adult. Further, given the epigenetic disruption of typical neuroanatomical and neuroendocrine patterns, individuals with a parent with a high number of ACEs can affect one's own health (Le-Scherban et al., 2018), however these relationships have yet to be documented within an Indigenous population.

Experiences of intergenerational trauma are previously documented with Indigenous populations (Gone et al. 2019; TRCC 2015), and it is likely that intergenerational involvement with the child welfare or the residential school system experienced by grandparents and parents of individuals within substance use treatment may negatively affect an individual's own mental and physical health. As such experiences have been previously associated with increased rates of abuse and neglect (TRCC, 2015), the ACE framework is a useful model to describe such intergenerational transmission. No studies have examined the prevalence of all ten ACEs exclusively within Canadian First Nations communities. Within two provincial-wide studies completed, there were limited representation of Indigenous populations, and such endeavors did not assess all ten ACEs, making it difficult to compare results across studies. Research that documents the prevalence of all ACEs for First Nations individuals, including ACEs across generations (parent and grandparent) can be particularly valuable for First Nations communities, and can inform existing prevention and treatment efforts.

### **Study Objectives and Hypotheses**

This study is divided into four discrete objectives, with a total of 15 hypotheses. The goal of these objectives was to comprehensively assess the relationships of ACEs, rates of chronic disease, and mental health for individuals with problematic substance use, in addition to their self-reported parent and grandparent ACEs and health.

#### **Objective 1**

The point prevalence of ACE scores was calculated within a First Nations population seeking treatment for substance use. As increased ACE scores are associated with an increased likelihood of adult alcohol problems (Dube et al., 2002), it is likely that scores in this sample would be higher than previously calculated general population mean of 1.31, as reported by the Alberta ACE study (Alberta Centre for Child, Family, and Community Research, 2014; McDonald et al., 2015) or 1.23, as reported by Chartier et al. (2010) using six ACEs from the Ontario Health Survey general population data. There were no specific hypotheses generated for Objective 1, as statistical comparisons among ACE scores calculated across groups were not feasible given diverse data collection methods and variables examined across national studies.

## **Objective 2**

Reported ACE scores were compared to additional health outcomes to determine how the collected participant scores compare to previously validated relationships when compared to majority non-Indigenous populations. Hypotheses of these relationships were generated and expand upon previously completed study results (Felitti et al., 1998) and were as follows:

2A. Participants with high ACE scores will report a greater number of physical and mental health concerns than participants with a lower number of ACE scores.

2B. Higher ACEs be associated with increased odds of having reported health concerns by participants, specifically related to chronic diseases, including heart disease, diabetes, emphysema, cancer, and stroke. as previously validated by Felitti et al., 1998. To be congruent with prior ACE research, a cut-point of 4 or more ACEs was used to compare low and high ACE groups.

2C. Participants with high ACE scores will report significantly more parenting difficulties than those with lower ACE scores, as measured by the Alabama Parenting Questionnaire.

2D. Participants with high ACE scores will report significantly lower scores on the Native Wellness Assessment upon entering treatment, indicating reduced hope, belonging, meaning, and purpose, in addition to less engagement in cultural activities.

### **Objective 3**

The collection of intergenerational ACE scores has not been previously completed and thus hypotheses assessing these relationships are exploratory in nature. Based on previous literature describing the intergenerational transmission of mental health symptoms within Indigenous populations (Bombay et al., 2014; Ross et al., 2015), it is possible that participants who report high ACE scores would be more likely to report high parental and grandparental ACE scores as well. Hypotheses related to this study objective were:

3A. Parental and grandparental ACE scores will significantly predict high participant ACE scores.

3B. High intergenerational (parent and grandparent) ACE scores will predict health outcomes for participants.

3C. Congruent with prior literature (Anda et al., 2009), reported family ACE scores will be significantly associated with presence of premature family member death.

### **Objective 4**

Explore the association between inter-generational experiences of historical trauma, specifically with residential school attendance and child welfare involvement, and current

participant health outcomes. Hypotheses dedicated to understanding client involvement with residential school attendances and reported mental health concerns were as follows:

4A. Participants who have attended residential schools will have significantly more health concerns than those who have not attended a residential school, even when the number of intergenerational ACE scores is entered as a covariate.

4B. Parent and grandparent residential school attendance will be associated with higher reported ACES for each parent and grandparent.

4C. Grandparent and parent residential school attendance will be significantly associated with higher reported health concerns.

4D. Parental and grandparental attendance at residential schools will be associated with increased parenting difficulties for participants who report having children, even when participant ACEs are controlled for.

Hypotheses dedicated to understanding client involvement with child welfare services as a child and reported mental health concerns were as follows:

4E. Participants with high ACE scores will be more likely to report one or more children being placed in foster care.

4F. Participants with high ACE scores will report a history of more personal foster care placements as children.

4G. Intergenerational placement (parents and grandparents) in foster care will be associated with current parenting difficulties, even when controlling for participant placement in foster care and current participant ACEs.

4H. Intergenerational placement (parents and grandparents) in foster care will be associated with a longer duration of foster care placement, and more frequent placements

of children, even when controlling for participant placement in foster care and current participant ACEs.

## **Method**

### **Participants**

A convenience sample of 141 adults seeking residential treatment for substance use completed this study. Of 216 potential participants (calculated by the sum of participants in all treatment cycles), 141 consented to participate in this study. Among this sample, 141 completed Time 1 questionnaires and 76 completed Time 2. Participant attrition between assessment periods was attributed to specific factors relating to client early treatment discharge (15 participants), staff related error/circumstance collecting data (19 participants), and participant withdrawal from the study (12 participants). Sixteen participants could not complete data collection due to one treatment cycle ending early as a protective measure due to the coronavirus disease (COVID-19) pandemic. For eight participants, we do not know the specific reason for client attrition.

At the time of data collection, all participants were clients of the Adult Residential Treatment Centre (ARTC). The ARTC is a 20-bed treatment facility that combines local Indigenous cultural teachings with additional mental health counselling services. It is located at Fort William First Nation, and is operated by a local First Nations mental health community organization, Dilico Anishinabek Family Care. The ARTC is open to adults aged 18 years or older, with approximately 85% of clients self-identifying as First Nations. The residential treatment duration is 6 weeks, followed by a 12-week after-care program that focuses on relapse prevention, group counselling, psychoeducation, and ongoing case management.

Potential study participant eligibility was determined by the following inclusion criteria, based on the treatment population at ARTC:

1. A current client of the partnering residential substance use treatment facility.
2. Eighteen years of age or older.
3. Capable to consent and competently participate in all study procedures (i.e., is not under the influence of non-prescribed substances; can read, speak, and understand English).

Potential participants were deemed ineligible to participate in the study if these criteria were not met. All clients who expressed interest in the study met these criteria and were thus able to participate. Relevant participant demographic information is described in Table 4.

**Table 4**

*Participant Demographic Information*

Participant Demographics		All Participants N= 141	Participants completing all measures n= 76
Mean Age (SD)		35.55 (10.3)	35.05 (10.0)
	Range:	20 to 65	20 to 65
Gender (%)	Female	59 (41.8%)	35 (46.1%)
	Male	80 (56.7%)	40 (52.6%)
	Gender Queer/Fluid	2 (1.4%)	1 (1.3%)
Ethnicity (%)	Indigenous	101 (74.8%)	55 (75.3%)
	Non-Indigenous	34 (25.2%)	18 (24.7%)
Employment Status (%)	Full-time	25 (17.7%)	12 (16.9%)
	Part-time	6 (4.3%)	3 (4.2%)
	Student	7 (5.0%)	5 (7.0%)
	Unemployed	34 (24.1%)	19 (26.8%)
	On Disability	56 (48.2%)	27 (38.0%)

	Parenting	4 (2.8%)	2 (2.8%)
Annual Income (%)	< \$10 000	53 (41.7%)	28 (40.6%)
	\$10 001 to \$19 999	35 (27.6%)	23 (33.3%)
	20 000 to \$29 999	16 (12.6%)	7 (10.1%)
	\$30 000 to \$39 999	8 (6.3%)	3 (4.3%)
	\$40 000 to \$60 000	6 (4.7%)	3 (4.3%)
	> than \$60 000	8 (6.3%)	4 (5.3%)
Highest Level of Education (%)	Grade 8 or less	3 (0.2%)	1 (1.5%)
	Some high school	43 (33.9%)	29 (43.9%)
	High School Graduate or GED	52 (40.9%)	26 (39.4%)
	Some college, university, technical school	12 (9.4%)	8 (12.1%)
	College Diploma	15 (11.8%)	10 (15.2%)
	University Degree	2 (1.6%)	2 (3.0%)
Living Conditions Prior to Program (%)	Living Alone/ single with kids	40 (29.4%)	24 (32.9%)
	With spouse/ partner	32 (23.5%)	18 (24.7%)
	With roommates/ friends	4 (2.9%)	2 (2.7%)
	With family	21 (15.4%)	11 (15.1%)
	No permanent residence	4 (2.9%)	0
	Recovery/treatment center	20 (14.7%)	10 (13.7%)
	Other	16 (11.8%)	8 (11.0%)
Prior Residential School Attendance (%)		5 (3.8%)	4 (5.6%)

Initial sample size estimations using Peduzzi and colleagues' (1996) recommendations for maximum likelihood estimation for logistical regression and an a priori analysis software (G\*Power 3; Faul et al., 2009) were completed. With an estimated effect size ( $R^2$ ) of .3, alpha at .05, power at .95, and odds ratio at 2, an estimated sample size of 120 participants was calculated. Given that maximum likelihood estimation using less than 100 cases has been

suggested to be “risky” (Long, 1997), and to account for potential losses, 200 participants were aimed to be recruited.

Data collection was prematurely terminated in March 2020 prior to reaching our target participant sample. The ARTC was closed due to government health mandates at this time in response to the COVID-19 pandemic, and given REB and university research requirements, all in person research activities were suspended. Although we did not reach our threshold for reliability of data, we made the difficult decision to provide initial descriptive statistics and preliminary relationships, as such data are useful to inform existing ACE literature related to Indigenous populations and inform clinical practices within ARTC. Future analyses will be completed to continue to address research questions posed in these studies. Although the unprecedented events in response to COVID-19 has continued to change how research and health services are implemented globally, particularly with respect to within Indigenous communities, we will continue to adapt study processes and continue research activities as it is safe to do so.

### **Measures**

The five measures used for this study were given in a questionnaire package. These measures have a total of 310 items and took participants approximately 60 minutes to complete. Time 1 measures were completed with the help of a research assistant, while Time 2 measures were completed with the help of a counsellor if requested by the client.

### ***Demographic Questionnaire***

During ARTC intake, all participants complete a brief demographics questionnaire describing employment status, educational attainment, family information, substance use concerns, and relevant health information (Appendix B). Information from this questionnaire

was used for study purposes when participants consented to the study. Some additional demographic questions not addressed in this questionnaire were also asked in the study questionnaire package.

### ***Participant ACE and Health History Questionnaires***

Items were predominately used from the Family Health History Questionnaire and the Health Appraisal Questionnaire, as these were the health outcome measures used in the initial ACE study completed by Felitti et al. (1998). These questions assess current physical and mental health, prior health histories, ACEs in childhood, and other relevant health information.

Questions were used from previously validated measures such as the Conflicts Tactics Scale (Straus & Gelles, 1990), as a way to conceptualize abuse and violence. Physical health questions were obtained from measures developed by the Centers for Disease Control and Prevention, such as the Behavioural Risk Factor Surveys (Siegel et al., 1991) and The Third National Health and Nutrition Examination Survey (Crespo et al., 1996). Additional questions were included to capture relevant health information pertinent to study goals. Two questionnaires were used in this study to assess male and female specific health outcomes.

ACE scores were derived from the Family Health History Questionnaire by cumulating client responses to specific ACE assessment items using the method described by Dube et al., (2003). Three ACEs, household member engaging in substance use, household member being incarcerated, and parental divorce, were assessed from participant endorsement using dichotomous “yes” or “no” responses to these items. Presence of household mental illness was quantified as an ACE by participant endorsement of either of the following two items, “Was a household member depressed or mentally ill?” or “Did a household member attempt suicide?”.

The remaining ACEs were assessed using participant responses on 5-item likert-type scale of “Never”, “Rarely”, “Sometimes”, “Often”, or “Very Often”. To assess intimate partner violence experienced by a participant’s mother, the following 5 items was asked: How often did your father (or stepfather) or mother’s boyfriend do any of these things to your mother or (stepmother)?

1. Push, grab, slap, or throw something at her?
2. Kick, bite, hit her with a fist, or hit her with something hard?
3. Repeatedly hit her for at least a few minutes?
4. Threaten her with a knife or gun?
5. Use a knife or gun to hurt her?

Any response ranging from “Sometime” to “Very Often” was classified as endorsement of this ACE for questions 1 to 3, while any response greater than “Never” for questions 4 and 5 was considered to be indicative of this ACE.

To assess parental emotional and physical neglect, Dube et al. (2003) adapted 5 items from the Childhood Trauma Questionnaire (CTQ), using the same 5-item likert-type scale. Emotional neglect was assessed from reverse scoring and summing scores from the following five items:

1. There was someone in my family who helped me feel important or special.
2. I felt loved.
3. People in family looked out for each other.
4. People in my family felt close to each other.
5. My family was a source of strength and support.

Participant endorsement of emotional neglect was considered to be a score greater than 15, which would indicate a CTQ score in a moderate to severe range. This scoring was used to quantify experiences of this ACE within our sample.

Similar to emotion neglect, we quantified experiences of physical neglect using 5 items derived from the CTQ in the same manner as Dube et al. (2003). These items were:

1. I didn't have enough to eat.
2. I knew there was someone to take care of me and protect me.
3. My parents were too drunk or high to take care of me.
4. I had to wear dirty clothes.
5. There was someone to take me to the doctor if I needed it.

Items 1, 3, and 5 were scored using the same likert-type ratings, while items 2 and 4 were reverse scored. All 5 items were summed and a score greater than or equal to 10 was considered to be participant endorsement of this ACE, as this score would fall in the moderate to severe range on the CTQ.

Emotional abuse was assessed by a participant response of "often" or "very often" to either of 2 items, "how often did a parent, step-parent, or adult living in your home swear at you, insult you, or put you down" or "act in a way that made you afraid you were going to get physically hurt?". Physical abuse was assessed by a participant response of "sometimes", "often", or "very often" to either of 2 items, "how often did a parent, step-parent, or adult living in your home push, grab, or throw something at you," or "hit you so hard that you had marks or were injured?". Sexual abuse was assessed by a "yes" responses to any of four items that described sexual experiences with an adult or some who was five years older than them at the

time of occurrence, including relatives, family friends, and strangers. The four items were if such adults had ever:

1. Touched or fondled your body in a sexual way.
2. Had you touch or fondle their body in a sexual way.
3. Attempted to have any type of sexual intercourse with you (oral, anal, or vaginal).
4. Had sexual intercourse with you (oral, anal, or vaginal).

### ***Family ACE Questionnaire***

To assess family history of ACE scores, a brief 11-item measure describing ACE experiences for each parent and grandparent (living or deceased) was completed by participants. Questions from this measure were created from the Adverse Childhood Experience (ACE) International Questionnaire (ACE-IQ) and adapted to reflect parent and grandparent ACEs as reported by participants. This self-report measure was modeled from the World Health Organization (WHO)'s measure of ACEs and has been assessed with various cultural groups, including a pilot study with large samples from China, Macedonia, Philippines, Thailand, Saudi Arabia, South Africa, and Vietnam (WHO, 2011). On this measure, household dysfunction was assessed by simple yes or no responses, and any item endorsed as "yes" was coded as indicative of each corresponding ACE. Child abuse or neglect ACE variables were calculated from three-item likert-type responses of "Never", "Once", and "More than Once." If a participant endorsed either "Once" or "More than Once" on an item, that was considered to be an ACE. All endorsed ACEs were then summed to calculate an ACE score for each parent and grandparent.

### ***Native Wellness Assessment (NWA)***

The NWA is 66-item measure of Indigenous individual wellness and can assess the effect of cultural intervention on an individual's wellness. It measures mental, physical, spiritual, and

emotional wellness for adults, through assessment of a range of individual actions or behaviours and through identification of frequently used cultural practices endorsed by self-report or observer-report. The NWA measures wellness using a strength-based approach, by examining the presence of hope, belonging, meaning, and purpose experienced by an individual. First published in 2015, the NWA has demonstrated good internal consistency, with Cronbach's alphas ranging from 77.8 to 85.2, and has been validated to be used with various genders, age groups, and Indigenous groups (Fiedeldey-Van Dijk et al., 2017).

### ***Alabama Parenting Questionnaire-Short Form (APQ)***

The APQ-Short Form is a 9 item self-report parenting measure that assesses three dimensions related to the development and treatment of child externalizing behavioural concerns (Elgar et al., 2007). The three domains are supervision and monitoring, use of positive discipline, consistency with discipline. Typical internal consistency reported across the APQ remains higher than a Cronbach alpha of .70 (Essau et al., 2006). The APQ has demonstrated good criterion validity differentiating between clinical and non-clinical levels of child behavioural concerns (Dadds et al., 2003).

### **Procedure**

As part of the ARTC client intake process, the study was explained to potential participants in a group format, and an informational letter (Appendix C) was reviewed. During this session, clients were made aware that participation in the study would not affect their treatment at ARTC. Clients were given the opportunity to ask any questions about the research process. When clients indicated they wished to participate in the study, they signed a study consent form (Appendix D).

Data collection was completed by the current treatment counsellor of each study participant with support by student researchers. Counsellors were trained on how to deliver the specific study measures to ensure collection processes remained uniform. Training incorporated information from the ACE-International Questionnaire Interview's Guide, although minimal training was required as all counsellors had the necessary clinical skills and experience required to complete interviews. The clients were given the choice to complete questionnaires individually using pen and paper or respond to questions orally that were read to them by their counsellor or student researcher.

To reduce participant burden, questionnaires were completed in two intervals. The first set of questionnaires were provided to participants on day 2 or 3 of their treatment cycle. These questionnaires asked about general health information, parenting, and wellness and consist of the first half of the Health History Questionnaire, the Alabama Parenting Questionnaire, and the Native Wellness Assessment. The second set of questionnaires (the remaining half of the Health History Questionnaire and the Family ACE Questionnaire) was completed at the end of week 2 of the treatment cycle, as this corresponded to program components that addressed past and current trauma with clients, including factors that may maintain substance use. These questionnaires asked trauma-focused questions, and assessed intergenerational family ACEs.

By Time 2, clients had completed some individual counselling, and were more likely to be emotionally and medically stable. Given that most variables assessed in time one were retrospective health data and long-term experiences of culture, two assessment time points were not theorized to induce testing bias, as data collection was inherently cross-sectional in nature. One positive aspect of asking trauma-based questions during time 2, was by the time of questionnaire completion, clients had established a therapeutic relationship with their counsellor

and may have been more comfortable disclosing previous trauma in these questionnaires. If these questionnaires induced feelings of distress, in addition to support received from their counsellor, cultural staff could be accessed and a staff psychologist was available to address any additional concerns that might arise from study participation, although this was not required throughout the study.

### ***Data Management and Cleaning***

Data management ensured study participation remained confidential. Participant names were replaced with ID codes in de-identified datasets. Only de-identified data (e.g., datasets without participant names and with contact information removed) were transferred outside the treatment facility for analysis. All study records will be stored for a period of five years past the date of publication. Any physical documentation, such as signed consent forms and paper participant measures, was stored in a restricted, secure area, within the community agency and will remain there for a period of 5 years post-publication, to be consistent with Ownership, Control, Access, and Possession (OCAP™) principles. Following this time, records will be destroyed in accordance with current best-practice research recommendations.

Relevant variables were transformed as required to complete relevant statistical analyses, including data modified to create dummy variables or qualitative data transposed to numerical values. Prior to hypothesis-testing, data were assessed for common assumptions of parametric analyses related to comparisons of group means and regression are assumptions of linearity, normality, homoscedasticity or homogeneity of variance, and statistical independence. Given data are cross-sectional, independence of errors was assumed, however potential violations of other assumptions were assessed. Frequency counts were calculated for each variable to detect illegal values, with 1 value detected and removed from this process. Descriptive tests, including

calculation of mean and median values for variables, and visual examination of data (using box plots, scatterplots, and bar graphs) were used to describe data normality and homoscedasticity, a measure of the distribution of error.

Potential outliers were identified by converting individual data items for each relevant variable to z scores. Any item with an absolute score greater than 3.29 was then replaced with a value represented by the mean score of that variable plus three standard deviations. Of all variables examined, two data items were identified as outliers and replaced.

To assess how missing data were distributed, Little's MCAR test determined data was not missing at random ( $\chi^2 = 154.20, p > .05$ ). Given this finding, missing data could theoretically be imputed, however a high percentage of missing data for some variables assessed in the Time 2 questionnaires (ranging from 39.7 to 76.6% of data missing) meant imputation did not occur. To correct for a high percentage of missing data for individual ACE scores, data were analyzed two ways. First, a list-wise deletion of cases occurred for all descriptive statistics, where only data collected were used for such analyses. For regression models, these ACE scores were used as the primary method of data analyses, however, a second individual ACE variable was created from single ACE variables collected from document review of client intake forms that was completed for all 141 consenting clients. This secondary ACE variable was composed of participant endorsement of six ACEs (composing of physical abuse, sexual abuse, emotional abuse, parental divorce, witness to domestic violence, and parental alcohol or substance use). These ACEs, although composed each of single item endorsement, are theorized to be a good estimate of ACE scores for the population. When this new ACE score was correlated with the original ACE obtained using the International ACE questionnaire, variables were moderately, and significantly, correlated ( $r = .457, p < .000$ ).

Normality of data was examined through skewness and kurtosis. Skewness, a measure of asymmetry within a sample distribution was calculated. Kim (2013) postulates that values closer to 0 indicate increased symmetry of data, while absolute values of 2.1 or more suggest a significant deviation from normality. Most study variables were within the range of -.05 to .830, however two variables within the sample were highly skewed (using Bulmer's 1979 classification). A count of chronic health concerns indicated a positive skewness (skewness of 1.27; SE= .205) and self-reported positive parenting practices) was negatively skewed (skewness of -1.69; SE= .261). When  $z$  scores were generated for these variables, chronic health conditions  $z= 6.20$  and positive parenting  $z= 6.48$ , both well above a 1.96 threshold. Given the nature of the chronic health conditions variable, a negative skew was expected, and therefore no adjustments to this variable were made. As there were limited analyses using positive parenting practices, this variable was also not adjusted. Kurtosis, a measure of the placement of distribution tails, examines the peakedness of the data distribution. Excess kurtosis, calculated in SPSS with a normal distributed data, has a kurtosis of 0 (Kim, 2013). Although many variables (total individual ACEs, maternal ACEs, DASS scores, and parenting scores) had kurtosis values ranging from -.880 to -.159, kurtosis of paternal ACEs was -1.44 (SE= .798) indicating platykurtic distribution with a flat-topped curve.

Multicollinearity within generalized linear models occurs when multiple predictor variables are highly correlated, resulting in unreliable estimates of regression coefficients if these variables are not entered into the regression model as covariates. To detect multicollinearity, the variance inflation factor (VIF) can be calculated by entering each predictor as an independent variable with all other predictors as dependent variables within a linear regression model. The VIF formula is  $1/(1-R^2)$ , and indicates how much variance explained by predictor variable is

bolstered by the correlation of that predictor variable with each other predictor. Generally, a VIF of 5 or higher is considered problematic (Thompson et al., 2017). VIF scores for all study variables ranged from 1.00 to 1.03.

## Results

### Objective 1: Prevalence of ACEs within an Indigenous Sample

Participant ACE scores were calculated using Dube et al.'s (2003) method of quantifying ACEs using the ACE Family Health questionnaire (WHO, 2018). The mean ACE score of participants was 5.22 ( $SD= 2.14$ ) and median score was 5.0. This was higher than a previously calculated general population mean of 1.31, as reported by the Alberta ACE study (Alberta Centre for Child, Family, and Community Research, 2014; McDonald et al., 2015). When an independent samples  $t$ -test compared ACE scores by gender, mean ACEs for males ( $M= 5.5$ ,  $SD= 2.16$ ) and females ( $M=4.90$ ,  $SD= 2.11$ ) were not significantly different ( $p= >.05$ ). The frequencies of individual ACEs endorsed by participants is described in Table 5, by total sample, males, and females. When ACEs were extrapolated from the entire sample from intake data, prevalence rates were similar (see Table 5). Figure 3 describes the frequency of ACE sum scores by total sample, male, and female samples.

**Table 5**

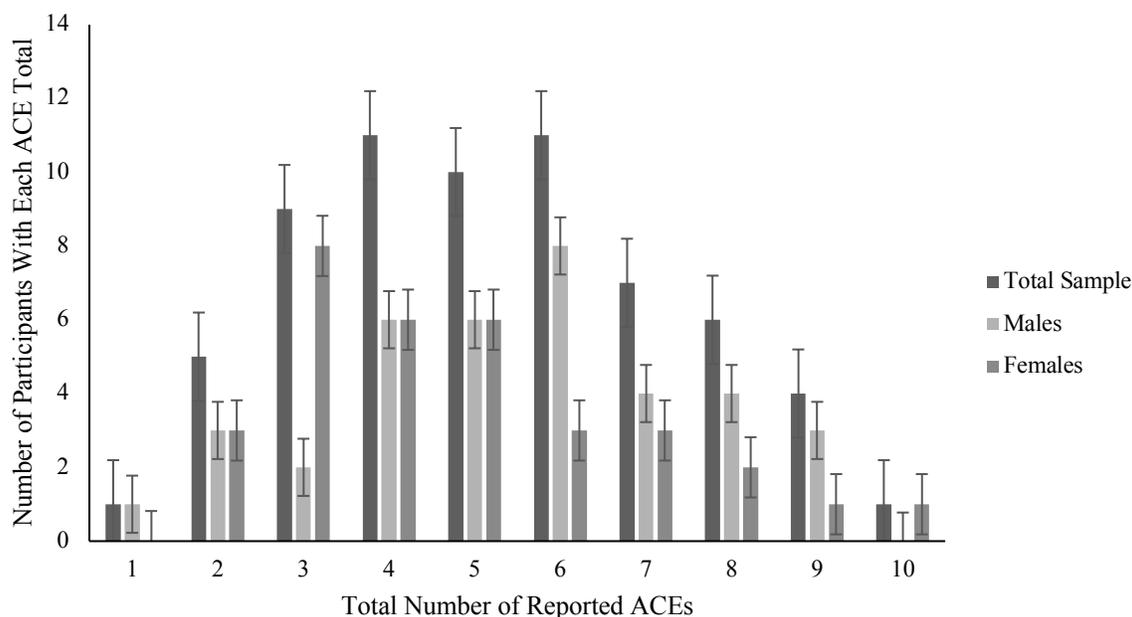
*Number of Participants Endorsing Each ACE*

Type of ACE	Total N Endorsing (% of sample)	Male (% of N sample)	Female (% of N sample)	ACEs from Intake Form
Physical Abuse	29 (44.6%)	19 (29.2%)	10 (15.4%)	50 (38.5%)
Sexual Abuse	38 (58.5%)	17 (26.2%)	21 (32.3%)	38 (29.0%)
Emotional Abuse	38 (58.5%)	23 (35.4%)	15 (23.1%)	60 (45.8%)
Emotional Neglect	8 (12.3%)	3 (4.6%)	5 (7.7%)	

Physical Neglect	23 (35.4%)	14 (21.5%)	9 (13.8%)	
Household Substance Use	57 (87.7%)	32 (49.2%)	25 (38.5%)	88 (67.2%)
Parental Separation or Divorce	49 (75.4%)	26 (40.0%)	23 (35.4%)	61 (46.9%)
Intimate Partner Violence	28 (43.1%)	13 (20.0%)	15(23.1%)	69 (52.7%)
Household Member Incarceration	22 (33.8%)	14 (21.5%)	8 (12.3%)	
Household Member Mental Illness	49 (75.4%)	28 (43.1%)	21 (32.3%)	

**Figure 3**

*Distribution of Cumulative Participant ACE Scores*



**General Health Outcomes of Participant Sample**

**Physical Health**

We related ACE scores to four leading causes of death attributed to chronic within Ontario: cancer, cardiovascular/cerebrovascular diseases, respiratory diseases, and diabetes (Public Health Ontario, 2019). Table 6 describes the ten leading causes of death (Statistics

Canada, 2020f), across all ages and genders with the four types of chronic diseases we measured marked with an \*. For groups with five or more participants, a mean ACE score for each group was also calculated.

**Table 6***Participant Endorsement of Chronic Health Concerns Attributed to Leading Causes of Death*

Leading Cause of Death	Participant Count (% of sample)	National Average	Mean ACE Score if sample > 5 ( <i>sd</i> )
1. Malignant neoplasms (cancer)*	2 (1.4%)	2.4% <sup>1</sup>	
2. Cardiovascular disease (heart disease)*	3 (2.2%)	8.5% <sup>1</sup>	
3. Cerebrovascular diseases*	10 (7.3%)	2.7% <sup>1</sup>	
4. Accidents (unintentional injuries)	Not assessed		
5. Respiratory diseases*	13 (10.1%)	9.6% (COPD) <sup>1</sup>	6.00 (2.51)
6. Influenza and pneumonia	Not assessed		
7. Diabetes mellitus*	14 (9.9%)	9.8% <sup>1</sup>	5.00 (3.03)
8. Alzheimer's disease	Not assessed		
9. Intentional self-harm/suicide	38 (27.0%)	3.1% <sup>2</sup>	5.50 (2.34)
10. Nephrosis and nephrotic syndrome	38 (27.9%)	10.6% <sup>3</sup>	5.58 (1.97)

<sup>1</sup>(Public Health Agency of Canada, 2017); <sup>2</sup>(percentage of suicide attempts; Public Health Agency of Canada, 2016); <sup>3</sup>(Bello et al., 2019).

Frequently endorsed chronic health concern not attributed as a leading cause of death included high blood pressure ( $n= 57$ ; 41.9% of sample), urinary tract/bladder concerns ( $n=38$ , 27.9% of sample), liver problems including yellow jaundice, hepatitis, or other concerns ( $n= 32$ ,

23.5% of sample), arthritis ( $n=22$ , 17.5% of sample), ulcers ( $n=22$  (16.2% of sample), and asthma ( $n= 20$ , 16% of sample).

### ***Risk Factors to Developing Chronic Disease***

Risk factors to development of chronic disease in Ontario have been related to increased tobacco use, increased alcohol consumption, decreased exercise, and higher body mass (Public Health Ontario, 2019). Within our sample, 105 (74.5%) used tobacco regularly, while 44 participants (44%) reported alcohol use more than 4 times per week. The mean number of drinks per instance across all reported alcohol users was 10.22 ( $sd=11.85$ , range from 0 to 50). When asked about visits to a physician or other health care provider, the mean number of visits per year was 7.27 ( $sd=9.5$ ), with range from 0 to 60. When asked about exercise per week, participants reported a mean number of times exercising per week of 2.97 ( $sd= 2.75$ , range of 0 to 12).

### **Mental Health**

Participants reported a range of mental health symptoms, and reported receiving either a diagnosis or treatment for a mean of 2.5 ( $SD= 2.29$ , range 0 to 11) categories of disorders (listed in Table 7). Of 137 respondents, 62 (44.3% of sample) indicated they had previously been under the care of a psychologist, psychiatrist, or therapist prior to treatment. Client intake data regarding suicidality and self-harm behaviours indicated 60 participants (43.8%) endorsed suicide ideation, 41 (29.9%) reported intentional self-harm behaviour, and 38 (27.7%) reported a previous suicide attempt. Forty participants reported previous hospitalization for a mental health issue and 67 (48.9%) reported engaging in prior counselling or therapy. Current symptoms of distress were measured by mean DASS-21 scores for anxiety ( $M=16.77$ ,  $SD=10.26$ ), depression ( $M=16.49$ ,  $SD=10.7$ ), and stress ( $M=19.53$ ,  $SD=9.47$ ).

Problematic gambling behaviours were examined using the PGSI. The mean sample score of gambling severity was 2.35 ( $SD= 4.46$ , range 0 to 19). Using the PGSI severity indexes, 95 participants (76.61% of sample) were in the range of a non-problem gambler (PGSI score of 0 to 2), 11 (8.9%) were in a moderate-risk range (PGSI score of 3 to 7), and 18 (14.51%) were in the range of problematic gambling (PGSI score of 8 or higher).

**Table 7**

*Number of Participants with Formal Diagnosis or Treatment of Mental Health Conditions*

Mental Health Disorder	Participant Count (%)	National Prevalence	Mean ACE ( <i>sd</i> )
Anxiety (Generalized Anxiety, Social Anxiety)	74 (52.5%)	12% <sup>1</sup>	5.22 (2.06)
Depression (Major Depression, Dysthymia)	68 (50.4%)	8% <sup>1</sup>	5.17 (2.08)
Substance Use Disorder (SUD)	66 (46.8%)	22% <sup>2</sup>	5.44 (1.93)
Post-Traumatic Stress Disorder (PTSD)	39 (27.7%)	10% <sup>3</sup>	5.45 (2.21)
Learning Disability (LD)	26 (18.4%)	14% <sup>4</sup>	5.40 (2.41)
Attention-Deficit Hyperactivity Disorder	25 (17.7%)	3% <sup>5</sup>	4.86 (2.21)
Personality Disorder (PD)	15 (10.6%)	1.5% <sup>1</sup>	5.42 (2.94)
Eating Concerns (Anorexia, Bulimia, Binge Eating; ED)	14 (9.9%)	2% <sup>1</sup>	6.00 (2.89)
Fetal Alcohol Spectrum Disorder (FASD)	12 (8.5%)	4% <sup>6</sup>	6.33 (3.06)
Schizophrenia or Psychosis	8 (5.7%)	1% <sup>1</sup>	5.00 (1.41)
Bi-polar Disorders	7 (5.0%)	1% <sup>1</sup>	4.00 (1.41)

<sup>1</sup>(Mood Disorders Society of Canada, 2019); <sup>2</sup>(Pearson, Janz, & Ali, 2015); <sup>3</sup>(Ameringen et al., 2008); <sup>4</sup>(Bizier, Till, & Nicholls, 2014); <sup>5</sup>(Connolly, Speed, & Hesson, 2019); <sup>6</sup>(Flannigan, Unsworth, & Harding, 2018)

### ***Parenting Difficulties***

Eighty-five parents in our sample answered questions related to parenting, including positive parenting, inconsistent discipline, and poor supervision using the APQ. Of these scales, each with a total scale score of 15, mean positive parenting ratings was high ( $m= 12.48$ ,  $sd=3.76$ ), while reported inconsistent discipline ( $m=6.77$ ,  $sd=2.95$ ) and poor supervision ( $m=4.93$ ,  $sd=2.43$ ) was not. Of 69 participants, 25 reported they struggled with parenting (36.2%), while 44 (57.9% of 76 respondents) described prior or current child welfare involvement with their family through the partnering organization.

### ***Native Wellness Assessment***

One hundred and twenty-one participants completed the NWA, which provided descriptive analyses of Indigenous constructs of wellness related to hope (spiritual wellness), belonging (emotional wellness), meaning (mental wellness), and purpose (physical wellness). Scores were described in seven categories of wellness, ranging from exceptionally low attentiveness to wellness (score of 1 to 2) to exceptionally high attentiveness to wellness (score of 99 to 100), with a score in the range of 33 to 67 considered average. Mean scores for hope were above average, in the high attentiveness to wellness range ( $m= 70.36$ , median=75.0, range= 16 to 100), similar to belonging ( $m= 70.68$ , median= 72.9, range 25 to 100), and meaning ( $m= 71.1$ , median= 75.2, range= 12.5 to 100). Purpose scores were in the average range ( $m= 63.2$ , median= 65.6, range= 5.1 to 100).

Of the Indigenous participants who were asked about their participation in cultural interventions, most commonly endorsed were receiving help or guidance from an Elder or traditional healer ( $n= 53$ , 52.5% of sample), going on nature walks ( $n= 53$ , 52.5% of sample), and use of traditional medicines ( $n= 53$ , 52.5% of sample). Other highly endorsed cultural

activities (calculated when participants indicated moderate or strong engagement) included smudging ( $n= 50$ , 49.5% of sample), engaging in cultural dances or pow wow ( $n= 50$ , 49.5% of sample), use of prayer ( $n= 49$ , 48.5% of sample), and engaging in talking or healing circles ( $n= 49$ , 48.5% of sample).

### Objective 2: ACEs and Health Outcomes

A linear regression assessed the hypothesis that participants with high ACE scores would report a greater number of physical and mental health concerns than participants with a lower number of ACE scores. A variable of total chronic health conditions (computed by participant endorsement of any prior history of cancer, heart disease, diabetes, stroke, emphysema, liver problems, and high blood pressure) was created. Regression results were reported two ways, first using a participant sample with all ten ACEs reported (Table 8) and second using ACE scores obtained from intake data (Table 9). Both analyses with these ACE variables supported the hypothesis that increased ACEs would significantly predict a number of chronic health conditions.

**Table 8**

*Linear Regression Results with Chronic Health Scores as Criterion Variable (n=71)*

Predictor	Model 1			Model 2		
	<i>B</i>	<i>SE B</i>	$\beta$	<i>B</i>	<i>SE B</i>	$\beta$
Age	.026	.011	.284	.025	.010	.279
Sex	.250	.204	.144	.292	.205	.168
Total ACEs				.065	.049	.158
	$R^2$	0.096				.121
	<i>F</i>	3.52*				2.97*

\* $p < .05$ ; \*\* $p < .01$ .

**Table 9***Linear Regression Results with Chronic Health Scores as Criterion Variable (n=141)*

Predictor	Model 1			Model 2		
	<i>B</i>	<i>SE B</i>	$\beta$	<i>B</i>	<i>SE B</i>	$\beta$
Age	.025	.007	.285	.023	.007	.268
Sex	.098	.147	.055	.035	.150	.020
Intake ACEs				.068	.038	.149
	<i>R</i> <sup>2</sup>	0.082				.103
	<i>F</i>	6.02**				5.12**

\**p* < .05; \*\**p* < .01.

Odds ratios related to chronic diseases and ACEs in the sample were calculated using logistic regression. It was hypothesized that congruent with previous research (Felitti et al., 1998), a score of four ACEs or higher would be associated with increased odds of having reported health concerns by participants. Prevalence rates of chronic diseases, including heart disease, diabetes, emphysema, cancer, liver problems, high blood pressure, and stroke were examined for both ACE samples (Table 10). Logistic regression analyses were completed for any health variable that was endorsed by five participants or more within each sample, with covariates of age and sex (Table 11).

**Table 10***Frequencies of Diseases Within Both ACE Samples*

	Total ACEs ( <i>n</i> = 71)	Intake ACEs ( <i>n</i> = 141)
Cancer	1	2
Diabetes	6	14
Emphysema	8	13

Heart Disease	2	4
High Blood Pressure	9	16
Liver Problems	17	32
Stroke	3	10

**Table 11***Logistic Regression Results Comparing ACEs with Chronic Health Conditions*

Criterion		<i>B</i>	<i>SE</i>	Wald	df	<i>p</i>	<i>Exp</i>	CI (95%)	
Variable							( <i>B</i> )	Lower	Upper
Diabetes ( <i>n</i> =71)	Age	.122	.049	6.203	1	.013	1.129	1.026	1.243
	Sex	-.269	.963	.078	1	.780	.764	.116	5.048
	Total ACEs	.085	.220	.151	1	.697	1.089	.708	1.676
Diabetes ( <i>N</i> = 141)	Age	.063	.027	5.396	1	.020	1.065	1.010	1.124
	Sex	-.104	.632	.027	1	.870	.902	.261	3.112
	Intake ACEs	.221	.171	1.675	1	.196	1.247	.893	1.743
Emphysema ( <i>n</i> =71)	Age	-.016	.051	.105	1	.746	.984	.891	1.087
	Sex	-1.04	.823	1.601	1	.206	.353	.070	1.771
	Total ACEs	.288	.193	2.211	1	.137	1.333	.913	1.948
Emphysema ( <i>N</i> = 141)	Age	.008	.031	.072	1	.789	1.008	.949	1.071
	Sex	-.257	.606	.180	1	.671	.773	.236	2.537
	Intake ACEs	.052	.166	.097	1	.755	1.053	.761	1.457

High blood pressure ( <i>n</i> =71)	Age	.046	.035	1.705	1	.192	1.047	.977	1.122
	Sex	.243	.743	.107	1	.744	1.275	.297	5.467
	Total ACEs	.123	.173	.501	1	.479	1.131	.805	1.588
High blood pressure ( <i>N</i> = 141)	Age	.062	.025	6.409	1	.014	1.064	1.013	1.117
	Sex	.334	.589	.321	1	.571	1.397	.440	4.433
	Intake ACEs	.199	.157	17.70	1	.206	1.220	.897	1.659
Liver Problems ( <i>n</i> =71)	Age	.016	.031	.268	1	.605	1.016	.957	1.079
	Sex	-.695	.597	1.357	1	.244	.499	.155	1.607
	Total ACEs	.126	.139	.815	1	.367	1.134	.863	1.490
Liver Problems ( <i>N</i> = 141)	Age	.017	.020	.707	1	.400	1.017	.978	1.057
	Sex	-.234	.425	.303	1	.582	.791	.344	1.821
	Intake ACEs	.039	.113	.118	1	.732	1.040	.832	1.298
Stroke ( <i>N</i> = 141)	Age	.045	.030	2.204	1	.138	1.046	.986	1.110
	Sex	-.442	.683	.418	1	.528	.643	.168	2.453
	Intake ACEs	.133	.181	.541	1	.462	1.142	.801	1.629

To compare adjusted odds ratios to previous literature describing relationships between 4 or more ACEs and prevalence of chronic disease, ACE scores were collapsed into three categories. For total ACE scores that reported all ten ACEs, groups were divided as 0 to 1 ACE, 2 to 3 ACEs, and 4 or more ACEs. For the six ACEs collected from intake forms, categories were 0 to 1 ACE, 2 ACEs, and 3 or more ACEs. Logistic regression results of these groups with 4 or more ACEs as categorical variables are described in Table 12, with age and sex entered as covariates. Reported adjusted odds ratios are those contrasted by the low ACE category group

(individuals with 0 to 1 ACE). Although no significant relationships across health conditions were found, adjusted odds ratios greater than 1 were found for diabetes, high blood pressure, liver problems, and stroke when analyses with a larger sample (using 6 ACEs) were used. No odds ratios were above 1 when the smaller samples (consisting of all 10 ACEs) was inputted.

**Table 12***Logistic Regression Results Comparing High ACE Group with Chronic Health Condition*

Criterion			<i>B</i>	<i>SE</i>	Wald	df	<i>p</i>	<i>Exp</i>	CI (95%)	
Variable								( <i>B</i> )		
	<i>N</i>								Lower	Upper
Diabetes	71	4+ ACEs	-.301	.960	0.00	1	.754	.740	.113	4.858
	141	3+ ACEs	.310	.683	.206	1	.650	1.363	.358	5.195
Emphysema	71	4+ ACEs	-1.13	1.16	.958	1	.328	.322	.033	3.114
	141	3+ ACEs	-1.14	1.09	1.09	1	.297	.321	.038	2.714
High blood pressure	71	4+ ACEs	-.301	.960	.098	1	.754	.740	.113	4.858
	141	3+ ACEs	.310	.683	.206	1	.650	1.363	.358	5.195
Liver problems	71	4+ ACEs	-2.25	1.12	4.05	1	.044	.105	.012	.943
	141	3+ ACEs	.105	.520	.041	1	.840	1.110	.401	3.077
Stroke	141	3+ ACEs	.975	.730	1.79	1	.181	2.652	.634	11.09

Hypothesis 2C predicted that participants with high ACE scores would report significantly more parenting difficulties than those with low ACE scores. Positive parenting, inconsistent discipline, and poor supervision (obtained from self-reported APQ parenting data) were compared among three categories of ACEs (low, 0 to 2; medium, 3 to 6; high, 7 to 10)

using a one-way ANOVA. No significant differences were found among low ACE, medium ACE and high ACE groups for positive parenting ( $F [2, 40]=.800, p=.456$ ), inconsistent discipline ( $F [2, 40]=.385, p=.683$ , or poor supervision ( $F [2, 35]=.068, p=.934$ ). This hypothesis was not supported.

Hypothesis 2D, that participants with high ACE scores would report significantly lower hope, belonging, meaning, and purpose scores (as measured by the NWA) was assessed by bivariate Pearson's correlations. Individual ACEs from both the client intake form ( $n=141$ ) and self-reported ( $n=71$ ) were examined, however correlations between these variables and hope (intake ACE  $r=.035$ ; total ACE  $r=.080$ ), belonging (intake ACE  $r=.018$ ; total ACE  $r=-.025$ ), meaning (intake ACE  $r=.093$ ; total ACE  $r=.029$ ), and purpose (intake ACE  $r=.114$ ; total ACE  $r=-.261$ ) showed small, non-significant effects.

### **Objective 3: Intergenerational ACEs and Health Outcomes**

#### ***Biological Parent Health***

The majority of participants reported their parents were alive at the time of the study (father  $n=53$ , 77.9% of sample; mother  $n=54$ , 83.1% of sample). The mean age of parents who were living was 60.19 ( $sd=11.61$ ; range=36 to 82) for fathers and 59.78 ( $sd=11.76$ ; range=38 to 93) for mothers. Among these families, participants provided information about chronic health outcomes of their biological mothers ( $n=38$ ) and fathers ( $n=41$ ), with results described in Table 13.

Among those who reported the age and cause of parental death ( $n=21$ ), both fathers' ( $m=59.6, sd=19.6, median=55.5, range=30$  to 93) and mothers' ( $m=41.4, sd=14.9, median=45.0, range=19$  to 60) ages were below the current national mean lifespan of 79.8 years for men and 83.9 years for women (Statistics Canada, 2020f). When compared to this average, 10 fathers

(71.4% of reported sample) and 9 mothers (100% of reported sample) were considered to be a premature fatality. The most commonly reported cause of death was accidental (including substance overdose, fatal accidents, and suicide) for fathers ( $n= 7$ ; mothers  $n=3$ ) secondary to chronic disease (6 fathers and 8 mothers), and natural causes (1 father and 0 mothers).

**Table 13**

*Frequencies of Parent Chronic Diseases*

	Paternal Count (% of sample)	Maternal Count (% of sample)
Total in Sample	41 (100%)	38 (100%)
Cancer	9 (22%)	3 (7.9%)
Dementia	2 (4.9%)	1 (0.7%)
Diabetes	14 (34.1%)	14 (36.8%)
Mental Health	5 (12.2%)	12 (31.6%)
Heart Disease/ Stroke	16 (38.1%)	4 (10.5%)
High blood pressure	4 (9.8%)	4 (10.5%)

***Biological Grandparent Health***

Among those who reported grandparent health outcomes, the majority of participants reported their grandparents were deceased ( $n= 154$ , 72.6% of sample). Of those whose reported a living grandparent, mean age for grandmothers (paternal and maternal) was 78.91( $sd=8.82$ , range 65 to 96) while the mean age for grandfathers was 76.27 ( $sd= 10.54$ , range= 63 to 98). Rates of chronic diseases, as reported by participants are described in Table 14.

**Table 14***Frequencies of Grandparent Chronic Diseases*

	Paternal Grandfather Count (% of sample)	Maternal Grandfather Count (% of sample)	Paternal Grandmother Count (% of sample)	Maternal Grandmother Count (% of sample)
Sample N	25(100%)	14 (100%)	20 (100%)	24 (100%)
Cancer	7 (28.0%)	5 (35.7%)	8 (40.0%)	9 (37.5%)
Dementia	4 (16.0%)	2 (14.3%)	1 (5.0%)	2 (8.3%)
Diabetes	6 (24.0%)	2 (14.3%)	4 (20.0%)	12 (50.0%)
Mental Health	4 (16.0%)	1 (7.1%)	2 (10.0%)	2 (8.3%)
Heart Disease/ Stroke	5 (20.0%)	5 (35.7%)	4 (20.0%)	4 (16.7%)
High Blood Pressure	1 (4.0%)	0	1 (5.0%)	2 (8.3%)

When reported causes of death among grandparents were examined, the majority of grandparents' death was attributed to the presence of a chronic health condition ( $n=55$ , 62.5% of sample), second to natural causes ( $n=22$ , 25% of sample), and thirdly to accidental death ( $n=11$ , 12.5% of sample). Females and males within this generation exhibited similar trends, for death attributed to chronic disease (27 females, 28 males), natural causes (12 females, 10 males), and accidental death (6 females, 5 males). Of the entire sample ( $n= 76$ ), 47 grandparents' deaths (61.8%) were classified as premature, (23 females and 24 males). The mean age of death for this generation was 71.78 ( $sd= 14.37$ , range 30 to 91) and the median was 74.00. For females, mean

age of death was 72.62 ( $sd=13.87$ , range 30 to 91) and median age of death was 74.50, while for males, the mean age was 70.87 ( $sd= 15.08$ , range 35 to 91) and the median was 74.00.

### *ACEs and Health Outcomes*

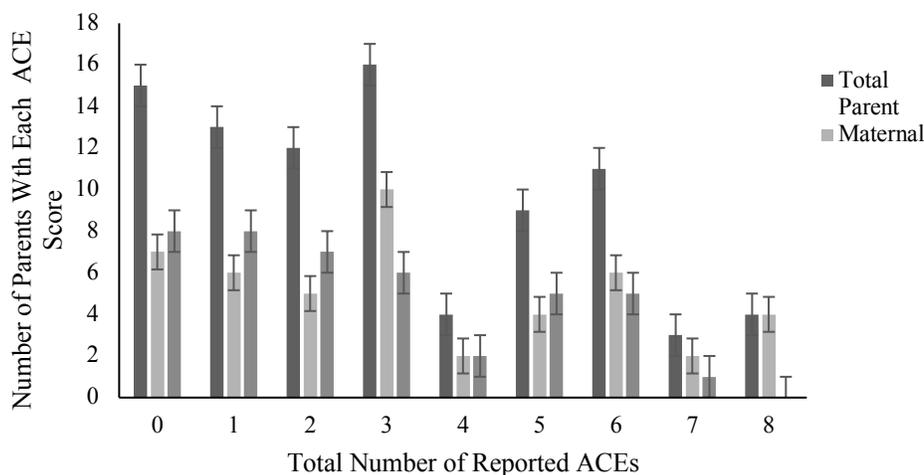
Participants were asked to retrospectively report on eight parent and grandparent ACEs (physical abuse, sexual abuse, emotional abuse, household substance use, household mental illness, parental incarceration, parental intimate partner violence, and parental divorce). Of the 71 participants who completed Time 2 measures, 47 completed ACE measures for at least one parent and five participants provided ACE data for a total of 14 grandparents. Of these participants, most indicated they did not know about any prevalence of ACEs in their grandparents' childhoods ( $n= 10$ ). Among the four other family scores, of a possible 44 test items among these variables, 30 were answered as "don't know" by participants.

Due to a small sample size, only parental ACE scores were used for subsequent analyses. Parent mean scores were compared and no significant differences were found ( $p= >.05$ ). The mean reported maternal ACE scores was 3.33 ( $SD= 2.53$ ; median=3) and mean reported paternal ACE scores was 2.74 ( $SD= 2.19$ ; median=2). A paired samples t test did not find mothers and fathers to differ on ACE scores  $t(29)= -.468$ ,  $p=.642$ . See Figure 4 and Table 15 for distribution of total ACE scores and frequency of type of ACE.

To assess if parent ACE scores significantly predicted high participant ACE scores, a linear regression was completed, with both age and sex of participants entered as co-variates. Based on these results, this hypothesis was not supported (Table 16). Hypothesis 3B, parental ACE scores prediction of health outcomes for participants, was also not supported (Table 17).

**Figure 4**

*Distribution of Cumulative ACE scores for Maternal and Paternal ACE Scores*



**Table 15**

*Number of Participants Endorsing each ACE for Fathers and Mothers*

Type of ACE	Maternal Endorsement <i>n</i> = 45				Paternal Endorsement <i>n</i> = 42			
	Yes	% of sample	No	Unsure	Yes	% of sample	No	Unsure
Physical Abuse	17	37.8%	11	17	23	54.8%	5	21
Sexual Abuse	12	26.6%	13	20	4	9.5%	13	31
Emotional Abuse	21	46.7%	6	18	17	40.5%	2	22
Household Substance Use	29	64.4%	11	5	27	64.3%	6	9
Parental Separation or Divorce	19	42.2%	24	2	11	26.2%	22	9
Intimate Partner Violence	21	46.6%	8	16	17	40.5%	3	21
Household Member Incarceration	9	20.0%	20	15	7	16.7%	17	18
Household Member Mental Illness	22	48.9%	9	14	19	45.2%	8	15

**Table 16***Linear Regression Results with ACE Total as Criterion Variable (N=141)*

Predictor	Model 1			Model 2		
	<i>B</i>	<i>SE B</i>	$\beta$	<i>B</i>	<i>SE B</i>	$\beta$
Age	.011	.035	.053	.032	.037	.156
Sex	-.585	.743	-.134	-.605	.727	-.139
Maternal ACEs				.279	.167	.320
Paternal ACEs				.017	.194	.016
	<i>R</i> <sup>2</sup>	0.02				.119
	<i>F</i>	.390				1.08

\**p* < .05;**Table 17***Linear Regression Results with Chronic Health as Criterion Variable (N=141)*

Predictor	Model 1			Model 2		
	<i>B</i>	<i>SE B</i>	$\beta$	<i>B</i>	<i>SE B</i>	$\beta$
Age	.023	.015	.253	.027	.016	.296
Sex	-.148	.304	-.078	-.143	.310	-.076
Maternal ACEs				.009	.073	.023
Paternal ACEs				.055	.084	.124
	<i>R</i> <sup>2</sup>	0.073				.090
	<i>F</i>	1.41				.837

\**p* < .05;

Hypothesis 3C, that reported parental ACE scores would be significantly associated with presence of premature family member death was partially supported. As all mothers in our sample with a reported cause of death were classified as a premature death, this ceiling effect reduced the ability to complete an independent *t*-test. When an independent *t*-test was completed for paternal ACEs and premature death, this relationship was significant,  $t(9) = 2.67, p = .025$ .

**Objective 4: Intergenerational experiences of residential school attendance and child welfare involvement relationship with participant health outcomes**

***Relationships with Residential School Attendance, ACEs, and Health***

Five participants indicated they had a history of residential school attendance. Of this sample, the mean age of these participants was 47.4 ( $sd= 8.01$ , range 36 to 57). When the mean number of ACEs were calculated for this sample, mean ACEs was 4.25 ( $sd= 2.62$ , range 2 to 8). Given the small sample size, Hypothesis 4A, that participants who have attended residential schools would have significantly more health concerns than those who have not attended a residential school, was not calculated. When parental history of residential school attendance was examined, of a total of 110 parents, 31 (28.1%) had attended a residential school (14 mothers and 17 fathers). Of 122 grandparents, 47 (38.5%) had attended a residential school (25 women and 22 men). Hypothesis 4B, that intergenerational residential school attendance would be associated with higher ACE scores, was not supported (Table 18) for any maternal and paternal grandparents on parent ACEs, nor for maternal and paternal parent residential school attendance on participant ACE scores.

**Table 18**

*Independent t-Test Results of Intergenerational Residential School Attendance and ACE Scores*

IV	DV		<i>M</i>	<i>sd</i>	<i>t</i>	df	<i>p</i>
			ACE				
Paternal Grandparent Residential School Attendance	Father ACE score	Attended:	5.25	1.71	2.34	18	.060
		Did not attend:	2.87	2.19			
Maternal Grandparent Residential School Attendance	Mother ACE score	Attended:	4.67	2.12	.216	26	.646
		Did not attend:	4.21	2.55			

Parent Residential	Individual	Attended:	5.56	2.29	.733	54	.396
School Attendance	ACE score (all ten)	Did not attend:	5.01	1.76			
Parent Residential	Individual	Attended:	3.44	1.47	.856	56	.359
School Attendance	ACE score (6 from intake)	Did not attend:	3.00	2.00			

It was hypothesized that grandparent and parent residential school attendance would be associated with more reported health outcomes for individual participants (Hypothesis 4C). Parent residential school attendance was not significantly associated with individual health outcomes when age and sex were entered as covariates into a linear regression (Table 19). Parent residential school attendance (Hypothesis 4D) was not significantly associated with a higher mean of reported parent health concerns (Table 20), calculated by combining rates of endorsement of cancer, dementia, diabetes, mental health concerns, heart disease/stroke, and high blood pressure.

**Table 19**

*Linear Regression Results with Chronic Health Scores as Criterion Variable*

Predictor	Model 1			Model 2		
	<i>B</i>	<i>SE B</i>	$\beta$	<i>B</i>	<i>SE B</i>	$\beta$
Age	.011	.012	.126	.011	.012	.127
Sex	.247	.223	.149	.259	.232	.156
Parent Residential School Attendance				.050	.234	.030
	$R^2$	0.037				.038
	$F$	1.02				.681

\* $p < .05$ ; \*\* $p < .01$ .

**Table 20***Independent T-Test of Intergenerational Residential School Attendance and Parent Health*

IV	DV		<i>M</i>	<i>sd</i>	<i>t</i>	df	<i>p</i>
ACE							
Paternal Residential School Attendance	Paternal Health Problems	Attended: Did not attend:	.819 1.35	.603 .831	-1.88	32	.140
Maternal Residential School Attendance	Maternal Health Problems	Attended: Did not attend:	.777 1.05	.667 .950	-.768	29	.417

Hypothesis 4E, that parent residential school attendance would be associated with increased parenting difficulties among participants. When ACEs were entered as a covariate, residential school attendance was related to positive parenting practices (Table 21), inconsistent discipline (Table 22), and for poor supervision (Table 23).

**Table 21***Linear Regression Results for Residential School History and Prediction of Positive Parenting Practices*

Predictor	Model 1			Model 2		
	<i>B</i>	<i>SE B</i>	$\beta$	<i>B</i>	<i>SE B</i>	$\beta$
Age	-.049	.065	-.118	-.056	.016	.296
Sex	3.45	1.18	.457	3.03	1.29	.401
Total ACEs	.615	.296	.335	.607	.297	.331
Parent RSA				-1.063	1.274	-.140
	<i>R</i> <sup>2</sup>	0.256				.273
	<i>F</i>	3.68*				2.91*

Age		-.046	.059	-.111		-.059	.059	-.143
Sex		2.79	1.06	.368		2.14	.1.14	0.283
Intake ACEs		1.09	.329	.472		1.15	.326	.496
Parent RSA						.883	.330	.401
	$R^2$	0.373			.411			
	$F$	6.34**			5.40**			

\* $p < .05$ ; \*\* $p < .01$ .

**Table 22**

*Linear Regression Results for Residential School History and Prediction of Inconsistent Discipline*

Predictor	Model 1			Model 2			
		$B$	$SE B$	$\beta$	$B$	$SE B$	$\beta$
Age		-.046	.059	-.111	.150	-.059	.059
Sex		2.79	1.06	.368	.556	2.14	1.14
Total ACEs		1.09	.329	.472	-.042	1.15	.326
Parent RSA					-1.67	1.08	-.257
	$R^2$	0.229			.284		
	$F$	3.17*			3.08*		
Age		.165	.056	.465	.152	.055	.429
Sex		1.28	1.00	.197	.639	1.08	.099
Intake ACEs		-.197	.311	-.099	-.142	.308	-.071
Parent RSA					-.301	.287	-.159
	$R^2$	0.238			.289		
	$F$	3.34*			3.14*		

\* $p < .05$ ; \*\* $p < .01$ .

**Table 23***Linear Regression Results for Residential School History and Prediction of Poor Supervision*

Predictor	Model 1			Model 2		
	<i>B</i>	<i>SE B</i>	$\beta$	<i>B</i>	<i>SE B</i>	$\beta$
Age	.119	.046	.392	.123	.047	.404
Sex	2.39	.807	.444	2.59	.877	.481
Total ACEs	-.211	.196	-.165	-.211	.198	-.165
Parent RSA				.539	.869	.100
	<i>R</i> <sup>2</sup>	0.401				.409
	<i>F</i>	6.24**				4.67**
Age	.130	.043	.429	.138	.043	.454
Sex	2.59	.738	.489	2.91	.795	.540
Intake ACEs	-.553	.235	-.330	-.596	.238	-.356
Parent RSA				.765	.762	.142
	<i>R</i> <sup>2</sup>	0.479				.500
	<i>F</i>	8.58**				6.76**

\**p* < .05; \*\**p* < .01.***Relationships with Child Welfare Involvement, ACEs, and Health***

Participants were asked about parental and grandparental involvement with child welfare services, including placement in a foster home, group home, or adoption. Of 41 participants who answered this question, 20 (48.79%) reported parents involved with such services. Five of 23 participants (21.74%) reported a grandparent previously involved with child welfare services. Among participants, 23 of 75 reported a prior history of child welfare involvement, with the mean age of the first placement being 6.48 years (*sd*= 4.60, range 0 to 15). The mean number of placements for those placed in care was 3.48 (*sd*= 4.08, range 1 to 20). Independent *t*-tests compared individual, parent, and grandparent prior involvement with child welfare services to assess hypotheses 4G (Table 24). Of 85 individuals who reported having children, 26 (30.6%)

indicated that they currently had a child in care at the time of the study. Hypothesis 4F, that participants with children currently in care would report higher number of ACE scores, was not supported when all ten ACEs were assessed ( $t[40]=.495, p=.140$ ) nor for when ACEs from the intake form were used ( $t[83]=.925, p=.507$ ). Mean ACE scores for those that did report child welfare involvement were higher than those who did not for both total ACES ( $m1=5.28; m2=4.92$ ) and ACES obtained from the intake form ( $m1=3.50; m2=3.10$ ). Hypothesis 4I, that intergenerational placement in foster care, particularly for a longer duration at a younger age, could not be assessed. Due to low endorsement rates of parental and grandparental foster care placements, and minimal data describing the length and duration of such placements for these generations, analyses could not be completed. Hypothesis 4H, that intergenerational placement of parents in foster care would be associated with current parenting difficulties was not supported for positive parenting (Table 25), inconsistent discipline (Table 26), or poor supervision (Table 27).

**Table 24***Independent T Test of Intergenerational Child Welfare Involvement and ACEs*

IV	DV		<i>M</i>	<i>sd</i>	<i>t</i>	<i>df</i>	<i>p</i>
			ACE				
Grandparent Child Welfare Involvement	ACE score (all ten)	Prior history:	6.60	.894	2.58	19	.158
		No prior history:	4.31	1.89			
Grandparent Child Welfare Involvement	ACE score (6 from intake)	Prior history:	2.60	2.79	-.275	21	.140
		No prior history:	2.89	1.88			
Parent Child Welfare Involvement	ACE score (all ten)	Prior history:	5.42	1.98	.926	37	.490
		No prior history:	4.85	1.87			
		Prior history:	3.20	1.67	.532	39	.673

Parent Child Welfare Involvement	ACE score (6 from intake)	No prior history:	2.90	1.87			
Participant Child Welfare Involvement	ACE score (all ten)	Prior history:	5.77	2.69	1.58	68	.002
		No prior history:	4.91	1.77			
Participant Child Welfare Involvement	ACE score (6 from intake)	Prior history:	3.57	1.85	1.72	73	1.00
		No prior history:	2.79	1.77			

**Table 25**

*Linear Regression Results with Positive Parenting as Criterion Variable*

Predictor	Model 1			Model 2		
	<i>B</i>	<i>SE B</i>	$\beta$	<i>B</i>	<i>SE B</i>	$\beta$
Age	-.029	1.42	-.088	.033	.095	.098
Sex	1.29	.075	.205	2.06	1.59	.327
Parent Child Welfare Involvement				1.89	1.77	.300
	<i>R</i> <sup>2</sup>	0.059				.112
	<i>F</i>	.631				.802

\*p <.05; \*\*p<.01.

**Table 26**

*Linear Regression Results with Inconsistent Discipline as Criterion Variable*

Predictor	Model 1			Model 2		
	<i>B</i>	<i>SE B</i>	$\beta$	<i>B</i>	<i>SE B</i>	$\beta$
Age	.169	.063	.523	.205	.081	.636
Sex	2.07	1.20	.338	2.53	1.36	.413
				1.12	1.52	.182

Parent Child Welfare		
Involvement		
$R^2$	0.292	.311
$F$	4.11*	2.86

\*p <.05; \*\*p<.01.

**Table 27**

*Linear Regression Results with Poor Supervision as Criterion Variable*

Predictor	Model 1			Model 2		
	$B$	$SE B$	$\beta$	$B$	$SE B$	$\beta$
Age	.146	.066	.437	.168	.097	.503
Sex	2.92	1.20	.481	3.10	1.36	.511
Parent Child Welfare				.577	1.82	.093
Involvement						
	$R^2$	0.355				.356
	$F$	4.68*				2.99

\*p <.05; \*\*p<.01.

### Discussion

The aim of the current study was to explore the relationship between individual ACE scores and health outcomes, to contextualize such experiences within intergenerational experiences of ACEs, health outcomes, residential school attendance, and child welfare involvement for Indigenous people seeking substance use treatment. As expected, reported ACEs in this sample were higher than previously reported ACE scores for Canadian and Indigenous samples, with a mean ACE score of participants as 5.22 and median as 5.0. This was lower than reported ACE scores for parents, which out of a total of eight ACEs, the mean ACE score for mothers was 3.33 and for fathers was 2.74.

Given robust relationships of how increasing ACEs affect chronic disease prevalence, substance use, and mental health (Felitti et al., 1998), high ACE scores among participants in our study may have implications on broader health outcomes and psychological functioning, including individual response to substance use treatment, including co-morbid challenges associated with chronic disease management. The prevalence of chronic diseases in our sample was slightly higher than national averages (Public Health Agency of Canada, 2017), particularly for kidney disease (28% of our sample compared to 10.6% national prevalence) and stroke (7.3% of our sample compared to 2.7% of all Canadians). When mean ACE scores were calculated for samples who endorsed kidney disease, intentional self-harm, diabetes, and respiratory diseases, mean ACE scores were all greater than or equal to 5, and all but the diabetes sample was greater than the total participant average of ACE scores. Such findings support previous data regarding the health disparities of Indigenous people in Canada (Reading & Wein, 2009).

Measures of hope, belonging, meaning, and purpose of these clients were explored in the current study in relation to ACEs using the NWA, however results were not significant. Although considered integral to the promotion of Indigenous wellbeing (Assembly of First Nations, 2015), relationships among these variables with scores of early childhood trauma were not significant. Of these variables, the measure of purpose showed a small effect in the appropriate direction. It is possible that with a larger sample size of Indigenous clients, the clarity of these relationships will increase, particularly with a broader range of ACE scores. Alternatively, as the NWA is a relatively new measure, a future study direction may be to assess the convergent validity of the NWA with other measures of hope, belonging, meaning, and purpose with Indigenous and non-Indigenous clients. Further evaluation is required to explore

these relationships and understand how these aspects can emphasize resilience for clients seeking substance use treatment, particularly when ACE scores are high.

Participant rates of reported diagnoses of mental disorders were also higher among our study sample when compared to national prevalence averages in Canada, on all categories of disorders. Notably, diagnosis of Major Depression Disorder or an Anxiety Disorder was endorsed by over 50% of participants, as compared to national averages of approximately 8% for MDD and 12% for an anxiety disorder with similar trends for a diagnosis of Post-Traumatic Stress Disorder (28% of sample when compared to 10% of a national sample). When samples were segregated by specific diagnosis, mean ACE scores for those diagnosed with an anxiety disorder, SUD, LD, PTSD, PD, ED, or FASD were above the mean average of ACEs within the entire study sample. Those reporting a diagnosis of Fetal-Alcohol Spectrum Disorder reported the highest mean number of ACEs, with an average of 6.33 ACEs within this sample. These high co-morbidities among those with substance use and additional mental health diagnoses suggest that those with increased ACEs may be particularly susceptible to concurrent mental health difficulties and require an increased level of care. Given that the causal mechanism of FASD is maternal alcohol use while pregnant, it is likely that higher ACE scores for those participants with FASD diagnoses in this sample illuminate an intergenerational transmission of alcohol use concerns, and subsequent concerns affiliated with parenting capacity while engaging in problematic substance use.

Participants self-reported maternal, paternal, and grandparent ACEs and rates of chronic disease. For both parent and grandparent health concerns reported by participants, rates of diabetes, cancer, heart disease, and stroke were all higher than national prevalence (Public Health Agency of Canada, 2017). If parents or grandparents were deceased, participants reported the

cause of death for parents to be accidental, while for grandparents, chronic disease related. Paternal ACE scores were also significantly higher for those with a premature death. Contrary to study hypotheses, residential school attendance for parents and grandparents was not significantly associated with increased ACEs for parents nor for individual participants.

Of those who reported a history of family residential school attendance, mean ACE scores were higher for those who reported a family member who attended residential school. Endorsement rates of residential school attendance was higher than previous research samples, which found approximately 10 percent of participants endorsed parental or self-attendance (Kaspar, 2010), as compared to 28 percent of parents and 39 percent of grandparents in our sample. Such high rates within this sample, when compared to national samples, may indicate greater experiences of adversity and experiences of intergenerational effects for Indigenous individuals currently in treatment for substance use. Similar to recommendations from Wilk et al.'s (2017) scoping review of relationships among health and residential school attendance, results from our study must be appropriately contextualized within broader social determinants contributing to development of disease. Despite the absence of significance within our analyses, results continue to depict higher rates of adversity among our sample participants and their families.

When parenting difficulties were examined, residential school attendance by parents was significantly related to positive parenting, inconsistent discipline, and poor supervision practices among individual participants. This finding partially supports study hypotheses, as results depicted a positive relationship for all three of these variables, which although trending in the expected direction for inconsistent discipline and poor supervision, was opposite than expected for positive parenting practices. Since previous literature has supported increased parenting

difficulties for offspring of residential school survivors, this result was unanticipated. In regards to child welfare involvement and parenting difficulties, there were not significant relationships between such histories and these aspects of parenting. As expected, participant child welfare involvement was significantly related to increased ACEs, given that rates of parental abuse and neglect (5 of 10 ACEs) would result in higher removal rates from parental care.

### **Study Limitations**

The major limitation of this study was the use of participant self-report data for parent and grandparent ACEs and health outcomes. Many participants did not answer these questions, and of those who did, many indicated they were not aware of specific experiences of their parents and grandparents in childhood. As many reported parents and grandparents were reported to have died prematurely, participant self-report remains a viable option for collecting inter-generational data with this population, however a larger sample size could reduce the floor effects associated with uncertainty of parent and grandparent experiences in addition to rates of chronic diseases.

A second limitation is the relatively small sample size. A larger sample size could allow for more robust analyses commonly used with analyses of ACEs and increase the statistical power to capture smaller effect sizes. For example, many logistic regression analyses compute odds ratios using the total number of ACEs as a categorical variable. This can allow better detection of trends related to an increase of one ACE within the dose-response relationship, and provide useful information related to health trends and outcomes. For the purposes of this study, categories were collapsed to two groups (above or below 4 ACEs), reducing the overall variance of individual data points within this model. Similarly, specificity of analyse could be improved by segregating each chronic disease and analysing separately. In the current study, linear

regression analyses examined frequency of the most common chronic diseases for participants, however if sample numbers were higher, we could examine how prevalence rates of chronic disease are distinctly associated with ACE scores.

### *Assessment of ACES*

There are some limitations of the current study with respect to how ACEs were operationalized and measured, as approaches describing when and how to measure ACEs within public health remain disputed in broader literature. For example, no studies to date have validated the ACE measure with First Nations populations. In addition, we compared high and low ACE groups (classified using a cut-point score of 4) of point prevalence of chronic disease. Roberta Anda, a co-principal investigator of the original ACE study (Felitti et al., 1998) and colleagues in 2020 emphasized that no arbitrary score should be used as a cut-point for clinical decision making. Although high ACE scores can be a crude measure of exposure to biomarkers of stress experienced across a lifespan, it does not account for severity and frequency of ACE exposure. In sum, not all ACEs have equivalent effects on health for individuals, and as such, there are no definitive cut-points to contrast low or high ACE exposure (Anda et al., 2020). Similar to previous ACE studies, we did not account for severity and chronicity of ACE exposure within study analyses.

Inconsistent measurement of ACEs makes it difficult to compare ACE scores across studies. A review of commonly used measures, including the ACEs-10, suggests that inconsistent operationalization of variables, including the use of single items to measure ACE constructs, and a wide variability of scoring approaches (including collapsing responses to “yes” or “no”), contributes to unreliable and unvalidated measures of ACEs (McLennan et al., 2020). Inconsistent use of ACE measures within this literature makes it difficult to compare ACE

findings across studies or understand various health disparities within a population. For example, in our study, we found a mean ACE score of approximately 5, however this was difficult to compare across previous studies with Indigenous populations, as not all studies measured all 10 ACEs using the same method (Radford et al., under review). Consistent measurement, using variables that are operationalized and validated across populations, can improve the utility of ACE data within academia and public health.

Embedding ACE assessment within public health approaches has been positioned as one way to inform prevention and treatment efforts in communities (Kia-Keating et al., 2019; Pataky et al., 2019). If ACEs are predictive of health outcomes, then theoretically, preventing ACEs will prevent chronic disease. Unfortunately, as expected, the mechanisms of action within these relationships remain poorly understood and difficult to assess using current approaches. For example, a seminal study by Baldwin and colleagues (2021) analyzed a longitudinal sample from birth to the age of 45, and found that ACEs did not accurately predict one's individual risk for later health concerns. Mental health outcomes were analyzed using receiver operating curve analysis, generating an area under the curve statistic. Findings suggested that high ACE scores of 4 or more accurately predicted only 58% of any type of later in life mental health concerns for individuals, a rate of only 8% above chance. When specific mental health disorders were considered, ACE scores were most accurate for identifying substance use dependence (rate of 60% accuracy), and least accurate for anxiety disorders (56% accurate). Similar findings were identified for physical health concerns, with a rate of 60% accuracy (Baldwin et al., 2021).

These findings show it remains difficult to accurately predict individual outcomes using population data, and doing so can facilitate increased likelihood of ecological fallacies, including misattributing findings from population level to predict an individual's experience or behaviour

(Robinson, 1950). Such endeavors can increase the likelihood of Simpson's paradox, where a trend within data can be visible when analysis occurs with a large population, but can disappear or even reverse directions when various sub-population groups are analyzed separately and do not consider mediating or moderating third variables (Pearl, 2014). As ACE research is often completed with large population-level datasets, it is possible that such analyses omit relevant nuances within these relationships and may not accurately inform ongoing inquiries of "what works" and "for whom." As such, the ability of ACE research to inform prevention and treatment endeavors has been a recent criticism of embedding ACE research in public health screening approaches (Finkelhor, 2018; McLennan et al., 2020; Turner et al., 2020). For example, when the predictive power of a variety of ACEs (approximately 40) were examined for groups of younger and older children, not all of the 10 conventional ACEs were predictive of trauma symptoms for both age groups. ACEs related to household dysfunction were more likely to predict trauma symptoms for younger children, while community and peer-related ACEs were more likely to predict trauma for older children (Turner et al., 2020). Such distinctions suggest that universal ACE screening, particularly endeavors that do not assess chronicity and severity of ACEs may not be useful for widespread public health approaches.

### **Future Directions**

To address the longstanding issue of what particular ACEs predict detrimental health outcomes at an individual level, diverse assessment approaches of ACEs are needed. Currently, the ACE framework is a simplified way to conceptualize sophisticated relationships among early life exposure to adversity, and subsequent pathways to chronic illness. This is a useful first step, however existing assessment approaches need to be expanded to recognize individual differences within populations. Currently, ACE research uses a top-down approach to assessing and

measuring adversity in childhood. We typically assess the ten predetermined ACEs originally conceptualized by Felitti et al. (1998) and Dube et al. (2001), while occasionally expanding or extracting variables depending on research interest and available data. Given the robust relationship of these ACEs observed at a population level, next steps are warranted to compare these data with those extracted at an individual level, using a bottom up approach.

I respectfully propose a bottom up approach for future ACE assessment that allows individuals to colour outside of the lines of previously contrived ACE categories. By allowing individuals to independently generate a list of relevant traumatic events that have occurred in their own lives, complete with a self-reported rating of both severity and chronicity, we can generate ACE test items at an individual level. This approach could allow individual to rate events that they feel have been particularly impactful in their life, and contrast these events to current health outcomes. It can also generate a broader list of ACEs that can be analyzed for commonalities across individuals to develop a list of ACE categories that are particularly pertinent for various population groups, such as Indigenous heritage, age categories, and genders. Although it is likely that many of the current ACEs would be endorsed by individuals, it is possible that other items not frequently discussed in ACE literature are also identified and specific relationships among ACEs and health may be better understood.

Additional directions will continue data collection to broaden our current sample size. This can allow for better detection of relationships among ACEs and health, across generations. Currently, in alignment with Ownership, Control, Access, and Possession (OCAP™) standards set by the First Nations Information Governance Centre (2014) results will be returned to the Research Advisory, and therefore will be used at their discretion. It is likely that study results, upon completion, will be shared through community reports and peer-reviewed publications as

requested by the Research Advisory. It is possible that results of this study will be used to inform further research relating to childhood outcomes and health needs for Indigenous populations. Study processes implemented with the partnering treatment facility will continue to collect ongoing ACEs data from future clients.

Additionally, chronic diseases were endorsed dichotomously by participants, and no data were collected regarding participant burden of each disease. Within psychology, we examine how symptoms impede or impair activities of daily living in association based on the presence of symptom. Collecting this type of information, including various symptoms experienced by each individual could contextualize how the presence of chronic disease has impeded life functioning, particularly in regards to ACEs and engagement in behaviours to reduce risk factors of disease (ie: exercise, nutrition, or reduced tobacco use). Relationships between specific use of substances and chronic disease prevalence, including pain management, could be useful to explore relationships between self-management of chronic disease within this population.

### **Conclusion**

This study has documented preliminary prevalence rates of ACE scores within an Indigenous treatment population, which were higher than national averages and previous data collected with Indigenous samples (Radford et al., under review). We provided preliminary descriptive analyses relating ACEs to health outcomes for Indigenous people, however not all study hypotheses relating to intergenerational experiences of ACEs among these relationships were supported. It is likely that a larger sample size may increase our statistical ability to detect differences among groups in the future. Findings show that although the gap between Indigenous and non-Indigenous health disparities is closing, particularly in regard to increasing life expectancies for Indigenous people in Canada, there remain segments of this population who are

particularly disadvantaged. Based on study results, those experiencing chronic health difficulties co-morbid with clinical levels of problematic substance use are likely to experience a higher burden of health, including higher rates of chronic disease, lower mental health outcomes, and higher risk factors of disease. To improve ongoing best-treatment options for those seeking substance use treatment, continued assessment of broader aspects of health and wellbeing is required, including the balance of physical, emotional, spiritual, and mental health and wellbeing across a lifespan.

## **Chapter 4: Preliminary Recommendations for ACE Assessment with Indigenous Populations**

The dose-response relationship between ACE prevalence and subsequent mental health concerns can inform individual psychological assessment approaches used with Indigenous populations. This chapter will describe potential assessment considerations when addressing ACEs within substance use treatment facilities for Indigenous populations. These proposed strategies are considered to be potential options for treatment providers and could be generalized to other Indigenous and non-Indigenous substance use treatment facilities depending on the needs of the client and provider.

The generalized assessment of ACEs has been disputed within recent ACE literature, with recent position papers discussing first whether such assessment should even occur, and second, specific processes of such an assessment if it is deemed worthwhile (McLennan et al., 2020; Finkelhor, 2010). To our knowledge, there has been no published literature dedicated to assessment of ACEs with Indigenous populations. The following recommendations are those that were useful throughout the current study and were generated from ongoing discussions with research advisory members, staff research assistants, and review of participant feedback forms. These recommendations are as follows:

1. Determine Necessity of ACE Assessment
2. Convey a Sense of Hope, Belonging, Purpose, and Meaning in Assessment
3. Use Therapeutic Assessment Techniques
4. Consider Culturally-Relevant Operationalization and Measurement of ACEs
5. Incorporate ACEs into Clinical Conceptualization.

## **1. Determine Necessity of ACE Assessment**

Within psychology, we are trained to carefully consider both the purpose of an intervention or assessment but also any relevant outcomes of such actions. Thoughtful contemplation prior to practice ensures that tasks asked of clients, particularly those who are vulnerable, are those that are likely to benefit them in some way, or at the bare standard, are unlikely to harm them. Therefore, the first step of ACE assessment is ensuring that such data collection is required and clarifying the intended use of data. Collecting data for data's sake, particularly within Indigenous populations, is not advised, nor are "fishing trips" of exploratory data collection without specific intent. When considering whether ACE assessment should occur, individual organizations can determine long-term goals related to the utility of data.

One concern with ACE assessment is the threat of potential harm to individuals disclosing trauma within a research or health setting (Yeater & Miller, 2014), although the majority of participants in ACE studies (Mersky et al., 2019) or trauma-focused studies (Jaffe et al., 2016) do not report discomfort. Within our study, reported discomfort did occasionally occur with participants, and was mitigated by immediate access to each individual client's counsellor on site. Participants in our study relayed that client discomfort with ACE measures was anecdotally associated with limited emotion regulation strategies by clients, and no previous experience of disclosing trauma, while previous American-based research found that increased ACEs, higher depression scores, and identifying as American Indian were associated with higher distress levels (Merskey et al., 2019). Given these findings, it may be worthwhile to examine indicators of participant distress during ACE assessment to inform the utility of various assessment techniques within potentially vulnerable populations prior to large-scale assessments.

Although the risk of generalized participant distress is low during ACE assessment, understanding specific indicators of distress within Indigenous populations is warranted.

## **2. Convey a Sense of Hope, Belonging, Purpose, and Meaning in Assessment**

Within our study, clearly conveying the purpose of the ACE assessment to clients, although required from our REB, was also a key factor to reducing any likelihood of potential harm. Hope, belonging, meaning, and purpose are centrally situated within the FNMWCF that promotes overall wellbeing for Indigenous individuals, families, and communities (Assembly of First Nations & Health Canada, 2015). Any collection of ACEs should be one that has some sort of benefit, however small, to each individual participant and can promote these facets in some capacity. Although participants in our study were provided with some individual-specific reports, often the benefit was one that was cited as contributing to greater understandings of ACE to inform ongoing preventative and treatment efforts for future generations. Demonstrating mutual respect for client participation in this study, and recognizing each individual contribution to a broader goal, conveyed to some participants a deeper meaning to study participation. This is consistent with a meta-analysis describing research participation of those bereaved by suicide, as the majority of participants in studies reported positive outcomes related to increased social support, engaging in altruistic behaviours, and increased personal growth (Andriessen et al., 2018).

Although the synthesis of meaning making follow traumatic events is inconsistent across population groups, contexts, and psychological indicators of wellbeing, meta-analytic research suggests that meaning-making attempts are common for those who experience trauma and the quality of meaning making attempts can influence growth (Park, 2010). For individuals in our study, many cited study participation as a way to “give back” and derive greater meaning from

their experiences. Meaning making following experiences of trauma is a therapeutic technique that can occur during ACE assessment simply through the structure of how it is completed. The structure of the assessment, including brief discussions of assessment purpose, can facilitate brief opportunities for meaning making for participants simply by informing participants about how results are used. An emphasis on a broader contribution to others affected by similar experiences can convey meaning to participants. This can be accomplished through a relatively safe experience completing a survey with an assessor, with an assessment experience that promotes validation, normalization of responses to trauma, and unconditional positive regard.

Emphasizing a sense of belonging in ACE assessment can include contextualizing shared experiences and symptoms trajectories of those with high ACEs, by describing common responses to trauma and early childhood adversity. Normalizing responses to trauma may partially alleviate client experiences of self-blame, guilt, or shame associated with such behaviours, as they can re-frame perspectives of emotion regulation, avoidance, and disrupted attachment behaviours as adaptive following responses to trauma. A discussion we found anecdotally useful within the ACE discussion group related to this theme. In this group, we described common responses to trauma (including increased substance use, increased impulsivity, and reduced self-esteem), and related to those behaviours as extremely adaptive ways to address mood difficulties in a short-term capacity. Discussion centered on how short-term strategies to address trauma symptoms may not be best-practices to promote long-term health, and how such approaches may need to be adapted over time.

Finally, embodiment of hope within ACE assessment can provide a new perspective to clients regarding their symptom trajectories and future quality of life. Contextualizing experiences of clients, and emphasizing aspects of resilience in their lives, can offer evidence-

based hope for their own outcomes in life. Hope has previously been associated with improved psychological flourishing (Munoz et al., 2020) in adult survivors of childhood trauma, and has mediated the relationship between attachment and depressive symptoms (Blake et al., 2020). It has also been negatively associated with trauma-symptoms in those who have experienced a traumatic event, particularly when high levels of social support and optimism are present (Weinburg et al., 2016). Exploring hope with clients, and establishing pathways to build optimism and hope for the future, can aid them to associate lived experiences of adversity with future growth and wellbeing.

### **3. Use Therapeutic Assessment Techniques**

Therapeutic Assessment refers to a model of psychological assessment that embeds brief intervention techniques with information gathering (Finn & Tonsager, 1997). The goal of the assessment still predominantly focuses on data collection; however, clinicians simultaneously interpret this data with clients to broaden individual understandings of their current symptomology. The role of the assessor is to establish both a process and outcome approach to psychological assessment. Although the outcome may be a diagnosis or obtaining symptom descriptions, the process by which this is achieved is fundamental to the assessment. The subjective experience of the participant remains guided by the assessor to increase mutual feelings of respect, understanding, openness, curiosity, and ultimately, therapeutic alliance.

The techniques used within therapeutic assessment can be applied when assessing for ACEs across research and treatment settings. Finn and Tonsager (1997) have described distinctive differences between information gathering and therapeutic assessment techniques which can be translated to a context of ACE specific assessment. When applied to assessing ACEs, therapeutic assessment techniques can vary within the specific context of the assessment,

but still can be adopted to provide opportunities for therapeutic moments of insight. Completing the ACE questions in a format that is appropriate for the client and setting can increase the therapeutic nature of assessment. Such techniques are:

- Allow the client to generate their own assessment questions at the beginning of the assessment, ie, “What would you like to know more about yourself as we begin our discussion today?”
- Allow the client to generate strategies on how they can emotionally regulate during the assessment, ie, “We are going to be discussing some things that may be hard to talk about. What do you need to feel safe or to help you keep feeling okay today?”
- Use motivational interviewing techniques such as asking open questions, affirming, reflecting, and summarizing (Miller and Rollnick, 2013) as this can build therapeutic rapport and increase client openness and engagement.
- Extrapolate described symptoms to a “living example” of current client experiences of discomfort or distress to contextualize results, such as relating prior experiences to current presenting concerns, ie, those related to increased substance use or parenting difficulties.
- Use therapeutic curiosity to situate each client as the expert in their own individual experiences to generate personal insight. Ask the client to provide personal insight of current individual concerns, or how such concerns could influence broader systems in their life, related to family, community, or culture ie, “Why do you think this may be?”
- Use of self-report questionnaires can be reviewed and interpreted in the moment with clients, ie, “I see you scored quite high on this measure, how has that affected your life right now?”

- Assessment results should be interpreted by both assessor and client by contextualizing findings with the client through a collaborative exploration of client life experiences.
- Providing feedback in a way that answers the client questions, rather than differential diagnoses, and meaningful clinical interpretation of ACE experiences.
- Explore potential future therapeutic approaches together following feedback or discussion, and discuss the possibility of these proposed recommendations. Offer other potential supports if requested by the client.
- Following the end of the assessment, re-affirm with the client selection of positive emotional regulation strategies and client autonomy to address potential distress.
- Schedule a session follow-up to allow time for the client to interpret this discussion and have an opportunity to discuss lingering questions or concerns.

This is a short list of techniques that are commonly used within psychological assessments to generate therapeutic rapport and to create shared meaning, but may not have yet translated to clinic-based screening or research studies for ACEs. These techniques are intended to be used with an assessor and client during in person assessment. Future work may explore how to apply such techniques within electronic surveys, however this may be challenging to do with potentially vulnerable populations. Further, these techniques can stimulate discussion through frequent use of open-ended questions, however can be applied during self-report likert-type measures as well. It is possible that use of these techniques may increase time of administering assessments, however a skilled assessor can integrate these strategies while simultaneously managing subsequent discussion in a meaningful way for each client.

#### **4. Consider Culturally-Relevant Operationalization and Measurement of ACEs**

Like many other contexts within Indigenous health, the measurement of psychological constructs can be influenced by both culture and context. Culturally-relevant operationalization and measurement of psychological variables has been cautioned, as inaccurate variable measurement can lead to over or under-reporting of symptoms, potentially influencing diagnostic considerations, population prevalence rates, and treatment of psychological conditions (Mashford-Pringle et al., 2019; Mushquash & Bova, 2007). Guidelines for measurement of psychological constructs have called for culturally-relevant measures that consider unique differences of Indigenous populations to obtain more accurate portrayal of mental health across cultures (American Psychological Association, 2013; Canadian Psychological Association & The Psychology Foundation of Canada, 2018).

These considerations can be applied to the measurement of ACEs. In the current study, we calculated ACE scores from the methods used by Dube et al. (2003), which used items from the Family Health Survey to create a variable for if each ACE was endorsed by a participant. Some of these variables have dichotomous answers, for example, endorsement of experiences of parental divorce or having a family member who was incarcerated. Other ACE variables require increasingly complex interpretation, which then require inclusion of culturally-relevant operationalization of variables.

One example of how cultural considerations within ACE assessment become particularly salient is related to the assessment of neglect. The assessment of child neglect within Indigenous populations has historically been associated with the imposition of non-Indigenous cultural values resulting in poor outcomes for Indigenous communities (Caldwell & Sinha, 2020). These values were used to sustain increased apprehension of Indigenous children by child welfare

service providers in actions now conceptualized as the Sixties' Scoop. In present day, Indigenous children in welfare services continue to be over-represented, with First Nations children up to 16 times more likely to be in child welfare services than other Canadian children (Statistics Canada, 2016). Indigenous children most are most likely to be placed in care due to histories of neglect, or intimate partner violence in the home, rather than experiences of abuse or alternative circumstances (Ma et al., 2019). As we seek to evaluate ACEs within Indigenous communities, care must be taken to avoid the "Sixties' Scoop" of ACEs, or over-classification due to use of non-Indigenous contextualization of ACEs, particularly those related to emotional and physical neglect.

ACEs can be better conceptualized for Indigenous populations by reviewing measures with communities, asking clients to report on specific events or experiences, using multiple items to assess each variable, and adhering to culturally-relevant best practices. An example of such an approach is provided by Luther (2019), who asked Indigenous participants to expand on definitions of ACEs through qualitative interviews and then rank-order these definitions in order of cultural relevance. Broader ACEs established in this approach related to historical trauma, lack of unfractured, gender specific adversity, household dysfunction, and discrimination. Measures of ACEs should continue to be reviewed for suitability with various client populations by those who have expertise with these communities. Asking communities to report on appropriateness, understandability, word choice, and content have been proposed as one way to do this with ACE measures (Quinn et al., 2018). Within the current study, although test items were generated from a non-Indigenous perspective of neglect, they were deemed to be representative of experiences of neglect within partnering communities. Operationalizing specific experiences of neglect can also inform how clients reliably interpret the meaning of each

variable. For example, the APA (2013) definition of child neglect encompasses acts that deprive a child of age appropriate needs, including, “abandonment, lack of appropriate supervision, failure to attend to necessary emotional or psychological needs, failure to provide necessary education, medical care, nourishment, shelter, and/or clothing” (p. 718). This definition, although thorough, is challenging to assess consistently if specific aspects of neglect are not concretely defined for participants. Within the current study, physical neglect was assessed with the following questions: “I didn’t have enough to eat.”; “My parents were too drunk or too high to take care of me.”; “I had to wear dirty clothes.”; “There was someone to take me to the doctor if I needed it.”; and “I knew there was someone there to take care of me and protect me.” This five-item measure used multiple test-items can increase the validity of the entire physical neglect variable by using concrete experiences that clients can recall. The psychometric evaluation of ACE measures with respect to Indigenous populations is warranted. Such work can align with the most recent knowledge of how each ACE is conceptualized within current literature. Until this occurs, embedded best-practices of psychological assessment across cultures can guide current approaches to ACE assessment.

Another alternative is to operationalize ACEs by considering alternative variables rather than the 10 initially identified by Felletti and colleagues (1998). Previously proposed alternative ACEs for Indigenous populations have included experiences of racism, exposure to residential schools, and lack of access to public health and educational services (Cave et al., 2019; Luther, 2019). Relationships among exposure to alternative ACEs in childhood, and adult mental and physical health outcomes can show similar trends to typical ACE scores. For example, experiences of racism for Indigenous children have been associated with decreased cortisol awakening responses, increased risk of mental disorders, sleep difficulties, and increased

physical health concerns such as obesity and asthma (Shepherd et al., 2017). Other studies have shown decreased allostatic load for Indigenous adults experiencing racism as children (Currie et al., 2019), including how the timing of experiences of racism influence mental health as adults (Cave et al., 2019). Further, alternative ACEs first explored with non-Indigenous samples, such as spanking, exposure to poverty, homelessness, and violent crime victimization (Afifi et al., 2017; Choi et al., 2020), could be relevant for Indigenous populations as well.

### **5. Incorporate ACEs into Clinical Conceptualization**

Universal screening of ACEs has been cautioned (Finklehor, 2018; McLennan et al., 2019) partially due to concerns that overall assessment will not lead to appropriate intervention approaches. Although there is limited evidence to justify how ACE assessment can inform treatment selection at an individual level for clients, there are alternative pathways to improve the clinical utility of ACE assessment. Screening of ACEs can inform case conceptualization within broader clinical assessments, and provide an understanding of precipitating factors that could influence further screening for frequently co-morbid chronic health conditions. ACE assessment could also influence clinician predictions regarding prognosis, related to how a client will respond to treatment, or offer insight into how best to triage client health concerns. For example, all participants in our study were seeking substance use treatment, although many likely could have met criteria for PTSD, given presenting symptoms in treatment and the fact that the sample ACE score was approximately five. If substance use is conceptualized to be a secondary effect from prolonged, unaddressed trauma symptoms, then it is possible that some of these clients' distress could be triaged to treatment of trauma rather than treatment of substance use. Assessment of ACEs can inform these types of clinical decisions. Finally, effective treatment of such trauma for clients can expand their own resilience and capabilities within their

own social environments. This can mean improving a client's ability to engage in healthy relationships (reducing risk of IPV), increasing positive parenting practices (reducing intergenerational exposure to ACEs of their children), and enhancing behaviours that promote improved physical health.

### **Additional Considerations and Cautions**

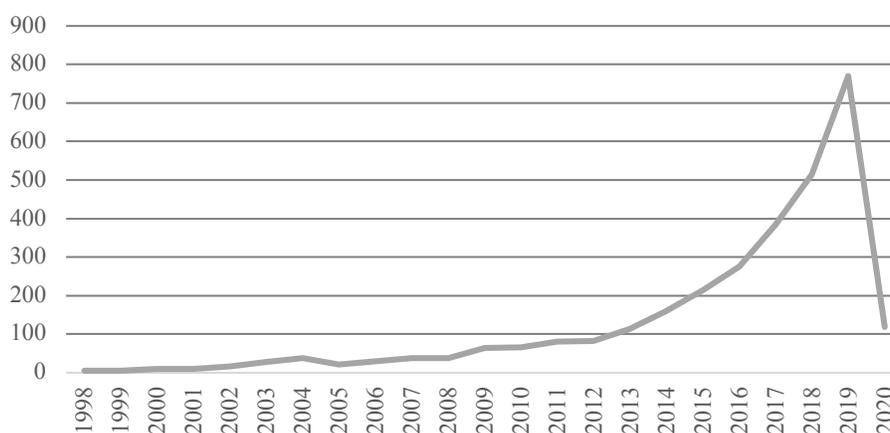
Examining ACEs within clinical practices can inform case conceptualization and be used to create additional explanatory frameworks of clients' current health. To best use ACEs in both research and clinical settings, ACE literature must be integrated with existing research dedicated to child wellbeing and mental health. Given that ACE-specific publications are increasing exponentially (See Figure 5), there is a risk that continued pursuit of exploring these relationships can segregate ACEs from the broader literature on childhood abuse, neglect, and trauma (Siddaway, 2019). Rather than isolating ACE literature into a distinctive research category, embedding findings with previous child mental health literature can integrate broader conceptualization and avoid silos of similar research.

Future research can harness the vast appeal of ACEs within public health and use this interest to advance and integrate subsequent interests related to research domains that do not receive such attention. The novelty and digestible nature of primary ACE data in 1998 piqued both lay-person and research interest resulting in findings that are easily integrated into public reports and extrapolated across disciplines. Use of common descriptors and jargon, embedded within a relatively simplistic linear explanatory model, complete with visual diagrams (i.e., the ACE pyramid), means that various health disciplines can apply findings to specialized bodies of literature. Although the original ACE study related to the ten leading chronic diseases causing death in the United States, researchers used such concepts to examine everything from telomere

lengths (Bürgin et al. 2019) to critical race theory (McAdam & Davis, 2019). This doctoral dissertation is also an example of how the ACE explanatory model has been applied within a specialized discipline for a specific population. The shared appeal of ACEs across disciplines means that we must work together to move current descriptive work to applied models of both prevention and treatment within our respective fields.

### Figure 5

*Number of ACE study Citations by Year Retrieved from Web of Science*



An organizational model of available literature can inform assessment and treatment recommendations that prioritize previously recognized developmental trajectories and recognize a shared etiology of ACEs and health outcomes, trauma literature, and related concepts. Careful distinction of these domains can also avoid “concept creep”, or the expansion of how psychological phenomena are classified over time (Haslam, 2016). Thoughtful incorporation of ACE-specific and trauma concepts can accurately reflect similarities and differences in these literatures. Effective integration of these bodies of literature can help develop explanatory relationships of how experiencing adversity leads to broader mental and physical health outcomes. ACE literature poses that for those individuals who experience a high number of ACEs, they will experience post-traumatic symptoms despite robust literature stating that the

development of such symptoms is not simply related to event exposure, but rather to an individual's interpretation and reaction to the event and the presence of additional environmental factors (Braithwait et al., 2017; Cusack et al., 2019; Fletcher et al., 2017).

With consideration of Indigenous-specific health literature, an integrative model of ACE literature within broader experiences of adversity can broaden a relatively small research field. Research completed in partnership with Indigenous populations is relatively minute when compared to the broader availability of health literature, and as Chapter 2 demonstrated, there are even fewer studies that describe ACE specific relationships within Indigenous populations. Creating more research silos is not a useful approach to extrapolate ACE findings to assessment and treatment approaches that can improve tangible health outcomes for Indigenous populations. Rather, an alternative approach, and potential future direction of research not previously mentioned, is to extend current ACE findings to broader literature related to each specific ACE construct. For example, exploring previously established relationships within published literature for each individual ACE concept (i.e., intimate partner violence or parental incarceration) specifically for Indigenous populations could organize current literature in a way that is more useful. Although the social and contextual factors of how ACEs develop or are sustained within populations may differ among Indigenous communities, biological reactions to such experiences are likely the same. Applying neuro-cognitive strategies assessed with non-Indigenous populations, particularly those aimed to regulate biological indicators of stress, can provide initial assessment and treatment consideration for ACEs within Indigenous communities.

Given the disparity of health outcomes for many Indigenous populations in Canada (First Nations Information Governance Centre, 2018), exploring potential preventative and tertiary care models is commonly aligned with research objectives. Many research participants in the current

study reported the utility of results for future generations was a main reason for study participation. Research for the sake of curiosity, although often a motivating factor for scientific inquiry, does not align with community-based participatory frameworks. The nature of Indigenous health research requires timely, innovative, yet evidence-based strategies that communities may wish to use.

### **Conclusion**

This chapter represented a first attempt at conceptualizing how current ACE findings could be extended to emerging psychological assessment approaches with Indigenous populations. Broader recommendations have encouraged the use of measures validated with Indigenous populations (Dingwell & Cairney, 2010), contextualizing test data within broader holistic assessments (Davison et al., 2017), and use of cultural formation interviews, such as the one formulated in the DSM-5 (Aggarwall et al., 2020). The recommendations provided in this chapter have described prospective pathways to future assessment and treatment approaches within these populations for those experiencing increased levels of ACEs. Measuring ACEs authentically remains a preliminary step to generating and prescribing useful treatments addressing such prolonged distress at an individual level, when integrated within other culturally-relevant assessment techniques.

One noticeable gap in this chapter is description of preventative and treatment models of ACEs within Indigenous communities. As present research did not encompass broader situational or contextual factors coinciding with increased ACEs, I did not feel that extending current findings would substantially contribute to existing knowledge at this time. As literature expands, and collective understanding of ACEs broadens, preventive care of ACEs will become a critical direction of research for Indigenous communities. For proposed preventative care for

non-Indigenous communities, see the work of Oral and colleagues (2016), who described parenting programs (Triple-P and the Circle of Security), provision of psychological first aid when events occur, and implementation of broader social programs that strengthen individual and community resilience as preventative care strategies.

Despite twenty years of ACE research combined with even more literature dedicated to trauma-based assessment and treatment, predictive in vivo prevention and treatment models remain elusive. With consolidated and continuous effort shared across disciplines, it will be possible to use the emerging data describing ACEs within Indigenous communities to inform evidence-based treatment models. The effective prevention and treatment of psychological harm from child abuse and neglect can reduce experiences of, and reactions to, adversity for future generations, thus potentially improving overall Indigenous health outcomes.

### **Chapter 5: Client and Staff Experiences of the *First Nations ACE Study***

A long-standing concern within the domain of Indigenous health research is correcting for historical injustices of researching “on” rather than “with” Indigenous communities. Current research practices must adhere to community, institutional, national, and global protocols in place to protect Indigenous rights (see Chapter 6 for a review). Methods that exemplify these guidelines and prioritize collaboration among Indigenous and non-Indigenous perspectives, such as the two-eyed seeing approach (Barlett et al., 2012; Colbourne et al., 2019) have become increasingly popular among those completing research with Indigenous communities. Using Indigenous research methods, including those promoted within community-based research partnerships, can create research practices that generate and share knowledge in a way that is more useful to communities (Drawson et al., 2017).

Although the use of these methods can promote better outcomes for Indigenous participants, research within any community is not without potential risk or harm to an individual. Many low-risk studies require some form of participant burden, whether that is personal time, changing emotional state (such as feeling uncomfortable, bored, or anxious), or physical fatigue (Canadian Institutes of Health Research et al., 2018). No form of research can occur without some form of inherent risk, however small. Within any research endeavor, there is a delicate balance of methods to simultaneously mitigate the potential for such harm, while still completing activities that could benefit the individual, the academic community, and the general population. For Indigenous communities, having representative research that meets their stated needs can improve access to resources, promote health outcomes, and increase overall wellbeing. These community-based participatory approaches can promote knowledge dissemination (Loyd Michener et al., 2012), however these strategies work best when implemented appropriately.

Indigenous individuals continue to experience systemic marginalization and discrimination through historical colonizing practices that aimed to reduce autonomy, health, culture, and wellbeing (TRCC, 2015). Through these experiences, Indigenous populations may be more likely to experience the burdens of participation in research differently than other participants, and could be more vulnerable to experiencing risks of harm. When Indigenous research experiences were compared to those of non-Indigenous participants, Indigenous participants were more likely to report caution with research practices (Guillemin et al., 2016). To mitigate individual burdens of participation, the value of a research project must be higher to justify the presence of risk for all participants in a study, specifically those more likely to be exposed to harm.

Understanding various stakeholder experiences within research processes can help determine how to reduce risk for Indigenous participants. Feelings of wariness or distrust of research do not always dissuade Indigenous participation (Goodman et al., 2018), meaning that there is an ethical obligation for researchers to ensure that participants feel comfortable with research activities. Examining experiences of participation within specific research endeavors can develop methods that better align with community-based research practices.

The purpose of this chapter was to examine both staff and participant experiences within the broader process of the *First Nations ACE* study. By examining the process of research, in addition to outcome data, we can assess the inherent value of the study partially through participant experiences of relation in addition to improving client outcomes. The inherent nature of community-based practices requires researcher flexibility, humility, and often times, humor, across study implementation. Study methods can therefore be implemented inconsistently or need to be adapted to meet the expressed needs of communities in the moment. Community

priorities can shift, and in the spirit of reciprocity, researchers may be required to adapt their roles within the community to meet such needs. Therefore, intentional review of participant and researcher experiences within a study can have particular value, as teams work towards agreed upon best-practices of engaging in research with community partners.

Although the data obtained through the *First Nations ACE Study* is useful to informing treatment approaches, future research will not continue if these procedures are diminishing client experiences within the substance use treatment center. Before funding will be obtained to increase the longevity and scalability of the project, we had three main objectives related to understanding both client and staff experiences to date with the study. Specifically, these objectives were to:

1. Obtain stakeholder feedback throughout the development and implementation of the *First Nations ACE Study*.
2. Develop sustainable data collection procedures that can continuously be implemented by staff, through development of internal research capacity.
3. Describe stakeholder experiences of participating in Indigenous community-based research, including those within the community-organization, including perspectives of best-practices for future research.

### **Study Hypotheses**

It was anticipated that involvement with study processes at the residential substance use treatment facility would be successfully implemented by staff and that study methods would be completed in a respectful and culturally appropriate manner. Although this evaluation was largely exploratory in nature, two formulated hypotheses were:

1. It was expected that staff experiences with the research project would be positive, and staff would report how the project met overall expectations for completing Indigenous-based research.
2. Client participants would report moderate levels of satisfaction with the ACE study process and the ACE informational group.

## **Method**

### **Participants**

Five staff members at the partnering treatment facility associated with the *First Nations ACE Study* agreed to participate in this evaluation. Staff held numerous positions within the treatment center, and included program management, counsellors, and support staff. To be eligible to participate, staff had to be currently or previously employed at the treatment center, and be directly involved in study development or implementation processes on-site. Only one potential participant, a staff member not employed at the center at the time of data collection, did not participate, as they could not be contacted.

### **Measures**

#### ***Client Satisfaction Questionnaire***

Five questions (Appendix E) asked clients to describe their overall experiences with the *First Nations ACE* study. These were two short answer and three likert-type, 5-item response questions. These were added to a general client satisfaction questionnaire completed at the end of each treatment cycle with all clients.

#### ***Qualitative Staff Interview***

Staff described their experiences with the *First Nations ACE Study* through prompts within a semi-structured qualitative interview guide (Appendix F). Questions asked participants

about the process of completing community-based research within the partnership, and how the project met the principals of Indigenous research, such as perceived adherence Ownership, Control, Access, and Possession (OCAP)<sup>TM</sup> (First Nations Information Governance Centre [FNIGC], 2014) principles and Smithers-Graeme's (2013) guiding questions of research within an Indigenous research paradigm.

## **Procedure**

### ***Initial Staff Training and Consultation***

Five counselling staff and program managers met with the research team to review their roles within the study. At this time, they received specific training on how to complete ACE data collection with client participants, modeled from the ACE International Questionnaire Interview Guide (World Health Organization, 2018). A secondary refresher training was completed at the mid-way point of data collection with all counsellors, partially to train staff new to the study, but also to ensure fidelity to the process remained among all counsellors.

Following one month of data collection (and thus a full treatment cycle of participants), six counsellors and program managers who were directly involved with the study were asked to provide feedback to study researchers about the process of data collection. This feedback occurred in focus group with the opportunity for private individual interviews with staff if requested. Interviewers recorded overall perceived impressions of staff related to study implementation, informal participant feedback, and experiences implementing study questionnaires.

### ***Mid-Point Study Staff Interviews***

Individual interviews with consenting staff were completed by a research assistant not previously affiliated with the project, and were recorded and transcribed mid-way through data

collection. Interested staff were provided with a study informational letter (Appendix G) and completed a consent form (Appendix H). These participants were asked to provide insight to developing best practices for engaging in community-based research within their organization, and provided perspectives of how to best collaborate with vulnerable treatment populations.

Data was aggregated, transcribed, and relevant descriptive themes relating to each study question were reported using thematic analysis, as such analyses can consolidate and interpret qualitative participant data in a consistent and replicable manner (Braun & Clark, 2006). Marshall and Rossman's (1999) six stages of thematic analysis were used as a guideline for analyses, as they included both open coding and theme validation. These stages are: data organization, theme generation, coding, testing emergent themes within the data, searching for alternative explanations, and reporting results. The obtained themes were reviewed independently by two student researchers and were returned to staff participants to be validated. Given that results obtained from Indigenous research endeavors must be situated in frameworks that are both relevant and useful for the communities completing studies (Toombs et al., in press), validation of these results remained a necessary step for thematic analyses.

### ***Document Review***

Researchers were provided with de-identified client satisfaction questionnaire data for five questions relating to the *First Nations ACE* study. This questionnaire was provided to all clients at the end of each treatment cycle and was completed anonymously. Clients were asked to complete ACE study-specific questions if they had participated in the study. Initially this data was to be collected from all treatment cycles, but given competing demands of staff, eight cycles (rather than 18) of client satisfaction questionnaire data were provided for review.

A secondary review of participant attrition rates was also completed. As the study was divided in two parts to reduce participant burden, participants completed the second half of questions a few weeks after initial consent. Staff were asked to track how many participants did not complete the second set of study measures, and to document reasons why this occurred.

### **Data Management**

Data management ensured participation remained confidential. Participant names were replaced with ID codes in de-identified datasets. Only de-identified data (e.g., datasets without participant names and with contact information removed) were transferred outside the treatment facility for analysis. All records will be stored for a period of five years past the date of publication. All physical participant documentation, such as signed consent forms and paper participant measures, were stored in a restricted, secure area within the community agency and will remain there for a period of 5 years post-publication. Following this time, records will be destroyed in accordance with current best-practice research recommendations.

Results were presented to counsellors and staff at the treatment centre, in addition to presentations provided to the research advisory group. Feedback of these results was provided by participants and Research Advisory members.

### **Results**

Staff and client experiences were evaluated using a mixed method approach. Staff consultation occurred prior to beginning the study and mid-way through study implementation. Results for these endeavors are analyzed using a qualitative, content-based analysis. Client experiences were analyzed using a descriptive quantitative analysis of client satisfaction questionnaire data and client participation rates across cycles. A qualitative content analysis of

client comments provided on the satisfaction questionnaires was also completed. Results are described below.

### **Initial Staff Consultation**

Staff were asked to provide feedback related to the feasibility and logistics of implementing a large-scale research study within their treatment center prior to study implementation. During the initial consultation with five staff members, study protocols were finalized and developed. Staff were asked to provide input to study hypotheses, and subsequent research queries they would like answered. Most staff ( $n=4$ ) indicated they were favourable of the current research questions, however when one staff member proposed the inclusion of a gambling questionnaire, all staff members agreed. This measure was added to the assessment battery.

All staff members expressed concern to minimize client burden while completing questionnaires. During consultation, staff reviewed the study questionnaires and suggested removal of questions to shorten the duration of the study. Given that some questions overlapped with client treatment intake information, staff suggested data from these forms be mined (with client consent) rather than re-asking questions. Staff also proposed that the study be broken into two portions to reduce participant burden and to integrate the study processes within predetermined blocks of treatment programming.

It was initially expected that counsellors could implement data collection relatively autonomously, with minimal research intervention. Upon review of these procedures with staff, most members expressed hesitation with this approach. They requested a member of the research team be present to explain the study purpose, risks and benefits of participating in research, confidentiality procedures, and to complete consent with interested clients. Research team

members also completed all study organization activities, participant consent, and Time 1 data collection.

### ***Requested Project Deliverables***

Project deliverables for the substance-use treatment program were requested by staff members and included tools for the ongoing program data collection and dissemination documents of study findings. Initially, proposed deliverables were related to tools that could increase staff capacity to complete research autonomously. These deliverables included a program evaluation manual that described how to complete ongoing data collection and analysis for staff, and data management tools (including a spreadsheet and training tool for how to input data). Upon consultation, staff requested increased researcher support, and had low interest for ongoing data collection following completion of the study without support from the research team. As a result, study resources were directed to requested supports and services for staff members following consultation. A grant was written to continue the project long-term and fund ongoing research activities for staff. Additional requested deliverables were:

**1. Providing an ACE Informational Group.** Staff members requested that clients receive general information about ACEs regardless of participation in the ACE study. As a result, on week three of each treatment cycle, a psychoeducational group was provided by student researchers to all clients. This group described ACEs and drew associations between health outcomes and ACE scores. It used a strength-based approach to provide material related to resilience, protective factors, parenting, and areas of intervention to reduce longitudinal effects of ACEs across a lifespan. Group materials for the psychoeducational ACE group were created and shared with treatment center staff.

**2. Individual Client Reports.** Data from Time 1 measures were initially analyzed and summary scores related to substance use motives and personality risk profiles related to substance use. Reports describing this participant data were generated in the first week of each treatment cycle and shared with counselling staff for treatment purposes. Counsellors indicated these reports increased the clinical relevance of the information collected and analyzed in the study.

**3. Organizational Treatment Cycle Reports.** Up to date data for each treatment cycle was requested by staff to assist with program planning. Following the end of each treatment cycle, participant data related to demographics, mean ACE score, substances used, previous treatment histories, and measures of mental health (including previous diagnoses, executive functioning, and post-traumatic symptoms) was aggregated and combined with all other study results to date. A community report from these findings will be drafted for the broader health organization and research advisory.

**4. Organizational Presentations.** A slideshow containing information about the study, results, and future directions of research was created and shared with the Research Advisory. Future presentations by student researchers will occur as requested by organizational leadership.

**5. Additional Dissemination Tools.** Research outcomes will be shared with clients in a plain language, one-page infographic. Any additional dissemination techniques requested by the Research Advisory, including brochures, posters, web-based info-graphics shared on the organization website will continue to be completed as requested.

### **Descriptive Analysis of Staff Research Experiences (Mid-Point Interviews)**

Staff interviews completed approximately half-way through data collection were focused on three distinct areas of inquiry: 1) staff perceptions of the study, including benefits or risks to

clients, 2) proposed modifications to the study to potentially improve outcomes for participants, and 3) broader experiences of the community-based research approach. Content analysis of each of these topics is described below.

### ***1. Staff Experiences with Research***

Some staff members ( $n= 3$ ) indicated it was their first time involved with a research study. Despite level of experience with research, many staff indicated learning about research, specifically about research processes in general, the role of research ethics boards, research jargon and language use, and more about the study topic and ACEs. All staff indicated they would be involved in the study again, although when asked if they could implement the study autonomously, without the assistance of a research team, all staff said no. The most common reason given for this answer was a lack of time required to implement a study of this size. In the current form, with the assistance of the research team, most staff members ( $n= 4$ ) reported the study did not add to their workload. One staff member reported that there was an initial increase in workload at the beginning of the study, however that dissipated over time.

Staff were asked if the study has been beneficial to them or their work at the treatment center. All staff indicated the research results would be beneficial in some way to clients and to ongoing treatment processes (Table 28). Content analysis of these transcribed interviews described four direct benefits of the study, as reported by staff. These benefits were:

- 1) increased staff understanding of clients' needs,
- 2) increased client understanding of individual needs,
- 3) targeted discussion of trauma with clients, and
- 4) potential use of data to obtain future funding.

**Table 28***Reported Benefits of the ACE Study by Staff*

Content Theme	Count	Representative Comment
1. Documentation of clients' needs	5	"I think it will give um, some understanding of, just how much the clients we see here, just how much they've experienced, and it will, it will validate what clients have been saying for a long time, it will just give that kind of academic understanding of it."
2. Increased client understanding of their needs	4	"It gives clients more knowledge and more literacy around their own experiences, so it helps them name some of the things that they've gone through or going through."
3. Targeted discussion with clients	4	"It kind of opened up avenues for some discussions, I would say. Well, talking about some of the past trauma, sometimes, some of the clients have a lot of difficulty starting that discussion..."
4. Use of data to obtain future funding	2	"I think it will be useful for staff in the sense that this, the data collected, and from the study, will maybe provide more opportunities for grant writing and things like that."

Staff members indicated that one benefit of the research study was to document the prevalence of client experiences of trauma. Many staff reported they were aware of higher than average experiences of childhood trauma with their clients. As one staff member stated, "There is an understanding that the clients we work with are most likely going to have higher scores than potentially other populations right?". Although staff displayed a good understanding of general client needs, one staff member expressed, "We all knew the scores were going to be high, but it was higher than expected. So that was interesting." It seemed despite a general knowledge of population needs within substance use treatment, the specific statistics were informative for staff members at this treatment center.

A benefit to calculation and documentation of client experiences of trauma was related to improved staff and broader academic understanding of ACEs within Indigenous populations, including the potential to use these data for future grants or funding. Documentation of client experiences was also helpful for staff treatment planning and support for clients. For example, a staff member reported, “I think it would just give staff a better idea on just the clientele that we’re working with, and if they have a higher score, you know, that there’s gonna be more, that the clients will have more needs.”

Staff found that implementing the study increased the focus on trauma-symptoms within general treatment for clients. This was reported to be both beneficial and detrimental to client experiences with the *First Nations ACE Study*. Direct client benefits were related to increasing their own understanding of precipitating factors to substance use, as stated by one staff member for clinical work related to, “kind of diving a little further into um, a client’s history based on their score, and trying to gain a better understanding of their score, and where those scores came from.” Another staff stated, “it’s kind of a validation in terms of, a lot of clients come here and they don’t have a rhyme or reason why they went down a certain path, and I think that it is a way to validate that you have had trials and tribulations throughout your life that may have led to”. Staff who implemented study measures that asked about ACEs to clients reported that the study facilitated natural discussion about trauma, which could be therapeutic for some clients to understand the relationships between early childhood experiences and substance use. It was reported that some clients found the focus on trauma to be unrelated or even detrimental to their substance use treatment. One staff member reported, “so a few of the clients have mentioned it’s kind of triggering. I had one client actually last cycle um, who actually stormed out of one of the groups.”

## ***2. Changes to Research Process***

Staff were asked what they would like to see modified prior to future implementation of the First Nations ACE study. Three changes were reported by staff members:

1. Increased relationship building with clients prior to research ( $n= 1$ )
2. Modification of language and research jargon ( $n= 4$ )
3. Provision of follow up resources following the study ( $n= 2$ ).

Initial introduction to the study began on day three of treatment with research assistants reviewing the study process, obtaining consent from interested clients, and completing one set of study measures. One staff member felt that clients would be more comfortable with the research process, and the study in general, if clients had developed better relationships with the research assistants prior to the study. One strategy to do this was provided, “even just one extra kind of hour or so, the week prior, come in and say, yeah, this is who we are, yeah, we’re going to be doing this study, let’s have some fun today. You know and kind of just break that ice with them first.” The development of working relationships was expressed to reduce initial hesitation with the study or with researchers.

Staff members ( $n= 4$ ) reported that changing the language used within client documentation describing research study improved the accessibility of the study to clients. Technical jargon used to describe study activities to meet requirements for REB review was modified and re-written in plain language. Changes to language within study questionnaires and how the study was described to clients were proposed by staff. This was described by one staff member as “some of the language around “study” and some of the more clinical terminologies, clients weren’t that receptive to.” Although this wording was useful to convey study intentions for REB review, it was reported to be initially confusing to potential participants. When the

suggested language changes to reduce jargon were implemented after the first cycle of participants, staff reported client concerns were diminished. Despite these changes, staff indicated that more changes are required for future studies. The information sessions used to describe the study processes were not clear to all clients, as one staff member stated, “Some clients don’t have that understanding of what research like this does, even following the information sessions.” A staff member noted that the level of language can influence client understanding of questionnaires, “I think also education is something to take into consideration, um, in terms of kind of literacy, and comprehension, and understanding, because we want to be sure that when we are asking these questions they are understanding the questions we are asking them right?”.

Staff also suggested that researchers within the study could provide some follow up resources and programming following participant completion of the study, particularly for those who voiced an interest in addressing trauma symptoms. Although after-care is provided to clients following treatment discharge, it was proposed that researchers could provide increased opportunities for psychoeducation of trauma symptoms and increased client-care. Increased informational groups were requested, including those that use a strength-based approach to emphasize individual resilience of participants and build upon current pro-social skills. This was proposed to be a way for clients to receive more information about study results, ACEs in general, and their individual results if interested.

### ***3. Utility of a Community Based Research Approach***

Staff emphasized that implementation of this study required a flexible approach that was adapted through continuous solicitation of feedback from both clients and staff members. As one staff member stated, “we’re kind of learning as we go throughout this study.” This was

recognized as a multi-faceted approach, described as, “having that ongoing communication, and dialogue, and meeting, and going through what’s working and what’s not working, I think. And getting feedback from the clients too.” The adaptability, open-mindedness, collaboration, and willingness to make changes following feedback was reported as a strength of the research design and the researchers. The bi-directional sharing of knowledge between staff and researchers, often related to the logistics of implementation, was reported to be helpful. Staff did not report any concerns with the research approach, nor with the research team implementing the study.

All staff described aspects of the project that were aligned with client-centered and Indigenous ways of knowing. They identified that knowledge of Indigenous histories, inclusion of cultural variances in healing or approaches to trauma, recognition of intergenerational trauma or residential school histories, and sensitivity to individual clients’ needs were all required for a study to adequately reflect these goals. Staff reported that the current study aligned with broader values of Indigenous mental health within the partnering organization, and felt that, overall, results could be beneficial to improving broader Indigenous health outcomes.

### **Descriptive Analysis of Client Research Experiences**

Descriptive statistics of 74 client satisfaction questionnaires were completed from three questions asking about their reported helpfulness of the informational ACE group, perceived quality of the ACE study, and if participants were interested in future research studies following their experience in the current study. For those participants who rated the ACE informational group ( $n=74$ ), 9 (12.2%) reported the group not at all or not so helpful, 32 (43.2%) indicated it was somewhat helpful, and 33 (44.6%) indicated the group was very or extremely helpful. Of

the 27 participants who provided comments regarding the ACE group, a content analysis derived six themes, described in Table 29.

Most participants described the study as a neutral experience ( $n= 39$ ; 55.7%), while 31 participants (44.3%), rated their experience as high or very high quality. Four participants did not participate in this question, and no participants indicated a low-quality experience. Of 69 participants, 16 (23.2%) indicated they were not at all or not so interested in participating in future research, 25 (36.2%) indicated they were somewhat interested, and 28 (40.6%) indicated they were very or extremely interested in participating in future research. Table 30 describes 5 content themes from 24 clients who provided comments about their experience with the ACE study.

**Table 29**

*Content Themes from Client Comments of ACE Psychoeducational Group*

Content Theme	Count	Representative Comment
1. Informative or Interesting	7	“Very knowledgeable students, interesting.”
2. Enjoyed Content/Process	8	“I liked the open discussions style of the group.”
3. Dislike of Group Content	4	“I didn’t like becoming aware of my underlying problems in life that lead to my addiction.”
4. Dislike of Group Structure	3	“Unclear instructions.”
5. Neutral	3	“It was ok, nothing stands out.”
6. Specific Suggestions	2	1. Need more depth (in content) 2. Include more content about systemic violence and intergenerational trauma

**Table 30**

*Content Themes from Client Comments of ACE Study Process*

Content Theme	Count	Representative Comment
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1. Enjoyed Helping Others	4	“That I will be part of a research I believe in that could help other people.”
2. Enjoyed Content/Process	5	“I liked the open discussions on topics that most wouldn’t feel comfortable with.”
3. Dislike of Research Topic	4	“It has been heavy.”
4. Dislike of Research Process	8	“We can’t get the results for years.”
5. Neutral	3	“It was just a survey.”

### Client Participation Rates

A review of attrition rates within the *First Nations ACE Study* revealed that of 216 clients across 12 treatment cycles, 141 consented to participate in the study and completed the first set of questionnaires. Among these participants, 71 completed the second set of questionnaires. Table 31 describes the documented reasons of participant attrition and percent of measures not completed due to competing staff demands or error. Participants who did and did not complete Time 2 questionnaires due to early termination of treatment or to personal refusal were compared using chi-squared tests and independent *t* tests. No statistical differences with respect to Indigenous identity, age, or sex were found among those who completed Time 2 questionnaires and those who did not.

**Table 31**

*Participant Attrition in the First Nations ACE Study*

Participant Tracking	Count (%)
Total consented sample	141 (100 %)
Completion of all measures	71 (50.4%)
All measures not completed due to competing staff demands	19 (13.5%)
Participant attrition	27 (19.1%)
Client Early Treatment Termination	15

Client refusal to complete Time 2 measures	10
Other	2
Early Termination of Treatment due to COVID-19	16 (11.3%)
Unknown	8 (5.7%)

### Discussion

This study described staff and client experiences completing a research study of early childhood experiences and health outcomes for Indigenous people seeking treatment for substance use. Overall, results of this study found that both staff and client experiences with the study were generally positive, thus supporting both study hypotheses. Staff reported positive experiences participating as stakeholders within a research study and reported that, generally, such approaches did not add to their workload. Staff described many potential benefits of study implementation at their treatment center, including increased client understanding of the relationships between substance use and trauma, documentation of study results to inform future programming, and the use of data to apply for future funding.

An initial concern of staff members was related to REB requirements relating to the specific policies and practices required to implement this study. Staff felt that the language used in initial study informational letters to participants and subsequent consent forms was not accessible to their client population. This tension is commonly reported by community-based researchers, as they strive to balance institutional and community needs within research practices (Wilson et al., 2018). Similar concerns with language use have been reported in other patient-oriented research and community-based research studies, with authors reporting amendments to research-specific language were required to encourage study participation (Tremblay et al., 2020). Further, use scientific jargon within CPBR protocols can reduce capacity of researchers to

communicate project goals, merits, and risks to participants and communities, and may deter engagement of potential community-based partners and in individual's capacity to provide informed consent (Fitzpatrick et al., 2016; Sjöberg et al., 2018).

The majority of clients also indicated either ambivalence or a positive experience with the research study. This finding is notable, as there has been some debate about how the collection of ACE data is perceived by participants. Some propose that disclosing trauma within a health setting could harm individuals (Yeater & Miller, 2014), however our findings support findings that most participants do not report discomfort (Jaffe et al., 2016; Mersky et al., 2019). One participant in our terminated study participation due to distress of study measures, and as per our research protocols, was supported to inform a representative of the university research ethics board. Minor modifications to the study were made, and the study resumed within two days. It is possible that study processes mitigated short-term participant stress related to some measures inquiring about potential adversity and negative life events. When this occurred, participants had access to a trained mental health professional, with whom they had ongoing therapeutic relationships, through the course of the residential program, including during study participation. Future endeavors will continue to explore how client exposure to their own traumatic experiences, particularly through mapping exercises encouraging personal reflection of life events, can be implemented within the treatment setting. As many clients reported understanding the relationship between trauma and substance use can be helpful, and such endeavors are supported by clinical research, the way in which these strategies are implemented is continuing to be explored.

Previous research has indicated that even when participants have reported experiencing distress completing trauma questionnaires, they reported overall research participation as a

positive experience (Jaffe et al., 2016). It is possible that, for some clients, experiencing mild to moderate distress of divulging trauma in a clinical setting may be outweighed by altruistic motivation related to the potential benefit of research to others. Prior literature has compared reasons for research participation among Indigenous and non-Indigenous participants (Guillemin et al., 2016). Indigenous participants more frequently reported they engaged with research to potentially benefit their communities, whereas non-Indigenous participants did so primarily for self-interest in the research topic. These results are reflective of self-reported client experiences with the research as generally, despite some reported dissatisfaction with the research process.

### **Future Directions**

Future analyses will also include broader mixed-method approaches, including completing individual interviews with a selection of participants completing the study. Although generalized participant distress was low during ACE assessment, understanding specific indicators of distress within the client population is warranted. Asking clients to self-report these indicators of distress, rather than having staff describe them, would be beneficial. Although we asked staff members to provide potential hypotheses or research objectives to be included in the study, we did not ask clients for input. Direct consultation with interested participants, perhaps through the development of a secondary research advisory, could provide feedback exploring facets of ACE research most interesting to participants.

All staff suggestions will be implemented in future iterations of this study. The process of disseminating results to participants will also be modified to address participant sources of dissatisfaction with the study. By providing more psychoeducational groups on a range of topics, including a group that describes results to date, participants can be informed of the study results more quickly. Additional therapeutic programming options, offered in the spirit of research

reciprocity, will also be explored and implemented. These include opportunities for individual feedback sessions of client individual results and the opportunity for on-site, evidence-based treatment of trauma. Although reports are currently provided to counsellors to review as desired with clients, providing these in a structured way by clinical research staff may be useful. Such endeavors may offer increased clinical care as a result of community-based research and attempt to address concerns of “being researched to death” with limited benefit (Bainbridge et al., 2015) within Indigenous communities and provide tangible clinical benefits for staff and clients. Bridge funding continues to support study activities for the next year and additional funding is being sought to promote future research directions.

### **Conclusion**

This study highlighted the use of a community-based participatory approach that emphasized Kirkness and Barnhardt’s (1991) four “R’s” of research, including reciprocity, respect, relationship-building, and responsibility of researchers. Continuous solicitation of stakeholder feedback at all aspects of the project can provide opportunities to amend study processes to better improve participant experiences. In this study, both client and staff experiences of community-based research assessing ACEs within Indigenous individuals in a residential treatment facility were generally positive. There were few modifications proposed to research processes prior to re-implementing the study, however future research will explore qualitative experiences of clients in the study in more detail. By understanding experiences of research from all stakeholder perspectives, we can generate better processes that simultaneously provide useful results and maximize participant benefit.

### **Chapter 6: Final Reflections on the Use of a Community-Based Participatory Approach<sup>3</sup>**

This chapter will describe my reflections of our community-based research approach, including specific research actions and how they aligned with broader Indigenous values. To best understand how our method exemplified Indigenous approaches to research, I completed a scoping review of 26 Indigenous-research guidelines. These recommendations were synthesized into a well-known framework of First Nations values used within communities in our region, the seven grandfathers' teachings. Principles within each guideline were organized in such a way to reflect each teaching and used to exemplify actions within our research approach. Personal reflexivity can be supported through authentic documentation of study processes and relating individual actions to a broader framework of Indigenous values.

#### **A Synthesis of Indigenous Community-Based Participatory Research Frameworks**

Embarking on research with Indigenous communities, particularly as a non-Indigenous researcher, requires careful consideration of research practices, relationships, and adherence to specific community-based research approaches. Previous reflections completing community-based research with Indigenous communities have described how such endeavors align with Indigenous frameworks of knowledge (Toombs et al., 2019). Through consciousness application of a two-eyed seeing approach that reflected both Indigenous and non-Indigenous ways (Barlett et al., 2012), data from a community-based qualitative study was adapted to better align with an Indigenous-specific framework of mental, emotional, spiritual, and physical wellbeing. These practices can improve the usefulness of data for Indigenous research partners, as data is aligned

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<sup>3</sup> Ms. Toombs extends thanks to Ms. Abbey Radford and Ms. Lauren Kushner for their assistance with completing database searches for this scoping review.

in a way that facilitates both understanding and dissemination of results and ultimately, may increase the clinical utility of research within communities.

Researcher reflections are often not considered to be a required step when adhering to a scientific method, however, within research completed with Indigenous research, such practices are often necessary. With a long-standing history of exploitative research within Indigenous communities, many frameworks have been generated to guide research practices to promote ethical, self-governed, culturally-appropriate research. This chapter will review previous research frameworks related to completing Indigenous health research and provide a descriptive synthesis of key considerations embodied across these frameworks. The synthesized values shared by these guidelines will be used to describe the community-based research approach embodied within the current study. Descriptions of the research process and key considerations will be presented through a value-based framework that aligns with Anishinabek communities within the Robinson Superior Treaty area, as these populations are most representative within our study samples.

Community-based participatory research (CBPR) with Indigenous communities remains subjective by region, community, and individual. Research objectives vary greatly by community, as chosen approaches must meet community needs. Therefore, many CBPR guidelines emphasize flexibility of approaches that tailor methods to meet community needs. Israel and colleagues (1998) have identified eight principles of CBPR to guide general processes. These principles include recognition of community identity, strengths, and resources, facilitating collaborative and mutually beneficial processes, integrating knowledge, addressing health in multiple ways, and disseminating knowledge to all partners (Israel, Schulz, Parker, & Becker, 1998). Although these were conceptualized for generalized CBPR, and not for methods that

specifically pertain to Indigenous communities, many of these values are reflected in guidelines for Indigenous research.

Using frameworks to guide community-based research has demonstrated success when completing research activities with under-represented or potentially vulnerable populations (Kwon et al., 2018). The perceived utility of some frameworks has resulted in compulsory implementation of such guidelines by researchers seeking funding, such as those mandated by the Canadian Interagency Advisory Panel on Research Ethics (2018) *Chapter 9: Research Involving the First Nations, Inuit, and Métis Peoples of Canada*. These frameworks can generate a shared understanding of cultural values associated with research activities with specific populations, often defined and documented by members of the populations for which such methods are intended.

Research protocols can differ by individual, community, and region, and therefore culturally-appropriate research processes in one area may not be applicable to another community. Many Indigenous frameworks have proposed recommendations related to research practices, ethical considerations, partnership development, and research dissemination specific to regional requirements. It is likely that many Indigenous frameworks can share commonalities across community protocols. Some frameworks have emphasized the dynamic nature of proposed recommendations and have suggested that ongoing modifications occur as community-based partnerships and expectations evolve. As specific frameworks continue to develop to meet community specifications, it is likely that the values such work represents are shared among various Indigenous community-based participatory standards.

Identification of shared values among Indigenous research frameworks can be beneficial to improving research with Indigenous communities. The heterogeneity of Indigenous research

methods (Drawson et al., 2017) means that frameworks must be flexible to be generalizable across study protocols, but still prescriptive in nature to ensure such methods remain ethical. Documentation of processes facilitates ongoing dialogue regarding community needs, and provides opportunities for collaboration among research stakeholders. The development and implementation of these processes can be supported through the development of Indigenous research ethics boards (Tauri, 2018). Guidelines can facilitate ongoing evaluation of research approaches by communities, researchers, and partnering institutions (including research ethics boards and funding agencies), to ensure proposed research meets community-determined standards. Comparing guidelines can provide a shared understanding of Indigenous-research across disciplines and can help refine the utility of implementing such standards within communities.

To identify shared commonalities across research frameworks, a scoping review of Indigenous research frameworks was completed between January 12 and April 15, 2020. The goal of this review was to synthesize shared commonalities among the retrieved frameworks, to provide a means of comparison for our method used in the current study. The adoption of shared research values can be used to determine how current study methods specifically align with cultural values of research.

### **Scoping Review Method**

A scoping review of six databases (EBSCO, ERIC via Proquest, Proquest, PsycArticles, PsycInfo, and Science Direct) in addition to Google Scholar searches and reference list reviews retrieved 26 Indigenous-specific research frameworks that outlined values or principles related to implementation of Indigenous research<sup>4</sup>. Appendix I presents a PRISMA

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<sup>4</sup> Keyword for this scoping review were: "Indigenous" OR "Aboriginal" OR "Inuit" OR "first nation\*" OR "Métis" OR "Native" AND "research guideline\*" OR "research principles" OR "research ethics" OR "research policy".

diagram of searches. Frameworks were included in this review if they were available in English, were specific to completing research with an Indigenous population, and were published after the year 2000. Appendix J describes a synthesis table of scoping review results.

### Scoping Review Results

When synthesized values within these Indigenous-based guidelines were translated into eight themes (Table 32), including six sub-themes embedded within these categories. Guidelines about specific actions within the research processes were analyzed separately, resulting in four general categorical themes and five sub-themes (Table 33).

**Table 32**

*Derived Themes from Synthesis of Retrieved Research Guidelines*

Theme ( <i>n</i> =guidelines endorsing theme)	Description	Relevant Sub-themes
1. Benefit to Community ( <i>n</i> = 15)	Benefit to Indigenous communities, related capacity building, relevance of results for communities, generating useful results, and completing ideas generated by community.	Local needs as first priority ( <i>n</i> = 5)
2. Respect ( <i>n</i> = 13)	Respect for culture, community history, diversity, authority structures, community customs and codes of practice, local laws, governance, individual dignity, and relationships.	
3. Reciprocal Relationships ( <i>n</i> = 11)	Relationships that facilitate partnership through community engagement, sharing of community knowledge and skills, and development of shared meaningful relationships and mutual benefit.	Good Relationships ( <i>n</i> = 4)
4. Recognize Diversity ( <i>n</i> = 11)	Recognizing individual differences, tribal diversities, distinct histories and heritages, diversity of interests, and various authority structures in region.	Knowledge of region ( <i>n</i> = 3)

5. Embed Indigenous Culture ( <i>n</i> = 10)	Incorporation of Indigenous knowledge and ways of knowing through sharing of traditional knowledge, inclusion of Elders, respecting and protecting Indigenous practices, complete through use of Indigenous values and cultural competency.	Knowing heritage/ history ( <i>n</i> = 5)
6. Autonomous, Active Participation ( <i>n</i> = 10)	Indigenous communities have an inherent right to be invited and actively involved in all steps of the research process, and research must reflect increased Indigenous control, empowerment, capacity-building, and self-determination.	Community control ( <i>n</i> = 4)
7. Consultation ( <i>n</i> = 9)	Ongoing engagement and consultation with community through a mutual understanding of risks and benefits of research.	
8. Authenticity ( <i>n</i> = 7)	There is a responsibility of the researcher to “do good,” be accountable to research agreements, building trust, and fulfilling obligations through authentic practices and actions.	

**Table 33**

*Synthesis of Research Guidelines relating to Research Process*

Research Step	Description	Sub-theme
1. Research Ethics Board Review ( <i>n</i> = 5)	Use of a set research agreement, including one that adheres to appropriate ethical standards within the community. Complete REB review when required.	
2. Method Selection ( <i>n</i> = 7)	Research processes that encourage authentic consent, address confidentiality and privacy concerns, use flexible methods, adhere to appropriate timelines, interpret data within a cultural context, increase self-awareness of subjectivity, are accountable, and provide summaries in local languages.	A. Consent ( <i>n</i> = 5) B. Method Flexibility ( <i>n</i> = 3)

3. Data Interpretation ( <i>n</i> = 11)	Indigenous ownership of data, including results, access to data, and control of how it is shared is prioritized. When analyzing data, researchers should recognize their subjectivity and use a reflexive approach during interpretation. Data should be protected and used with community consent.	A. Reflexivity in Analysis ( <i>n</i> = 4) B. Access to Data ( <i>n</i> = 3) C. Protection ( <i>n</i> = 3)
4. Publication ( <i>n</i> = 8)	All knowledge dissemination should be made with community consent, collaborative, in appropriate languages, and recognize appropriate contributions of all stakeholders.	Language use ( <i>n</i> = 3)

Of the retrieved frameworks, most were specifically for Indigenous populations in Canada (*n*= 11), while fewer were retrieved for populations living in Australia (*n*= 4), the United States of America (*n*= 3), or New Zealand (*n*= 1). Seven studies did not specify location of relevance. For most of these countries (Australia, Canada, and New Zealand), there were regulated national guidelines retrieved to which all researchers within the country are expected to adhere (Australian Institute of Aboriginal and Torres Strait Islander Studies; 2012; Canadian Interagency Advisory Panel on Research Ethics, 2018; First Nations Information Governance Centre, 2014; Health Research Council of New Zealand, 2014). In the United States, there were no specific guidelines retrieved that related to national oversight of Indigenous research, despite increased calls to action for an updated research approach of the Belmont Report (Friesen, Kearns, Redman, & Caplan, 2017; Parker et al. 2019). Eight guidelines were community or region specific (Association of Canadian Universities for Northern Studies, 2003; Inuit Tuttarvingat, 2010; ITK & NRI, 2006; Jamieson et al., 2012; National Health and Medical Research Council, 2003; Noojmowin Teg Health Centre, 2003; Ontario Federation of Indian

Friendship Centres, 2012; Parker et al., 2019), while the remainder ( $n= 14$ ) were either proposed by individual researchers or were more generalist approaches.

### **Discussion**

This scoping review synthesized values exemplified within research guidelines pertaining to Indigenous populations. Themes were listed by the count of guidelines described in this review to facilitate ease of comparison, however this synthesis may not necessarily reflect the relevance or priority of values within specific communities. Within the retrieved guidelines, most emphasized ( $n= 15$ ; 57.7% of retrieved guidelines) that research must directly benefit the community in which it occurs, research activities must be completed with respect ( $n= 11$ ; 50% of retrieved guidelines), must involve reciprocal relationships ( $n= 11$ ; 42.3% of retrieved guidelines), and recognize diversity ( $n= 11$ ; 42.3% of retrieved guidelines).

Among these reviewed guidelines, most suggest the prescribed values are applied well before research activities commence. The inherent necessity of these approaches, implemented with oversight of institutional research ethics boards mandated and guided by federal research organizations such as the Canadian Interagency Advisory Panel on Research Ethics (2018) Chapter 9, further reinforce researcher adherence. The implementation of these regulations varies broadly by researcher and communities. Often, the specific details of these approaches are not described, and many frameworks emphasize that proposed actions are not a checklist, but rather a guideline to research activities. It is recognized that simply knowing research principals is not enough to ensure compliance or participant safety (Morton Ninomiya, 2017). Rather, completing the proposed activities (ex: informed consent or Indigenous ownership of data) disingenuously or half-heartedly would not be considered compliance with the guidelines.

Despite the many guidelines retrieved in this review, minimal published literature has described how such frameworks are implemented within in vivo research settings. Of those that have been identified, most describe research completed within successful partnerships and with expected successful results. Although these continue to be favourable contributions to broader literature relevant to Indigenous people, examination of both project strengths and weaknesses can build research partnerships and projects in a manner that reflects community best-practices. The nature of Indigenous health research within academia can reflect a similar “file-drawer” problem within many other scientific disciplines, where only successful Indigenous-community based partnerships are touted within current published literature. Although many communities do not seek to publish work outside of their region, the majority of projects that are published in academic literature depict positive results and describe collaborative community-based partnerships. This is encouraging for ethical Indigenous-based approaches, however may reflect a gap in current literature. Minor difficulties and delays are inevitable within any research project, and there remains a notable absence of these conversations within CBPR literature describing research with Indigenous communities.

No guideline or research framework can prescribe authentic researcher intentions when completing Indigenous-specific research within Indigenous communities, however there is an immense number of guidelines that focus on relational aspects of research rather than scientific methodology. This can make scientific replication of Indigenous research challenging, as initial research processes that reflect these values are completed informally across multiple settings and in ways that are natural fit with research personality and community. For example, Castleden and colleagues (2012) description of community-based participatory research within Indigenous communities described researcher perspectives of geographers completing work with Indigenous

communities. This seminal article described how respect, relevance, reciprocity, and responsibility were embedded within research processes. As stated in the title, by one participant, one “spent the first year drinking tea” to begin research with Indigenous communities (Castleden et al., 2012).

How these values are upheld is based on researcher judgement and is reported inconsistently across contexts. This is similar to other scientific processes across research domains related to processes that are mandatory for implementation of research processes, but not necessarily included in descriptions of methods. For example, washing hands prior to beginning a procedure or keeping food out of a laboratory would not typically be recorded in the method section of a manuscript. Although these types of details are necessary for the study to occur, they are not considered relevant in the general protocol, however these actions are assumed to occur. Within Indigenous health research, the inclusion of these details becomes particularly relevant when describing study research methods given the history of injustices by scientists completing research *on* rather than *with* Indigenous communities. The requirement of adherence to specific protocols Indigenous is widely accepted among REBs and Indigenous community governance, yet the documentation of specific actions related to this process is inconsistent.

It seems that when the necessary relational approaches used within Indigenous research do not align with traditional scientific reporting methods, these methods are not included in manuscripts, reports, academic posters, or documentation of results. The omittance of these methods can undermine key processes within the study related to relationship building and respect, reduce potential replication of results, and could reflect the idea that such informal approaches do not have equivalent academic merit. The use of two-eyed seeing approaches

dictates that multiple forms of knowledge are considered, resulting in distinct methods to incorporate various ways of knowing.

Including specific descriptions of study methods can increase transparency by researchers and encourage them to be held accountable to standard used. The inherent nature of Indigenous research guidelines is that they remain flexible to allow them to be adopted to specific community needs. Although useful, the nature of these guidelines can be broadly interpreted based on personal values or experience. Personal values related to “respectful research practices”, “culturally-safe”, or “power-sharing” embedded within the retrieved guidelines remain broadly interpretable. Understanding the specific nature of these processes and thoughtfully describing how broad frameworks were implemented could therefore improve future research activities.

The operationalization of research practices therefore remains at the liberty of individual researchers, with few steps in place to ensure accountability. This system can be appropriate if researchers are well intentioned and equivalently well trained, however for those unfamiliar with Indigenous research may struggle to adhere to appropriate standards. There is an extensive history of malicious and harmful research with Indigenous communities, including intentional starvation and neglect in attempts to understand treatment of nutritional deficits at residential schools in Canada. Despite the Nuremberg Code being established in 1947 following highly publicized criminal trials against Nazi doctors and researchers for human medical experimentation, these nutritional experiments persisted until 1952 (MacDonald et al., 2014). To reconcile for this history, researchers must continuously be held accountable to community-determined codes of conduct to ensure that best-practices that prioritize the wellbeing of Indigenous participants ahead of research priorities. To do so, documentation of appropriate

research practices continues to be required and can inform future method development and implementation.

### **Seven Grandfathers' Teachings as a Model for CBPR**

The seven Grandfathers' Teachings have guided the development of values, morals, and beliefs associated with "the good life", partially related to living life in a way that best promotes well-being through a specialized worldview held by Anishinaabe people (Debassige, 2010). Despite guiding pro-social beliefs within Indigenous communities, these teachings were notably absent within the current scoping review of Indigenous research methods. Many CBPR principles and guidelines have dictated prescriptive protocols of researchers, rather than a focus on value-based approaches. Authentic CBPR within First Nations communities in the Robinson Superior Treaty Area can be related to genuine adherence to traditional beliefs and values held by communities within this region. Within the scope of this chapter, we cannot (and should not) convey community-specific spiritual or cultural meanings of these teachings. Rather, we have used this framework to further synthesize themes from our scoping review of Indigenous research guidelines (Table 34). Many actions and guidelines can be embodied by multiple teachings, as such values occur in conjunction with other teachings within the broader context of the research. For example, it would be challenging to reflect Truth without Love, or Respect without Humility. Many actions taken by a research team can reflect multiple values and can therefore be associated with multiple categories. To reduce repetition, each theme was only listed in one category.

**Table 34***Scoping Review Themes Organized by Grandfather Teaching*

Grandfather Teaching	Themes from Synthesized Frameworks
Humility (Dabaadendiziwin)	<ul style="list-style-type: none"> <li>- Local Needs as First Priority</li> <li>- Community control</li> <li>- Consultation and Engagement with Community</li> </ul>
Bravery (Aakwa'ode'ewin)	<ul style="list-style-type: none"> <li>- Research Ethics Board Review</li> <li>- Method Flexibility</li> <li>- Autonomous, Active Participation</li> </ul>
Honesty (Gwekwaadziwin)	<ul style="list-style-type: none"> <li>- Access to data</li> <li>- Adhering to consent</li> <li>- Protection of data</li> <li>- Appropriate knowledge sharing</li> </ul>
Wisdom (Nbwaakaawin)	<ul style="list-style-type: none"> <li>- Recognize Diversity</li> <li>- Knowledge of region</li> <li>- Embed Indigenous Culture</li> <li>- Knowing heritage/ history</li> </ul>
Truth (Debwewin)	<ul style="list-style-type: none"> <li>- Authenticity</li> <li>- Reflexivity in Analysis</li> </ul>
Respect (Mnaadendimowin)	<ul style="list-style-type: none"> <li>- Reciprocal Relationships</li> <li>- Respect</li> </ul>
Love (Zaagidwin)	<ul style="list-style-type: none"> <li>- Good Relationships</li> <li>- Benefit to Community</li> </ul>

The themes retrieved in our scoping review of Indigenous research guidelines were used to show how Grandfathers' teachings could be applied to a research setting. This organizational framework was used to reflect actions within the current research project, including community-based research approaches. The specific themes affiliated with researcher actions, as organized

by teaching, are described in Appendix K. The values embodied in these teachings reflect authentic CBPR approaches, including relationship-building and successful implementation of research methods.

### ***Humility***

Stakeholders approached this project with a range of diverse backgrounds. The collective team experiences related to Indigenous mental wellbeing, trauma, addiction, and child development were drawn from lived experience and professional roles, such as through program development and management, clinical practices (including mental health and addictions counselling and clinical psychology), cultural mentorship, and research. Team members obtained expertise through a multitude of training experiences, and subsequently, educational attainment among stakeholders ranged from those who did not complete high school to those who had obtained a doctoral degree. Expertise in subject matter, regardless of educational attainment or professional distinction, did not influence credibility or control of the research. Rather, the research prioritized communities rather than research team members. Mutual respect was not embodied through the use of professional titles or formal distinctions, but rather within the relationships held between researchers, participants, and community partners. As a student researcher, my job was to genuinely listen and learn from experts in the room, that is, from each and every project stakeholder.

### ***Bravery***

Bravery as a Grandfather Teaching was explained as upholding values in the face of adversity. In the context of this project, this meant to adhere to research agreements with communities and partnering institutions, even when doing so created difficulty for research team members. For example, in one instance, while our project was under review by our partnering

institution's research ethics board, we faced criticism of our study methods. Concerns were raised that our study methods would potentially traumatize a vulnerable population, primarily due to questions eliciting information about potential past childhood trauma. As a student researcher, challenging a REB decision can be daunting, however in this case, was required. Study methods were created by stakeholders whose unparalleled expertise with this population dictated that methods were appropriate to both protect the client population but also meet research goals. Our role in this instance was to uphold these methods and represent the collective expertise of project stakeholders in this context. Following an in-person presentation to the full REB board, we were successful in retaining project methods, and research activities began as prescribed. By respecting the expertise of stakeholders' collective knowledge and trusting their judgement, we were able to maintain integrity and uphold our community research agreement despite initial institutional criticism.

### *Honesty*

Being open and honest during the preliminary processes helped build trust among a newly formed team. Frank conversations regarding study procedures and individual roles or expectations occurred early in the conceptualization process. Authentically representing expectations to both staff members and prospective clients occurred at all stages of the study. For clients, this meant carefully reviewing inherent risks and benefits to participation, and clearly stating that study outcomes may not necessarily inform their own individual treatment, but potentially could for future clients. For staff members at the treatment center, honesty in the research process was reflected through initial conversations about additional (and uncompensated) changes in case management and workload, expectations and roles of the

researchers, and clear study protocols. If clients, staff, or stakeholders were promised something by the research team, this was upheld.

### *Wisdom*

Recognition and appreciation of various forms of knowledge across project activities helped guide study activities. The use of a two-eyed seeing approach integrated non-Indigenous and Indigenous knowledge of wellbeing and mental health care. As the inherent goal was to gather knowledge to further inform client care at the treatment center, wisdom remained a core value of this study. The intended use of this knowledge was to better inform treatment, and therefore, previous dissemination of research results has been strictly tied to community wellbeing. Community presentations, reports, and word of mouth presentation of results continues to be controlled by the Research Advisory, and completed using methods that convey respect for the knowledge gathered and the client effort. One inherent paradox to the community-based sharing of wisdom is the affiliation of this work with the current dissertation. Negotiation for the use of these results for academic purposes occurred prior to data collection. Honest conversations were had about the academic requirements of a dissertation and the expectations surrounding use of knowledge to meet these criteria. Although results were agreed to be disseminated for student learning, subsequent sharing of this knowledge for conference presentations, manuscripts, or academic posters remains negotiated on a case by case basis. Further, time in kind will always be provided to share these results with interested communities.

The inclusion of clinical psychology student researchers was also considered to be a strength of this project, as the inclusion both built capacity for the students and helped alleviate some tasks for treatment staff. One benefit of merging clinical students with staff treatment counsellors was that it allowed greater collaboration of all team members unrelated to research

activities, and researchers shared a common clinical understanding with staff. Student researchers possessed the necessary skills to facilitate the clinical ACE group to potentially alleviate additional work for counsellors. For clients, this allowed a chance to consult with clinical psychology students to answer general questions they may have about ACEs, trauma, mental health assessment, or treatment approaches. Many clients indicated this was the first time they had interacted with clinical psychology, and wished to answer additional questions. For some individuals, this type of informal consultation and knowledge-sharing seemed more valuable than the group itself. The mutual appreciation of shared wisdom was a merit of this study, and reflected the high value placed on ultimately improving client care.

### *Respect*

This teaching was a cornerstone of almost all of the previously reviewed research guidelines for Indigenous health research, and was prioritized throughout this study's development, from project conceptualization, implementation, data analysis, and dissemination of results to communities. Respect was embodied through researcher words and actions, and conveyed our appreciation for staff members and clients participating in this project. As staff members at the treatment center often gave their time in kind for research, we reduced barriers to tasks as much as possible. Additional actions that have embodied respect relate to the scheduling of research activities, such as completing research at times most convenient for staff and clients. When staff or clients suggested viable changes to study processes, student researchers quickly implemented them and made required changes to REB documents. For example, staff requested an ACE information group be delivered to clients midway through the treatment cycle. This was added into study processes, and remains facilitated by student researchers.

The mutual respect of shared clinical expertise among researchers and staff at the treatment center was an asset to study implementation and outcomes. The collective experience of four counsellors at the treatment center spanned over 40 years of working with high-needs Indigenous populations. Their specialized training and insight often aligned well with the clinical training of the student researchers. A collective understanding of mental health service provision and mutual professional respect improved many aspects of this project. For example, many lunchtime conversations were had about treatment approaches, barriers, and population-specific needs. Informal consultation was occasionally sought, and clinical resources shared. The clinical skills that build a therapeutic alliance with clients (including shared goals, bond, and clinical tasks) were transferred to research activities at the treatment center, and were all implemented through initial shared respect for one another.

### *Love*

The longevity of this project, spanning over four years, required working relationships to remain constructive, collaborative, and kind. The development of such positive relationships between research team members and the research advisory were challenging to describe as these relationships developed naturally, with few to no ruptures. Researchers represented themselves authentically with project stakeholders, to form genuine, lasting friendships. Formal relationship-building practices did occur, such as regularly scheduled meetings, facilitated open-communication, and solicitation of stakeholder input in all research activities. This approach promoted positive relationships. Although these interactions were useful, informal relationship-building techniques seemed much more valuable. A relaxed, adaptable approach to project tasks, including flexibility with implementation, humor, and friendliness, ensured that the relationship

with stakeholders was always prioritized above the research and helped embody this Grandfather Teaching.

### ***Truth***

The nature of honest reflection on one's individual actions, particularly related to adhering one's values and beliefs, required the Grandfathers' Teaching of truth. Speaking the truth of this process, away from researcher bias or impression management, and accurately reflecting moments of significance, is the final way these teachings were reflected in the project. The process of doing so required careful interpretation of the qualitative findings collected from both staff and clients, reflection of personal experiences with the project, and searching for alternative explanations. For example, the absence of significant research problems in this chapter does not necessarily mean they did not occur, but rather reflect an individual's reflection on the research process. The process of writing this reflection has clarified the many strengths of this project, and actions implemented by research team members that could be associated with success of the project.

### **Final Thoughts**

Engaging with Indigenous communities through CBPR principles can be challenging. The needs of communities are often complex, thus the research endeavors documenting or attempting to address such concerns within communities must be those that are truly representative of community, contextual, and cultural environments. Community-based research is fraught with unexpected deviations, moving timelines of research activities well beyond expected deadlines, graduations, or other well-intentioned temporal restrictions. For a graduate student, engaging in a true CPBR project can be daunting, as one cannot ever be sure when institutional degree requirements will be met and the commitment to research becomes based on

guidance from a community partner, rather than an academic committee. From the preliminary inception of the *First Nations ACE Study* to today, this project has been nothing short of a journey, filled with many opportunities for learning and knowledge sharing, but more importantly, the development of new relationships. These relationships, forged along the way with participants, program and organizational staff, and broader community, make the perceived difficulties of CPBR inconsequential. Through over 5 years of partnership, even if it seems like the end of this stage of my formal education and doctoral research, I know it is only the beginning of a long-term and sustainable collaboration, in a joint effort to improve health and well-being for First Nations individuals in our communities.

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## Appendix A: Data Synthesis Table of ACE Review

Author	Participant Description	ACEs Reviewed	Associated Outcomes	
Basu et al., 2019	Australian Aboriginal $n = 48$	Physical Abuse	Family conflict and death	
		Sexual Abuse	Domestic violence	
		Emotional Abuse	Emotional abuse	
	Non-aboriginal Australians $n = 53$	Neglect	Incarceration	
Gippsland, Victoria, Australia		Parental substance abuse	Disconnection from culture	
		Parent in jail	Perceived loss of cultural identity	
		Parental Separation	Conduct Disorder diagnoses	
	Total sample 60% male; Aboriginal males less than half	Parent with mental illness	Child welfare involvement	
Bjerregaard et al., 2018	Data obtained from the 2014 Greenland Health Survey, whereas: ~90% Inuit ~10% Non-Inuit;	Sexual Abuse	Losing family to suicide ACE prevalence scores	
		Parental		
		Substance Use		
		Household Violence		
Greenland				
Bombay et al., 2011	FN Female, $n = 107$ FN Male, $n = 36$	Physical Abuse	Depressive symptoms	
		Sexual Abuse	Revictimization	
		Emotional Abuse	Household income	
	Canadian		Emotional Neglect	Residential school history
			Physical Neglect	
			Single parent household	
			Household Violence	
			Household Substance Abuse	
			Household Mental Illness	
			Household Criminal Behaviour	
Brockie et al., 2015	Native American $N = 288$  15-24 years (15–19 year age group = 59 %; Mean=19.25 years)	Physical Abuse	Gender prevalence comparisons	
		Sexual Abuse	Age prevalence comparisons	
		Emotional Abuse		
		Physical Neglect		
		Emotional Neglect	Poly-substance use	

	Female: 147 (51%) Male: 135 (49%)  Attending school: 48%	Witness to IPV	Post-Traumatic Stress Disorder diagnoses Suicide attempts Depressive symptoms
Brockie et al., 2018	American Indian men and women with Type 2 Diabetes  N=192  55.7% Female M <sub>age</sub> = 46.3, (12.2)  AI Tribal Clinics in five reservations in the Upper Midwest, USA	Physical Abuse Sexual Abuse Emotional Abuse Physical Neglect Emotional Neglect Witness to IPV Parental Separation Family Incarcerated Family with Mental Illness Family Substance Abuse	ACE prevalence scores Self-reported mental health Self-reported physical health Social support Involvement in spiritual activities
Burnette et al., 2017	American Indian and Caucasian participants  Age: 50 years+ N = 479 American Indian /Alaskan Native (AI/AN) <i>n</i> = 231  M <sub>age</sub> = 60.6 Male: 45.6%  Non AI/AN: <i>n</i> = 248 M <sub>age</sub> = 74.0  United States	Physical Abuse Sexual Abuse Emotional Abuse Physical Neglect Emotional Neglect Witness to IPV Parental Separation Family Incarcerated Family with Mental Illness Family Substance Abuse	Prevalence scores Depressive symptoms Employment Social Support
De Ravello et al., 2008	American Indian/Alaskan Native women who were incarcerated in New Mexico  N = 36 M <sub>age</sub> = 36 years Range 20-60 years	Physical Abuse Sexual Abuse Emotional Abuse Physical Neglect Witness to IPV Family Substance Use Family Incarcerated Family with Mental Illness	ACE prevalence scores Attempted suicide Suicidal ideation Age of early substance use Poly-substance use Mental health disorder diagnoses Incarceration

Fuller-Thomson et al., 2015	18 years+ With data regarding ACEs and ADHD dx.  <i>n</i> = 10 496 Male <i>n</i> = 12 877 Female 10 Canadian provinces  2012 Canadian Community Health Survey – Mental Health: Statistics Canada	Physical Abuse Sexual Abuse IPV	ACE prevalence scores ADHD diagnosis rates
Hamdullahpur et al., 2018	<i>n</i> = 83 Aboriginal women <i>n</i> = 89 Non-Aboriginal women  16 years+ in Canada  Referrals from centers providing: social services, basic need support, mental health supports, medical services,	Physical Abuse Sexual Abuse Neglect Witness IPV	Parental psychological concerns Parent substance use
Kenney et al., 2016	American Indians N=1453 Male: 54.2% Female: 45.8%  Non-Hispanic White N=61,381 Male: 51.6% Female: 48.4%  2011-2012 National Survey of Children's Health	Witness IPV Parent Mental Illness Parent Substance Abuse Parent Incarceration	ACE prevalence scores Depression rates ADHD diagnostic rates Anxiety Disorder rates
Klest et al., 2013	N = 833 Hawaiians ( <i>n</i> = 148 Native Hawaiian)  47% Men 53% Women  Age 51-60 years; $M_{age} = 55.05$ , $SD = 2.00$  Members of the Hawaii Personality and Health cohort	Physical Abuse Sexual Abuse Emotional Neglect Physical Neglect Witness to IPV Family Substance Use Family Incarcerated Family with Mental Illness	Gender ACE comparisons Trauma symptoms Depression symptoms Anxiety symptoms

Koss et al., 2015	Native Americans N= 1660 in 7 tribes  41% Male M <sub>age</sub> =40.5 59% Female M <sub>age</sub> = 39.5  United States	Physical Abuse Sexual Abuse Emotional Abuse Physical Neglect Emotional Neglect Parental Alcohol Use Out-of-home placement	ACE prevalence scores Alcohol dependence
Libby et al., 2008	American Indians from 2 tribes (Southwest and Northern Plains) who are parents  <i>n</i> = 2221 Age: 15-54 years  United States	Physical Abuse Sexual Abuse Witness IPV	ACE prevalence scores Parent satisfaction Parent roles Perceived social support
Moon et al., 2018	N=735 <i>n</i> = 233 AI M <sub>age</sub> = 60.69 <i>n</i> = 502 non-AI  South Dakota, United States	All ten ACEs	ACE prevalence scores Incomes Self-perceived physical health Mental health service use Depression
Moon et al., 2015	<i>n</i> = 182 AI adults 55% Female <i>n</i> = 167 Caucasian adults  Age: 50 years+ South Dakota, United States	All ten ACEs	ACE prevalence scores Chronic disease Obesity Self-perceived physical health Alcohol intake
Remigio-Baker et al., 2017	Women N = 3354  Hawaii  Data from 2010 Hawaiian Behavioral Risk Factor Surveillance System Survey	Physical Abuse Sexual Abuse Emotional Abuse Witness to IPV Family Substance Use Family Incarcerated Family with Mental Illness	ACE prevalence scores Prevalence of smoking Obesity
Roh et al., 2015	American Indian N= 233  Age: 50 years+	All ten ACEs	ACE prevalence scores Depression Social support

Roh et al., 2019	AI/AN women cancer survivors N = 73	All ten ACEs	ACE prevalence scores Depression Social support
Twizeyem ariya et al., 2017	N = 1671 cohort of Indigenous infants (Australian)	Parent incarceration Physical Abuse Sexual Abuse Verbal Abuse Witness IPV Neglect Parent with problematic drinking Household with drug/alcohol problem Divorce Parental Distress Family conflict	ACE prevalence scores Psychological distress
Warne et al., 2016	American Indian N= 516  Non AI <i>n</i> = 7078  Males: 42.5% Females: 57.47%	All ten ACEs	ACE prevalence scores Mental health diagnoses Substance use
Yuan et al., 2006	N = 1368 Females = 793 Males = 575  Data from Ten Tribes Study  Native American	Parent Substance Use Physical Abuse Physical Neglect Sexual Abuse Emotional Abuse Emotional Neglect	ACE prevalence scores Alcohol dependence

Appendix B: ARTC Intake Form



Date: \_\_\_\_\_

**IDENTIFYING INFORMATION**

FIRST NAME:		LAST NAME:	
Street/Mailing Address:			
City and Province:	Postal Code:	Phone Number:	Contact Number:
Marital Status: (i.e. single, separated, divorced, common-law, widow, married)	DOB: (M/D/Y)		Age: Sex: <input type="checkbox"/> Female <input type="checkbox"/> Male
Name of Spouse/Partner:			
Health Card Number:		Social Insurance Number:	
Band:		Status Card Number:	
Education: Highest Grade:		Employment Status: (i.e. unemployed, full-, part-time, student, Ontario Works, ODSP, etc.)	
Preferred Language:			

**PERSON TO CONTACT IN CASE OF EMERGENCY:**

Name:	
Phone Number (mandatory):	Relationship to Applicant:

**REFERRAL SOURCE INFORMATION**

Name of Referring Person:	Position:
Agency Name and Address:	
Phone Number:	Facsimile Number:
What is the nature of your relationship with the client: (i.e. counselor, advocate, family, doctor etc.)	
How long have you known the client:	
Reason for involvement with referring person/agency:	
Give a brief description of the client's problem as you see it:	
What is your assessment of the client's level of motivation at this time?	
To your knowledge, has the client ever experienced psychiatric or psychological problems? (If so please explain)	
Please list the programs and /or services available in your community for aftercare or follow up for this client.	

**THIS SECTION: TO BE COMPLETED BY CLIENT**

**ADDICTION HISTORY**

Primary Substance	Approximate Date of Last Time Used	Age of First Use	Age Regular Use Began
1.			
2.			
3.			
<b>Substances used in the last 12 months: (please check all that apply)</b>			
<input type="checkbox"/> Alcohol <input type="checkbox"/> Amphetamines, <i>i.e. Ritalin</i> <input type="checkbox"/> Barbiturates, <i>i.e. Phenobarbital</i> <input type="checkbox"/> Benzodiazepine, <i>i.e. Ativan, Valium</i> <input type="checkbox"/> Cocaine	<input type="checkbox"/> Crack <input type="checkbox"/> Glue/inhalant <input type="checkbox"/> Hallucinogens, <i>i.e. Ecstasy</i> <input type="checkbox"/> Heroin/opium <input type="checkbox"/> Marijuana	<input type="checkbox"/> Methadone <input type="checkbox"/> Oxycontin <input type="checkbox"/> Over-the-counter Codeine, <i>i.e. Tylenol #1 &amp; 3's</i> <input type="checkbox"/> Prescription Opiods, <i>i.e. Morphine</i>	
<b>Have you ever experienced any of the following: (please check all that apply)</b>			
<input type="checkbox"/> Hangovers <input type="checkbox"/> Blackouts	<input type="checkbox"/> Vomiting <input type="checkbox"/> Seizures	<input type="checkbox"/> Shakes <input type="checkbox"/> Hallucinations	<input type="checkbox"/> Paranoia <input type="checkbox"/> Health Problems
Injection Drug Use: <input type="checkbox"/> Yes <input type="checkbox"/> No			

**TREATMENT HISTORY**

Previous Treatment Attempt(s)  No  Yes (Please complete the information below)

Name of Facility	Date	Completed
		<input type="checkbox"/> Yes <input type="checkbox"/> No
		<input type="checkbox"/> Yes <input type="checkbox"/> No
		<input type="checkbox"/> Yes <input type="checkbox"/> No
		<input type="checkbox"/> Yes <input type="checkbox"/> No
How long were you clean/sober after treatment:		
What do you identify as the reasons for returning to drinking/drug using:		

**MENTAL HEALTH HISTORY**

<b>Do any of the following apply to you? (please check all that apply)</b>		
<input type="checkbox"/> Tension, anxiety, nervousness	<input type="checkbox"/> Depression	
<input type="checkbox"/> Eating disorder (bingeing, starving)	<input type="checkbox"/> Fears, phobias	
<input type="checkbox"/> Sexual abuse/assault	<input type="checkbox"/> Sexuality concerns	
<input type="checkbox"/> Physical/emotional/mental abuse	<input type="checkbox"/> Anger/aggression problems	
<input type="checkbox"/> Low self-esteem	<input type="checkbox"/> Difficulty expressing emotions	
<input type="checkbox"/> Grief issues	<input type="checkbox"/> Sleeping disorders	
<b>Have you ever had one of the following? (please check all that apply)</b>		<b>Please describe the incident in detail: (i.e. what you did you do, when, how, current plan, etc.)</b>
Suicidal thoughts	<input type="checkbox"/> Yes <input type="checkbox"/> No	
Self-harm behavior	<input type="checkbox"/> Yes <input type="checkbox"/> No	
Attempted suicide	<input type="checkbox"/> Yes <input type="checkbox"/> No	
Use this space to give more detail, if required:		
<b>Have you ever been hospitalized for a mental health issue?</b>		<input type="checkbox"/> No <input type="checkbox"/> Yes
When:	Facility:	
<b>Have you ever had counselling for mental health issues?</b>		
<input type="checkbox"/> No <input type="checkbox"/> Yes (if yes, Complete below information)		
Name:	Agency:	
Date:	How long:	
Please indicate what issues were addressed:		
Would you be willing to sign a release of information for Dilico to access reports from the above agency(s)? <input type="checkbox"/> Yes <input type="checkbox"/> No (If not, why)		
Is counseling/therapy ongoing?		

**MEDICAL HISTORY**

Family Doctor Name		Address	Telephone Number
<b>Please list any and all medication below:</b>			
Name and Dose of Medication:	Prescribed By:	Reason Prescribed:	When was it started:
Do you have any allergies? <input type="checkbox"/> Yes <input type="checkbox"/> No (If yes, please list)			
Is an Epi-pen required for the above allergies? <input type="checkbox"/> Yes <input type="checkbox"/> No			
Do you have any of the following? (please check all that apply)			
<input type="checkbox"/> Arthritis	<input type="checkbox"/> Asthma	<input type="checkbox"/> Bowel problems	
<input type="checkbox"/> Ear/hearing problems	<input type="checkbox"/> Eye problems	<input type="checkbox"/> Stomach problems	
<input type="checkbox"/> Tuberculosis	<input type="checkbox"/> Heart Disease	<input type="checkbox"/> Blood Pressure	
<input type="checkbox"/> Hernia	<input type="checkbox"/> Diabetes	<input type="checkbox"/> Cancer	
<input type="checkbox"/> Convulsions/seizures	<input type="checkbox"/> Head injury	<input type="checkbox"/> Pregnancy	
Are there any major health concerns that you have that are not listed here?			

**LEGAL STATUS AND HISTORY**

<b>Current/Pending Charges:</b>	<input type="checkbox"/> No <input type="checkbox"/> Yes	List charge(s):
<b>In Jail:</b>	<input type="checkbox"/> No <input type="checkbox"/> Yes	Release Date:

**LEGAL STATUS AND HISTORY- con't**

<b>On Probation:</b>	<input type="checkbox"/> No <input type="checkbox"/> Yes	<b>Start Date:</b>	<b>End Date:</b>
<b>Condition(s):</b>			
<b>On Parole:</b>	<input type="checkbox"/> No <input type="checkbox"/> Yes	<b>Start Date:</b>	<b>End Date:</b>
<b>Condition(s):</b>			
<b>Do you have to attend criminal court?</b>	<input type="checkbox"/> No <input type="checkbox"/> Yes	<b>When?</b>	<b>For What?</b>
<b>Probation/Parole Officer:</b>	<b>Address:</b>		<b>Telephone Number:</b>
<b>Please indicate if you have had any of the past offences listed below: (Check all that apply)</b>			
<input type="checkbox"/> Arson	<input type="checkbox"/> Forgery	<input type="checkbox"/> Probation violation	<input type="checkbox"/> Criminal negligence causing death
<input type="checkbox"/> Assault	<input type="checkbox"/> Impaired driving	<input type="checkbox"/> Robbery	<input type="checkbox"/> Possession stolen property
<input type="checkbox"/> Break & Enter	<input type="checkbox"/> Manslaughter	<input type="checkbox"/> Sexual assault	<input type="checkbox"/> Willful damage/mischief
<input type="checkbox"/> Burglary	<input type="checkbox"/> Murder	<input type="checkbox"/> Theft	
<input type="checkbox"/> Drug charges	<input type="checkbox"/> Parole violation	<input type="checkbox"/> Weapon offenses	

**FAMILY BACKGROUND INFORMATION**

<b>Family Type (please check)</b>	
<input type="checkbox"/> Living alone	<input type="checkbox"/> With spouse
<input type="checkbox"/> Single Parent	<input type="checkbox"/> With parents
<input type="checkbox"/> Spouse and children	<input type="checkbox"/> Other

**YOUR FAMILY OF ORIGIN**

<b>Parent Names:</b>			Living	Deceased
Mother:				
Father:				
Step-mother:				
Step-father:				
<b>Brothers' Names:</b>	Biological	Step/half	Living	Deceased
<b>Sisters' Names</b>	Biological	Step/half	Living	Deceased

**FAMILY HISTORY**

Who raised you? <input type="checkbox"/> Parents <input type="checkbox"/> Grandparent(s) <input type="checkbox"/> Foster parent(s) <input type="checkbox"/> Adoptive parent(s)	
Do any of the following apply to your childhood? (please check all that apply)	
<input type="checkbox"/> Alcohol/drug abuse	<input type="checkbox"/> Witness to domestic violence
<input type="checkbox"/> Happy home life	<input type="checkbox"/> Suicide death of family member/close friend
<input type="checkbox"/> Sexually abused	<input type="checkbox"/> Divorce/separation of parents
<input type="checkbox"/> Physically abused	<input type="checkbox"/> Emotionally abused

**Dependent Child(ren) Information**

<b>Please list the names and ages of your children below:</b>		
Full Name	Date of Birth/Age	Where is the child now

**FAMILY HISTORY- con't**

<b>If your child(ren) is not in care, who will care for your child/ren while you are in treatment? (complete below)</b>			
Name:		Phone Number:	
Relationship to the children:		Address:	
Do you struggle with parenting?			
Has Dilico or CAS ever been involved in the care of your children? If yes, why?			
<b>Is Dilico, CAS, or any other Child Welfare Agency currently involved with your family? (If so, please complete below)</b>			
Name of Worker:		Telephone Number:	
Name of Agency:		Fax Number:	
<b>Do you have to attend family court?</b>	<input type="checkbox"/> No <input type="checkbox"/> Yes	When?	For What?

## Appendix C: Informational Letter

**Study Information Letter: Understanding Childhood Experiences and Substance Use for First Nations People**

Principal Investigator: Dr. Christopher Mushquash, Lakehead University, in collaboration with Dilico Anishinabek Family Care

Email: [chris.mushquash@lakeheadu.ca](mailto:chris.mushquash@lakeheadu.ca)

Phone: (807) 343-8239

Student Investigators: Elaine Toombs and Jessie Lund, Lakehead University

Email: [etoombs@lakeheadu.ca](mailto:etoombs@lakeheadu.ca) or [jlund@lakeheadu.ca](mailto:jlund@lakeheadu.ca)

**Introduction**

We invite you to take part in a research study being conducted by Dr. Christopher Mushquash, Elaine Toombs, and Jessie Lund, in partnership with Dilico Anishinabek Family Care. This project is funded in part by the Canadian Institutes of Health Research. Your participation in this study is voluntary and you may withdraw from this study at any time. You should discuss any questions you have about this study with Dr. Mushquash, Elaine Toombs, Jessie Lund, or your counsellor at Dilico.

**Purpose of this study**

The main purpose of this study is to understand how childhood experiences of trauma may influence substance use and other health outcomes for First Nations people.

**Who can participate in this study?**

You must be a current client at the Adult Residential Treatment Centre (ARTC) and aged 18 years or older to participate in this study.

**Who will be conducting the research?**

Dr. Christopher Mushquash, Elaine Toombs, Jessie Lund, and staff at Dilico Anishinabek Family Care will be conducting the research.

**What will I be asked to do?**

Participants in this study will complete questionnaires with their individual counsellors at ARTC. If you consent to participate in this study, information collected as part of your intake to ARTC will also be provided to study participants. Additional questions will ask participants about individual and family life experiences about substance use, addiction, health outcomes, and trauma. Some questions will ask about difficult experiences you may have had in your life, which may be difficult to answer or may cause distress. It will take approximately 60 minutes to complete these questions. If you agree to participate,

you will have the option to complete questions individually using pen and paper or have the questions read to you and you respond orally. You do not have to answer all questions and can skip questions that you are not comfortable answering.

### **What are the burdens and potential harms to participation?**

There is a possibility that answering some of the questions or participating in the program asked in this study may make you feel upset. There is a small burden of time associated with the completion of the assessment questions and program content. If you feel upset at any time completing the study, please contact your counsellor at ARTC as they can connect you with appropriate resources. If you have research related questions, please contact your Dr. Mushquash by phone at (807) 343-8239 or by email at [chris.mushquash@lakeheadu.ca](mailto:chris.mushquash@lakeheadu.ca).

### **What are the potential benefits?**

There are minimal individual benefits to participating in this study. Participants may find it satisfying to contribute to research programs and help First Nations communities understand how adverse childhood experiences may influence substance use.

### **Can I withdraw from the study?**

This study is voluntary. You are free to withdraw from the study at any time, and free to remove your answers from the study, up until the point at which the study is complete (approximately December 2019). Your decision to take part or not to take part in the study, or to drop out of the study at a later time, will never affect your access to services or supports at Dilico Anishinabek Family Care.

### **Will the study cost me anything?**

The study will cost a small burden of time. You will not be reimbursed time to complete the study questionnaires.

### **How will my privacy be protected?**

**Anonymity:** Your individual information will not appear in any reports or publications. All information will only be used when it is combined with other participants' information, without your name or other information that would identify you. Several steps have also been taken to protect your confidentiality (see below).

**Confidentiality:** All information obtained is strictly confidential. The information you provide will only be accessed by designated members of the research team. All Dilico staff are trained to maintain participant confidentiality and have signed confidentiality agreements.

Consistent with Lakehead University's policy on research data storage, paper copies of your information will be securely stored for 5 years after the completion of the study at Dilico. These files will be stored in a locked filing cabinet in a locked office at Dilico, like all other client files. Electronic versions of the data will be held for an indefinite period of time and will be kept in a password-protected USB drive in Dr. Mushquash's locked laboratory or at Dilico.

Electronic versions of the data will never include your name or contact information but will contain the following information about you: age, sex, ethnicity (i.e., self-reported ethnicity and country of birth), occupation, and nature of employment (e.g., full-time, part-time, etc.). Electronic information will be used by researchers at Lakehead University for a brief time and then stored at Dilico.

**How can I receive a copy of the study results?**

If you would like to receive a summary of study results, you can indicate this on the study consent form and provide your contact information. Individual results will not be made available to participants.

**What if I have study questions or problems?**

If you have any questions about this study or your participation, you may contact Dr. Mushquash by emailing [chris.mushquash@lakeheadu.ca](mailto:chris.mushquash@lakeheadu.ca).

**What are my research rights?**

If you have any difficulties with, or wish to voice concern about, any aspect of your participation in this study, you may contact Lakehead University's Research Ethics Board for assistance at (807) 343-8934.

## Appendix D: Participant Consent Form

**CONSENT FORM: Understanding Childhood Experiences and Substance Use for First Nations People**

## Agreement to Participate

- 1) **Study Purpose:** Dilico Anishinabek Family Care, in collaboration with Dr. Christopher Mushquash at Lakehead University, is doing this study to understand how childhood experiences of trauma may influence substance use and other health outcomes for First Nations people.
- 2) **Participation:** We are inviting clients of the Adult Residential Treatment Centre (ARTC) to participate in approximately an hour interview asking about individual and family life experiences about substance use, addiction, health outcomes, and trauma.
- 3) **Confidentiality:** All information given is private and we will not share your individual answers with anyone outside of the research team. All Dilico staff are trained to maintain participant confidentiality and have signed confidentiality agreements. Study information will be kept in locked cabinets at Dilico Anishinabek Family Care offices in Thunder Bay for 5 years, and then destroyed. Electronic information will be password protected. All information that you provide will be combined with information from all the other people interviewed, so no one will know what you said specifically. We will never use your name in our reports or presentations.
- 4) **Benefits and Risks:** There are minimal benefits and risks to you during your study participation. Some people may find it satisfying to participate in research activities. There is a possibility that answering some of the questions or participating in this study may make you feel upset. If you do feel uncomfortable or upset during your participation, please tell your counsellor at ARTC as they can help support you and connect you with appropriate resources to help.
- 5) **Reporting:** When our study is complete, we will prepare a summary of findings. You will also be able to request a summary of results by contacting the research team. In collaboration with the project advisory, we may prepare additional reports for publication in order to share the information for the benefit of others working with First Nations people with substance use concerns. Again, as a participant in this study, we will never include your name – your confidentiality and privacy will always be respected.
- 6) **Further Information:** If you have questions about the study after the study is completed or wish to receive a copy of the study results, you can contact Dr. Christopher Mushquash by telephone at (807) 343-8239 or by email at [chris.mushquash@lakeheadu.ca](mailto:chris.mushquash@lakeheadu.ca). If you wish to speak to someone other than a researcher about the study, you may call the Lakehead University Research Ethics Board at (807) 343-8283.

7) **Confirmation of Agreement to Participate:** It is your choice if you would like to participate in this study. Your decision to take part, or not take part, will never affect the services you receive from Dilico Anishinabek Family Care.

a) I have read and understand the study informational letter.

\_\_\_\_\_ Yes      \_\_\_\_\_ No

b) I volunteer to take part in this study.

\_\_\_\_\_ Yes      \_\_\_\_\_ No

c) Would you like to receive a copy of the study results?

\_\_\_\_\_ Yes      \_\_\_\_\_ No

If you would like to receive a copy of the results, please provide us with your contact information:

**Mailing Address**

**Email Address**

d) In order to understand more about how childhood experiences affect health outcomes for First Nations people, we would like to contact study participants again to ask other questions that relate to your overall health and wellbeing, including how biological stress hormones may influence overall health.

Would you like to be contacted to receive more information about these studies?

\_\_\_\_\_ Yes      \_\_\_\_\_ No

To receive more information, please provide us with your contact information:

**Mailing Address**

**Email Address**

**Telephone Number**

**Participant Name:** \_\_\_\_\_

**Witness Name:** \_\_\_\_\_

Signature: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Date: \_\_\_\_\_

## Appendix E: Client Satisfaction Questionnaire Items

1. Did you participate in the ACE research project?

YES

NO

If NO, is there anything that could have been done differently that would have made you more interested in participating?

2a. As part of your treatment, you took part in an ACE information group at the beginning of the cycle. How would you rate the ACE information group?

5- Extremely Helpful

4- Very Helpful

3- Somewhat Helpful

2- Not so Helpful

1- Not at all Helpful

2b. What did you like/dislike about the ACE informational group?

3a. If you participated in the ACE research study here at ARTC, how would you rate the experience?

5- Very High Quality

4- High Quality

3- Neither High Or Low Quality

2- Low Quality

1- Very Low Quality

3b. What did you like/dislike about being involved in the research study?

4. Based on your experience with the ACE Research Study, how interested would you be in participating in future research here at ARTC?

5- Extremely Interested

4- Very Interested

3- Somewhat Interested

2- Not So Interested

1- Not At All Interested

## Appendix F: Semi-structured Interview Guide

1. What has your experience been like working with the First Nations ACE study?
  - A) What things do you like about the study?  
(Example: usefulness to treatment, client perceptions, etc)
  - B) What things do you not like about the study?  
(Examples: time away from work, work load, client perceptions, etc)
  - C) If we were to do the ACE study again, what would you like to see changed/modified?
2. How useful (and in what ways) do you think the results of the study will be for:
  - A) Clients at ARTC?
  - B) Staff at ARTC?
- 3). How could the usefulness of the study and the results be improved for:
  - A) clients at ARTC?
  - B) Staff at ARTC?
4. Did you learn anything from working with the First Nations ACE Study? Please give examples if so.
5. Have you had any prior experience working with a research project? What has your experience been like working with this research? Is there anything that surprised you or that you learned from this work?
6. There were some student researchers involved in this project (Jessie and Elaine). How did they help and/or hinder this project? Is there anything you would have liked to see them do differently?
  - A) Ask about specific program activities: The ACE group, group meetings, scheduling, and data collection)
7. Has the research impacted your clinical work? Why or why not?
8. After participating in this research, do you feel like you would be able/willing to complete this type of research project on your own?
  - A) If no, what would you need to be able to do so?
9. What sort of things do you think are important to take into account when doing (quantitative) research with indigenous participants?
  - A) If you were going to give insight to others beginning to be involved in a similar research project based on your experiences/what you've learned through this process, what would you tell them?

10. How did/didn't the study align with Dilico's values related to Indigenous mental health care? Broadly speaking, do you think the study will improve Indigenous mental health? If so, how?

A) What could be done to better improve this?

11. How does/didn't the study fit with Indigenous ways of knowing and Indigenous cultural values?

12. Would you help facilitate this study again? Why/why not?

13. Are there any research questions that you would like to see explored or answered at ARTC?

14. Any final thoughts?

## Appendix G: Staff Interview Informational Letter

**Understanding Childhood Experiences and Relation to Substance Use  
for First Nations People**

Principal Investigator: Dr. Christopher Mushquash, Lakehead University, in collaboration with Dilico Anishinabek Family Care

Email: [chris.mushquash@lakeheadu.ca](mailto:chris.mushquash@lakeheadu.ca)

Phone: (807) 343-8239

Student Investigators: Elaine Toombs and Jessie Lund, Lakehead University

Email: [etoombs@lakeheadu.ca](mailto:etoombs@lakeheadu.ca) or [jlund@lakeheadu.ca](mailto:jlund@lakeheadu.ca)

Dear potential participant,

We invite you to take part in a research study being conducted by Dr. Christopher Mushquash, Elaine Toombs, and Jessie Lund, in partnership with Dilico Anishinabek Family Care.

Your participation in this study is voluntary and you may withdraw from this study at any time. **Your decision to take part or not to take part in the study, or to drop out of the study at a later time, will never affect your employment or access to services at Dilico Anishinabek Family Care.** You should discuss any questions you have about this study with Dr. Mushquash, Elaine Toombs, or Jessie Lund. Please take as much time as you need to decide if you'd like to participate.

**Purpose of this study**

The purpose of this study is to understand how your experience has been with the *First Nations ACE Research Study*. We would like to gather your insight regarding your experiences as a staff member working with the research team on the *First Nations ACE Research Study*.

**Who can participate in this study?**

You must be staff member of the Adult Residential Treatment Centre (ARTC) and aged 18 years or older to participate in this study.

**Who will be conducting the research?**

Dr. Christopher Mushquash, Elaine Toombs, Jessie Lund, and a research assistant, Abbey Radford.

**What will I be asked to do?**

You will be asked to complete an interview with a research assistant about your experiences with the First Nations ACE study. Additional questions will ask you about your experiences completing research in general, about any information you would like

from future studies, and if/how the current research has influenced your current clinical work. Interviews will last approximately an hour and a half, and can occur in person or by telephone. You do not have to answer all questions and can skip questions that you are not comfortable answering. If you would like, a copy of the questions can be provided to you prior to beginning the study.

Following the completion of all the interviews, generalized and anonymous results will be presented back to participants through a group presentation. We will ask you if you think the results are representative of your experiences with the study. Following this presentation, results will be provided to organizational leadership at Dilico.

### **What are the burdens and potential harms to participation?**

There is a small possibility that answering some of the questions may make you feel upset. There is a small burden of time associated with the completion of the assessment questions and program content. If you feel upset at any time completing the study, please contact your Manager at ARTC as they can connect you with appropriate resources. If you have research related questions, please contact your Dr. Mushquash by phone at (807) 343-8239 or by email at [chris.mushquash@lakeheadu.ca](mailto:chris.mushquash@lakeheadu.ca).

### **What are the potential benefits?**

There are minimal individual benefits to participating in this study. You may find it satisfying to contribute to research programs and/or help First Nations communities understand how adverse childhood experiences may influence substance use.

### **Can I withdraw from the study?**

This study is voluntary. You are free to withdraw from the study at any time, and free to remove your answers from the study, up until the point at which the study is complete (approximately December 2019). Your decision to take part or not to take part in the study, or to drop out of the study at a later time, will never affect your employment or access to services at Dilico Anishinabek Family Care.

### **Will the study cost me anything?**

There are no financial costs required for you to complete the study. Answering the study interview will take some of your time, and as a token of our appreciation, we will provide you with a \$50 gift card.

### **How will my privacy be protected?**

**Anonymity:** Your individual information will not appear in any reports or publications. All information will only be used when it is combined with other participants' information, without your name or other information that would identify you. Several steps have also been taken to protect your confidentiality (see below).

**Confidentiality:** All information obtained is strictly confidential. The information you provide will only be accessed by designated members of the research team to maintain your confidentiality and have signed confidentiality agreements.

Consistent with Lakehead University's policy on research data storage, paper copies of your information will be securely stored for 5 years after the completion of the study at Dilico. Your consent form will be stored separately from any collected data. These files will be stored in a locked filing cabinet in a locked office at Dilico, like all other client files. Electronic versions of the data will be held for an indefinite period of time and will be kept in a password-protected USB drive in Dr. Mushquash's locked laboratory or at Dilico.

Electronic versions of the data will never include your name or contact information but will contain the following information about you: age, sex, ethnicity (i.e., self-reported ethnicity and country of birth), occupation, and nature of employment (e.g., full-time, part-time, etc.). Electronic information will be used by researchers at Lakehead University for a brief time and then stored at Dilico.

**How can I receive a copy of the study results?**

If you would like to receive a summary of study results, you can indicate this on the study consent form and provide your contact information. Individual results will not be made available to participants.

**What if I have study questions or problems?**

If you have any questions about this study or your participation, you may contact Dr. Mushquash by emailing [chris.mushquash@lakeheadu.ca](mailto:chris.mushquash@lakeheadu.ca).

**What are my research rights?**

If you have any difficulties with, or wish to voice concern about, any aspect of your participation in this study, you may contact Lakehead University's Research Ethics Board for assistance at (807) 343-8283.

This study has been approved by the Lakehead University Research Ethics Board. If you have any questions related to the ethics of the research and would like to speak to someone outside of the research team please contact Sue Wright at the Research Ethics Board at 807-343-8283 or [research@lakeheadu.ca](mailto:research@lakeheadu.ca).

## Appendix H: Consent Form for Staff Interviews

**CONSENT FORM: Understanding Childhood Experiences and Substance Use for First Nations People Agreement to Participate**

- 1) **Study Purpose:** Dilico Anishinabek Family Care, in collaboration with Dr. Christopher Mushquash at Lakehead University, is doing this study to understand how childhood experiences of trauma may influence substance use and other health outcomes for First Nations people.
- 2) **Participation:** We are inviting staff of the Adult Residential Treatment Centre (ARTC) to participate in approximately an hour and a half interview asking about their experience supporting *the First Nations ACE Research Study*.
- 3) **Confidentiality:** All information given is private and we will not share your individual answers with anyone outside of the research team. We are trained to maintain participant confidentiality and have signed confidentiality agreements. Study information will be kept in locked cabinets at Dilico Anishinabek Family Care offices in Thunder Bay for 5 years, and then destroyed. Electronic information will be password protected. All information that you provide will be combined with information from all the other people interviewed, so no one will know what you said specifically. We will never use your name in our reports or presentations.
- 4) **Benefits and Risks:** There are minimal benefits and risks to you during your study participation. Some people may find it satisfying to participate in research activities. There is a possibility that answering some of the questions or participating in this study may make you feel upset. If you do feel uncomfortable or upset during your participation, please tell your manager at ARTC as they can help support you and connect you with appropriate resources to help.
- 5) **Reporting:** When our study is complete, we will prepare a summary of findings and give you an opportunity to validate the results. You will also be able to request a summary of results by contacting the research team. In collaboration with the project advisory, we may prepare additional reports for publication in order to share the information for the benefit of others working with First Nations people with substance use concerns. Again, as a participant in this study, we will never include your name – your confidentiality and privacy will always be respected.
- 6) **Further Information:** If you have questions about the study after the study is completed or wish to receive a copy of the study results, you can contact Dr. Christopher Mushquash by telephone at (807) 343-8239 or by email at [chris.mushquash@lakeheadu.ca](mailto:chris.mushquash@lakeheadu.ca). If you wish to speak to someone other than a researcher about the study, you may call the Lakehead University Research Ethics Board at (807) 343-8283.

7) **Confirmation of Agreement to Participate:** It is your choice if you would like to participate in this study. Your decision to take part, or not take part, will never affect your employment or any services you receive from Dilico Anishinabek Family Care.

a) I have read and understand the study informational letter.

\_\_\_\_\_ Yes      \_\_\_\_\_ No

b) I volunteer to take part in this study.

\_\_\_\_\_ Yes      \_\_\_\_\_ No

c) Would you like to receive a copy of the study results?

\_\_\_\_\_ Yes      \_\_\_\_\_ No

If you would like to receive a copy of the results, please provide us with your contact information:

**Mailing Address**

**Email Address**

**Participant Name:** \_\_\_\_\_

**Witness Name:** \_\_\_\_\_

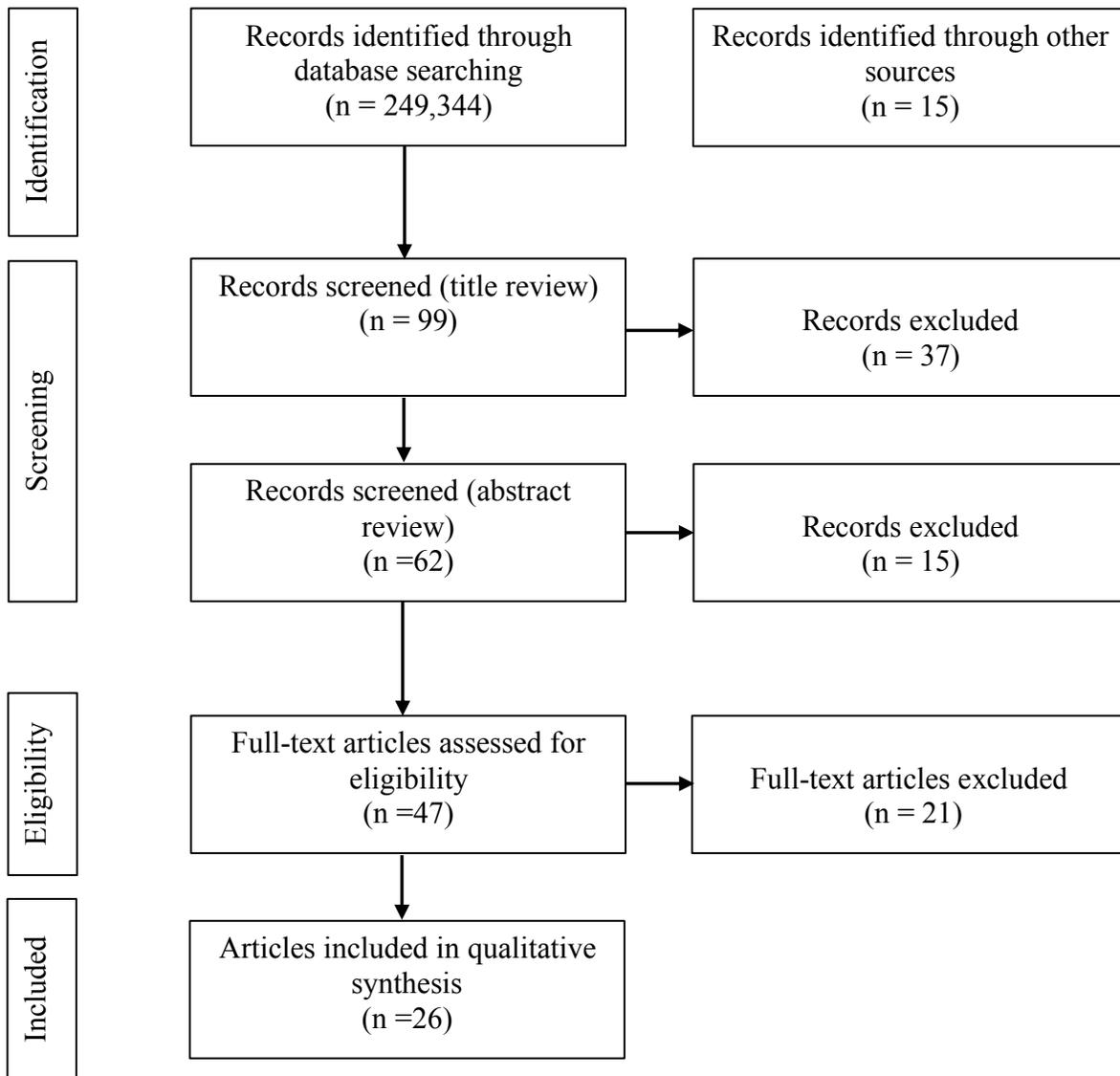
Signature: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Date: \_\_\_\_\_

Appendix I: PRISMA Diagram of Indigenous Research Framework Review



## Appendix J: Data Synthesis Table of Indigenous Research Framework Scoping Review

Authors	Intended Population	Guideline	Description
Absolon & Willett (2004)	Aboriginal communities	None given	<ol style="list-style-type: none"> <li>1. Respectful representations: consider how you represent yourself, your research and the people, events, or phenomena you are researching</li> <li>2. Revising: consider changing your methods, listen to the community and be flexible and open to processes that are culturally relevant</li> <li>3. Reclaiming: consider asserting and being proud of yourself; trust in your traditions and cultural identity to inform and guide your process of sharing and creating knowledge</li> <li>4. Renaming: consider 'Indigenizing' language by restructuring and reworking it to create meanings that are Indigenous</li> <li>5. Remembering: consider journeying into the ancestral memory banks through ceremony, tradition and ritual in order to reconnect and remember who you are</li> <li>6. Reconnecting: consider creating research processes that foster and maintain connections with community and with contemporary issues</li> <li>7. Recovering: consider incorporating our histories, diversities, traditions, cultures and ancestral roots</li> <li>8. Researching: consider innovative Indigenous methodologies, be a trailblazer, have courage, tenacity and faith</li> </ol>
Association of Canadian Universities for Northern Studies (2003)	Northern Indigenous communities in Canada	Ethical Principles for the Conduct of Research in the North	<ol style="list-style-type: none"> <li>1. Abide by local laws and regulations</li> <li>2. Appropriate community consultation</li> <li>3. Mutual respect within partnerships</li> <li>4. Respect of privacy and dignity of people</li> <li>5. Consideration of experience of people in research process</li> <li>6. Enhancement of local benefits of research</li> <li>7. Accountability of research by person in charge</li> <li>8. Obtaining informed consent</li> <li>9. Clear identification of research activities during consent</li> <li>10. Explanation of risks and benefits</li> <li>11. Informed consent for data collection</li> <li>12. Consent for release of information or breaking confidentiality</li> <li>13. No undue pressure to consent to research</li> <li>14. An individual or community has right to withdraw consent</li> <li>15. Community should have access to project descriptions</li> <li>16. Local storage of community data</li> <li>17. Provision of research summaries in local languages</li> <li>18. Publications should refer to community consent</li> <li>19. Publications should appropriately credit contributions</li> <li>20. Greater prioritization of community rather than research</li> </ol>
Australian Institute of Aboriginal and Torres Strait Islander Studies (2012)	Indigenous communities in Australia	Guidelines for Ethical Research in Australian Indigenous Studies	<ol style="list-style-type: none"> <li>1. Recognition of the diversity and uniqueness of peoples, as well as of individuals, is essential</li> <li>2. The rights of Indigenous peoples to self-determination must be recognized</li> <li>3. The rights of Indigenous peoples to their intangible heritage must be recognized</li> <li>4. Rights in the traditional knowledge and traditional cultural expressions of Indigenous peoples must be respected, protected, and maintained</li> <li>5. Indigenous knowledge, practices, and innovations must be respected, protected, and maintained</li> <li>6. Consultation, negotiation, and free, prior and informed consent are the foundations for research with or about Indigenous peoples</li> <li>7. Responsibility for consultation and negotiation is ongoing</li> </ol>

			8. Consultation and negotiation should achieve mutual understanding about the proposed research 9. Negotiation should result in a formal agreement for the conduct of a research project 10. Indigenous people have the right to full participation appropriate to their skills and experiences in research projects and processes 11. Indigenous people involved in research, or who may be affected by research, should benefit from, and not be disadvantaged by, the research project 12. Research outcomes should include specific results that respond to the needs and interests of Indigenous peoples 13. Plans should be agreed for managing use of, and access to, research results 14. Research projects should include appropriate mechanisms and procedures for reporting on ethical aspects of the research and complying with these guidelines
Bainbridge et al. (2013)	Aboriginal communities in Australia	Coming to an Ethics of Practice	1. Developing meaningful relationships 2. Being reflective 3. Recognizing difference 4. Making research relevant
Ball & Janyst (2008)	Indigenous people in Canada	Not titled	1. Community relevance 2. Community participation 3. Mutual capacity building 4. Benefit to Indigenous communities
Baskin (2005)	Aboriginal communities in Canada		1. Direct involvement of participants and community 2. Reciprocal relationship between researcher and participant 3. Goal of self-determination and decolonization 4. Direct benefit to the community 5. Potential for learning and healing
Bull et al. (2010)	Aboriginal community in Labrador	Authenticity in Research	1. Community consent 2. Consent in relation to power 3. Consent as partnership 4. Consent as Dissemination 5. Use of OCAP™ Standards 6. Research relevance to community
Canadian Interagency Advisory Panel on Research Ethics (2018)	Indigenous people in Canada	Chapter 9: Research Involving the First Nations, Inuit, and Métis Peoples of Canada	1. Community engagement occurs 2. Nature of engagement is determined jointly 3. Respect for First Nations, Inuit, and Métis governance 4. Engagement with organizations and communities of interest 5. Recognition of complex authority structures 6. Recognition of diverse interests within community 7. Critical inquiry throughout process 8. Respect for community customs and codes of practice 9. Institutional research ethics review 10. Inform REB of community engagement plan 11. Set research agreement 12. Use of collaborative and/or participatory approach 13. Research is relevant to community needs 14. Research should strengthen capacity in community 15. Recognition of role of Elders and knowledge holders 16. Address privacy and confidentiality concerns of communities 17. Collaborative interpretation and dissemination of results 18. Intellectual property owned by community 19. Address of individuals in communities, specifically for biological materials 20. REB review for use of secondary data
Castellano (2004)	Aboriginal communities in Canada	Ethics of Aboriginal Research	1. Aboriginal people have an inherent right to participate as principals or partners in research that generates knowledge affecting their culture, identity, and well-being.

			<ol style="list-style-type: none"> <li>2. Obligation to protect Aboriginal rights in research activities.</li> <li>3. Establishing ethical standards of research should strike a balance between regulations that restrict infringement of Aboriginal rights and those that respect the primacy of ethical codes originating in affected communities.</li> <li>4. Ethical regulation of research affecting Aboriginal Peoples should include protection for “all knowledge, languages, territories, material objects, literary or artistic creations pertaining to a particular Aboriginal Peoples, including objects and forms of expression...”</li> <li>5. Review legislation of the protection of intellectual property to ensure that Aboriginal interests and perspectives are protected.</li> <li>6. Development and implementation of ethical standards should be completed by Aboriginal Peoples.</li> <li>7. Costs of community consultation should be recognized within research budget plans.</li> <li>8. Shared responsibility to educate communities and researchers in ethics of Aboriginal research in a collaborative process.</li> </ol>
Christopher (2005)	Native American communities in the United States of America	Recommendations for Conducting Successful Research with Native Americans	<ol style="list-style-type: none"> <li>1. Researchers must understand historical relations between government and Native Americans, including present day effects</li> <li>2. Researchers must show knowledge of issues specific to tribes being studied and avoid the common mistake of grouping all tribes together</li> <li>3. Native communities must receive information back from researchers and have access to data collected from them</li> <li>4. Native American individuals and communities must be invited to be involved with research</li> <li>5. Native communities must receive benefits from research</li> <li>6. Researchers must place the needs of the community ahead of their own interests</li> <li>7. Researchers must address assets and broader social issues.</li> </ol>
De Crespigny et al. (2004)	Indigenous communities	Partnership model for ethical Indigenous research	<ol style="list-style-type: none"> <li>1. Respect</li> <li>2. Collaboration</li> <li>3. Active Participation</li> <li>4. Meeting Needs</li> </ol>
First Nations Information Governance Centre (2014)	First Nations communities in Canada	Ownership, Control, Access, and Possession Standards ®	<ol style="list-style-type: none"> <li>1. Ownership of cultural knowledge, data, and information</li> <li>2. Control of all aspects of research process</li> <li>3. Access to information and community rights to manage information</li> <li>4. Possession of physical data to retain ownership</li> </ol>
Hart (2010)	Indigenous communities	No title	<ol style="list-style-type: none"> <li>1. Indigenous control of research</li> <li>2. Respect for individuals and community</li> <li>3. Reciprocity and responsibility</li> <li>4. Respect and safety</li> <li>5. Non-intrusive observation</li> <li>6. Deep listening</li> <li>7. Reflective non-judgement</li> <li>8. Honoring what is shared by participants</li> <li>9. Connection of mind and heart</li> <li>10. Self-awareness of self in research process</li> <li>11. Recognition of subjectivity of researcher</li> </ol>
Herman (2014)	Indigenous communities	Nine Guidelines for Research with Indigenous Peoples	<ol style="list-style-type: none"> <li>1. Open consultation of research activities</li> <li>2. Research conducted with values of Indigenous community</li> <li>3. Respect of cultural protocols and traditions</li> <li>4. Informed consent</li> <li>5. Confidentiality of research results</li> <li>6. Protection of Indigenous knowledge</li> <li>7. Partnership with Indigenous organization</li> <li>8. Review of methods by community members</li> <li>9. Benefit sharing of research results</li> </ol>

Health Research Council of New Zealand (2014)	Pacific peoples in New Zealand	Pacific Health Research Guidelines	<ol style="list-style-type: none"> <li>1. Respect</li> <li>2. Cultural competency</li> <li>3. Meaningful engagement</li> <li>4. Utility</li> <li>5. Rights</li> <li>6. Reciprocity</li> <li>7. Balance</li> <li>8. Protection</li> <li>9. Capacity-building</li> <li>10. Participation</li> </ol>
Inuit Tuttarvingat (2010)  Retrieved from Riddell et al. (2017)	Inuit communities	No title	<ol style="list-style-type: none"> <li>1. Respect of intangible cultural property in the form of language and traditional knowledge</li> <li>2. Empowerment of the community and positive outcomes for regions and communities involved</li> <li>3. Mutually beneficial research through knowledge sharing with individuals, regions, and government</li> <li>4. Respecting animals through the research process and methods</li> </ol>
ITK & NRI (2006)	Inuit communities	Negotiating Research Relationships with Inuit Communities	<p>Numerous recommendations provided related to:</p> <ol style="list-style-type: none"> <li>1. Elements of a negotiated research relationship</li> <li>2. Determining level of community involvement</li> <li>3. Initiating community contact</li> <li>4. Research licensing</li> <li>5. Community strategies</li> </ol>
Jacklin et al. (2008)	Aboriginal communities in Canada	Eight Principles of Appropriate Community-Based Participatory Research	<ol style="list-style-type: none"> <li>1. Partnership</li> <li>2. Empowerment</li> <li>3. Community Control</li> <li>4. Mutual Benefit</li> <li>5. Wholism</li> <li>6. Action</li> <li>7. Communication</li> <li>8. Respect</li> </ol>
Jamieson et al. (2012)	Indigenous Australian populations	Ten principles relevant to health research among Indigenous Australian populations	<ol style="list-style-type: none"> <li>1. Addressing health issue identified by community</li> <li>2. Mutually respectful partnerships</li> <li>3. Capacity building is a key focus within research partnership</li> <li>4. Flexibility in study implementation</li> <li>5. Respect community history and current needs</li> <li>6. Recognition of diversity</li> <li>7. Conduct research in appropriate time</li> <li>8. Preparing for leadership turnover</li> <li>9. Support community ownership of project</li> <li>10. Develop systems to manage multi-center partnerships</li> </ol>
LaVeaux & Christopher (2009)	Native American communities	No title, however authors compiled a list for completing CBPR with Indigenous communities	<ol style="list-style-type: none"> <li>1. Acknowledge historical experience of communities</li> <li>2. Recognize tribal sovereignty</li> <li>3. Differentiate between tribal and community membership</li> <li>4. Understand tribal diversity and implications</li> <li>5. Plan for extended timelines</li> <li>6. Recognize key gatekeepers</li> <li>7. Prepare for leadership turnover</li> <li>8. Interpret data within cultural context</li> <li>9. Use Indigenous ways of knowing</li> </ol>
National Health and Medical Research Council (2003)	Aboriginal and Torres Strait Islander Australians	Guidelines for ethical conduct in Aboriginal and Torres Strait Islander health research	<ol style="list-style-type: none"> <li>1. Reciprocity</li> <li>2. Respect</li> <li>3. Equality</li> <li>4. Responsibility</li> <li>5. Survival</li> <li>6. Protection</li> </ol>

Noojmowin Teg Health Centre (2003)	First Nations Communities in the Manitoulin, Ontario area	Guidelines for Ethical Aboriginal Research	<ol style="list-style-type: none"> <li>1. Research must emphasize a direct benefit to local community health</li> <li>2. Research projects should have the guidance of a local steering committee</li> <li>3. Issues surrounding the protection of traditional knowledge must be addressed</li> <li>4. Research methodologies must be culturally acceptable at the community level</li> <li>5. Research should incorporate traditional values into the research approach</li> </ol>
Ontario Federation of Indian Friendship Centres (2012)	Indigenous people in Ontario, Canada	The Utility, Self-Voicing, Access, and Inter-Relationality (USAI) framework	<ol style="list-style-type: none"> <li>1. Research is useful, practical, and benefiting communities</li> <li>2. Research is authored by communities, who remain recognized as knowledge holders</li> <li>3. Research recognizes local knowledge, practice, and experience</li> <li>4. Research is historically situated and explicit about perspectives used to create it</li> </ol>
Parker et al. (2019)	American Indian and Alaska Native communities	Risk and Protection module or our research Ethics Training for Health in Indigenous Communities (rETHICS)	<ol style="list-style-type: none"> <li>1. Do good</li> <li>2. Invest time</li> <li>3. Obtain community approval</li> <li>4. Build trust</li> <li>5. Include culture</li> <li>6. Consider vulnerability</li> <li>7. Partner in dissemination</li> <li>8. Maintain high ethical standards</li> </ol>
Snow et al. (2016)	Indigenous communities in Canada	Guiding Principles for Indigenous Research Practices	<ol style="list-style-type: none"> <li>1. Indigenous identity development</li> <li>2. Indigenous paradigmatic lens</li> <li>3. Reflexivity and power sharing</li> <li>4. Critical immersion</li> <li>5. Participation and accountability</li> <li>6. Methodological flexibility</li> </ol>
Weber-Pillwax (2001)	Indigenous communities	Indigenous research values	<ol style="list-style-type: none"> <li>1. Respectful relationships between the topic and the researcher</li> <li>2. Respectful relationships between researchers and research participants</li> <li>3. Respectful relationships within research partnerships</li> <li>4. Identification of researcher's role and responsibilities</li> <li>5. Fulfilling obligations within research partnerships</li> <li>6. Relationship reciprocity</li> </ol>

## Appendix K: Researcher Actions Reflected Through Grandfather Teachings

Teaching	Application within the Current Project	Researcher Actions
Humility	Consultation with Research Advisory, community members, participants, and treatment staff members	<ul style="list-style-type: none"> <li>- Recognition that each individual has value and can contribute to the project in an equitable way</li> <li>- Limited use of professional titles or distinctions</li> <li>- Active listening rather than insertion of researcher ideas</li> <li>- Admitting mistakes and accepting criticism of project activities and/or researcher actions</li> <li>- Recognition of self-limitations and individual strengths</li> <li>- Acknowledgement of contributions to research</li> <li>- Eliminating use of technical jargon</li> </ul>
Bravery	Upholding research agreements with community, research institution, and REB	<ul style="list-style-type: none"> <li>- Adhering to all research agreements, across contexts</li> <li>- Maintaining integrity to communities even when consequences could be detrimental</li> <li>- Prioritizing community needs over self-interest</li> <li>- Consistently following through on promises and keeping your word</li> <li>- Filling client requests (ex: removal of data from study)</li> </ul>
Honesty	Adhering to consent procedures, generating clear expectations about project to staff and clients, and generally keeping one's word	<ul style="list-style-type: none"> <li>- Carefully reviewing consent procedures with clients in a way that was easily understood</li> <li>- Reviewing roles of team members</li> <li>- Discussing risks and benefits to study participation with both staff and clients</li> <li>- Being clear about potential individual benefits for researchers (ie: expectation data would be used for a academic student purposes)</li> <li>- Stating objectives of research in a transparent way</li> </ul>
Wisdom	Use of multiple systems of knowledge and integration with a two-eyed seeing approach	<ul style="list-style-type: none"> <li>- Similar to humility, equivalent recognition of many forms of knowledge and expertise</li> <li>- Integrative hypotheses testing using multiple knowledges, data, and experiences</li> <li>- Use of a two-eyed seeing framework blending Indigenous and non-Indigenous ways of knowing</li> <li>- Use of research methods that reflect two-eyed seeing</li> <li>- Seeking stakeholder feedback regarding the representation of study results for Indigenous people</li> </ul>

		<ul style="list-style-type: none"> <li>- Sharing authorship in a way that is reflective of stakeholder contributions, regardless of academic affiliation</li> <li>- Integration of cultural teachings and guidance</li> <li>- Knowledge dissemination to share insights in ways that are useful to communities. This has included community reports, presentations, handouts, and oral feedback</li> </ul>
Respect	Showing mutual appreciation for each individual role and contribution to the project	<ul style="list-style-type: none"> <li>- Scheduling research activities during best times for staff</li> <li>- Respecting strengths and needs of staff and clients</li> <li>- Seeking feedback from staff and clients about study processes, and acting in a timely manner to address suggestions or concerns</li> <li>- Recognition and reliance on staff clinical training, including their knowledge of the client needs</li> <li>- Seeking consultation from staff members and Research Advisory when problems arise</li> <li>- Showing respect and appreciation for each individual role of the project</li> <li>- Sincerely showing appreciation and gratitude for stakeholders across project stages (ie: bringing coffee or treats for staff members, writing informal thank you notes, verbally expressing gratitude)</li> </ul>
Love	Relationship building with community partners, participants, and staff members	<ul style="list-style-type: none"> <li>- Holding regularly occurring meetings</li> <li>- Soliciting honest communication and feedback from stakeholders</li> <li>- Allowing time for relationships to naturally develop</li> <li>- Flexibility, humor, and friendliness of researchers</li> <li>- Authenticity in relationships</li> <li>- Prioritization of relationships with stakeholders rather than research goals</li> </ul>
Truth	Representing self authentically, including personal goals, values, and beliefs associated with project	<ul style="list-style-type: none"> <li>- Recognizing personal strengths, limitations, and values</li> <li>- Being authentic to individual beliefs and values</li> <li>- Reflection of individual actions within broader research context, and whether such actions helped or hindered project goals</li> <li>- Consideration of how individual and organizational values were or were not reflected in the research</li> </ul>