EXAMINING CHILD HEALTH AND HEALTH CARE SUPPORT IN A GROUP OF OFF-RESERVE CANADIAN INDIGENOUS CHILDREN DIAGNOSED WITH EPILEPSY

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Abstract

In comparison to children with epilepsy in the general population, little is known about the profile and outcomes of Indigenous children with epilepsy. The 2006 Aboriginal Children's Survey (ACS) was used to examine risk and resiliency factors in a sample of Indigenous children between one and five years of age. Logistic regressions were completed on a subset of the ACS population (epilepsy group N = 600; Control group N = 5890), where children were matched according to age, sex, and health status.

Indigenous children in Canada had higher rates of epilepsy compared to the overall rate of epilepsy for children in Canada. Children with epilepsy compared to those without epilepsy had significantly higher rates of vision and hearing issues, allergies, asthma/bronchitis, and speech-language difficulties. Children with epilepsy were less likely to see a specialist than those without epilepsy. Children who received breast milk were significantly less likely to have epilepsy than those children who did not receive breast milk. If a child had a medical, neurodevelopmental or mental disorder, they were more likely to have epilepsy. Caregivers who rated themselves as healthy were less likely to have a child with epilepsy; even when comparing children with poor health status those caregivers who were healthy had less chance of having a child with epilepsy. In addition to caregiver health, those caregivers who were removed from the home as children were also more likely to have children with epilepsy regardless of the child's health status.

Canada will continue to face challenges in providing care to Indigenous children, unless it addresses some important gaps in how health care is provided to this vulnerable population.

Keywords: Indigenous, health, SDQ, epilepsy, children, milestones

Dedication

York University acknowledges its presence on the traditional territory of many Indigenous Nations. The area known as Tkaronto has been taken care of by the Anishinabek Nation, the Haudenosaunee Confederacy, the Wendat, and the Métis. It is now home to many Indigenous peoples. We acknowledge the current treaty holders and the Mississaugas of the Credit First Nation. This territory is subject of the Dish With One Spoon Wampum Belt Covenant, an agreement to peaceably share and care for the Great Lakes region.

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Chapter One: Introduction

Relevance

When examining the entire non-Indigenous Canadian population, children in Indigenous populations are the largest growing age group and form a significant proportion of Indigenous people in Canada. Indigenous children under 14 comprise 28% of the total Indigenous population, with 7.7% being children between ages 0 to 4 years old (Statistics Canada, 2016). With such a growing and young population, appropriate measures are needed to ensure Indigenous children's health and safety; this involves knowing more about their needs and how to best support them in a caring and respectful manner.

Throughout Canadian history, Indigenous groups have been neglected, abused and often overlooked with respect to health (The Truth and Reconciliation Commission of Canada [TRC], 2015a, 2015b, 2015c). As recently as 2016, the Canadian Human Rights Tribunal placed a demand on the Department of Indigenous Affairs to address the gap in basic services for Indigenous children (Porter, 2016). Children's long-term health prognosis is greatly impacted by the care they receive, and thus respectful health care must also consider the important role culture plays in access and provision of services.

According to Indigenous healers, health care involves healing the body, mind, and also the spirit (Struthers, 2000). Connecting with one's culture plays a vital role in resilience (Struthers, 2000, 2003). Traditional culture is an integral part of health care for many Indigenous people and, for many, both Canadian mainstream health care and traditional health care go hand in hand (Struthers, 2003; Struthers, Eschiti, & Patchell, 2008). In order to better understand how to best support Indigenous groups in a holistic manner, it is important to understand their needs.

The health of Indigenous people is of particular concern, given that their life expectancy is about a decade less than that of the general Canadian population, with lower life expectancy at birth, particularly for the Inuit population (A Report of the Chief Public Health Office, 2016). A number of factors contribute to poor health outcomes, these include: low income, education, lack of adequate housing, food insecurity, and smoking, along with significant disparities in access to health care (Bowen, 2000). Childhood neurological disorders are of particular concern, because children with neurological disorders require additional and multi-faceted services along with specialized care. The findings stemming from this research will contribute to our understanding of child development and comorbid disorders for Canadian Indigenous children with epilepsy.

Epilepsy is the most common neurological disorder in childhood with 0.36 to 0.46% of children having epilepsy. Epilepsy is characterized by unpredictable seizures that can cause a vast number of health and mental health problems because it occurs during brain development (Beilmann, Napa, Soot, Talvik & Talvik, 1999; Sidenvall, Forsgren, & Heijbel, 1996). Children with epilepsy have an increased risk of behavioural, emotional and academic problems (Beilmann et al., 1999; Ettinger et al., 1998; Sidenvall et al., 1996; Hanssen-Bauer, Heyerdahl, & Eriksson, 2007). Twenty-six to 57% of children with epilepsy have an intellectual difficulty, 28% have speech disorders and 23% have learning difficulties (Cormack et al. 2007, Berg et al., 2008, Sillanpaa, 1992). Children with epilepsy are more likely to also have psychopathology and family adjustment problems (Otero, 2009). In terms of quality of life, individuals with epilepsy experience rejection and stigmatization. Adults with child-onset epilepsy and poor cognitive development are more likely than those with poor cognitive development alone to suffer from poor mental health (Chin et al., 2011). Quality of life is negatively impacted in children with epilepsy, as they experience feelings of loneliness/social isolation and financial burden

(Hamama-Raz & Hamama, 2015). Within this population, parents worry about their child's removal from the home and that physicians will not address the needs of the child in a holistic manner that involves collaboration (Denison, Varcoe, & Browne, 2013; Struthers, 2003; Larson, Herx, Williamson, & Crowshoe, 2011). Epilepsy has a strong impact on both physical and mental health, and with disparities in access to care by Indigenous children, the impact may be greater than that of the general population.

Epilepsy can have a devastating impact on a child's well-being. Currently, there are gaps in our knowledge in how epilepsy impacts preschool children. For the present research, I used the "2006 Aboriginal Children's Survey" to gain a better understanding of the health of Indigenous Children in Canada who have epilepsy. The goal of this research was to promote knowledge exchange between health care workers in the community at large and those in Indigenous communities, to provide better services to children with epilepsy. Improved understanding of the protective and risk factors impacting Indigenous children with epilepsy will inform a collaborative effort to provide optimal care.

Indigenous Culture in Canada

According to the 2016 Census, Indigenous groups make up 4.9% (1.7 million people) of Canada's total population, with 42.5% growth in the population over the last 10 years. Fifty-eight percent of Indigenous people identify as First Nations, 35.1% as Metis, and 3.9% as Inuit. There are 70 Indigenous languages used in Canada, with 36 of those languages spoken by at least 500 speakers (Statistics Canada, 2016). According to the National Household Survey (NHS), the largest number of Indigenous people in Canada live in Ontario and the western provinces (Manitoba, Saskatchewan, Alberta, and British Columbia), while Nunavut and the Northwest

Territories make up the largest shares of the Inuit population. According to Focus on Geography Series (Statistics Canada, 2017) 38.9% of the Indigenous population live in rural settings, 30.3% live in large population centres (i.e., populations of 100,000 or more), 20% live in small population centres (i.e., population between 1000 to 29,999), and 10% live in medium population centres (i.e., population between 30,000 to 99,999) (Statistics Canada, 2017). About 20% of Indigenous people live in dwellings that are in need of major repairs, and 18.3% live in households that are overcrowded. Over 80%, or 297 Indigenous reserves have median incomes that fall below the poverty line ($22,133), with 27 communities reporting median total incomes below $10,000 (Statistics Canada, 2017).

Within the Indigenous population, the average age is 32.1 years, which is about a decade younger than the Canadian population (Statistics Canada, 2016). Unlike Canada's population, which has undergone a generational shift with now more seniors than children, the opposite trend exists among Indigenous groups. According to the 2011 National Household Survey (Statistics Canada, 2011) 392,100 Indigenous children under the age of 14 live in Canada, representing about 28% of the total Indigenous population. In comparison, children represent 17% of the total non-Indigenous population. The birth rate of Indigenous children is about 1.5 times higher than the non-Indigenous birth rate. According to the 2016 Census, there are 145,645 Indigenous children under 4 years of age, accounting for 8.7% of the total Indigenous population.
In terms of living arrangements, about 60% of Indigenous children under 4 years of age live with both parents, over 33% live with a lone parent, and 16% live in a two-generational household, and approximately 7.7% live in foster care; of all children in foster care about half are Indigenous children in the 0 to 4 age group. In 2011, over 14,000 Indigenous children under 14 lived in

foster care, accounting for 48% of all foster children in the general population, even though they represent only 7% of all Canadian children (Statistics Canada, 2011).

Indigenous People and their Relationship with Canada

The Indigenous people of Canada have had and continue to have a strained relationship with the Canadian government, resulting in multi-generational trauma. In the late 1800's residential schools were created by the Canadian government and later run by churches, separating approximately 150,000 Indigenous children from their families. The schools were created to assimilate Indigenous children and youth and remove their cultural identity (TRC, 2015a, 2015b, 2015c). Children in residential schools were provided minimal academic instruction. Many suffered severe health concerns, along with physical, psychological and sexual abuse. Families were threatened that they would not be provided with supplies if they did not send their children to school, along with other tactics like the power to arrest a child, and transport and detain children in school. In 1894 residential schools became voluntary; however, if a child was deemed not properly cared for, that child would be placed into a residential school (The Truth and Reconciliation Commission of Canada [TRC], 2015a, 2015b, 2015c).

The Truth and Reconciliation Commission documented over 6,000 deaths as a result of the residential school system. From 1960 to approximately 1985, many children were removed from families through child-welfare agencies and placed with non-Indigenous families, with thousands of children sent across North America and Europe. In the 1970's the management of residential schools was given to provincial and territorial governments, along with a number of Indigenous groups running their own schools. In 1998, the Aboriginal Healing Foundation was

founded, and money was given by the government to address the abuse and suffering of individuals who attended residential schools (TRC, 2015a, 2015b, 2015c).

Indigenous groups have often felt neglected by the Canadian government. In 2005, the prime minister and premiers met with Indigenous leaders in Kelowna to put forth a plan to improve the lives of First Nations, Metis and Inuit people. The conference yielded a plan that included improvements in education, housing, health services, and economic development (Webster, 2006). In 2006, the Conservative government budget suggested that commitments made in the Kelowna deal would not be kept, nor were exact budget amounts disclosed (Webster, 2006). In 2012, Canada's Conservative government terminated funding for First Nations organizations dedicated to developing health policies for over 600 Indigenous groups (Webster, 2012).

Racism involves erroneous beliefs and preconceived notions about a particular group of people, these beliefs are used to perpetuate dominance, and in the case of health care services it means withholding or providing inadequate health care (Henry, Houston, & Mooney, 2004) Indigenous people have experienced a history of racism within the health care system, losing faith in the system responsible for their well-being. The legal rule that resulted from Jordan's Principle was adopted by the House of Commons in 2007 ensuring timely health care access. Jordan's Principle is named after Jordan River Anderson, a four-year-old boy with complex needs who died in hospital in 2005 after a drawn-out court battle between the Federal government and Manitoba government over his home care costs. Jordan's Principle, that care should be provided immediately, and any issues over which level of government should pay for it must be resolved after the patient has been attended to. Previously a patient had to have several disabilities, requiring multiple service providers to qualify for immediate treatment.

In 2016, the Canadian Human Rights Tribunal gave the Department of Indigenous Affairs two weeks to implement Jordan's Principle. The tribunal noted a gap between basic services for Indigenous children compared to non-Indigenous children, sighting that the Canadian government discriminated against First Nation Children living on reserves by failing to provide same level welfare services that exist elsewhere (Fontaine, 2016; Porter, 2016).

Chronic Health Conditions in Indigenous Groups

The Health Status of Canadians 2016: A Report of the Chief Public Health Officer provides an overview of the health status of Indigenous Canadians in comparison to non-Indigenous Canadians. The data about Indigenous individuals was collected in the years between 2004 and 2014.

Life expectancy. According to the report, Indigenous populations have an average life expectancy over a decade lower than that of non-Indigenous Canadians (A Report of the Chief Public Health Officer, 2016). A higher proportion of Inuit children are born with a low birthweight, adding to the complexity of the care they require. According to Webster (2012), infant mortality rates are about 20% higher when compared to the rest of Canada's population; however, this rate is considered to be an underestimate, as there are Indigenous people who may not be registered or identify as Indigenous according to government census (Smylie, Fell, Ohlsson, & Joint Working Group of First Nations, Indian, Inuit and Metis, 2010). A number of reports suggest that the mortality rate of infants is 190% higher for First Nations compared to non-First Nations, and 360% higher for Inuit-inhabited areas compared to non-Inuit inhabited areas (Shah, Zao, Al-Wassia, & Shah; 2011; Luo et al., 2010). These infant mortality rates may be underestimates since some Indigenous individuals may be missed in reporting because of

movement between reserves or off reserves, and government issues with their identification as Indigenous people (Elias, 2014).

Physical and mental health. When evaluating their own physical and mental health, Indigenous Canadians rated themselves lower than non-Indigenous Canadians; 45 to 55% of Indigenous people rate their own health as excellent to very good, compared to 63% of non-Indigenous Canadians (A Report of the Chief Public Health Office, 2016). According to an American survey with over 14,000 Indigenous youth respondents, those with a chronic illness had a high incidence of eating disorders and were more likely to attempt suicide, with the rate of suicide attempts doubling for those Indigenous youth with a physical condition and a comorbid learning, behavioural, or emotional condition (Blume, Potthoff, & Resnick, 1997). Indigenous youth with chronic illnesses were also at a greater risk for physical and sexual abuse in comparison to their healthy counterparts. This group also reported higher rates of family rejection (Blume et al., 1997). Research has shown that Indigenous people with epilepsy have a higher number of visits to physicians, emergency rooms and hospitalizations, but significantly fewer specialist visits compared to non-Indigenous people with epilepsy, as specialists are not available in remote communities (Jette et al, 2008).

In terms of mental health, 65% to 67% of Indigenous people rated their mental health between excellent and very good, in comparison to 75% of non-Indigenous Canadians (A Report of the Chief Public Health Office, 2016). However, the 2000/2001 Canadian Community Health Survey found that off-reserve Indigenous populations were 1.5 times more likely than non-Indigenous populations to experience a major depressive episode. There was a significant relationship between major depressive symptoms and income level, physical/social environment, social support, health services and culture for Inuit and Metis respondents (Brass, 2010).

Additionally, anxiety was related to amount of social support, community satisfaction and feeling safe when alone at home (Brass, 2010).

Factors impacting health. The report noted a number of factors influencing the health of Canadians, these included income, education, housing, food security, smoking, immunization completion and physical activity; across all factors Indigenous people fared worse, with the exception of immunization completion and physical activity which were similar for both groups (A Report of the Chief Public Health Office, 2016).

According to the report, 25-30% of Indigenous people experience low income in comparison to only 15% of non-Indigenous individuals (A Report of the Chief Public Health Officer, 2016). According to the Aboriginal People's Survey in 2001, unemployment rates are four to five times higher for Indigenous Canadians over 15 years of age when compared to non-Indigenous Canadians (Smylie & Adomako, 2009). In 2006, Children under 5 years of age who were First Nations living off-reserve, Metis, or Inuit living outside of Inuit Nunaat (known as the Inuvialuit Region in the Northwest Territories, the territory of Nunavut, Nunavik in northern Quebec, and Nunatsiavut in northern Labrador) were almost twice as likely to live in low-income families, compared to non-Indigenous children (Smylie & Adomako, 2009). Information about Inuit children living in Inuit Nunaat regions and on-reserve First Nations children are not available, but data reveals that more often Indigenous children are living in poverty, as compared to non-Indigenous children.

In terms of education, around 52% to 79% of Indigenous people complete high school, in comparison to 88% of non-Indigenous individuals (A Report of the Chief Public Health Office, 2016). Census data from 2006 suggests that Inuit children who live inside Inuit Nunaat regions

have more access to Indigenous teachers and more opportunities for Indigenous-based teachings and philosophies (Smylie & Adomako, 2009).

In terms of housing, on average 19% (about 100,000) of Indigenous households are in core housing need (i.e., dwelling is considered unsuitable, inadequate or unaffordable) in comparison to only 12% of non-Indigenous households (A Report of the Chief Public Health Officer, 2016). The Inuit population has the highest need for housing with 34% living in overcrowded households (i.e., the required number of bedrooms for a household based on age, sex and relationship among members) (A Report of the Chief Public Health Office, 2016). Some data suggest that overcrowding occurs for 32% of Indigenous adults, with 34% reporting the need for major home repairs and 32.3% reporting that their main water supply was not safe for drinking (Anderson, Smylie, Anderson, Sinclair, & Crengle, 2006; First Nations Information Governance Committee, 2006).

Food insecurity is significantly higher in Indigenous households ranging from 15% to 27%, in comparison to non-Indigenous households at 7%, with 63% of Inuit people reporting food insecurity (A Report of the Chief Public Health Office, 2016). Rates between 21% to 83% of food insecurity have been estimated for First Nations populations living on-reserve (Power, 2007). Nearly 70% of Inuit preschoolers reside in households that reported food insecurity, with 60% of these children not eating for at least a whole day when there was severe food insecurity (Egeland, Pacey, Cao & Sobol, 2010). Weekly food costs are estimated to be between $350-$450 in Inuit Nunaat in comparison to $200 in the south (Gionet, 2014), adding further to food insecurity.

About 50% of Indigenous people smoke, in comparison to half that in non-Indigenous individuals (A Report of the Chief Public Health Office, 2016). Prenatal environmental tobacco

exposure has been reported to be as high as 50% in families of First Nations living on reserve (First Nations Information Governance Committee, 2007). About 30% of First Nations children between 12 and 14 living on-reserve reported smoking tobacco (First Nations Information Governance Committee, 2007), and 56% of Inuit children between 12 to 19 smoked, in comparison to about 15% of the general Canadian population (National Collaborating Centre for Aboriginal Health, 2011). Exposure to tobacco whether first or second hand impacts respiratory health. First Nations children living on reserve had bronchitis at more than double the rate of the Canadian population (3.6% versus 1.4%) (First Nations Information Governance Committee, 2007).

In terms of immunization, data were not available for Indigenous populations. Early immunization records for First Nations on-reserve children below age two show that they are receiving vaccines for measles, mumps, and rubella, similarly to non-Indigenous groups in Canada, although data for other Indigenous groups were not available (A Report of the Chief Public Health Officer, 2016).

Physical activity is similar in both Indigenous and non-Indigenous individuals with over half the population reporting participation in physical activity as determined by the Canadian Physical Activity Guidelines (A Report of the Chief Public Health Officer, 2016).

Chapter Two: Theoretical Perspective

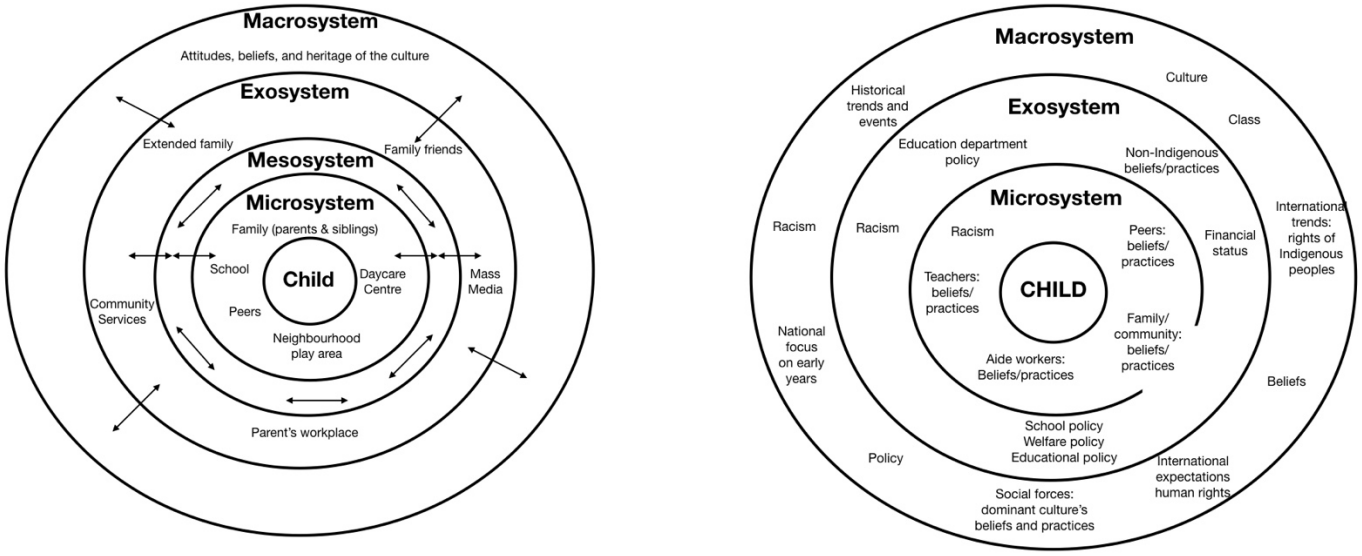
Bio-Ecological Systems Theory

Bronfenbrenner's Bio-ecological systems theory examines human development as a "mutual accommodation, throughout the life course, between an active, growing human being and the changing properties of the immediate settings in which the developing person lives, as this process is affected by the relations between these settings and by the larger contexts in which the settings are embedded". (Bronfenbrenner, 2005, p. 107). This perspective emphasizes the influence of the microsystem, mesosytem, exosystem and macrosystem on the development of an individual, which are linked together both proximally or distally and change with time and as a result of interactions. That is, this theoretical perspective indicates that immediate and distant environments in which the child lives influence the child's development and that these environments in turn influence one another. These influences are transactions that occur between the child and the setting within which the child functions.

This model highlights that the immediate setting is not the only setting that interacts with and impacts the child; distal settings do as well because of the transactions that occur between levels of settings. Additionally, children impact the settings they interact with based on their own characteristics. The system is dynamic and changing both in the interactions and as a result of the passage of time. Figure 1a depicts Bronfenbrenner's Bio-ecological Model (Bronfenbrenner, 2005). The individual lives within the microsystems that interact with one another (i.e., mesosystem), more distal settings are labelled exosytems, and finally, the macrosystem houses all the other systems and comprises the attitudes and ideologies of the culture. The arrows in Figure 1a denote the possibility for interactions and influences at each level.

Adapted Bio-Ecological Systems Theory

Figure 1b features the adapted model by Maher (2013) who includes Human agency theory within the model (Bandura, 2001), which states that one's agency can be exercised individually, through a proxy who acts on one's behalf, and through a collective agency in order to make changes to future outcomes (Bandura, 2001). According to this model, direct agency is seen through the child's interactions with individuals in the microsystem (e.g., teachers, parents), proxy agency roles are seen in those individuals in the microsystems (e.g., teacher's aide) who advocate on behalf of the child. The adapted model represents Human Agency theory through the open circle in Figure 1b. According to Maher (2013), "children actively motivate others to work on their behalf" (e.g., Community Elders'), this adapted Bio-ecological model is more evident in a collective society where there is responsibility for all and others must take action as a collective agency in order to succeed and make key changes (Maher, 2013, p. 22). According to Maher (2003), the non-Indigenous community (known as the dominant community) act as gatekeepers, often imposing their beliefs and practices on the Indigenous community. These beliefs may have an enabling or inhibitory effect on Indigenous people, impacting how society treats Indigenous people, what policies are adapted, and what non-Indigenous people believe when they interact with Indigenous community members. In essence, racism may be present for Indigenous people at every level (Maher, 2013). Figure 2 is based on the present study and incorporates the Bio-ecological model as explained by Bronfenbrenner (2001), as well as the adaptation as presented by Maher (2013).



a) Bio-Ecological Model b) Adapted Bio-ecological model

Figure 1. *(a) Bio-Ecological Model (b) Adapted Bio-Ecological Model*

(a) Bronfenbrenner's Bio-ecological Model (Bronfenbrenner 2005; Kail, 2001), (b) adapted Bronfenbrenner Bio-ecological model (Maher, 2013) incorporates Indigenous child's environment with respect to educational development. The adapted model represents Human Agency theory through the open circle. The Mesosystem exists in the adapted model but is not shown pictorially.

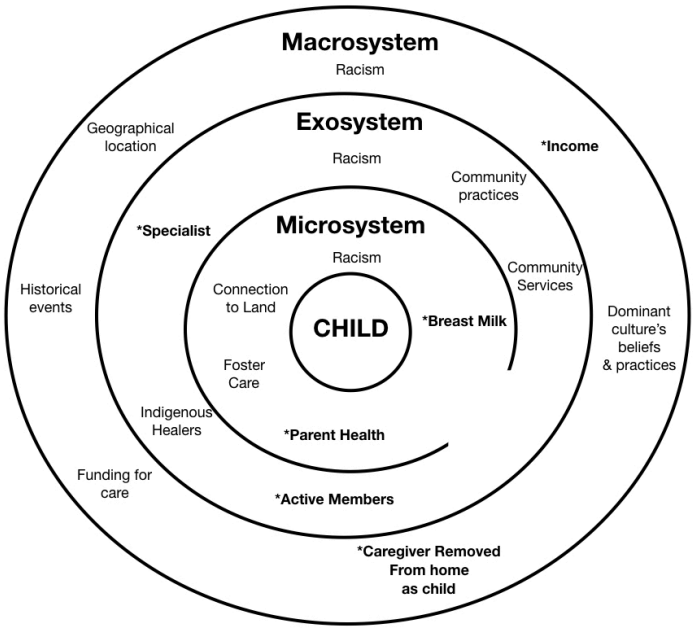


Figure 2. *Bio-ecological Model adapted by author*

Adapted Bio-ecological model incorporating the Indigenous Child's environment with respect to health development. *Indicates the risk and resiliency factors used in logistic regression analyses in present sample.

Microsystem. The microsystem is a "a pattern of activities, roles, and interpersonal relations experienced by the developing person in a given face-to-face setting with particular physical and material features and containing other persons with distinctive characteristics of temperament, personality, and systems of behaviour" (p.148, Bronfenbrenner, 2005). The microsystem consists of things like people or places in the individual's immediate environment that she/he interacts with face-to-face, such as family, school, peers, religious institutions, or health services (Figure 1).

For Indigenous children the microsystem contains immediate family and also family members across generations that live in the home or nearby who are directly involved in care. The microsystem also contains the relationship the individual has with the land, as it helps guide spirituality and connects the youth to their roots. Connecting with the land provides healing and nurturing experiences for Indigenous youth, guiding them in their development. For Indigenous children with illnesses, healers also play a vital role in their care and are seen as important members in the child's recovery. If these children require medical attention from western medicine, hospital staff are part of that microsystem. At this level children also experience racism, as Indigenous people's opinions are often overlooked, and a holistic approach is not taken in healing. In some instances, reports about symptoms are minimized and Indigenous individuals are not seen as adequate reporters in their own care or health. Additionally, racism is present in how the government judges parental fit, owing to the fact that many Indigenous children are in foster care, with some children placed with non-Indigenous families thereby losing their connection with land and larger family system (Figure 2).

Mesosystem. The mesosystem is made up of connected microsystems, and what happens in one microsystem will influence another, as the child is nested in each microsystem (Figure 1).

Often western medicine interacts with Indigenous medicine in a negative way. Individuals in the microsystem that house western medicine may show a lack of sensitivity to past experiences, and a disregard for the Indigenous person as an expert in his/her own child's health. Such actions devalue the parent's contribution to a child's care, which is opposite of the holistic manner in which Indigenous medicine functions. These discrepancies in how health experts interact with the child and family highlight contradictory messages received by the child and act as stressors. When connections are made between western and Indigenous medicine and are valued, it promotes consistency in messages across microsystems and may promote working together (Figure 2).

Exosystem. The exosystem refers to social settings that are not experienced by the child firsthand (i.e., do not affect the child directly) but, nevertheless, influence the child's development. These settings may include some of the following: Industry, mass media, local politics, neighbours, and social services (Figure 1). It is the interaction between two or more settings, with one containing the child and one or more settings not containing the child but influencing the immediate system of the child (i.e., for a child, it may be the Non-Indigenous community dictating what healthcare is received that may be shaped by beliefs about Indigenous people).

For Indigenous children who require western medicine, racism is prevalent at this level. Parents are fearful that if they bring their child to a western hospital, he/she will be taken from them by social services. These fears are connected to historical events experienced by parents who were raised in residential or federal schools or who were taken into foster care. These fears are also connected to the current situation with a large proportion of Indigenous children placed in foster care. Many physicians admit that they would like to attend to the needs of Indigenous

groups but feel ill equipped. Physicians report that racism prevails, which in turn limits the training required to provide proper care to Indigenous people (Figure 2).

Macrosystem. The macrosystem is the broadest environmental context and holds the subcultures and cultures in which the microsystem, mesosystem and exosystem are embedded. The macrosystem evolves over time. (Figure 1)

At this level are historical events, such as the parents of these children having been placed in institutions, federal schools, or foster care. Their experiences impact how willing they are to trust the western health care system. For Indigenous groups the macrosystem holds the jurisdictional barriers, and the costs of health care to be covered. The macrosystem also houses language barriers and geographical barriers to health care, along with poor infrastructure when it comes to provision of care to remote groups. Indigenous families tend to live in more remote areas, thereby experience greater financial burdens as a result of costs of travel and parental leave from work in order to provide care to the child (Figure 2).

Chapter Three: Literature Review of Epilepsy and Outcomes

Overview of Epilepsy

Epilepsy is the most common neurological disorder in childhood with prevalence rates between 3.6 to 4.6 per 1000 children in the general population. It is characterized by unpredictable seizures that can cause a vast number of health and mental health problems given their onset with brain development and growth (Beilmann, Napa, Soot, Talvik & Talvik, 1999; Sidenvall, Forsgren, & Heijbel, 1996). Epilepsy is a disorder that is characterized by two or more unprovoked seizures more than 24 hours apart in a child over one month of age (International League Against Epilepsy, 1993). Seizures are defined according to three categories: (1) focal-onset seizure which originates within a neural network and is limited to one hemisphere; (2) generalized-onset seizure which originates at any point, and rapidly engages bilateral distributed networks, and (3) seizures of unknown origin (Fisher et al., 2017).

Focal-onset seizure classification includes: (1) atonic with no awareness specification (loss of tone); (2) tonic (i.e., sustained stiffening), (3) clonic (i.e., rhythmic jerking); Some seizures are focal and bilateral tonic-clonic seizures, these are considered a common occurrence and are reflective of a propagation pattern of seizure activity (Fisher et al., 2017); (4) myoclonic (i.e., irregular brief jerking); (5) hyperkinetic (i.e., thrashing); (6) epileptic spasms (e.g., flexion or extension of arms and flexion of trunk); (7) automatisms (e.g., lip-smacking); (8) autonomic (e.g., gastrointestinal sensations); (9) behaviour arrest (e.g., staring blankly); (10) cognitive deficits (e.g., hallucinations); (11) emotional (e.g., laughing); (12) sensory (e.g., olfactory sensations).

Generalized-onset seizure classification is subdivided into motor (i.e., bilateral motor activity from the onset) and non-motor (absence) seizures (i.e., lack of awareness and

movement). Awareness is not used to subcategorize generalized-onset seizures as most generalized seizures involve impaired awareness. Generalized onset seizures types include: (1) tonic (i.e., limb stiffening often with neck stiffening); (2) clonic (sustained rhythmic jerking of the limbs on both sides of the body, often including the head, neck, face and trunk); (3) tonic-clonic (i.e., early movements are tonic followed by clonic phase that shows a decrease in rhythmic jerking over the course of the seizure); (4) myoclonic (i.e., briefer movements and not regularly repetitive or rhythmic three-per-second myoclonic movements); (5) eyelid myoclonic (i.e., jerks of the eyelids and upward deviation of the eyes, often followed by eyes closing or eyes closing in response to light). (6) myoclonic-tonic-clonic (i.e., begin as myoclonic jerks followed by tonic-clonic activity); (7) myoclonic-atonic occurs with brief jerks followed by a limp drop; (8) atonic, (9) epileptic spasms (i.e., flexion, extension or flexion-extension of predominantly proximal and truncal muscles); (10) typical or atypical (i.e., atypical seizure occurs when changes in tone are more pronounced than typical and this distinction is associated with different EEG findings) (Fisher et al., 2017).

Epilepsy etiology is subdivided into the following categories: genetic cause (e.g., inherited or as a result of mutation), structural cause (e.g., malformations of cortical development, traumatic brain injury, tumors), metabolic epilepsies (e.g., creatine disorders, cerebral folate deficiency), immune disorder (e.g., Rasmussen syndrome, antibody disorders), infection (e.g., cerebral malaria), or unknown cause (Shorvon, 2011).

According to a national survey where over 5000 Americans were polled regarding their knowledge and familiarity of epilepsy, only one-quarter considered themselves knowledgeable about epilepsy, with most individuals reporting fear around witnessing a seizure (Kobau & Price, 2003). Those living in rural and remote areas compared to those in urban areas were more likely

to hold inaccurate beliefs about epilepsy and were less likely to report it. Prior to an educational session by the Ghana Fight against Epilepsy Initiative, 40 representatives attending the sessions were polled, from each of the districts in the northern region of Ghana, about their community's perception of the causes of epilepsy; 35% reported believing that epilepsy was a contagious disease, followed by 20% attributing it to taboos and spiritual causes (Adjei et al., 2013). In a rural community in Mexico, 33 individuals from 162 housing units were identified with seizure history; from this group only 39.3% were able to identify an epileptic seizure as such, with 38.5% seeking medical attention and 60% receiving no epileptic drugs (San-Juan et al., 2015). Of this group, almost 70% considered seizures and epilepsy to be a divine intervention, and 94% reported some type of discrimination as a result (San-Juan et al., 2015). According to Indigenous people in Central Africa and in Central and South America, epilepsy is treated with traditional herbal remedies, rituals, and/or spiritual cures resulting from beliefs in mythical causes (Carod & Vazquez-Cabrera, 1998). Ismail et al. (2005) conducted a semi-structured survey with individuals of South-East Asian descent living in the United Kingdom; over half of the responders attributed any illness to fate and the will of God, or as punishment for sins of a past life. Such beliefs in the cause of epilepsy, or illness in general, may alter the rate of reporting and the course parents take when addressing their child's need.

Physical and Mental Health Impact of Epilepsy

Canadians with epilepsy, irrespective of gender, have a two-to five-fold risk of an associated chronic health condition relative to the general Canadian population. They are significantly more likely to develop stomach/intestinal ulcers, stroke, urinary incontinence, bowel disorders, migraine, Alzheimer's disease or chronic fatigue (Tellez-Zenteno, Matijevic, & Wiebe,

2005). Both epidemiological and community studies reveal that children with epilepsy have increased risk of behaviour problems and psychopathology, at a rate of three to six times that of the general population (Austin & Caplan, 2007; Plioplys, Dunn, & Caplan, 2007; Rodenburg, Meijer, Dekovic, & Aldenkamp, 2005). This increase is even greater in families with psychiatric history and children with more acute seizure disorders (Kavanaugh, Scarborough, & Salorio, 2015; Hanssen-Bauer, Heyerdahl, & Eriksson, 2007). Anxiety disorders have been reported in children with epilepsy at higher rates than the general population (Caplan et al., 2005; Jones et al., 2007). It is difficult to note whether anxiety is a result of the epilepsy diagnosis or presence of unpredictable seizures, or a part of the adjustment to having a chronic disorder, or a true co-morbidity with separate etiology (Jones et al., 2015). Children with epilepsy and comorbid anxiety are more likely to have a first-degree relative with a history of anxiety or depression than those with epilepsy without comorbid disorders or healthy controls (Jones et al., 2015). Childhood/adolescent psychopathology and family adjustment problems are more likely to occur with pediatric epilepsy (Otero, 2009). Children with epilepsy have a 3 to 9 times higher risk of psychopathology compared to healthy controls and children with non-central nervous system (CNS) chronic illnesses (Pliplys, Dunn, & Caplan, 2007). A national survey of 31,897 children comparing children with epilepsy to healthy controls between the ages of 6-17 years old, did not find differences in their reports of feeling anxious/depressed or making/keeping friends. However, the study revealed that children with epilepsy who did not have comorbid internalizing (i.e., anxiety, depression) disorders tended to act out and fight/bully others when compared to children without any conditions (Pastor, Reuben, Kobau, Helmers, & Lukacs, 2015). Prevalence rates for autism spectrum disorder (ASD) in children with epilepsy range from 7.1% to 32%, which is greater than that of the general population where the rate of ASD is 0.6-1% (Clarke et

al., 2005; Saemundsen, Ludvigsson, Hilmarsdottir, & Rafnsson, 2007). Hara (2007) reported that 25% of patients with ASD who were followed up over a 10-year period developed epilepsy. These individuals had lower IQ and lower social maturation raising the question of whether the presence of seizures added to the symptoms of ASD (Hara, 2007).

Baca and colleges (Baca, Vickrey, Caplan, Vassar, and Berg, 2011) conducted a prospective study of 277 children diagnosed with epilepsy around age four and reassessed nine years later. They found that at the time of reassessment 64% of these children had been seizure free for 5 years, 31% were taking antiepileptic drugs, and 19% had complicated epilepsy (i.e., intractable seizures in need of multiple treatment modalities). At follow-up the findings showed that a number of comorbid diagnoses were present: 26% had psychiatric diagnosis (e.g., internalizing psychiatric disorder, depression, anxiety, Bipolar, Obsessive-Compulsive disorder, ADHD, conduct disorder), with the highest reported being attention deficit hyperactivity disorder (ADHD); 39% had either a developmental delay, language delay, dyslexia, or autism, with the highest reported to be developmental delay and language delay; and, 24% also had a chronic illness (e.g., asthma, diabetes, cancer, arthritis, or allergies) (Baca, et al., 2011).

Many studies suggest that various epilepsy factors (e.g., type and location of seizure, age at onset, severity, duration, abnormal EEG or MRI findings and medication) act as important contributors to the presentation of comorbidities. In a retrospective chart review of 607 children (ages 6-14) with ADHD, 2.3% of these children had a history of epilepsy that had been diagnosed 1.8 years before their ADHD assessment (Socanski et al., 2010). The children who had a comorbid diagnosis of epilepsy and ADHD also had focal seizures and tended to have abnormal EEG patterns. It is important to note that antiepileptic medications (barbiturates, benzodiazepines) often have side effects on behavioural and cognitive outcomes that resemble

ADHD symptoms (Bourgeois, 2004). Barriers to mental health access for children with epilepsy include resistance of mental health clinicians to treat children with epilepsy, the stigma of mental health problems, and the need for providers to be educated about the comorbid behavioural and cognitive conditions (Smith et al., 2007).

Cognitive Changes

Overall intelligence. In a cohort study of 64 children who were between ages three and six years, children with epilepsy on average had a significantly lower IQ (M=76, SD=26.06) than the normative mean (M=100, SD=15), where 21.9% of children with epilepsy had mild impairment and 28.1% had moderate to severe impairment. Children with complicated epilepsy (defined as those with remote symptomatic cause or an epileptic encephalopathy) had significantly lower cognitive functioning than children with uncomplicated epilepsy (i.e., when cause is unknown) (IQ=91.27 vs. IQ=62.56, respectively), but not that this analysis did not include children who were so impaired that they could not be evaluated with existing testing material (Rantanen, Eriksson, & Nieminen, 2011). Significant correlations were found between cognitive impairment and group (complicated vs. uncomplicated epilepsy) as well as neurological diagnosis, age at onset, and MRI results. No significant correlations were found between impairment, and seizure frequency, etiology, duration, status epilepticus, EEG results or number of antiepileptic medications. When examining a predictive model of cognitive impairment only, age at onset of seizures was a significant predictor (Rantanen et al., 2011). Later age at onset and a shorter duration of epilepsy both correlated with a higher IQ score, whereas number of current and previous antiepileptic medication trials was inversely correlated with IQ (Sherman et al., 2012).

A three-year follow-up of children with epilepsy and sex-matched controls in rural northern Tanzania found that children with epilepsy had significantly more behavioural and cognitive difficulties than controls, with improvement in behaviour for those children whose seizure activity decreased or who had good seizure control (Powell et al., 2015).

Verbal abilities. In another study examining verbal intelligence in children between the ages of three to six, verbal intelligence differed between children with epilepsy who did not have EEG abnormalities and the healthy control group. Children with epilepsy tended to be more heterogeneous in their performance on neurocognitive tasks. The authors failed to show that epilepsy factors such as seizure control, antiepileptic medication, and onset of treatment or seizure location were related to verbal intelligence (Rantanen, Nieminen, & Eriksson, 2010). Another study found that, compared to healthy controls, children who have a high number of seizures have significant cognitive difficulties in verbal expression (Sherman, Brooks, Fay-McClymont, & MacAllister, 2012).

Executive functioning skills. Some studies have shown that processing speed deficits may be related to younger age at onset, epilepsies with known causes (e.g., genetic, structural), generalized seizures, or frequent interictal discharges (Fastenau, Shen, Dunn, & Austin, 2008; Dunn et al., 2010; Nacolai et al., 2012; Rathouz et al., 2014). Studies have shown that children with epilepsy have lower processing speed and executive functioning, impaired visual perceptual reasoning, visual attention, motor abilities and motor speed, all of which contribute to the higher order cognitive functions that can be impaired (Braakman et al., 2012; Gottlieb, Zelko, Kim & Nordli, 2012; Bhise, Burack, & Mandelbaum, 2010). Children with a high number of seizures compared to healthy controls had significant cognitive difficulties in working memory and processing speed (Sherman, Brooks, Fay-McClymont, & MacAllister, 2012). Menlove and Reilly

(2015) performed a systematic review of 88 studies that assessed memory in children with epilepsy and found that most studies reported lower memory scores for children with epilepsy in comparison to controls. Research suggests that difficulties are not related to intelligence but rather specific factors such as executive functioning, processing speed, memory and attention, with the latter being related to earlier age at onset of seizures (Rantanen et al., 2010; Van Mil et al., 2008).

Memory. Nehra et al. (2013) examined 56 children, ages 7-12, with drug resistant/refractory epilepsy and temporal lesions and found that 63% of children had average intelligence. However, these children showed difficulties with remembering information from minutes, hours, or day ago, difficulty with temporal sequencing, attention and concentration, and learning visually presented information (Nehra et al., 2013). Children with childhood absence epilepsy, frontal lobe epilepsy and temporal lobe epilepsy are at risk for memory difficulties (Nolan et al., 2004). Of these particular groups, children with temporal lobe seizures fared the worst, with poorest overall memory functioning and poor verbal memory when compared to the other two groups (Nolan et al., 2004). Children with temporal lobe seizures had poor visual and verbal memory when compared to normed means. The results varied for children with frontal lobe epilepsy and absence seizures. Children with frontal lobe epilepsy performed lower than normed means only on some verbal and visual memory tasks (Nolan et al., 2004). The least impacted of the three groups were children with absence seizures, where their results indicated lower than the normed means on some visual memory tasks (Nolan et al., 2004). Children who exhibited epilepsy within the area of the brain that controls the face, located within the temporal area and specifically the area that controlled the face, exhibited difficulties with spatial orientation and spatial memory (Volkl-Kernstock, Willinger, & Feucht, 2006). Additionally,

children that required surgery with left-temporal re-sectioning often were also at high risk for post-operative verbal memory impairment (Elger and Kurthen, 2004).

Academic difficulties. Correlations have been found between reading disorders and epilepsy, with lower verbal abilities and difficulties with verbal memory and learning (Vermeulen, Kortstee, Alpherts, & Aldenkamp., 1994; Dunn et al., 2010). No significant correlations have been found between seizure frequency and math disorders specifically. Recently, school attendance has been highlighted as an important contributor to cognitive impairments. School attendance may also contribute to suboptimal school achievement (Aldenkamp, Weber, Overweg-Plandsoen, Reijs, & van Mil, 2005; Aldenkamp Overweg-Plandsoen, & Arends 1999; Pastor et al., 2015). Aguiar, Guerreiro, McBrian, & Montenegro (2007) noted that, from a sample of 50 children with epilepsy between ages six to eighteen, 88% missed at least one day of school per school year as a result of a seizure (60%), medical appointment (62%), or medical tests (52%). Sixty percent of children had a seizure at school, and 70% of parents admitted they would allow their child to stay home from school even if they did not have any health-related issues the day of a seizure. Seizures may have a significant impact on school attendance and may increase academic difficulties. Parents of children in Northern Tanzania reported poor school attendance as a result of behavioural problems or learning difficulties, influenced by poor support from the school (Quereshi et al., 2017). Parents reported that schools could not appropriately manage seizures and the behavioural disturbances that followed seizures (e.g., confusion or sensitivity to stimuli or anger post seizure). Students with epilepsy reported feeling excluded by other students and by teachers as a result of their anger outbursts (Quereshi et al., 2017). Parents reported that their children learned at a slower pace, often falling behind, without any additional support (Quereshi et al., 2017).

Quality of Life

The health-related quality of life in school-aged children with epilepsy is worse than that of healthy children on dimensions of physical well-being and school environment, where children with more severe forms of epilepsy fare much worse (Bompori, Niakas, Nakou, Siamopoulou-Mavridou, & Tzoufi, 2014). Parents of children with epilepsy worry about peer and social support more than parents of healthy children (Bompori et al., 2014). These worries are even more pronounced for parents whose children also have severe cognitive deficits, physical disabilities, abnormal brain imaging findings, learning problems, multiple medications or prolonged treatment (Bompori et al., 2014). Parents also worry more about their child's mental health if their child has drug resistant epilepsy and comorbid neurodevelopmental problems (Bompori al., 2014). Eom et al. (2014) examined epilepsy-related clinical factors and psychosocial functions in children with epilepsy and found that 40-50% of these children show deficits with adaptive functioning, school competence, and quality of life (e.g., cognitive and social functioning) (Eom et al., 2014). Factors such as longer duration of illness, older age at time of testing, and polypharmacy use have a negative impact on psychosocial functioning (Eom et al., 2014).

A study of 60 children with epilepsy, aged six to twelve, with epilepsy revealed that the children were most distressed as a result of daily life restrictions (i.e., loss of independence), how they were perceived and treated by peers, how others handled their seizures, and medication side effects (Ronen, Rosenbaum, Law, & Streiner, 1999). Major themes in their quality of life concerns included the experience of epilepsy (e.g., nature of seizures, how seizures feel, knowledge of epilepsy), life fulfillment and time use (e.g., school issues, home activities, safety), social issues (e.g., loss of independence, stigma, support, relationships), impact of epilepsy (e.g.,

self-concept, feeling of uncertainty, limitations, cognitive and physical impacts) and attribution (e.g., concerns related to other health factors, development or social issues combined with epilepsy) (Ronen, et al., 1999). In a two-year longitudinal study of health-related quality of life in children newly diagnosed with epilepsy, parent/family stress, fears and concerns, and perceived stigma were all factors that negatively impacted child health-related quality of life above and beyond disease and demographic factors. At epilepsy diagnosis, parenting/family stress played an important role in health-related quality of life of the child; however, after two years, parenting and family stress had less of an effect on child health-related quality of life, suggesting that families and/or children had improved illness adjustment (Wu, Follansbee-Junger, Rausch, & Modi, 2014). Both children and their caregivers reported decreased epilepsy-related stigma from first diagnosis to two-year follow-up, regardless of whether they were seizure free. Caregivers reported higher levels of stigma at first diagnosis than at two-year follow-up suggesting that caregivers may initially worry most about their child being excluded or judged by others (Rood, Schultz, Rausch, & Modi, 2014).

Epilepsy is a risk factor for injuries in childhood and also contributes to lower quality of life. Lagunju, Oyinlade, & Babatunde (2016) found that 57% of children with epilepsy suffered seizure-related injuries with 24.8% suffering multiple injuries. The most frequent injuries included skin/soft tissue lacerations, injuries to the tongue and soft tissues of the mouth, minor head injuries, and dental injuries with tooth loss. Children who had a higher seizure frequency had more seizure-related injuries (Lagunju et al., 2015).

Nonadherence to antiepileptic medication is more likely to occur in the first six months of treatment, with children who do not adhere to medication regimes being 3.24 times more likely to have continued seizures four years after their diagnosis (Modi, Rausch, & Glauser, 2014).

Barriers to medication adherence by children between two and twelve years of age included: difficulty swallowing mediation, parent forgetting, medication refusal, and running out of medication (Ramsey, Zhang, & Modi, 2018). Parents who were recent immigrants and had lower parental education, non-English speaking, and lower income, were more likely to keep appointments and avoid unscheduled contacts with medical staff (Mitchell et al., 2000). Seizure frequency and duration, previous treatment failures did not individually contribute to the likelihood of treatment adherence (Mitchell et al., 2000). However, behavioural difficulties exhibited by the child lowered adherence to medication and visits, owing to the fact that parents may find children with behavioural issues difficult to manage (Mitchell et al., 2000). Families that reported high levels of stressful life events where more likely to adhere to treatment, suggesting that families use medical guidance and contact with medical staff as an instrumental coping mechanism (Mitchell et al., 2000).

For young patients with epilepsy, their caregiver's attitudes about epilepsy impact medication adherence, with health education playing a vital role in adherence (Chen, Lee, & Hie, 2013; Sureka, & Sureka, 2007). Many parents have significant knowledge gaps regarding medications and therapy. Despite having knowledge about the nature of epilepsy including characteristics, causes and prognosis, caregivers have limited knowledge about the use of drugs, potential side effects or drug interactions, and the duration of treatment; these are factors related to nonadherence (Shaju, Vinayan, & Abraham, 2014). The main reason that caregivers reported medication non-adherence was a fear of side effects (Shaju et al., 2014).

Chapter Four: Applying Theory to Literature

Bronfenbrenner's bioecological model suggest that a child's development is influenced by interactions between the child and the microsystems, and the interactions between multiple microsystems, exosystems and macrosystem. These interactions are also affected by the characteristics of children and their impact on the system. Children's settings are always changing because they are influenced by the relations and transactions between settings. As a result, children's circumstances are unique, thus the needs, abilities and barriers will also be unique. The adapted model suggests that children also motivate others to work on their behalf, which is more evident in collective societies. This adapted Bio-ecological model (Figure 2) showcases the importance of understanding risk and resiliency factors that impact Indigenous children both directly and indirectly.

Protective Factors across Systems in the Adapted Bio-ecological model

Protective factors are considered important in mitigating or eliminating risks in families and/or communities and contribute to the well-being of the child; these factors may include conditions or attributes such as coping strategies, specific resources or supports. Protective factors are present in all cultures and Indigenous populations are no exception. Protective factors are present throughout the many layers of the model; In the microsystem (e.g., connection to land, connection to family), in the exosystem (e.g., Indigenous healers), and in the macrosystem (e.g., sharing in history, spirituality, coming together to support traditional growth).

Inuit youth self-identified protective factors that enhance their mental health and well-being, despite the impact of climate change, which included: being on the land which fostered confidence and self-control (i.e., the land possesses healing and nurturing abilities, connecting the

person with nature, themselves and their ancestors), connecting to Inuit culture (i.e., maintaining the traditional knowledge of the land from elders), having strong communities (i.e., feeling connected to others in the community and across generations offers a trusted support network), having relationships with family and friends (i.e., forming caring and loving relationships with others through kinship and shared experiences), and staying busy (i.e., keeping active and busy helps to lessen negative coping strategies and provides opportunity for connecting with others through shared activities) (Petrasek MacDonald, Ford, Cunsolo Willox, & Ross, 2015).

Forty protective factors were found to promote and enhance youth mental health in the Arctic and Subarctic regions that were broadly based at the individual, family and community level (Petrasek et al., 2015). Individual factors included practicing traditional knowledge and skills, the need to contribute to the community, the positive impact of role models, and believing in oneself. Family and community factors included the importance of positively creating and impacting the social environment, which in turn enhanced resilience. Overall, the importance of land-based activities, history and language, family and social support also served as protective factors (Petrasek et al., 2015).

For Indigenous youth, cultural connection through participation in cultural traditions played an important role in resilience and moderated suicide risk (Chandler & Lalonde, 2008; Kirmayer 2014). Characteristics such as optimism, creativity, and social support, along with activities that facilitate a collective identity (e.g., traditional storytelling, Indigenous language, spirituality, connection to land or sacred places) can function as protective factors for Indigenous youth (Anderesson & Ledogar, 2008; Currie, Wild, Schopflocher, Laing, & Veugelers, 2013; Hatala, Desjardins, & Bombay, 2016; Kirmayer, Dandeneau, Marchsall, Phillips, & Williamson, 2011; Liebenberg, Ikeda, & Woods, 2015).

Plains Cree and Metis youth living in an urban centre in Canada identified nurturing a sense of belonging (i.e., being understood by others and cared for by others), developing self-mastery (i.e., taking actions toward a planned future), and fostering cultural continuity bring forth a sense of belonging and pride (i.e., developing a clear understanding of their cultural past, present and future). These protective factors are felt to develop a positive future orientation that in turn builds resilience (Hatala et al., 2017).

Indigenous culture is an integral part of health care for many Indigenous people and for many, the two forms of medicine, traditional and western, often go hand in hand (Struthers, 2003; Struthers, Eschiti, & Patchell, 2008). Interviews from Anishinabe male healers and Ojibwa-Cree female healers identified the importance of culture within traditional healing and the need for a holistic approach, stating that western medicine was very good at healing the mind and body but seldom addressed the spirit; healers emphasized the important role of connecting with culture in the healing process (Struthers et al., 2008). Healers often have an abundant wealth of knowledge around herbology, energy medicine, counselling and ceremonies, and by interweaving these practices with western medicine, a holistic approach can be taken when providing care, and in turn, Indigenous groups may feel respected and may trust the support they receive from western medicine (Struthers et al., 2008).

Paraschak and Thompson (2014) found that Indigenous groups identified a holistic approach to physical care within the context of mind, body and spirit, highlighting the importance of strong body to both family and community, an openness to drawing from cultural and mainstream values, practices and services, and a dedication to self-determination. Appropriate training is needed for mental health workers who work with Indigenous children and adolescents, particularly those with chronic health conditions such as epilepsy (Kirmayer, Simpson, & Cargo,

2003; Bartik, Dixon, & Dart, 2007). An Australian mental health hospital that served a large population of Indigenous people employed and trained Indigenous social workers to serve as the supportive and empowering partner linking the community and hospital (Nagel & Thompson, 2006). The study revealed that between 1993 and 2001, after implementing this initiative, more individuals from Indigenous communities accessed and received proper health care. Part of the initiative included gathering social history and consulting with the caregivers of the patient as well as providing a case manager for those individuals living remotely. The study revealed that providing care and communication and engaging Indigenous communities promoted the use of mental health interventions (Nagel & Thompson, 2006).

Risk Factors across Systems in the Bio-ecological model

Individuals of any age living with epilepsy experience rejection and stigmatization (i.e., attributes associated with the condition that are discrediting to the person and potentially lead to psychopathology), resulting from inaccurate knowledge by others around epilepsy (Baker, Buck, & Jacoby, 2000; Doganavsargil-Baysal, Cinemre, Senol, Barcin, & Gokmen, 2017; Gambhir, Kumar, Singhi, & Goel, 1995; Rwiza at al., 1993). Health related quality of life in children with epilepsy may vary depending on culture. Yam et al. (2008) compared health-related quality of life in children from Canada and Hong Kong and found that children from Hong Kong, despite being older at onset, having a longer duration of epilepsy, less severe seizures and more regular school program attendance, were likely to report more interpersonal/social difficulties, more worries, and more secrecy about their epilepsy compared to Canadian children (Yam et al., 2008).

Large multi-country European study of 5211 individuals with epilepsy, aged eight to twenty-three, 51% reported feeling stigmatized, with high scores also correlating with worry, negative feelings about life, long-term health problems, injuries, and reported drug side-effects (Baker et al., 1999). Researchers found that higher levels of reported stigmatization were related to impact of epilepsy, age of onset, country of origin, feelings about life, and injuries (Baker et al., 1999). Baker et al. (1999) speculated that the cultural differences in stigmatization could potentially be related to the sociocultural bias against epilepsy, the health system within the particular country, high profile figures publicly announcing their diagnosis of epilepsy, educational differences, unequal opportunities, cultural norms related to concealing or disclosing the condition, and the way in which cultures respond to such disclosure (Baker et al., 1999).

Not seeking support services has a vast impact on the health-related quality of life of individuals with epilepsy and their families. Children who are not provided with appropriate treatment for epilepsy and its comorbid disorders face many difficulties as adults. Parents may not seek out mental health services for their child with epilepsy for a number of reasons, these include: their knowledge and beliefs, if the physician does not provide a referral to mental health, the stigma of mental illness, or having a minority status, and access factors such as travel distance, insurance coverage, missing work for appointments, and transportation availability (Pescosolido et al., 2008; Angold, Messer, Stangl, Farmer, Costello, & Burns, 1998; Flisher et al., 1997; Hoagwood, Hibbs, Brent & Jensen, 1995; Owens et al., 2002; Brown, Wissow, Zachary, & Cook, 2007; Briggs-Gowan et al., 2000; Horwitz, Leaf, Leventhal, 1998; Angold et al., 2002; Howell & McFeeters, 2008; Yeh et al., 2004; Stiffman, Pescosolido, & Cabassa, 2004).

Parents play an important role in the care of children during chronic illness, and thus parents' quality of life in turn has an impact on the care they can provide to their child. Canadian

children between ages 8-12 who had epilepsy reported no difference in their quality of life in comparison to same aged children in the general population (Mezgebe et al., 2015). Their parents, however, reported poorer quality of life for their children in the domains of mood and emotions, suggesting that lower ratings by parents may be related to their own worries (Mezgebe et al., 2015). Parents of children with severe forms of epilepsy and concomitant neurodevelopmental problems reported their children to be generally compromised in the dimensions of physical well-being, school environment, and peer and social supports (Bompori, Niakas, Nakou, Siamopoulou-Mavridou, & Tzoufi, 2014). Factors impacting reported quality of life included cognitive delay, physical disability, learning about abnormal brain imaging findings, learning problems, polypharmacy, and prolonged treatment (Bompori et al., 2014). Parents of children with epilepsy were asked to rate their own quality of life with respect to physical functioning, psychological functioning, functional state, and social functioning; the more parents rated themselves as flexible in adapting to their situation, the better their rating of quality of life (Hamama-Raz & Hamama, 2015). In contrast, the higher parents rated their loneliness/social isolation and the greater the financial burden, the lower they rated their quality of life (Hamama-Raz & Hamama, 2015). Interestingly, parental optimism was not significantly correlated with ratings of quality of life (Hamama-Raz & Hamama, 2015).

Parents who are at a disadvantage based on socioeconomic status (SES), rural settings, or feel a disconnect with western health care workers may not have the opportunity to seek out the health care their child requires. In a study focused on perception of epilepsy among Americans of Hispanic and non-Hispanic origin, the authors found that Americans of Hispanic origin were more likely to believe that people with epilepsy were a danger to others, did not report familiarity with epilepsy and a small proportion believed that seizures were a result of sin and required

exorcism (Sirven, Lopez, Vazquez, & Van Haverbeke, 2005). Specific cultural attitudes play an important role in how treatment is sought out and what health care is delivered. It is widely recognized that there are significant disparities in the health of Indigenous people in Canada (Bowen, 2000). Access is limited by a number of factors that can be seen at the exosytem and macrosystem: socio-economic status, geography, lack of infrastructure, jurisdictional issues, and cultural or language barriers, with racism present at each system level.

In general, children who live in more rural areas are less likely to be seen by a neurologist (Mattsson, Tomson, Eeg-Olofsson, Brannstrom, & Weitoft, 2012). Income also contributes to care, as higher income families are more likely to see a specialist and as a result be prescribed the top five anti-epileptic medications in countries where universal health care does not exist (Mattsson, et al., 2012). In countries where universal health coverage does not exist, barriers to mental health access for children with epilepsy includes insufficient health coverage for and expertise in pediatric epilepsy (Smith et al., 2007). Children's health is positively associated with household income and this relationship becomes stronger as the child grows older (Case, Lubotsky, &Paxson, 2002). Children from lower-income households with chronic conditions have worse health than children from higher-income households owing to factors such as access to health care and parental work flexibility (Case et al., 2002). Children from poor households are more likely to have poor health with an increased number of serious chronic health conditions like epilepsy, causing them to miss school which in turn limits future earning opportunities (Case et al., 2002). The Ontario Health Survey found that adults with epilepsy had a low annual income (i.e., <$12,000) regardless of family size, they were less likely to work in the service or transport industry in comparison to those chronically ill or the general population and were less likely to complete secondary or post-secondary education (Wiebe, Bellhouse, Fallahay, &

Eliasziw, 1999). Thereby, children diagnosed with epilepsy face a number of long-term difficulties as they transition into adulthood.

For 50% of Indigenous groups, barriers include living in rural and remote locations or low population density centres where there are harsh climates, limits in transportation and appropriate health care resources as a result of cost and medical professionals' interest in remaining. These factors impact wait times, the amount of money available to provide care, and limit the ability for Indigenous people to receive care in their mother-tongue which may impact their understanding of their health and subsequent likelihood they will follow that prescribed to them (Halseth & Ryser, 2006). Many Indigenous people have moved off-reserve in search of better living. However, Indigenous people are overrepresented in Canada's homeless population by about 10 times that of the total population (Hwang, 2001). Homeless Indigenous people face a number of additional barriers, including accessing health services as a result of proof of coverage, mental illness and substance abuse issues, and inadequate treatment based on biases (Hwang, 2001).

Many Indigenous people living in large metropolitan cities like Toronto find their rights (e.g., right to health and education services) are compromised leading to serious implications in accessing health care services (Senese &Wilson, 2013). Indigenous people perceive a high level of disrespect and restriction, expressing a great deal of stress and frustration when trying to access services (Senese &Wilson, 2013). These difficulties in accessing care in an urban city is in line with Indigenous people not being considered as part of the government's historical and ongoing settlement framework (Senese & Wilson, 2013). Within Indigenous populations, those living in urban settings versus those living on-reserve experience higher rates of inequality in health care services (Tjepkema, 2002; Young, 2003); Inequities exist with respect to their status as an individual using the health care system, the kind of health care services offered to them and

higher morbidity and mortality rates in comparison to non-Indigenous individuals (Adelson, 2005; MacMillan et al., 1996; Waldram et al., 2006; Marrett& Chaudhry, 2003). Research has shown that there is a complex relationship between racism and health, that links depression, anxiety, psychological distress, and internalizing stereotypes, to health damaging behaviours coupled with a lack of resources to promote health (Bradolo ver Halen, Pencille, Beatty, & Contrada, 2009; Kreiger, 1999; Paradies, 2006; Paradies & Cunningham, 2012; Ziersch et al., 2011). Depression and racism are strongly linked among Indigenous people, with lack of control, stress and powerlessness as strong mediators in the relationship (Paradies & Cunningham, 2012).

In a national poll on Indigenous health and health care, only 65% of First Nations respondents rated the quality of their health care experience as positive, in comparison to 85% of non-Indigenous Canadians (National Aboriginal Health Organization, 2003). Canadian Indigenous groups continue to be impacted by inequalities in access to health care and services used (Adelson, 2005, Shah et al., 2003; Cameron et al., 2014). The stereotypical beliefs by medical staff may limit the care given, specifically for vulnerable groups such as those impacted by addictions. Indigenous people have described the feeling of being lessened as a person and having analgesics withheld (Browne & Tarlier, 2008; Kurtz Nyberg, Van Den Tillaart, Mills, & (OUAHRC), 2008). This feeling of persecution draws from what Fiske and Browne (2006) described as Indigenous people not being seen as reliable patients within the health care context. Goodman et al. (2017) noted that a number of Indigenous people identified substance use to treat their pain and trauma in the context of giving up on mainstream health care.

When delivering health services to Indigenous people, often health care providers bring expert solutions to problems without considering the knowledge base of the Indigenous group in how they provide healing. They often lack sensitivity to past experiences, an understanding of

Indigenous perspectives and culture, and communication skills needed to build rapport and trust (Levin & Herbert, 2004). Several focus groups conducted with Indigenous women in Vancouver's downtown East-side noted that participants expressed a strong desire for a place that approached their health concerns from an integrated perspective, where they were shown respect and given the opportunity to shape and influence decision-making toward services; many women identified a centre which addressed physical, spiritual and mental well-being, and took a more holistic approach to care (Benoit, Carroll, & Chaudhry, 2003). Using a semi-structured interview, Ly and Crowshoe (2015) conducted focus groups with medical students aimed at understanding stereotypes in Canadian Indigenous medical education. Many of the students felt they were exposed to negative views of Indigenous people and acknowledged that the culture gap between Indigenous and non-Indigenous people is both a cause and a consequence of discrimination against Indigenous groups. Over half of family medicine residents admitted feeling underprepared to provide services to Indigenous individuals despite a strong willingness to do so (Larson, Herx, Williamson, & Crowshoe, 2011).

With the North American population becoming more diverse, physicians are finding challenges in providing the best care. A systematic review examining disparities in epilepsy care found that, on the whole, individuals with epilepsy had lower education and employment status and that access to services was worse for Indigenous people, as well as for women and children. Challenges to attaining health care were associated with lower SES, insufficient insurance, and poor relationships with treating physicians (Burneo et al., 2009). Racism, judgement and discrimination played a key role in how Indigenous mothers accessed health care for their children. Mothers tended to experience sociopolitical and economic challenges, and threats of apprehension. Although these challenges did not impact their decision to seek care for their

children, it did influence the decision to seek care for their own health needs (Denison, Varcoe, & Browne, 2013).

When examining the adapted Bio-ecological model, Indigenous people experience racism in every system. Colonization is linked to many issues including a loss of connection to the Indigenous community and its values, destruction of one's self-development, and disruption of family bonds with outcomes such as problems with alcohol, drug and solvent use, abuse and suicide (Mussell, Cardiff, & White, 2004). A report by Mussell et al., (2004) noted that programs need to take a collectivist perspective and address multi-generational losses experienced by First nations people. The report indicated that for these health programs to be successful, health staff implementing them need to recognize and include the contributions of the cultural group, and must connect with community leaders that will bridge the gap between the community and governments, public policy and health professionals. The report underlined the value on relying on Indigenous leaders to provide additional training and input to the health care community, and that providing support to community leaders will allow the opportunity for the programs that are developed to adapt to the changing needs of the community (Mussell et al., 2004). The report sited that if programs do not take the roles of the family and community when examining a child's care, along with the historical context within which the group has lived, then the care provided to children will be limited and ineffective (Mussell et al., 2004).

Chapter Five: Purpose and Objectives

Purpose

The health of Indigenous children in Canada has been called into question on numerous occasions throughout history, and Indigenous people continue to see gaps in their care. Indigenous children under 14 make up 28% of the total Indigenous population, and this young population is projected to continue to grow. As such, appropriate measures are needed to ensure their health and safety; this involves knowing more about the population, their needs and how to best support them in a caring and respectful manner. Children's long-term health prognosis is greatly impacted by the care they receive, and so respectful health care must also consider the important role culture plays in care.

The life expectancy of Indigenous people is a decade lower than that of the general Canadian population, likewise there are a high number of low birthweights and high infant mortality rates in the Indigenous population in comparison to the rest of Canada. A number of factors contribute to poor outcomes, and include low income, education, housing, food insecurity, and parental smoking, along with significant disparities in access to health care.

Epilepsy is the most common neurological disorder in childhood and can cause a vast number of health and mental health problems given its onset during key periods of brain development and growth. Epilepsy is a disorder that has an impact on the cognitive, physical and mental development of a child. Its impact on the Indigenous population is not well understood. Epilepsy has a strong impact on both physical and mental health, and with disparities in access to care by Indigenous children the impact may be more negative than that of the general population.

Objectives

1. In order to understand health needs, we examined the rate of epilepsy in this 2006 Aboriginal Children's Survey (ACS) population in order to compare it to the national rate in Canada. Additionally, demographic information, living conditions, health and health care access information, child development, satisfaction with current infrastructure, and strengths and difficulties questionnaire were examined for all groups (i.e., epilepsy group and sex and age matched controls, and ACS sample excluding epilepsy group) in order to provide a better understanding of the population.

2. The present study examined the risk (*i.e., having a disorder, low birth weight, low income, lack of specialists, parent illness, parental removal from home as a child*) and resiliency factors (*i.e., community support, breast feeding*) in our sample (N=600 Epilepsy group; N=5890 Without Epilepsy group) in order to help inform future research and policy directions. Guided by previous research we examined the following relationships and their impact on caregiver report of the child's health through the use of binomial and multinomial logistic regressions:

a) To examine whether birth weight, disorders (both count and types of disorders), consumption of breast milk and income predict whether a child has epilepsy.
b) To examine how health status is defined by caregivers of children with and without epilepsy and whether the types of disorders and parental health status impact a caregiver's rating of the child's health.
c) To examine whether health status in children with and without epilepsy is predicted by whether or not they are part of a community that supports their needs, whether they visit a specialist, whether a caregiver has been removed from the home as a child, and whether parental health impact whether children have a positive or negative health status.

Chapter Six: Methods

Great care was taken by researchers at Statistics Canada in Partnership with Human Resources and Social Development Canada and Indigenous advisors from across the country when creating the ACS dataset (Statistics Canada: Social and Aboriginal Statistics Division, 2008a). Researchers ensured that the collection of data (1) honoured and acknowledged the needs of Indigenous children, was based on informed decision-making, and supported academic research (Statistics Canada: Social and Aboriginal Statistics Division, 2008a). Meetings were set up with representatives from various Indigenous organizations, service-providing agencies, researchers and parents of Indigenous children in selected regions across Canada to discuss what important issues and topics should be considered. The National Aboriginal Organization (NAO) provided input into the ACS. A technical advisory team was involved in developing the survey to ensure it was culturally appropriate and respectful to the values of Indigenous people.

Data were collected using paper questionnaires and conducted using personal interview in Inuit regions. Telephone interviews were conducted in the rest of Canada. The questionnaires were provided in a number of languages and interpreters were hired as needed. A detailed account was provided indicating that Indigenous members were involved at every step of the research process (Statistics Canada: Social and Aboriginal Statistics Division, 2008a). As a result, the survey had approximately an 81% response rate. Additionally, the present study only included caregivers who reported information about their children's health status and health information, this resulted in approximately 18% of the data being removed due to incomplete information about health.

The present data set provided information for First Nations living off reserve, Metis and

Inuit children who were living in urban, rural or northern locations in Canada. Indigenous children living on settlements and reserves in ten provinces were not included, detailed information about why these groups were not included was not provided.

Survey Population

The 2006 Aboriginal Children's Survey (ACS) (Statistics Canada: Social and Aboriginal Statistics Division, 2008a) was used for the present research study. The survey was named the "Aboriginal Children's Survey", however the author shall refer to the survey as ACS and the term "Aboriginal" will be replaced by "Indigenous" in order to reflect appropriate cultural usage. Data for the ACS were collected between October 2006 to March 2007, parents or guardians of the child were either called or completed the survey in person. The survey collected information about early development in Indigenous children and the social and living conditions in which they were learning and growing. Questions informed surveyors about the child's health, sleep, nutrition, motor, social and cognitive development, nurturing opportunities, child care, school attendance, languages used, behaviour and activities. In order to supplement the ACS, some community information (e.g., income) was obtained from the 2006 Census and was appended to the ACS file. An important caveat is that the Census was collected at a different time point (May 16, 2006) than the ACS data (October 2006 to March 2007), thereby potentially not accurately reflecting the child's situation at the time of the ACS interview (Statistics Canada: Social and Aboriginal Statistics Division, 2008a)

The target population of the ACS included all children in Canada whose identity or ancestry included one of the following: First Nations living off reserve, Metis children and Inuit children living in urban or rural areas and in northern locations throughout Canada. All children

were under 6 years of age as of October 31, 2006; this reference point was selected based on the approximate date of data collection. Indigenous children living in settlements or reserves in the 10 provinces were not included in the data collection. In the territories, all First Nations children were included in the survey. Some First Nations communities in Quebec were also included. Children living in institutions, on reserve or in settlements in provinces, other than Quebec were not included. A detailed explanation why this decision was made was not included in the survey documentation (Statistics Canada: Social and Aboriginal Statistics Division, 2008a).

The survey was developed by Statistics Canada in partnership with Human Resources and Social Development Canada, along with Indigenous advisors from across Canada. The Technical Advisory Group was made up of educators, researchers and professionals involved in Indigenous research and early childhood development; the group helped guide the creation and collection of data for the ACS. The ACS is a post-census survey; that is the ACS sample was selected based on reported answers on four screening questions from the Census questionnaire. Questions examined ethnic origin, Indigenous self-reporting, identifying Indian Band/ First Nation membership and identifying as Treaty of Registered Indian (Statistics Canada: Social and Aboriginal Statistics Division, 2008a).

Population Sampled

The total sample consisted of 17,472 children with an 81.10% response rate, thereby the number of total respondents for the ACS was 14,170, with 653 of these respondents who did not identify as Indigenous at the time of this survey but who were identified at the time Census was collected (For further breakdown on response rate by province and territory refer to Concepts and Methods Guide). Adjustments were made for respondents who overlapped with other surveys,

responders who were out of scope (i.e. deceased, no longer living in Canada or over 6 years of age), and non-respondents. Details of how the weights were adjusted were not made available due to confidentiality reasons (see Statistics Canada: Social and Aboriginal Statistics Division, 2008 for more information).

Data Quality

Sampling errors. The survey is based on a sample of individuals, rather than a complete census and as a result may have been different if the survey was done by a complete census. The initial survey weight (based on the first phase of collection where individuals identified as Indigenous) was adjusted for bootstrap subsampling to produce initial bootstrap weights, by resampling them 1000 times with replacement. The multiplicity of the unit (i.e., child) was also taken into account, which is the number of times a unit (i.e. child) was picked during bootstrap resampling. The final bootstrap weights were derived from the original weight multiplied by a random adjustment factor (i.e., how many times the child may be picked in bootstrap resampling). Units were sampled in a two-phase sampling process; the first through identification of Indigenous heritage, and the second phase strata was based on region. This two-phase sampling generated a random adjustment factor for each phase of sampling. Thereby the initial bootstrap weight of a given unit (i.e., child) in a bootstrap sample was the product of their initial sampling weight by the values of two random adjustment factors for that unit.

The method mentioned above is slightly biased in that it overestimates the variance, however this overestimation was found to be negligible in the ACS. The method above can lead to negative bootstrap weights, as a result a transformation was done to make all bootstrap weights

positive. This transformation is handled by the Fay adjustment factor, which is 3 for the ACS. Each unit was multiplied by the original weight and a Fay adjustment factor. Exact details on the bootstrap method are not provided in order to maintain confidentiality (Statistics Canada: Social and Aboriginal Statistics Division, 2008a).

Non-sampling errors. The entire survey process was evaluated in order to reduce non-sampling errors. The bias introduced by coverage is assumed to be relatively small given the high coverage rate and response rate obtained in the Census, along with the adjustments made on the initial Census sampling weights. In order to reduce non-responders, surveyors were highly trained and followed up with phone calls to encourage respondents to participate in the survey. The extent of partial non-response (i.e., not answering a specific question on the survey) was small; where necessary "refused" categories were added. In order to reduce a response error, interviewers were trained to decrease incorrect notation or misunderstanding in the way a question was asked. Lastly, quality control procedures were put in place to ensure the data were captured and coded correctly (Statistics Canada: Social and Aboriginal Statistics Division, 2008a).

Adjustments made to ACS Sample

Weights. Each selected person represents themselves and also those who were not sampled. A weight is associated with each selected person to indicate the number of people he/she represents. The initial weight was the product of two components: (1) *The inverse of the stratum (sub-population) sampling fraction*; The stratum sampling fraction is determined by the number of children selected in each stratum divided by the number of long forms available in that stratum in the Census frame; (2) *The inverse of the initial Census sampling fraction*; The initial

Census sampling fraction is determined by the number of completed long forms divided by the total number of short and long forms for each collection unit. A total of six steps were used in the weighting process, however, these were not made available to the public for reasons of confidentiality (Statistics Canada: Social and Aboriginal Statistics Division, 2008a).

Post-stratification adjustments. This adjustment ensures that the final weights for the responding units matches the population counts from the Census, according to groups (known as post-strata). Groups were defined by the following variables: The Census Indigenous Group, the Indigenous population type, the geographical domain, province of residence, and age group. Weights were adjusted using the ratio of the *Census weighted count* to the *sample weighted count* for each group (post-strata). Post-stratification adjustments ensure that the sample did not over or underrepresent certain Censes Indigenous groups, regions or age groups (Statistics Canada: Social and Aboriginal Statistics Division, 2008a).

Participants

Missing data. Only children who belonged to an Indigenous group and who were considered "responders of the survey" were included in the study. Only children whose caregiver indicated epilepsy status (yes/maybe versus no) and who rated their child's health (Excellent to poor) were included in the study. Additionally, children were included only if the caregiver indicated (yes/maybe or no) whether the child had any of the following conditions: respiratory issues/allergies, asthma or Chronic bronchitis, Tuberculosis, Diabetes/high glucose levels, heart condition or disease, kidney condition or disease, iron deficiency anemia, cerebral palsy, down syndrome, spina bifida, attention deficit disorder with and without hyperactivity, anxiety or depression, fetal alcohol syndrome or fetal alcohol spectrum disorder, autism, and speech or

language difficulties. If caregivers did not answer these questions that child was not included as a participant. As a result, multiple imputations were not required because data was complete.

Survey sample. The present study included 111, 270 participants once weights were assigned. From the original sample, 82% of the data was used as a result of missing variables. The data set used was complete and variables were re-coded or collapsed in order to ensure confidentiality.

Children with epilepsy. The epilepsy group consisted of 600 children once weights were assigned. Only children whose guardian indicated that their child had epilepsy expected to last 6 months or more were included in the study. When completing logistic regressions, the children were separated into Epilepsy group healthy (i.e. children with epilepsy whose caregiver indicated Excellent to very good health status), Epilepsy group unhealthy (i.e. children with epilepsy whose caregiver indicated good-poor health status).

Children without epilepsy. The control group had 110, 670 children once weights were assigned. Children whose caregivers indicated that their child did not have epilepsy, was healthy (Excellent to Very good) or unhealthy (good to poor) were included in the study. Children were matched according to age, sex and health status (excellent to very good vs. good to poor). The sample consisted of ten times the epilepsy group sample (Hamilton L. C., 2013) as suggested when completing multinomial logistic regressions. From the 110,670 children in this group, 5890 children were subsampled when completing logistic regressions.

Variables

In order to maintain confidentiality, cells with less than 10 respondents were collapsed, as per the guidelines set forth by Statistics Canada when using the 2006 ACS (Statistics Canada:

Social and Aboriginal Statistics Division, 2008a). The variables were chosen based on previous research in the area of epilepsy, along with the unique risk and resiliency factors in Indigenous populations. A number of variables were collapsed into broader categories in order to maintain confidentiality, which is described below.

Demographic information. Variables included: age group of child (0 to 1, 2 to 3, 4 to 5), sex (male, female), Indigenous group membership (self-reported as: First Nations, Metis, Inuk), urban or rural living, region in Canada (Atlantic provinces and Quebec; Ontario; Prairies; British Columbia and Territories), number of moves (none, one, two or more), household size (i.e., number of individuals living in the home), living arrangements (one or both biological parents; Other: two adoptive/foster parents, non-biological parent, relatives or non-relatives), caregiver's age (years), caregiver's sex (male; female), caregiver's responsibilities (work only; family care only; school only, combination or other), caregiver's highest education completed (some high school or less; completed high school; some post-secondary or completed university or post - secondary), whether caregiver had been removed by social services or residential school placement, caregiver's health status (excellent to very good; good to poor), income level was calculated as economic family total income which was defined as two or more individuals who live in the same dwelling and are related by blood, marriage, common-law or adoption, with couples being same or opposite sex and foster children included (Statistics Canada: Social and Aboriginal Statistics Division, 2008b), dwelling in need of repair (minor/major vs. no repair needed).

Child health information. Variables included: quality of health (Excellent to very good; Good to poor), whether illness limited physical activity, whether child had illnesses (epilepsy, vision or hearing issues, ADHD, anxiety/depression, speech/language difficulties, asthma,

chronic bronchitis, hypoglycemia or diabetes, heart condition, kidney condition, cerebral palsy, down syndrome, spina bifida, fetal alcohol syndrome, autism), disorder count (none; one; two; three; four or more) medication type (anti-convulsant, puffers/inhalers, Ritalin, insulin, traditional medicine, vitamins and herbals), medication count that does not include Indigenous medicine, herbal medicine or vitamins and minerals (none, one or two, three or four, five plus medications), seen by specialist (yes/no), seen by traditional healer (yes/no), seen by psychologist (yes/no), seen by social worker (yes/no), seen by doctor specifically for epilepsy (yes/no), number of generations living in the home (Two generations; Other).

Developmental milestones. Developmental milestones were divided into the following categories: social/emotional (offers toys, food, items to others, takes turns playing games or during conversations), language/communication (understands names of objects, expresses needs using full sentences), cognitive which includes learning, thought, problem solving (looked at something or someone out of sight, sorted objects, clothes or food or any other items by group), and movement/physical development (sat up by him/her self, dressed self without any help except for tying shoes and buttoning the backs of outfits). The ACS separated developmental milestones into two categories, those asked to caregivers of zero to one-year old children and those of two to five-year-old children. Privacy prevented breakdown by age as a result of low counts when groups were separated into their respective milestones.

Health habits, food nutrition and co-sleeping. Variables included: breast fed (yes/no), experience of hunger, (yes/no) co-sleeping (yes/no), languages spoken in home (English or French primarily; Indigenous language primarily). Cells had to be collapsed for languages spoken at home in order to maintain confidentiality.

Satisfaction with community support. Variables included: satisfactions with housing

conditions (very satisfied to satisfied versus dissatisfied to very dissatisfied), satisfaction with network, support from family and friends (very satisfied to satisfied versus dissatisfied to very dissatisfied), finances (very satisfied to satisfied versus dissatisfied to very dissatisfied), importance of culture and history in life (very important to somewhat important versus not at all important), community as a place with health facilities (excellent to very good versus good to poor), community as a place with involved members (excellent to very good versus good to poor), community as a place for cultural activities (excellent to very good versus good to poor).

Strengths and difficulties questionnaire. The Strengths and Difficulties Questionnaire has a self-report version, parent version and teacher version. The questionnaire is aimed at providing information on a child's social and emotional behaviour (Goodman, 1997). The questionnaire consists of 25 items that are grouped into five subscales designed to address behaviours and relationships and includes a sum of the five scales known as the total score (Goodman, 2001). The questionnaire is scored using either a three outcome (i.e., Normal, borderline, abnormal) or a four-outcome approach (i.e., Close to average, slightly raised/slightly lowered, high/low, very high/very low), which indicates children who fall into a clinical range. The three-outcome approach was mainly used and individual group scores (i.e., Control group vs. Epilepsy group) were calculated. The four-outcome approach was also included however, because of confidentiality, individual group scores could not be provided for those in the Very High/Very low ranges but rather the percentage for the entire sample is provided. The questionnaire used in the present study was designed for three to four-year-old children. Sub-scales included: Emotional Symptoms (score between 5-10 is considered Abnormal; 7-10 is considered Very high/Very low), Conduct Problems (a score between 4-10 is considered Abnormal; 6-10 is considered Very high/Very low), Hyperactivity/Inattentiveness (a score

between 7-1 is considered Abnormal; 9-10 is considered Very high/Very low), Peer relationships problems (a score between 4-10 is considered Abnormal; 5-10 is considered Very high/Very low), Prosocial Behaviour (a score between 0-4 is considered Abnormal; 0-5 is considered Very high/Very low).

Statistical Analysis

Survey command. STATA 15 (StataCorp., 2017) was used to carry out all analyses in the present study. The following survey command in STATA 15 was used to carry out all analyses (svyset [pweight=wtpm], bsrweight(wrpm0001-wrpm1000) vce(bootstrap) fay(1-1/sqrt(3))). Survey design weights were included in the analyses along with bootstrap weights. Variances were estimated using 1000 bootstrap weights provided by Statistics Canada. Additionally, variances were multiplied by 9 to allow for the complex sampling design, this was achieved by a Fay adjustment factor of 3 in the SVYSET command (Statistics Canada: Social and Aboriginal Statistics Division, 2008a).

Descriptive tables. The epilepsy group as a whole (healthy and unhealthy) was compared to the rest of the survey sample in order to provide information about their wellbeing and adjustment in comparison to the rest of the sample. Holm-Bonferroni correction was used in order to adjust for the p-values given the number of comparisons tested (Holm, 1979). The Holm-Bonferroni method is used to correct familywise error rates for multiple hypothesis tests, it reduces the possibility of a Type I error (i.e., a statistically significant result when there is not one).

Logistic regressions. In order to address the study's objectives, the epilepsy group was matched on sex, age and health status and compared to ten times that of the non-epilepsy group.

Binomial logistic regressions and multinomial logistic regressions were completed on this subsample. Assumptions for binomial and multinomial logistic regressions were examined, there was no evidence of linearity or multicollinearity. Assumptions were met for both weighted and unweighted regressions.

Chapter Seven: Results

Indigenous Status

The majority of children in the present study were identified as having First Nations ancestry (70%), followed by Metis (26%), with the smallest group identifying as Inuit (4%). Only 58% of caregivers identified as having Indigenous Identity (i.e., those who reported First Nations, Metis, Inuk, a Treaty Indian or a Registered Indian as defined by the Indian Act of Canada or a member of a Indian Band of First Nation) (Statistics Canada: Social and Aboriginal Statistics Division, 2008b). Most caregivers who were surveyed reported few moves, with 46% reporting no moves. Most families lived within an urban setting (75%) (i.e., defined as a population with at least 1000 people and no fewer than 400 people per square kilometer) (Statistics Canada: Social and Aboriginal Statistics Division, 2008b). The highest population of Indigenous people lived in Ontario (25%) (Table 1).

Table 1

Ancestry, Geography, and Identification

Descriptive	Without Epilepsy N=110670	Epilepsy N=600	Total N=111270	p-value
Ancestry				
First Nations and multiple backgrounds	70%	62%	70%	n.s
Metis and Metis/Inuit	26%	30%	26%	
Inuit	4%	8%	4%	
Indigenous Indicator for Caregiver	58%	73%	58%	n.s
Number of Residence Moves				
0 moves	46%	27%	46%	n.s
1 move	26%	30%	26%	
2 moves	13%	23%	13%	
3 or more moves	16%	20%	16%	
Region				
Atlantic Canada and Quebec	19%	17%	19%	n.s
Ontario	25%	35%	25%	
Prairies	37%	28%	37%	
British Columbia and Territories	18%	20%	18%	
Urban*	75%	85%	75%	n.s

Note. *Urban area is defined as a population with at least 1000 people and no fewer than 400 people per square kilometer.

Environmental Characteristics

Most children lived in a two-generation household with either one or two biological parents (97%). The average age for caregivers was in their early thirties; ranges could not be provided due to confidentiality. Forty-seven percent of caregivers identified outside of home work as their main responsibility, with 42% of caregivers having some or completed post-secondary education. About seventy percent of caregivers reported excellent to very good health status. Family income (i.e., net income for all members living in the home) was significantly lower for caregivers of children with epilepsy in comparison to those without epilepsy ($p = 0.04$). Ranges for income could not be provided in order to preserve confidentiality. Only three percent of caregivers in this population reported attending residential schools, however 10% of caregivers of children without epilepsy and 27% caregivers of children with epilepsy were removed from their homes as children ($p = 0.02$) (Table 2).

Table 2

Living Conditions and Family Information

Descriptive	Without Epilepsy N=110670	Epilepsy N=600	Total N=111270	p-value
Household size M(SE)	4.20 (0.01)	4.21(0.07)	--	n.s
Living Arrangements				
1 or 2 biological parents in home	--	--	97%	
Other*	--	--	3%	
Caregiver is birth parent	95%	87%	95%	n.s
Caregiver's age M(SE)	31.47 (0.03)	32.36 (0.38)	--	n.s
Caregiver's Job				
Work only	47%	40%	47%	n.s
Home/family life only	31%	42%	31%	
Combination	22%	17%	22%	
Caregiver removed as child	10%	27%	10%	**0.02**
Caregiver attended residential school	3%	0%	3%	n.s
Caregiver's education				
Less than high school	22%	28%	23%	n.s
High school only	35%	33%	35%	
Some or completed post-secondary	42%	38%	42%	
Caregiver's health				
Excellent to very good	71%	53%	71%	n.s
Good to poor	29%	47%	29%	
Home requires repairs (major or minor)	52%	55%	52%	n.s
Family income M(SE)**	$59,168 (182)	$52,067 (2058)	--	**0.04**

Note. * Living with two adoptive/foster parents, non-biological parent, relatives or non-relatives; **Income defined as two or more individuals who live in the same dwelling and are related by blood, marriage, common-law or adoption, with couples being same or opposite sex and foster children included.

Demographic Information: Subgroup Analysis

A subgroup of children without epilepsy (N=5890) were matched according to age, sex and health status that was approximately ten times the size of the epilepsy group (N=600). No differences were found between these groups with respect to ancestry, region, urban dwelling, or caregiver's age, job or education (Table 3).

Table 3

Demographics for Subpopulation without Epilepsy and Epilepsy Group

Descriptive	Without Epilepsy N=5890	Epilepsy N=600	Total N=6490	p-value
Ancestry				
North American & multiple ancestry	68%	62%	67%	n.s
Metis & multiple ancestry	27%	30%	27%	
Inuit	5%	8%	6%	
Region				
Atlantic and Quebec	17%	15%	17%	n.s
Ontario	23%	35%	25%	
Prairies	39%	28%	38%	
British Columbia and Territories	21%	20%	21%	
Urban	75%	85%	76%	n.s
Caregiver's age M(SE)	31.49 (0.11)	32.26 (0.38)	--	n.s
Caregiver's job				
Home only	45%	40%	45%	n.s
Work only	30%	41.67%	31%	
Combination	25%	18.33%	25%	
Parent education				
Less than high school	27%	28%	28%	n.s
High school completed	33%	33%	32%	
Some Post-secondary and completed post-secondary school	40%	38%	40%	

Health Status

When looking at the entire sample, most children in the study were between 2-6 years of age with 50% being female. Prevalence rates for tuberculosis, diabetes/prediabetic or hypoglycemia, heart condition or disease, kidney condition or disease, iron deficiency or anemia, cerebral palsy, down syndrome, spina bifida, FASD, ADD/ADHD, and anxiety/depression ranged between two percent and below one percent. Less than one percent of the ACS sample had epilepsy. Eight percent of children required hospitalization for physical injuries. Eighty-eight percent of children without epilepsy compared to 42% of children with epilepsy identified as having excellent to very good health status ($p < 0.001$), with 58% of children with epilepsy also having their movement impacted as a result of a disorder ($p < 0.001$).

Significantly higher rates of vision or hearing issues, allergy issues, asthma or bronchitis, speech/language difficulties, and other disorders were found in the epilepsy group in comparison to the group without epilepsy ($p < 0.001$). Fifty-five percent of children with epilepsy used anti-convulsant medication, additionally the epilepsy group reported higher rates of usage with respect to puffers, and other medicine, the other medication was not identified when the ACS data were collected ($p < 0.001$). Children in the epilepsy group also used a higher number of medications than the control group ($p < 0.001$), excluding those medications labelled as “other medicine”. Very few controls took insulin, or Ritalin and no children took tranquilizers. (Table 4).

Table 4

Child Variables and Health

Descriptive	Without Epilepsy N=110670	Epilepsy N=600	Total N=111270	p-value
Age range (years)				
0 to 1	27%	22%	27%	n.s
2 to 3	36%	35%	36%	
4 to 6	37%	43%	37%	
Female	50%	55%	50%	n.s
Birthweight (g) M(SE)	3448 (2.44)	3356 (41.62)	--	n.s
Child's Health status				
Excellent to very good	88%	42%	88%	**<0.0001**
Good to poor	12%	58%	12%	
Child's movement impacted	3%	48%	4%	**<0.0001**
Epilepsy	--	--	0.54%	
Vision or Hearing issues	4%	25%	4%	**<0.0001**
Allergy issues	10%	33%	11%	**<0.0001**
Asthma or Bronchitis	11%	33%	11%	**<0.0001**
Tuberculosis	0.07%	0%	0.07%	n.s
Diabetes, pre-diabetic or hypoglycemia	--	--	0.32%	
Heart condition or disease	--	--	2%	
Kidney condition or disease	--	--	1%	
Iron deficiency anemia	--	--	1%	
Cerebral palsy	--	--	<1%	
Down syndrome	--	--	<1%	
Spina bifida	--	--	<1%	
Fetal alcohol syndrome disorder	--	--	1%	
ADD/ADHD	--	--	2%	
Anxiety or depression	--	--	1%	
Speech or language difficulties	8%	38%	8%	**<0.0001**
Other disorder	4%	33%	4%	**<0.0001**
Disorder Count				
Zero	72%	0%	72%	**<0.0001**
One	19%	25%	19%	
Two	6%	30%	6%	
Three	2%	15%	2%	
Four to Nine	1%	30%	1%	
Anti-convulsant	0%	55%	<1%	--
Puffer	12%	35%	12%	**<0.0001**
Ritalin	--	--	<1%	
Insulin	--	0%	--	
Other medicine	7%	35%	7%	**<0.0001**
Indigenous medicine	--	--	2%	

Western medicine count*				
None	88%	32%	87%	**<0.0001**
One	12%	45%	12%	
Two to eleven	<1%	23%	<1%	
Injury requiring hospital visit	--	--	8%	

Note. *Western medicine does not include medicine labelled as "other", vitamins, herbals or

Indigenous medicine

Health Care Changes and Needs

Most children saw a family doctor or nurse practitioner (81%). Less than two percent of children saw a psychologist or Indigenous health healer. Children without epilepsy were more likely to see a specialist (87% versus 43% respectively, $p < 0.001$) than those with children with epilepsy. However, the type of specialist included surgeon, allergist and orthopaedist. Significantly more caregivers of children with epilepsy reported difficulty accessing healthcare or medicine for the child (7% for those without epilepsy versus 23% of those with epilepsy, $p < 0.001$). More caregivers of children with epilepsy received child welfare assistance (8% versus 32%, $p < 0.001$) (Table 5).

Table 5

Health Access

Descriptive	Without Epilepsy N=110670	Epilepsy N=600	Total N=111270	p-value
Specialist**	87%	43%	87%	**<0.0001**
General Practitioner or nurse			81%	
Indigenous healer	--	--	2%	
Psychologist	--	--	1%	
Welfare assistance	8%	32%	8%	**<0.0001**
Difficulty accessing healthcare/medicine	7%	23%	7%	**<0.0001**

Note. **Specialist is a broad term that includes surgeon, allergist or orthopaedist

Health Habits

Overall, nutrition and sleeping arrangements were similar for children with and without epilepsy, however, physical activity tended to be lower in children with epilepsy. Most caregivers reported that children were breast fed during infancy, with only about 4% of caregivers reporting a lack of food. When a shortage of food did occur, most caregivers sought out the help of relatives, if that was not available caregivers would skip meals, and lastly some of these caregivers reported using institutional aid. About 30% reported co-sleeping with no difference reported between groups. Children with epilepsy were significantly less likely to participate in physical activity daily in comparison to children without epilepsy (68% versus 86%, $p = 0.01$).

Although only 30% of caregivers reported participating in traditional activities themselves 60% indicated the importance of culture and history in their lives. About half of the caregivers reported that it was important for their child to become fluent in their Indigenous language. Most children were exposed to Indigenous language and culture through books followed by participating in cultural activities, with only a quarter of exposure to language done in the home or through media. Additionally, very few parents reported attending parent-child programs (Table 6).

Table 6

Health Habits and Cultural Exposure

Descriptive	Without Epilepsy N=110670	Epilepsy N=600	Total N=111270	p-value
Breast fed	76%	65%	76%	n.s
Lack of food	4%	10%	4%	n.s
Co-sleeping	30%	30%	30%	n.s
Child participates in physical activity at least daily	86%	68%	86%	**0.01**
Caregiver attended parent-child program	16%	22%	16%	n.s
Participation in traditional activities	31%	45%	31%	n.s
Importance of Indigenous culture and history in your life	62%	72%	62%	n.s
Exposed to Indigenous language at home	27%	35%	27%	n.s
Exposure to Indigenous language in media	21%	25%	21%	n.s
Important for child to be fluent in Indigenous language	45%	53%	45%	n.s
Exposure to cultural activities	31%	42%	31%	n.s
Exposure to Indigenous books (one or more/day)	86%	68%	86%	n.s

Satisfaction with Living Conditions

Caregivers were asked to rate their satisfaction with their living conditions. Differences in satisfaction were noted with respect to housing (89% without epilepsy 72% epilepsy group, p = 0.003) and finances (77% without epilepsy versus 57% epilepsy group, p = 0.008) between the two groups. Over 90% of Indigenous people were satisfied with the support they received from their families and close friends. However, satisfaction ranged between 33-49% when asked about health facilities, and their community as a place where members are active participants in promoting the group needs and where Indigenous activities are practiced, with no differences found between groups (Table 7).

Table 7

Satisfaction with Living Conditions

Descriptive	Without Epilepsy N=110670	Epilepsy N=600	Total N=111270	p-value
Finances	77%	57%	77%	**0.008**
Housing	89%	72%	89%	**0.003**
Support network, support from family, friends or others	--	--	94%	
Health facilities	49%	43%	49%	n.s
Involved members of the community*	44%	43%	49%	n.s
Community as a place for Indigenous activities	33%	35%	33%	n.s

Note. *Members speaking for the community; Indicates level of satisfaction

Child Development

To protect confidentiality, developmental milestones could not be provided for each individual age group (0 to 1, 2 to 3, 4 to 6 years old age groups); rather data were collapsed to indicate if a particular developmental milestone was achieved by the child. Questions were chosen that examined cognitive, language, social and physical development from milestones achieved between 0 to 1 years of age and those between 2 to 5 years of age, as this is how they were grouped in the ACS (Statistics Canada: Social and Aboriginal Statistics Division, 2008b). Overall, 92-98% of children (both children with and without epilepsy) reached the developmental milestones (Table 8).

Table 8

Developmental Milestones

Descriptive	Milestone Achieved N=111270
Cognitive Development	97%
Looks at something or someone out of sight	
Sorts objects, clothes, food or any other items by group	
Finds things s/he needs with or without prompting	
Says the name of a familiar object	
Counts three objects correctly	
Counts up to 10 out loud	
Understands how many three is	
Language Development	98%
Expresses his/her needs using gestures or facial expressions	
Waits his/her turn when asked	
Stops making sounds or looked at you when you spoke to him/her	
Expresses his/her need using other sounds than crying	
Expresses his/her needs using a single word	
Expresses needs using two-three words	
Expresses needs using full sentences	
Understands when you speak to him/her	
Can tell or retell stories using own words	
Draws picture and tells story about it	
Understands names of common objects	
Social Development	97%
Offers toys, food, items to others	
Copies or imitates someone else's actions or sounds	
Takes turns playing games or conversation	
Physical Development	92%
Sits up by him/herself	
Child has started walking on his/her own	
Child can run	
Child has made line with crayon, stick or another object	
Dresses self without any help except for tying shoes and buttoning the backs of outfits	
Toilet trained	

Note. Percentages for the three age groups could not be provided in order to ensure confidentiality. Instead the milestones examined are listed for each developmental milestone.

Strengths and Difficulties Questionnaire

The present study examined strengths and difficulties using the original SDQ subscale items since this provided information about whether a child's behaviours scored in the clinical range and warranted attention. The present study did not find any significant differences between the two groups when examining the number of children reported in the clinical range on the SDQ. Overall, scores in the clinical ranges were reported by 33 to 50% of caregivers, with the exception of the prosocial subscale where scores in the clinical range were only seen in four percent of the entire sample (Table 8). When examining the four-outcome approach of the SDQ, scores in the very high/very low (i.e., clinical range) were reported for 31 to 40% of children, with the exception of the prosocial subscale where scores in the clinical range were reported for three percent of the group (Table 9).

Table 9

Strengths and Difficulties Questionnaire

Descriptive	Without Epilepsy N=110670	Epilepsy N=600	Total N=111270	p-value
Emotions subscale M (SE)	1.4 (0.01)	2.54 (0.13)		
Abnormal range	33%	53%	33%	n.s
Very High/Very Low range	--	--	31%	
Conduct Problems subscale M (SE)	2.48 (0.01)	3.12 (0.09)		
Abnormal range	50%	58%	50%	n.s
Very High/Very Low range	--	--	36%	
Hyperactive/Inattentive subscale M (SE)	3.26 (0.1)	4.16 (0.17)		
Abnormal range	39%	48%	39%	n.s
Very High/Very Low range	--	--	33%	
Peer Problems subscale M (SE)	1.46 (0.01)	2.21 (0.14)		
Abnormal range	39%	53%	39%	n.s
Very High/Very Low range	--	--	35%	
Prosocial subscale M (SE)	8.65 (0.01)	7.41 (0.21)		
Abnormal range	*	*	4%	n.s
Very High/Very Low range	--	--	3%	
Total Problems subscale M (SE)	8.53 (0.03)	11.8 (0.37)		
Abnormal range**	40%	53%	40%	n.s
Very High/Very Low range **	--	--	37%	

Note. **SDQ Total difficulties score based on 4 scales: Emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems; SDQ 3 outcome approach indicated by "Abnormal range"; SDQ 4-outcome approach indicated by "Very high/very low" range". Ranges could not be provided in order to maintain confidentiality.

Summary: First Objective

In the present sample, 5.4 out of 1000 children had epilepsy. Children with epilepsy had lower health status than children without epilepsy and their movement was impacted. Children with epilepsy had significantly higher rates of hearing/vision issues, asthma or bronchitis, allergies, speech/language difficulties and other disorders that were not specified. Children with epilepsy were less likely to see a specialist and caregivers of these children reported less access to care and medicine for their child. Caregivers of children with epilepsy reported significantly lower satisfaction with housing and finances compared to those caregivers of children without epilepsy.

Predictors of Epilepsy

In the regression below, income was rounded to the nearest $10,000 and set for about the average range. In the present group, the family income for children without epilepsy was $59,168 while the income for children with epilepsy was $52,067. Thereby when examining the effect of income, an average rounded income was used of $50,000.

In the present study if a predictor increased or decreased the likelihood of an outcome, this was described in odds percentages to help make results more meaningful and easier to interpret. The present study grouped disorders into three categories: (1) neurodevelopmental and mental health disorder (i.e., epilepsy, cerebral palsy, down syndrome, spina bifida, fetal alcohol syndrome disorder, ADD/ADHD, anxiety/depression); (2) medical disorder (i.e., vision or hearing issues, allergy issues, asthma or bronchitis, tuberculosis, diabetes/pre-diabetic or hypoglycemic, heart condition or disease, kidney condition or disease, iron deficiency anemia) which were primary medical in nature; and (3) Speech-Language difficulties. Total disorders

grouped the above disorders into a count.

Birthweight, total number of disorders, income and whether a child received breast milk were examined as predictors of epilepsy (Table 10). Overall, high total number of disorders increased likelihood of having a child with epilepsy, whereas receiving breast milk increased the likelihood of having a child without epilepsy. Specifically, there was 164% higher odds of having epilepsy for those children who had one disorder/disease in comparison to those children who had no disorders/disease, with 821% higher odds of having epilepsy when these children had two more disorders compared to none. There were 27% higher odds of not having epilepsy for those children who received breast milk compared to those who did not. When examining each disorder type individually, there was 164% higher odds of having epilepsy for those children with a neurodevelopmental + mental health disorder (i.e., epilepsy, cerebral palsy, down syndrome, spina bifida, fetal alcohol syndrome disorder, ADD/ADHD, anxiety/depression) compared to those children without a medical disorder (Table 11). There were 318% higher odds of having epilepsy for those children with a medical disorder (i.e., vision or hearing issues, allergy issues, asthma or bronchitis, tuberculosis, diabetes/pre-diabetic or hypoglycemic, heart condition or disease, kidney condition or disease, iron deficiency anemia) compared to those children without a medical disorder (Table 12). There were 470% higher odds of having epilepsy for those children with Speech-language difficulties compared to those children without Speech-language difficulties (Table 13). Across the three separate regressions, there was a 27 to 32% higher odds of not having epilepsy for those children who received breast milk compared to those children who did not (Table 11-13).

Table 10

Examining Predictors of Epilepsy

	B(SE)	p-value	95% CI	
Without Epilepsy vs. Epilepsy Group				
Constant	-3.60 (0.31)	<0.0001	-4.19	-3.00
Birth weight (kg)	0.15 (0.08)	0.06	0.00	0.30
Total number of disorders				
One	0.97 (0.15)	**<0.0001**	0.68	1.26
Two or more	2.22 (0.13)	**<0.0001**	1.96	2.48
Income*	0.03 (0.01)	0.07	0.00	0.05
Receiving breast milk	-0.32 (0.11)	**<0.0001**	-0.54	-0.11

Note. *Income was set at $50,000 as average income.

Table 11

Examining Neurodevelopmental and Mental Health disorders as a Predictor of Epilepsy

	B(SE)	p-value	95% CI	
Without Epilepsy vs. Epilepsy Group				
Constant	-2.78 (0.28)	<0.0001	-3.32	-2.24
Neurodevelopmental + mental health disorder*	1.93 (0.12)	**<0.0001**	1.69	2.17
Birth weight (kg)	0.07 (0.08)	0.38	-0.09	0.23
Income**	-0.40 (0.11)	0.07	0.00	0.05
Receiving breast milk	-0.40 (0.28)	**<0.0001**	-0.61	-0.18

Note. * epilepsy, cerebral palsy, down syndrome, spina bifida, fetal alcohol syndrome disorder, ADD/ADHD, anxiety/depression; **Income was set at $50,000 as average income.

Table 12

Examining Medical Disorders as Predictors of Epilepsy

	B(SE)	p-value	95% CI	
Without Epilepsy vs. Epilepsy Group				
Constant	-3.06 (0.30)	<0.0001	-3.65	-2.48
Medical disorder*	1.43 (0.11)	**<0.0001**	1.21	1.65
Birth weight (kg)	0.07 (0.09)	0.44	-0.10	0.24
Income**	0.02 (0.01)	0.21	-0.01	0.05
Receiving breast milk	-0.37 (0.30)	**<0.0001**	-3.65	-2.48

Note. * vision or hearing issues, allergy issues, asthma or bronchitis, tuberculosis, diabetes/pre-diabetic or hypoglycemic, heart condition or disease, kidney condition or disease, iron deficiency anemia. **Income was set at $50,000 as average income.

Table 13

Examining Speech-Language Difficulties as a Predictor of Epilepsy

	B(SE)	p-value	95% CI	
Without Epilepsy vs. Epilepsy Group				
Constant	-2.71 (0.27)	<0.0001	-3.25	-2.18
Speech-language difficulties	1.74 (0.12)	**<0.0001**	1.52	1.97
Birth weight (kg)	0.08 (0.08)	0.29	-0.07	0.23
Income*	0.007 (0.01)	0.59	-0.02	0.00
Receiving breast milk	-0.39 (0.11)	**<0.0001**	-3.25	-2.18

Note. *Income was set at $50,000 as average income.

Summary: Second Objective Part A

When looking at predictors of epilepsy, children who did not receive breast milk, had more disorders, or had medical, neurodevelopmental + mental health disorders, speech-language difficulties were more likely to have epilepsy.

Health Status

The present study examined whether disorders (i.e., neurodevelopmental + mental health disorders, medical disorders, speech-language difficulties), and good parental health impacted how caregivers rated a child's health and if this health rating changed depending on whether the child had epilepsy.

Health status and disorders. Children with medical disorders and speech difficulties had 465% and 129% respectively, higher odds of being labelled as a healthy child with epilepsy versus a healthy child without epilepsy. Children with neurodevelopmental + mental health disorders, medical disorders, and speech-language difficulties had 448-741% higher odds of being labelled as a child who was unhealthy and had epilepsy versus belonging to the healthy group of children without epilepsy. When comparing children with epilepsy whose caregiver's rated them as healthy versus those who rated them as having poor health, children with neurodevelopmental + mental health disorders had 499% higher odds of belonging to the epilepsy group with poor health status, additionally children with speech-language difficulties had 267% higher odds of also belonging to the epilepsy group with poor health status.

When both groups were seen as unhealthy and the groups differed based on whether they had epilepsy or not, children with neurodevelopmental + mental health disorders (i.e., epilepsy, cerebral palsy, down syndrome, spina bifida, fetal alcohol syndrome disorder, ADD/ADHD,

anxiety/depression), medical disorders (i.e., vision or hearing issues, allergy issues, asthma or bronchitis, tuberculosis, diabetes/pre-diabetic or hypoglycemic, heart condition or disease, kidney condition or disease, iron deficiency anemia), or speech-language difficulties had 44 to 72% higher odds of being in the epilepsy group compared to the group of children without epilepsy even when both were labelled as having poor health status (Table 14).

Health status and parental health status. When comparing healthy children without epilepsy to healthy children with epilepsy, caregivers who also rated their own health positively versus those who rated their own health poorly had 64% higher odds of having a child without epilepsy who was healthy versus having a healthy child without epilepsy. When both groups of children had epilepsy and differed on healthy status, caregivers who saw themselves as healthy had 54% higher odds of rating their child with epilepsy as healthy. When both groups had poor health but varied in whether or not they had epilepsy, caregivers who rated their own health positively had 41% higher odds of having a child with epilepsy versus having a child without epilepsy. Interestingly, no differences were found between unhealthy controls and the healthy epilepsy group with respect to predictors of health status (Table 14).

Table 14

Examining Predictors of Health Status in Children with and without Epilepsy

	B(SE)	p-value	95% CI	
Healthy Control Group vs. Healthy Epilepsy Group				
Constant	-2.55 (0.17)	<0.0001	-2.88	-2.21
Neurodevelopmental + mental health disorders*	-0.09 (0.27)	0.74	-0.61	0.43
Medical disorders**	1.73 (0.15)	**<0.0001**	1.43	2.03
Speech-language difficulties	0.83 (0.21)	**<0.0001**	0.42	1.25
Good parental health	-1.04 (0.15)	**<0.0001**	-1.35	-0.74
Healthy Control Group vs. Unhealthy Epilepsy Group				
Constant	-3.50 (0.18)	<0.0001	-3.85	-3.15
Neurodevelopmental + mental health disorders*	1.70 (0.18)	**<0.0001**	1.33	2.06
Medical disorders**	2.04 (0.17)	**<0.0001**	1.70	2.38
Speech-language difficulties	2.13 (0.17)	**<0.0001**	1.81	2.45
Good parental health	-0.78 (0.15)	**<0.0001**	-1.09	-0.48
Healthy Epilepsy Group vs. Unhealthy Epilepsy Group				
Constant	-0.95 (0.23)	<0.0001	-1.41	-0.50
Neurodevelopmental + mental health disorders*	1.79 (0.26)	**<0.0001**	1.28	2.29
Medical disorders**	0.31 (0.22)	0.16	-0.12	0.73
Speech-language difficulties	1.30 (0.23)	**<0.0001**	0.85	1.75
Good parental health	0.26 (0.20)	0.19	-0.13	0.65
Unhealthy Control Group vs. Healthy Epilepsy Group.				
Constant	2.67 (0.16)	<0.0001	2.35	2.99
Neurodevelopmental + mental health disorders*	-0.12 (0.24)	0.60	-0.34	0.59
Medical disorders**	0.28 (0.15)	0.06	-0.57	0.01
Speech-language difficulties	-0.03 (0.20)	0.90	-0.37	0.42
Good parental health	0.28 (0.15)	0.06	-0.57	0.01
Unhealthy Control Group vs. Unhealthy Epilepsy Group				
Constant	-3.62 (0.18)	<0.0001	1.36	1.96
Neurodevelopmental + mental health disorders*	1.66 (0.15)	**<0.0001**	-1.96	-1.36
Medical disorders**	0.59 (0.17)	**0.001**	-0.92	-0.25
Speech-language difficulties	1.28 (0.15)	**<0.0001**	-1.56	-0.99
Good parental health	0.54 (0.15)	**<0.0001**	-0.83	-0.25

Note. *cerebral palsy, down syndrome, spina bifida, FASD, ADD/ADHD, anxiety/depression; **vision/hearing issues, allergies, asthma/bronchitis, tuberculosis, diabetes/pre-diabetic or hypoglycemic, heart condition/disease, kidney condition/disease, iron deficiency anemia.

Summary: Second Objective Part B

When looking at health status, children with medical disorders, speech-language difficulties were more likely to be labelled as children with epilepsy, additionally if they also had a neurodevelopmental + mental health disorder, they were more likely to be children with epilepsy who were labelled as unhealthy. Caregivers who rated their own health positively were less likely to have children with epilepsy.

Risk and Resiliency Factors Impacting Health Status

In the regression below, income was rounded to the nearest $10,000 and set for about the average range. In the present group, the family income for children without epilepsy was $59,168 while the income for children with epilepsy was $52,067. Thereby when examining the effect of income, an average rounded income was used of $50,000.

Healthy status: Without epilepsy vs epilepsy. Income significantly predicted whether a child was in the epilepsy group or not, when both groups were deemed healthy (b = -0.08, Wald χ^2 (27) = 1370.03, $p > 0.001$). There were 33% higher odds of not having epilepsy versus having epilepsy when caregivers reported $50,000 income versus 15% higher odds of having epilepsy when caregivers reported $20,000 income. In general, children who came from families with higher incomes had lower odds of having epilepsy.

The likelihood of having a child with epilepsy depended on whether the child saw a specialist and whether they belonged to a community with active members (b = 2.01, Wald χ^2 (27) = 1370.03, $p > 0.001$). When children saw a specialist and were part of a community that was active, they had 4940% higher odds of belonging to the epilepsy group, but when they were not part of a community with active members, children had 596% higher odds of belonging to the

epilepsy group. In general, those children who saw a specialist and belonged to an active community had higher odds of having a diagnosis of epilepsy.

The likelihood of having a child in the epilepsy group depended on whether the child saw a specialist and whether their parent was also healthy (b = -1.95, Wald χ^2 (27) = 1370.03, $p >$ 0.001). When children saw a specialist and their caregiver was healthy, they had 51% higher odds of belonging to the group of children without epilepsy versus when a child saw a specialist and their caregiver was not healthy, they had 596% higher odds of belonging to the epilepsy group. In general, those children who saw a specialist and whose caregiver was healthy were less likely to belong to the epilepsy group.

Healthy children without epilepsy vs. unhealthy children with epilepsy. Whether or not a caregiver was removed from the home as a child significantly predicted whether a child was considered to have epilepsy and be unhealthy or whether they were a healthy child without epilepsy (b = 1.75, Wald χ^2 (27) = 1370.03, $p > 0.001$). There were 476% higher odds of being an unhealthy child with epilepsy versus a healthy child without epilepsy when the caregiver had been removed from the home. In general, caregivers who were removed from the home also had children with epilepsy who were unhealthy.

When examining the interaction between seeing a specialist and parental health ((b = -1.01, Wald χ^2 (27) = 1370.03, $p > 0.001$), those children who saw a specialist and had an unhealthy parent had 3146% odds of being in the unhealthy epilepsy group versus a 352% odds of being in the unhealthy epilepsy group if their caregiver was healthy. In general, for those children who saw a specialist and had a healthy caregiver, they were less likely to have epilepsy than those who saw a specialist but had an unhealthy caregiver.

Children with epilepsy: Healthy vs. unhealthy status. Whether or not a caregiver was removed from the home as a child significantly predicted whether a child with epilepsy was considered healthy or unhealthy ($b = 1.56$, Wald χ^2 (27) = 1370.03, $p > 0.001$). There were 376% higher odds of being in the unhealthy group when a caregiver was removed from the home as a child. In general, those caregivers who had been from the home as children tended to have children with epilepsy who were also unhealthy.

The likelihood of having a child with epilepsy in the unhealthy group depended on whether the child saw a specialist and how their income changed ($b = -0.18$, Wald χ^2 (27) = 1370.03, $p > 0.001$). When children saw a specialist and the family income was $50,000, they had 29% higher odds of belonging to the unhealthy epilepsy group versus when they saw a specialist but the family income was $20,000, they had 44% higher odds of belonging to the unhealthy epilepsy group. In general, those children who saw a specialist and whose family income was higher were less likely to be in the unhealthy group of children with epilepsy.

The likelihood of having a child with epilepsy in the unhealthy group depended on whether the child saw a specialist and if they were part of a community with active members ($b = -1.47$, Wald χ^2 (27) = 1370.03, $p = 0.004$). When children saw a specialist and were part of a community with active members, they had 23% higher odds of being in the healthy epilepsy group versus when children did not belong to a community with active members, they had 366% higher odds of being in the unhealthy epilepsy group. In general, children who saw a specialist and were part of a community with active members were less likely to be in the unhealthy epilepsy group compared to the healthy epilepsy group.

The likelihood of having a child with epilepsy in the unhealthy group depended on whether the child saw a specialist and had a healthy parent ($b = 0.93$, Wald χ^2 (27) = 1370.03, p

= 0.024). Children with epilepsy who saw a specialist and had a healthy parent had 830% higher odds of belonging to the unhealthy epilepsy group versus those children with an unhealthy parent who had 366% higher odds of belonging to the unhealthy epilepsy group. In general. Children who saw a specialist and had a healthy parent were more likely to be in the unhealthy epilepsy group perhaps parents were more likely to compare their own health to that of their children.

Unhealthy status: Children without vs. with epilepsy. When considering those with poor health status, income predicted whether a child was in the epilepsy group versus not, (b = 0.14, Wald χ^2 (27) = 1370.03, $p > 0.001$). There were 32% higher odds of being in the unhealthy group with epilepsy versus the unhealthy group without epilepsy, when family income was $20,000 and 100% higher odds of being in the unhealthy epilepsy group versus the unhealthy group without epilepsy when family income was $50,000. In general, as income increased children who were unhealthy were more likely to be in the epilepsy group suggesting that other disorders may take more of a financial toll on family income than epilepsy.

Seeing a specialist predicted whether a child was in the epilepsy group versus not, when considering those with poor health status (b = 2.36, Wald χ^2 (27) = 1370.03, $p > 0.001$). There were 959% higher odds of being unhealthy but in the epilepsy group versus the group without epilepsy. In general, those children who saw a specialist were more likely to be in the epilepsy group, when considering those with poor health status.

Having a parent removed from the home as a child predicted whether a child was in the epilepsy group or not, when considering those with poor health status (b = 1,25, Wald χ^2 (27) = 1370.03, $p > 0.001$). There were 249% higher odds of being in the unhealthy group with epilepsy versus the group without epilepsy. In general, those children who had a parent who was removed

when they were a child were more likely to be in the epilepsy group, when considering those with poor health (Table 15).

Table 15

Examining Risk and Resiliency Factors in Children with Epilepsy

	B(SE)	p-value	95% CI	
Healthy Control Group vs. Healthy Epilepsy Group				
Constant	-1.91 (0.17)	<0.0001	-2.24	-1.57
Income*	-0.08 (0.02)	**<0.0001**	-0.13	-0.40
Members**	-0.03 (0.19)	0.874	-0.41	0.34
Specialist	1.94 (0.37)	<0.0001	1.21	2.68
Removal of Parent from home as child	0.19 (0.25)	0.77	-0.30	0.68
Healthy Parent	-0.71 (0.17)	<0.0001	-1.04	-0.39
Interaction				
Specialist x Income*	-0.11 (0.07)	0.09	-0.25	0.02
Specialist x Removal of Parent from home as child	-0.74 (0.61)	0.23	-1.94	0.46
Specialist x Members**	2.01 (0.42)	**<0.0001**	1.26	2.92
Specialist x Healthy Parent	-1.95 (0.17)	**<0.0001**	-2.24	-1.57
Healthy Control Group vs. Unhealthy Epilepsy Group				
Constant	-3.36 (0.27)	<0.0001	-3.88	-2.84
Income*	0.04 (0.02)	0.10	-0.01	0.09
Members**	-0.36 (0.25)	0.15	-0.85	0.13
Specialist	3.48 (0.39)	<0.0001	2.72	4.25
Removal of Parent from home as child	1.75 (0.26)	**<0.0001**	1.23	2.26
Healthy Parent	-0.96 (0.24)	<0.0001	-1.42	-0.49
Interaction				
Specialist x Income*	0.07 (0.04)	0.09	-0.01	0.14
Specialist x Removal of Parent from home as child	-0.38 (0.41)	0.35	-1.19	0.42
Specialist x Members**	0.62 (0.34)	0.07	-0.05	1.29
Specialist x Healthy Parent	-1.01 (0.37)	**0.006**	-1.75	-0.29
Healthy Epilepsy Group vs. Unhealthy Epilepsy Group				
Constant	-1.46 (0.30)	<0.0001	-2.05	-0.86
Income*	0.13 (0.03)	<0.0001	0.06	0.19
Members**	-0.33 (0.30)	0.28	-0.92	0.26
Specialist	1.54 (0.44)	<0.0001	0.68	2.40
Removal of Parent from home as child	1.56 (0.35)	**<0.0001**	0.88	2.24
Healthy Parent	-0.24 (0.28)	0.40	-0.80	0.32
Interaction				
Specialist x Income*	0.18 (0.07)	**0.015**	0.04	0.32
Specialist x Removal of Parent from home as child	0.36 (0.64)	0.57	-0.90	1.61
Specialist x Members**	-1.47 (0.51)	**0.004**	-2.47	-0.47
Specialist x Healthy Parent	0.93 (0.41)	**0.024**	0.12	1.74
Unhealthy Control Group vs. Unhealthy Epilepsy Group				
Constant	-4.36	<0.0001	-4.89	-3.83

Income*	0.15 (0.02)	**<0.0001**	0.10	0.20
Members**	0.22 (0.25)	0.37	-0.27	0.71
Specialist	2.36 (0.34)	**<0.0001**	1.70	3.02
Removal of Parent from home as child	1.25 (0.26)	**<0.0001**	0.74	1.77
Healthy Parent	0.12 (0.24)	0.62	-0.35	0.59
Interaction				
Specialist x Income*	-0.05 (0.04)	0.16	-0.13	0.02
Specialist x Removal of Parent from home as child	0.39 (0.35)	0.27	-0.31	1.08
Specialist x Members**	-0.07 (0.32)	0.82	-0.70	0.55
Specialist x Healthy Parent	0.11 (0.33)	0.74	-0.54	0.76

Note. *Income was set at $50,000 as average income; **Means active members in the community.

Summary: Second Objective Part C

Children who came from higher incomes were more likely to be healthy children without epilepsy. Caregivers who were removed from the home as children were more likely to have children with epilepsy who were unhealthy. Children were more likely to have a diagnosis of epilepsy if they saw a specialist and belonged to a community of active members. Upon further inspection, when looking at children with epilepsy only, those who saw a specialist and belonged to a community that had active members, these children were less likely to be rated as unhealthy.

Chapter Eight: Discussion

The current study examined the health needs and health status of Indigenous children with epilepsy using the 2006 Aboriginal Children's Survey (ACS) sample. In particular, we examined the risk (*i.e., having a disorder, low birth weight, low income, lack of specialists, parent illness, parental removal from home as a child*) and resiliency factors (*i.e., community support, breast feeding*) in our sample in order to help inform future research and policy directions.

The main findings of the present study were: (1) Indigenous children in Canada had higher rates of epilepsy compared to the overall rate of epilepsy for children in Canada; (2) Children with epilepsy compared to those without epilepsy had significantly higher rates of vision and hearing issues, allergies, asthma/bronchitis, and speech-language difficulties; (3) Children with epilepsy were less likely to see a specialist than those without epilepsy; (4) Children who received breast milk were significantly less likely to have epilepsy than those children who did not receive breast milk; (5) If a child had a medical, neurodevelopmental or mental disorder, they were more likely to have epilepsy; (6) Caregivers who rated themselves as healthy were less likely to have a child with epilepsy; even when comparing children with poor health status those caregivers who were healthy had less chance of having a child with epilepsy; (7) In addition to caregiver health, those caregivers who were removed from the home as children were also more likely to have children with epilepsy regardless of the child's health status.

When comparing only those children with a good health status, those children who lived in communities with active members and who had access to a specialist were more likely to be identified as having epilepsy. This suggests that the opportunity to access care and have adults advocate for the community, allows children to be identified and receive proper treatment where they otherwise may have been ignored because of their good health status. Children with epilepsy

who also had poor health status were more likely to see a specialist and be part of a community with active members than those children with epilepsy who had good health status. This suggests that specialist care and having members who are active in the community provides the opportunity for children to be seen by a professional who will notice ailments the child has. Children who saw a specialist and had a healthy parent were less likely to have epilepsy. When comparing children with epilepsy, children who saw a specialist and had a healthy parent were more likely to also belong to the group of children with good health status. This suggests that in addition to specialist care, having a healthy caregiver also impacts health both in terms of an epilepsy diagnosis and also in terms of health status. However, because most of the caregivers in the present study were biological parents it cannot be excluded that the parents who were healthy also had healthy children.

The present study fits well with the adapted model (Figure 2) in that it highlights that distal and immediate settings impact a child's development and health. In the present study, immediate and distal settings impacting Indigenous children's care included: if the setting has active community members, receives breast milk, has a healthy parent, if the child sees a specialist, income, policies around how children were treated in the past (i.e. caregiver removed from home as a child). It also fits well with the Adapted model which includes Bandura's Human agency theory, in that those children in communities with active members were healthiest. This suggests that perhaps these children actively motivated others to work on their behalf, with a reciprocal motivation on the part of the caregivers to access the resources they needed for optimal health.

Disorder Rates and Health of Indigenous Children

In the present study, 5.4 per 1000 children had epilepsy, as compared to the Canadian rate for children which is 3.6 to 4.6 per 1000 children (Beilmann, Napa, Soot, Talvik & Talvik, 1999; Sidenvall, Forsgren, & Heijbel, 1996). Additionally, rates of tuberculosis, diabetes, hypoglycemia or prediabetic state, kidney condition or disease, iron deficiency, cerebral palsy, down syndrome, spina bifida, fetal alcohol syndrome disorder, heart disease or condition, ADHD/ADD also occurred one to two percent in the entire sample

Of particular interest were the significant differences between the children without epilepsy and the epilepsy group in rates of vision or hearing issues, allergies, asthma or bronchitis, speech language difficulties and other disorders that were not specified, ranging from 4-10% for children without epilepsy and 25-38% for children with epilepsy. In a prospective community-based study of newly diagnosed children with epilepsy, at the nine-year reassessment 19% had complicated epilepsy. At follow-up the comorbidities included: 26% psychiatric diagnosis, 39% neurodevelopmental spectrum disorder, 24% chronic medical illness, and 15% migraine (Baca et al., 2011). Psychiatric comorbidities were strongly associated with long-term quality of life (Baca et al., 2011). Given that the children in our sample are quite young it is possible that these difficulties will continue to increase with age and with a lack of intervention and may be higher than that reported by Baca et al., (2011).

In the present sample, less than 50% of caregivers reported satisfaction with health facilities. Less than 50% of children with epilepsy saw a specialist, in comparison to about 90% of children who saw a specialist in the group of children without epilepsy. The National Collaborating Centre for Aboriginal Health identified a number of factors associated with limited

access to health services, these included; socio-economic status, geography, lack of infrastructure and staff, jurisdictional ambiguities and language or cultural barriers. Given that average income was around $50,000, few noted food shortages and families lived off-reserve, it is possible that we are not seeing the full picture of what hardships Indigenous groups face in remote areas and areas were many barriers are present both physically and psychologically.

Health Status Ratings

Significantly more caregivers of children with epilepsy in comparison to those caregivers of children without epilepsy, were themselves removed from their home by welfare when they were children. Additionally, more caregivers of children with epilepsy rated their own health worse than that of caregivers whose children did not have epilepsy. Caregivers of children with epilepsy had about $10,000 lower family income and were four times more likely to seek out welfare assistance than caregivers whose children did not have epilepsy. When health rating was examined and compared between controls and the epilepsy group, poor parental health status predicted whether a child would be in the epilepsy groups versus healthy control group, and children who were deemed as being unhealthy in the epilepsy group were more likely to also have a parent with poor health status even when compared to unhealthy children without epilepsy. In general, parents with poor health were more likely to have children with epilepsy regardless of health status. Future research should examine prenatal health and prenatal stress and access to resources as predictors of epilepsy in children.

Jensen et al., (2017) asked caregivers of children with epilepsy so discuss the impact of the disorder across a number of domains. Focus groups with caregivers of children with epilepsy noted the impact of epilepsy on a number of domains: (1) physical domain which included

having sleep deprivation because of their worries regarding their child's around the clock needs and care, with most feeling too exhausted to care for themselves; (2) mental health domain which included parents reporting more emotional changes (e.g., feeling angry, anxiety, guilt and helplessness) whereas those who could obtain breaks found that they were more effective caregivers upon their return; (3) financial resources: caregivers reported highest stressors at early stages of diagnosis and many reported issues with employment and financial burden as a result of seeking treatments not covered by insurance; (4) relationships with others: reported that these tended to deteriorate as the focus was on the child and not everyone understood the burden of caring for a child with epilepsy (Jensen et al., 2017). Previous research has shown that caregivers of children with special needs experience more demands with respect to their time, effort and emotional demands yet there are not adequate enough questionnaires and surveys to examine these stressors that parents of children with epilepsy face (Aras et al., 2014; Gallagher & Hannigan, 2014; Jensen et al., 2017).

In a study by Verstraete, Ramma, & Lebogang (2018), when comparing health rating status of parents with the rating they gave their child who were either acutely-ill, chronically-ill or from the general population, parents' self-rating scores were similar to the rating scores parents gave to their own children which were independent of the presence or absence of their own problems. In another study, duration of epilepsy, and family history of epilepsy predicted caregiver ratings of their child's and their own quality of life (Momeni, Ghanbari, Bidabadi, & Yousefzadeh-Chabok, 2015). Others have found that among youth between 8 and 17 years of age, poor psychiatric status in youth was related to parent reported and child-reported poor quality of life (Bilgic, Isik, Colak, Derin, & Caksen, 2018). Adverse effects are seen in quality of life for school children and their parents when children have resistant epilepsy (e.g., intellectual

or physical disability, abnormal brain imaging findings, learning problems or polypharmacy or prolonged treatment) and accompanying neurodevelopmental problems (Bompori et al., 2014). Ferro, Landgraf, and Speechley (2013) examined quality of life in the first 24 months after diagnosis, as rated by parents, identifying a number of trajectories dependent on the following factors: number of antiepileptic drugs prescribed, presence of comorbid behaviour or cognitive problems, parent depression, family functioning and demands. In the present study it is possible that caregiver health ratings were derived from not only their own disorders, but also in relation to their child's current health and living situation, family functioning and demands.

Developmental Milestones

Developmental milestones were separated into the following categories: social and emotional development, language/communication development, cognitive development and movement/physical development (Centers for Disease Control and Prevention, 2018). In the present study, most children met developmental milestones for their age group regardless of whether or not they had epilepsy. A previous study by Findley, Kohen, and Miller (2014) examined the ACS and found that gross motor and self-help skills were achieved earlier in comparison to language skills which were achieved later than Canadian children not of Indigenous descent. Low birth weight and chronic health conditions were associated with late achievement outcomes, even when controlling for sociodemographic characteristics (Findley et al., 2014). In the present study, 98% of caregivers identified that their child had acquired the language/communication milestone, yet when asked specifically about any speech or language difficulties 8% of the total ACS population noted that their child had difficulties, while 38% of children in the epilepsy group had speech/language difficulties. When examining the

Physical/movement milestone, 92% of caregivers noted that the child had accomplished this goal, yet 48% of children with epilepsy had physical movement difficulties resulting from a disorder and 3% of the controls also reported physical movement difficulties. These findings are consistent with Findley et al. (2014) who noted that children with health conditions seemed to achieve milestones later.

Previous research has found that specific developmental milestones may serve as risk markers for later disorders (Kover, Edmunds, & Weismer, 2016; Poll & Miller, 2013; Rescorla, 2011; Flensborg-Madsen & Mortensen, 2018). Milestones such as age at first word predicted expressive language and adaptive skills. (Kover et al., 2016). The number of words a child knew before the age of 6 years, served as a positive predictor for the level of receptive language, expressive language, nonverbal cognitive skills, and adaptive behaviour achieved (Kover et al., 2016). However, some research has found mixed results. In one study, 60% of children in the sample had weak oral language abilities at age eight, although this was not predicted by late development of language (Poll & Miller, 2013). This study found that children who did not combine words when they were two years old showed difficulty with reading comprehension at age eight, additionally math ability at age eight was mediated by a child's oral language skills (Poll & Miller, 2013). More importantly, some children who showed typical vocabulary or word combining at age two had weak language skills at age eight suggesting, other factors were at play (Poll and Miller, 2013). The contradictory nature of these findings makes it difficult to draw firm conclusions about predictors of outcome. Research has found that although expressive language screening between 18-35 months of age may help to identify children with an expressive language delay, for those children who do not show a delay in developmental milestones but later exhibited language delays, a causal factor may be low socio-economic status (Rescorla, 2011).

In a 50-year follow-up study, authors found that the later attainment of language milestones could account for 6.7% of the variance in midlife IQ (intelligence quotient) and milestones related to social interaction explained 3.1% of the variance in midlife IQ (Flensborg-Madsen & Mortensen, 2018). A large body of research has focused on language/communication and social/emotional development as risk markers for autism spectrum disorder. One study found that when early language milestones were reached, children with specific disorders such as autism did not experience the same communication issues as those children who did not meet the milestones (Kenworthy, Wallace, Powell, & Anselmo, 2012). That is, acquisition of phrase speech by 24 months served as a sensitive marker to language and communication problems in children with autism (Kenworthy et al., 2012). Another study found that fine motor development predicted severity of autism spectrum disorder symptoms within a 30-month re-assessment (Iverson et al., 2019). Screeners aimed at examining developmental milestones in children with down syndrome and global developmental delay have found that these groups of children often have difficulties with motor and personal-social development (Matson, Hess, Sipes, & Horovitz, 2010). Perna & Loughan (2012) found that children with developmental delays had an increased risk of ADHD but not learning disorders or emotional/behaviour problems. Another study examined neuromotor milestone development and found although all individuals who developed schizophrenia reached all neuromotor milestones as children (e.g., smiling, lifting head, sitting, crawling and walking) the age that they reached them compared to healthy controls was significantly later, additionally those who developed other psychiatric disorders seemed to reach these milestones later than controls but earlier than individuals with schizophrenia (Sorensen et al., 2010). Another study found that fine motor, gross motor and math/premath abilities on a screener test showed significant developed abnormalities in children with neurofibromatosis type

I (Soucy, Gao, Gutmann, & Dunn, 2012).

Checklists may overestimate what is considered normal development, items on the checklist may not be age specific and may be expected at a number of age levels, thus in order create a measure/checklist a number of psychometric studies need to be completed to gain a better understanding of important milestones that predict problematic outcomes (Brothers, Glascoe, Robertshaw, 2008). Gladstone et al., (2009), highlight that although developmental milestones often help with child evaluation these tools have been created for "western settings" and may be inaccurate as they include items that are unfamiliar to different cultural settings. The authors sought the help of individuals from Southern Malawai to participate in focus group discussions. Through thematic content analysis a Malawian developmental tool was created. This developmental tool noted that the main focus was related to motor skills (e.g., peeling bananas, sorting maize), social development (e.g., duties and chores, sharing) and language skills (e.g., reporting events, shrugging to indicate 'no'). Social and community integrity were used to describe intelligence rather than western culture's view of intelligence which includes numeracy and literacy (Gladstone et al., 2009). Western tools aimed at evaluating developmental milestones may not take into account the culture, language and environmental exposure of children not raised in Western societal norms (Ngoun, Stoey, van't Ende, & Kumar, 2011). Even simple milestones such as "waves bye-bye" are inappropriate and that instead "play chab chab" is a more common gesture taught to children in Cambodia (Ngoun et al, 2011). Thus, while milestones serve an important role in determining that a child is developing appropriately, continued work must be done to ensure that the milestones being measured also make sense in the cultural context within which the child is developing.

Strength and Difficulties Questionnaire

In the present study, no significant differences were reported in children with epilepsy when compared to children who did not have epilepsy. When looking at the entire sample, scores in the clinical range varied between 30-40% for the emotions, conduct problems, hyperactive/inattentive, and peer problems subscales with the exception of prosocial subscale which showed very low clinical levels (i.e., 4%). Overall, 37% of children had total scores in the clinical range.

In a community sample of 7984 children between 5-15 years of age, using a multi-informant method, the SDQ had good specificity and sensitivity (Goodman, Ford, Simmons, Gatward, & Meltzer, 2003). Sensitivity ranged from 86% to 51%, with higher sensitivity for any psychiatric disorder, conduct disorder, hyperkinetic disorder, ADHD, pervasive developmental disorders, social phobia and obsessive-compulsive disorder, or post-traumatic stress disorder, and lower sensitivity for other anxiety disorders (e.g., specific phobia, separation anxiety, generalized anxiety disorder), eating disorder, or tic disorder (Goodman et al., 2003). SDQ scores in the clinical range increased the likelihood that an individual for meeting diagnostic criteria specifically for behaviour disorders more than mood disorders (He, Burstein, Schmitz, & Merikangas, 2012). The SDQ's predictive ability was not significantly impacted by sex, age, income and race/ethnicity, within their sample of American youth of white, black and Hispanic backgrounds (He et al., 2012). The validity of the SDQ in a community sample of Spanish three-year-old children showed acceptable psychometric properties for use in identifying behavioural and emotional problems in preschool children. (Ezpeleta, Granero, de la Osa, Penelo, & Domenech, 2013).

The SDQ has been validated and shown to have satisfactory reliability across a number of

cultures (e.g., British, Dutch, American, Greek, Japanese, Indian Gujarati) and has been translated into many languages (Goodman, 2001; Muris, Meesters & van den Berg, 2003; Palmieri and Smith, 2007, Croft, Stride, Maughan, & Rowe, 2015; Giannakopoulos, Dimitrakaki, Papadopoulou, & Tzavara, 2013; Doi, Ishihara, & Uchiyama, 2014; Stone et al., 2015; Kumar and Fonagy, 2018). Although the SDQ has received attention for having good psychometric properties, there are some exceptions (e.g., Arab children from the Gaza strip, New Zealand preschoolers of New Zealand European, Maori, Pasifika, Asian backgrounds, South African children, Children from Honduras, children from Indigenous groups in urban and rural settings in Australia), where some subscales fall below reliability cut-offs and authors caution against using individual subscales (Thabet, Stretch, and Vostanis, 2000; Kersten, Vandal, Elder, & McPherson, 2018; Vries, Davids, Matthews & Aaro, 2018; Harry, Acevedo, & Crea, 2019, Williamson et al., 2010; 2014).

Oliver, Findlay, McIntosh, and Kohen (2009) examined the SDQ in the Aboriginal Children's survey 2006 (ACS) that the present study also used. Prior to their study, the SDQ had not been validated with off-reserve First Nations, Metis, and Inuit children between 2 and 5 years old in Canada. When the SDQ was examined within this ACS population, goodness of fit measures indicated low reliability for off –reserve First Nations and Inuit children (Oliver, et al., 2009). More specifically, similarly to Williamson et al., (2010; 2014), the peer problems subscale showed low reliability across all three groups, additionally the emotional symptoms subscale showed low reliability in Inuit children (Oliver et al., 2009). The authors cautioned using the original SDQ subscales for Indigenous children, especially those of Inuit descent (Oliver et al., 2009). Although the SDQ was used for the entire ACS population which fell outside the SDQ age range, results were similar across age groupings, with the conclusion that including children

outside the ages of the questionnaires did not have a large impact on the results (Oliver et al., 2009). An exploratory factor analysis examined alternative groupings of items within the subscales and although there was improvement in the reliability of the subscales, the emotional subscale continued to indicate poor reliability for Inuit children (Oliver et al., 2009). Based on previous work done on the ACS sample by Oliver et al., (2009), the SDQ may not be reliable for the present sample.

Satisfaction and Resiliency

In the present study majority of children were identified as First Nations with or without multiple backgrounds. Most families noted very few moves and only a quarter identified living in rural settings. Indigenous people participated across Canada, with the largest sample being from Ontario. Over 75% had either high-school or post-secondary education and most lived in two generational households. The majority of caregivers considered themselves to have excellent to very good health. The average income was between $50,000 to $60,000 for participants in the ACS dataset, which closely matched median household income in the 2006 census (Statistics Canada, 2016). Given that about 75% of participants in the present dataset lived in urban settings and the sample included off-reserve children only, perhaps household income would have been lower if those living in rural settings were also included. Despite average family income, about half of the participants in the survey reported homes that required repairs.

In this particular sample a very small group of caregivers had been removed by welfare (i.e., about four percent) as children and an even smaller group attended the residential school system. Over 90% of caregivers indicated having a support network of family, friends or others. Yet when asked about their community as a place for Indigenous activities, only 35% indicated

that their community provided this. Less than half the sample participated in traditional activities although more than half indicated the importance of culture and history within their life. When asked about how caregivers exposed children to Indigenous culture, most did so through books, followed by cultural activities, with only about a quarter exposing their children to Indigenous language either at home or through media. Only about half the population noted that they thought it was important for their child to learn the Indigenous language.

Previous research has shown that cultural identity and connectedness supports Indigenous health as seen over a two-year period of children participating in a mentoring program aimed at promoting positive mental health (Crooks, Exner-Cortens, Burm, Lapointe, & Chiodo, 2017). While others argue that the impact of traditional activities on health is less clear and needs to be further investigated, others have shown that when Indigenous youth take on health education through their cultural lens examining holistic values of balance and respect as taught by their community and elders, they are more engaged and empowered to share health knowledge with their peers (Wilson & Rosenberg, 2002; Riecken, Tanaka, & Scott, 2006).

Limitations

The present study is not without limitations. First, on-reserve First Nations children were not included in data collection, the ACS did not justify the unique choice in data collection. As a result, the present study cannot be generalized to those children who live on reserve or on settlements. Second, the present sample did not include Indigenous individuals who refused to answer questions, or did not know the answer to specified questions, were not included in the data set. Demographic information from this group cannot be compared with the present sample to assist in understanding this unique population due to confidentiality issues. Third, as a result of confidentiality, there were limitations in interpreting data and many variables had to be collapsed

resulting in loss of rich information. Fourth, data were collected via questionnaires and thus although great care was taken in creating these questionnaires, the method of data collection may have limited knowledge that could have been acquired in open-ended questions. Fifth, epilepsy and other diseases and disorders indicated by a parent were not verified by a health care practitioner, either Indigenous or Western. Sixth, the present study is limited in that it was only assessed at one time point and as a result the findings are correlational and do not provide directionality. Future work that continues to explore outcomes in this population should consider asking caregivers to return and complete a second set of questionnaires to examine prognostic markers with respect to their health and healthcare needs. Seventh, the present survey did not word epilepsy and other disorders in a culturally significant way and so some individuals may have answered incorrectly as they may have not understood the question. These are all issues that could be addressed in future studies.

Participation in Research

Parents are more likely to participate in research when they are well informed of its purpose, have decision aids (e.g., doctors or health care professionals), see collaboration among those running the research and those in the community, and if incentives are present and inconveniences are minimized (Caldwell, Butow, & Craig, 2003). In a systematic review of barriers and facilitators to minority research participation, George, Duran, and Norris (2014), found that minority groups were willing to participate in research for altruistic reasons embedded in cultural and community priorities despite expressing mistrust of researchers and noted that a better understanding of cultural differences could assist research participation. Participation improves when recruitment material has cultural and linguistic adaptation and focuses on the

needs of that community, yet culturally meaningful and appropriate discussions around consent and informed decision making is lacking (George, Duran & Norris, 2013). Families and communities may need to also be included in the dialogue when discussing research participation and the costs and benefits to the community (George et al., 2013). Continued work with the community and building relationships with the leaders of the community can foster retention in research studies (George et al., 2013).

For ethnic or minority participants there are also concerns around psychosocial issues such as mistrust, fear, lack of confidence that logistical matters will be addressed (e.g., childcare, schedule conflicts), or that there will be appropriate support around research related factors (e.g., consent forms appropriate to group, length of documentation appropriate for allotted time) (George et al., 2013). Past treatment of particular ethnic groups has caused a mistrust in the medical system and medical research (George et al., 2013). Participation is less likely if previous medical needs have been ignored, delayed or individuals have felt discriminated against (George et al., 2013). There is also a level of internalized racism, where stigmatized populations accept negative messages and stereotypes about their own abilities and worth and this affects the provider-caregiver relationship and may breakdown communication, leading to discounting of information and lower adherence to protocols or medical advice (George et al., 2013).

Research in Indigenous communities and on Indigenous matters is often initiated by agencies from which Indigenous people receive essential services and governments that control resources the community needs are also the ones that are funding the research (Castellano, 2014). As a result, Indigenous people may fear that refusing to participate in research may lead to a loss of funding of essential services. The imbalance of power within these communities may cause

researchers to not listen to the communities' priorities (Castellano, 2014). When asking Indigenous people to participate in research it is important to abide by principles that protect their inherent right to self-government (Castellano, 2014; Schnarch, 2004). There are a number of principles that are foundational steps in improving research participation with Indigenous groups. First, Indigenous people have a right to participate as partners in research and participate in research that will generate information that is related to their culture, identity and well-being and ensures data are collected in a way that meets the cultural expectations of the community. Second, safeguards must be put in place that are also endorsed by Indigenous people and where the government acts to the benefit of Indigenous people. Third, Indigenous people must be major members in Indigenous research, serving on various boards to ensure ethical standards and cultural perspectives are taken into account and ensure that research questions and methods match the cultural practices of the community and maintain sovereignty of Indigenous people. Research should support self-determination and cultural preservation and development. Fourth, ethical practice, such as costs for research, consent, safety and social benefit of the research being undertaken must be monitored to ensure that regulations are met. Fifth, educating Indigenous individuals about research and Ethics in Indigenous research rests with Indigenous communities, research institutions and individual researches working together (Castellano, 2014). The strength of the collaboration ensures community support and higher rates of participation in research (Boffa, King, McMullin, & Long, 2011).

Future Directions and Clinical Implications

The present study examined the health status of Indigenous children under six years of age, with a specific focus on the health and well-being of children with epilepsy in comparison to

those children without epilepsy. Future work that continues to explore outcomes in this population should consider asking caregivers to return and complete a second set of questionnaires to examine prognostic markers with respect to their health and healthcare needs.

If caregivers were invited back to participate in survey data, data collection should include open-ended questions and follow-up questions to health information. For example, the present survey asked if the child had other disorders, caregivers who answered "yes" to this question were not asked to specify the disorder type or describe what they consider this other disorder, as a result information about their health was missed with respect to severity and possible disorder count. Families were asked about their need for welfare assistance, but further probing did not provide information for what assistance was received and if it was helpful to them. Given the low number of caregivers who experienced removal by welfare or residential school systems, along with data missing for on-reserve First Nations, and those living in rural communities, research should expand and include these groups in order to provide a clearer understanding of the health needs of this vulnerable population.

Indigenous children have higher rates of epilepsy in comparison to non-Indigenous Canadian children and higher rates of comorbidities (i.e., speech-language difficulties, vision or hearing difficulties, allergies, asthma) than Indigenous children without epilepsy. Caregiver health is an essential part of a child's health. Depending on the health status of the child, poor parental health in combination with not seeing a specialist impacts a child's health status and is even more pronounced for children with epilepsy. One quarter of caregivers of children with epilepsy admit they have difficulty accessing healthcare or medicine.

Indigenous children are one of the fastest growing groups within Canada, yet there continue to be knowledge gaps with respect to their needs and the health care they receive. The

present data show that Indigenous children have higher rates of epilepsy than non-Indigenous Canadian children and that these children are more likely to also have complex needs that result from multiple diseases or disorders. When it comes to health, health status of the caregiver is just as important as the health status of the child and so research focusing on examining the social and environmental context is important.

Although collaboration and mutual respect are growing between non-Indigenous researchers and Indigenous communities, continued work and dialogue around shortcomings need to be addressed if we are to produce research that is respectful, meaningful, and beneficial to Indigenous communities. Continued work in examining culturally appropriate methods to determine physical, cognitive and emotional development is needed if we are to truly understand the needs of Indigenous children. Additionally, when describing epilepsy or other health variables it is important to ensure that they are described in a culturally significant manner.

Take-Away Message

Canada will continue to face challenges in providing care to Indigenous children with healthcare needs, unless it addresses some important gaps in how health care is provided to Indigenous children. Echoing previous literature, the present study found that when creating health programs/services or policies a number of factors should be kept in mind:

(a) Indigenous children with epilepsy have caregivers who were themselves removed from the home as children. Indigenous families experience multi-generational trauma through foster-care and colonization and this greatly impacts their trust in health care programs, their connection with their own communities and their health. Care for the child must also then take into consideration the health of the parent, family and community, and how best they can be

supported.

(b) When it comes to children's health, epilepsy rates in Indigenous children in Canada are higher than those of the general population (i.e. 5.4 per every 1000 children compared to 3.6 to 4.6 per 1000 children from non-Indigenous groups). Indigenous children with epilepsy have complex needs because they are likely to also have additional medical conditions, neurodevelopmental and mental disorders. There continue to be gaps in the health care that is needed to support Indigenous children. Only half of Indigenous caregivers reported satisfaction with health care facilities, with one-quarter of children with epilepsy limited by access to care or medicine. Less than a quarter of Indigenous children saw a specialist, with even fewer being those with epilepsy. The health needs of children with epilepsy are complex and require collaboration among health care professionals, Indigenous leaders, communities and families.

(c) When examining the community within which Indigenous children grow, those who receive breast milk, have heathy parents, and come from a higher SES fare better. Health care professionals and policy makers that work collaboratively with the community have the potential to develop effective programs that support these factors.

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