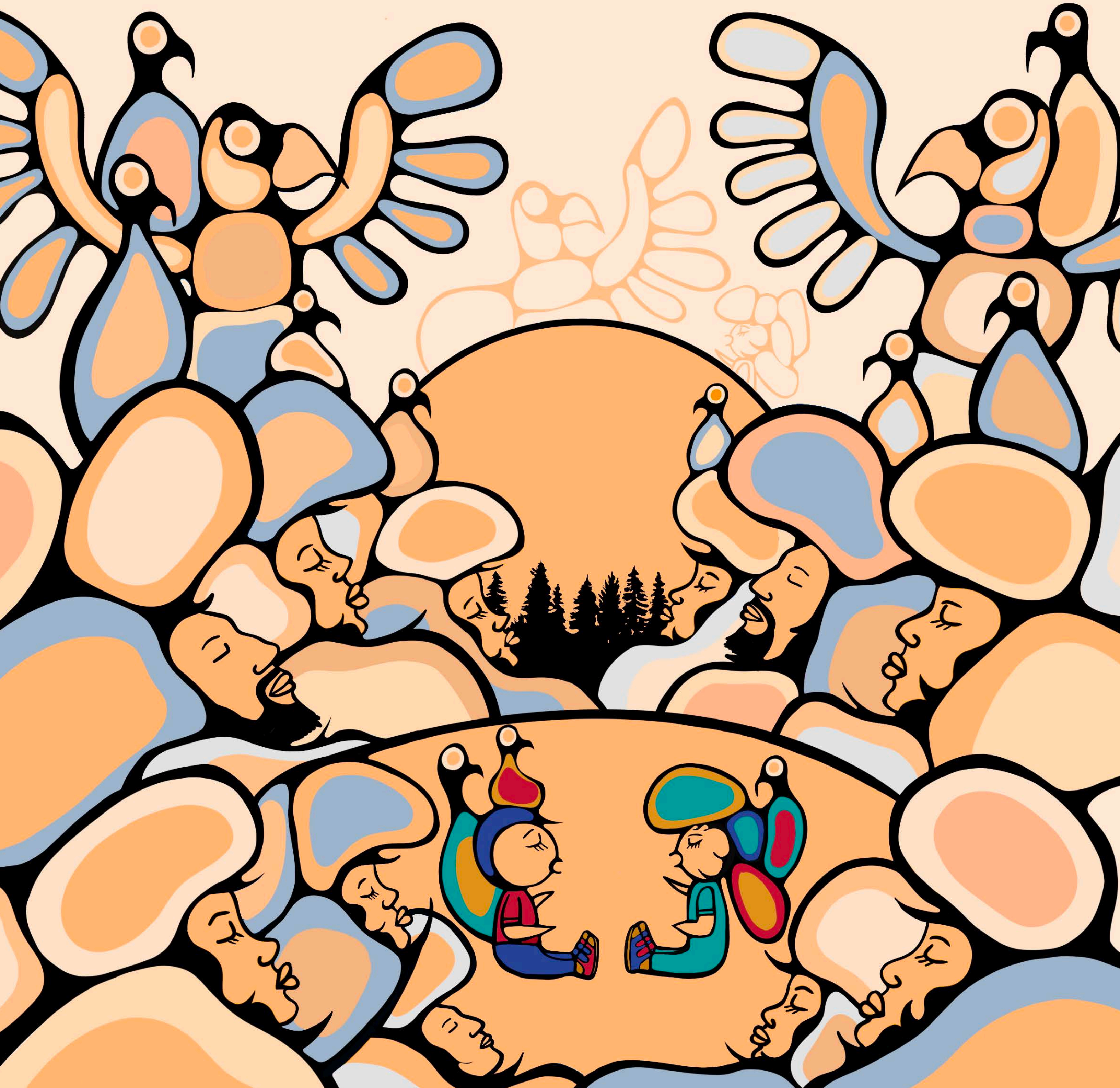
FNIGC ≀ CGIPN
First Nations Information Governance Centre
Le Centre de gouvernance de l'information des Premières Nations

# LITERATURE REVIEW FOR THE FEASIBILITY STUDY ON LONGITUDINAL RESEARCH WITH FIRST NATIONS CHILDREN



**Our data. Our stories. Our future.**

ISBN: 978-1-988433-44-8

General inquiries: info@fnigc.ca

www.FNIGC.ca

This literature review was conducted between 2019 and 2021, and reflects the knowledge, research, and perspectives available during that time. FNIGC acknowledges that significant advancements have continued since then, and this review may not encompass more recent developments among First Nations children health and well-being research. FNIGC is grateful for the collective efforts of First Nations communities, leaders, scholars, and organizations who continue to advance this work through their knowledge, experience, and leadership.

# ABOUT THE ARTIST

Blake Angeconeb is an Anishinaabe woodlands artist who hails from Treaty 3 territory. His first venture into art began six years ago during a fun painting session with his younger niece, which has since launched him into a full-time career as an artist. Blake's primary practice involves acrylics and multimedia on canvas, blending the school of woodlands art with pop culture references. Blake is a self-trained painter with a growing collection of small and large-scale works who enjoys collaborating with other artists. He is part of the Caribou clan and a proud member of Lac Seul First Nation.

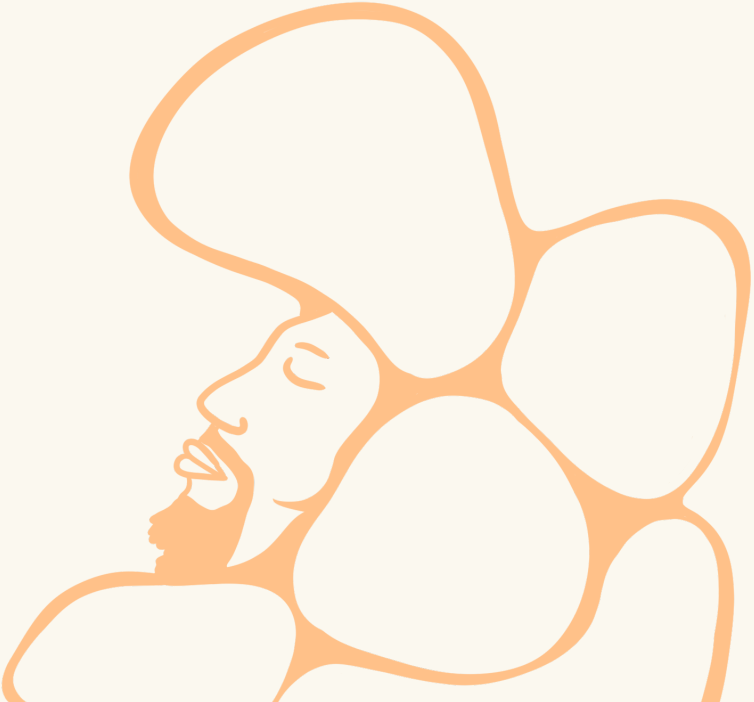
# ABOUT THE ART

This artwork honours Indigenous youth and sovereignty, placing children at the centre of family, community, and land. Encircled by fathers, mothers, and ancestors, the children are supported by generations of love and responsibility.

Above, Thunderbirds spread their wings in protection and strength, guiding the future with spiritual power. Forest silhouettes ground the work in place, reminding us that connection to land is inseparable from well-being.

The flowing forms and cycles reflect reciprocity, resilience, and the responsibility to carry knowledge forward. This piece affirms that research with First Nations must honour youth, uphold sovereignty, and remain rooted in relationships, so the next generations may grow strong and protected.

# TABLE OF CONTENTS



# BACKGROUND

In December 2018, the Assembly of First Nations' Chiefs-in-Assembly passed a Resolution (#76, 2018), requesting that FNIGC "produce a paper on the feasibility of conducting a longitudinal study of First Nations child development and well-being based on the Adverse Childhood Experiences Study (ACE Study) which accounts for structural inequalities and cultural and linguistic needs of First Nations children and youth" (AFN, 2018a). They further called on Canada to provide funding for the feasibility study and commit to long-term investments for a multi-year longitudinal study of First Nations child development and well-being.

The ACE Study, developed in the United States, has demonstrated an association between adverse childhood experiences and health and social problems across the lifespan, including youth suicide. Research shows that chronic exposure to adverse experiences can have a detrimental effect (Felitti et al., 1998, 2019; Monnat & Chandler, 2015) on children's health and well-being. The ACE Study was conducted with a sample that largely consisted of white, middle-class Americans; it is unclear how relevant these results may be to the experiences of First Nations children and youth. Furthermore, previous research on the health of First Nations children has involved numerous studies with limited scope and those designed in ways that make comparative data analysis challenging.

First Nations children fare poorly on many Western health and well-being indicators, and the use of these indicators has not effectively contributed to improved health outcomes for First Nations communities. These communities continue to experience higher rates of injury, accidental deaths (Park et al., 2015), suicide (Kumar & Tjepkema, 2019), incarceration (Justice Canada, 2019), dental caries (FNIGC, 2012), infant mortality (Sheppard et al., 2017) and health conditions like type 2 diabetes and tuberculosis (Halseth, 2019; Jetty, 2021). They also experience disproportionately higher rates of poverty (Beedie et al., 2019) and food insecurity (Chan et al., 2019). First Nations children are also more likely to be seized by child welfare agencies and removed from the family home (Statistics Canada, 2017). According to the 2016 Census of Population, First Nations children accounted for 41.4 percent of all foster children aged zero to four living in private homes, although they accounted for only 4.9 percent of all children in this age group (Statistics Canada, 2017).

The current data is lacking and consequently provides an incomplete and fractured picture of First Nations children's health status and well-being. There is limited data concerning key social determinants of health that resonate with First Nations, including outcomes associated with a sense of cultural identity and connectedness, spirituality and resilience, and strengths-based perspectives. First Nations child and youth data gaps include, but are not limited to, "child and youth mental health needs and service access; children and families who come into contact with child welfare including children and youth, in, and leaving care; connections between child welfare and juvenile justice; [and] addictions" (AFN, 2018b). There are information gaps concerning access to clean water, safe housing, food security and other basic human rights. This lack of information is a significant barrier to improving the health of First Nations children and youth, as well as addressing the social determinants of health.

The Truth and Reconciliation Commission of Canada's (TRC) Calls to Action #19 and #55 call on all levels of government to provide reports and current data on progress in the areas of health, child welfare, educational attainment, and youth in custody among First Nations (TRC, 2015). This includes reporting on health indicators like infant mortality, maternal health, suicide, mental health, addictions, life expectancy, birth rates, infant and child health issues, chronic diseases, illness and injury incidence, and the availability of appropriate health services (TRC, 2015).

Additionally, on January 26, 2016, the Canadian Human Rights Tribunal issued a landmark ruling that First Nations children living on reserve and in the Yukon are treated in a discriminatory manner by the federal government in its provision of child and family services (First Nations Child and Family Caring Society of Canada, n.d.). The Tribunal ordered the federal government to overhaul its on-reserve child welfare program completely and to cease applying a narrow definition of Jordan's Principle and adopt measures to implement its full meaning and scope immediately. Based on the experience of Jordan River Anderson, who passed away amid an intergovernmental dispute over health services funding, Jordan's Principle ensures that "there is substantive equality and that there are no gaps in publicly funded health, social and education programs, services and supports for First Nations children" (Assembly of First Nations, 2018c, p. 1). To effectively address and fulfil Jordan's Principle and provide equitable child and family services, better information and data collection are needed to measure access to health programs and services, as well as the health and developmental outcomes for Indigenous children.

The 2017 United Nations International Children's Emergency Fund (UNICEF) Report Card 14 on the Index of Child and Youth Well-being and Sustainability ranked Canada 25th out of 41 countries, identifying wide gaps in "child health, violence experienced by children and their own sense of well-being" (UNICEF, 2017). The report found that these gaps are often "symptoms of higher rates of poverty, social competition, and stress" (UNICEF, 2017), all of which can impact the future life path of children. The report also found that "national averages conceal forms of vulnerability, often rendering invisible the most disadvantaged and excluded children" (UNICEF, 2017) from official statistics. Indigenous children specifically are missing from the data. Based on the results of Report Card 14, UNICEF called on countries to act by "leav[ing] no child behind and improving the collection of comparable data — in particular on violence against children, early childhood development, migration and gender" (UNICEF, 2017).

UNICEF Canada, in their 2017 companion document to UNICEF Report Card 14, noted one way to promote dramatic change in the lives of Indigenous children and youth is to "support Indigenous communities in the advancement of comprehensive, culturally relevant data" (UNICEF, 2017). In addition, these efforts "must respect the [First Nations' Principles of] OCAP® ... Ownership, Control, Access and Possession of data, respecting their particular cultural contexts, their worldviews about child well-being and their rights. Such data and monitoring can support a stronger focus on policy responses for inclusion and equity" (UNICEF, 2017).

In May 2018, the Auditor General of Canada released its Spring Report, which included two performance audits of government programs and activities specific to First Nations and other Indigenous Peoples. The report concluded that government departments were not sufficiently utilizing existing data, measuring, or reporting the effectiveness of their programs in achieving their intended goals, or closing the socioeconomic gaps (Office of the Auditor General of Canada, 2018). First Nations must be engaged in the design and development of measurable outcomes and indicators, as well as research instruments and processes, to ensure their relevance and effective use. As expressed by AFN National Chief Perry Bellegarde, “Canada is requiring data and then not using it effectively to improve the lives of First Nations people” (AFN, 2018b).

The First Nations component of the Canadian Incidence Study on Reported Child Abuse and Neglect is the only national data collection on First Nations child welfare. This is a cross-sectional study that tracks cases reported to child welfare from the time a case is reported to the time a case decision is made. While valuable, this study provides a limited scope of information.

The Canadian Institute for Child Health (CICH) has a history of developing excellent profiles on the health of children in Canada, but its most recent profiles are based primarily on 2006 census data, making them more than a decade old (CICH, n.d.). A 2018 Report by Children First Canada and O’Brien Institute for Public Health discusses the existing challenges in accessing recent, comparable data and reports on the health and well-being of children in Canada (O’Brien Institute for Public Health, 2018). These challenges are even more prominent for data related to Indigenous populations.

It is clear that Canada has a serious deficit of detailed information on the health and well-being of First Nations’ children and youth and is struggling to address challenges facing them, in part because of a lack of information. This literature review examines examples of longitudinal research with children to explore the role of longitudinal methods for collecting more comprehensive and accurate data on the health and well-being of First Nations children and youth in Canada.

# METHODS

This literature review employed a targeted approach to understand the opportunities and challenges of conducting longitudinal research with First Nations in Canada. The review included a wide variety of search strategies and techniques to identify and explore examples of large-scale longitudinal research with children from which key learnings could be relevant for First Nations.

The search included consulting academic peer-reviewed articles, websites and reports, as well as grey literature on longitudinal research projects, technical reports and published work on longitudinal methodology in general. A key focus for the search was to identify examples of longitudinal research that has been conducted with Indigenous children. The search began by looking for examples of longitudinal research in Canada with Indigenous populations and was then extended to include large-scale longitudinal studies from multiple countries, with a particular emphasis on projects where research teams sought to work with Indigenous communities and other hard-to-reach populations.

Once promising longitudinal studies were identified, websites and reports were explored with a focus on understanding methodological choices, planning and governance of the project, research ethics and community partnerships, the development of conceptual frameworks for the project, the inclusion of culturally relevant content on data collection tools, as well as strategies used to maintain low attrition rates. The research team continued to follow work, reports, newsletters and publications from these projects throughout the period in which this literature review was prepared. Additional strategies for the literature search included scanning reference lists of academic articles as well as web searches to identify and explore grey literature from First Nations and other Indigenous organizations in Canada, the United States, Australia and New Zealand focused on child health and well-being.

This targeted search strategy did not involve standardized techniques for a full scoping or systematic review, and as such, it should not be taken as representative of all longitudinal research conducted with Indigenous Peoples over a given time period. Instead, the focus of the review was on identifying promising examples of longitudinal research for First Nations children. This approach allowed for an in-depth analysis of technical and methodological aspects of these studies in support of the research goals of FNIGC's *Feasibility Study on Longitudinal Research with First Nations Children*, which sought to provide a well-informed analysis to determine the interest of First Nations to conduct, be involved with, or participate in a longitudinal study.

# LITERATURE REVIEW

FNIGC conducted a wide-ranging literature review to explore methods and strategies in longitudinal research examining the health and well-being of children and youth, with a focus on research applicable to Indigenous populations. This literature review is divided into four parts. The first part begins with a brief introduction to various longitudinal research designs. This is followed by a report on four Canadian and six international studies relevant to this topic. A summary of learnings from these studies concludes the first section. The next three sections discuss research on adverse childhood experiences (ACEs), as well as research on cultural frameworks and strengths-based indicators. Key results and learnings from this literature review are summarized in the larger feasibility report, and Appendix A presents a comparison table of methodologies and key learnings from many of the longitudinal studies reviewed below.

## LONGITUDINAL STUDIES AND OTHER RELEVANT RESEARCH DESIGNS

The purpose of this section of the literature review is to explore the benefits and impacts of longitudinal research designs to address information gaps on the health and well-being of First Nations children and youth. There are various types of longitudinal research designs, which include prospective approaches (selecting a participant pool in the present and repeatedly collecting data over a predetermined length of time into the future) and retrospective approaches (utilizing historical records to identify patterns in desired populations). Several other common longitudinal research designs can provide information about child and youth health and well-being, which are also explored here. Following this, the advantages and disadvantages of these longitudinal and other research designs are considered.

### Types of Research Designs

Different types of research designs can be employed to provide information about child and youth health and well-being, as well as children's development over time. The most comprehensive approach is a total population longitudinal survey. This would involve surveying every single First Nations child and youth over multiple points in time. An example of this type of survey is the national census of the population, which happens every five years. This kind of research provides extensive information about patterns of change over time, but it is expensive and time consuming, and there is often a lag in data collection, limiting the capacity of policymakers and leadership to work with the most recent data at more frequent intervals. For this reason, a number of other research designs have been developed, each with its own advantages and disadvantages (Menard, 2002). Below are four commonly used designs:

1. **Single-cohort panel designs:** These follow a particular group of people, called a cohort, who share statistical or demographic characteristics over a number of years or measurement points. For example, all members of the cohort are born in the same year. This design provides evidence about patterns of change over time for individuals within the cohort and evidence of temporal relationships between measured variables. Despite some clear advantages, single-cohort designs can be vulnerable to cohort effects, where the results are explained by the fact that all individuals within the sample share a common experience that may differ in important ways from that of another potential cohort, perhaps born five years later.

2. **Repeated cross-sectional designs:** Data is collected with different samples over a number of time periods, or data collection waves, in this study design. One such example is collecting data from different kindergarten classrooms once per year. While not truly longitudinal because it does not follow the same individuals over time, this type of research design can present evidence of change over time or trends at the population level. For example, measuring changes in aspects of children's development by surveying kindergarten classes in a given region over several years could provide policy and decision-makers with some insight into what early learning programs are effective for a particular region. Importantly, though, these designs do not provide evidence of patterns of individual-level change and development.

3. **Revolving panel designs:** In this design, a set of participants is selected, interviewed and surveyed for more than one time period, then replaced by a new but comparable set of participants. By utilizing multiple measurement points with specific individuals, this design can provide evidence of change over time. In addition, the involvement of multiple samples can provide some evidence to rule out cohort effects. The amount of information provided about temporal precedence and patterns of change over time is limited, however, and this design does not provide evidence of long-term change or development at the level of the individual. It is often used in situations where researchers expect particular difficulties in attrition, or participants dropping out of the study, for example, longitudinal studies of aging, where researchers have to deal with losses of participants due to mortality.

4. **Cohort sequential (longitudinal panel) designs:** This process involves sampling two or more cohorts of individuals of different ages and following each cohort over time. Cohort sequential designs have a number of advantages. By following the same individuals over time, this type of design provides information about temporal precedence and patterns of change, allowing researchers and decision-makers to explore relationships between aspects of children's early experiences and their health and well-being at a later stage. In addition, by following multiple cohorts over time, this design controls for cohort effects. It can also provide evidence of age differences between the cohorts in the first wave.

This literature review also considered the value of data linkage as an alternative or supplement to other research designs. Data linkage is the process of connecting two different sets of information about the same person, for example, linking housing data with tuberculosis rates to identify any connections. Linked data can provide relevant information for longitudinal studies, for example, as individual records are updated year after year.

## Advantages and Disadvantages of Longitudinal Studies

There are multiple advantages to longitudinal studies, including:

- Identifying connections or potential causal relationships between events or conditions and outcomes;
- Establishing sequences of events over time that could explain a particular outcome;
- Identifying and explaining change over time in the health and well-being of particular individuals;

- Limiting recall bias, that is, requiring individuals to think back in time to describe an experience or recollect an event; and
- Providing evidence to decision-makers to develop targeted and evidence-based programs for children and youth.

There are also significant disadvantages associated with longitudinal studies, including:

- Participants dropping out of the study, or "attrition," which can undermine the validity of the representative sample;
- The potential of cohort effects, or effects that are specific to the group being followed, especially a concern with single-cohort designs;
- A need for complex analytical techniques to avoid risks of incorrect conclusions due to the use of inappropriate statistical measurements — although these risks can be addressed with proper attention to methodology;
- The potential for longitudinal studies to be very expensive and time consuming; and
- Difficulties and uncertainty about the availability of sustainable funding that is required for the duration of a longitudinal study that may extend over a decade or more.

# CANADIAN STUDIES

This review begins with the largest national study of children and youth in Canada that truly implements a longitudinal design: the Canadian National Longitudinal Survey of Children and Youth. A review of the *First Nations Component of the Canadian Incidence Study on Reported Child Abuse and Neglect* follows this. The Human Early Learning Partnership (HELP), a comprehensive research partnership focused on monitoring child and youth health and wellness in British Columbia, is described next. The section concludes with a report on a culturally based measurement tool for child well-being, developed through a partnership between Wikwemikong Unceded Territory and Laurentian University, known as the Aboriginal Children's Health and Wellness Measure (ACHWM) or "Aniish Naa Gegii."

## Canadian National Longitudinal Survey of Children and Youth

The Canadian National Longitudinal Survey of Children and Youth followed a representative sample of Canadian children from birth to approximately 25 years old (Statistics Canada, 2008). It was conducted by Statistics Canada from 1994 to 2009 with survey waves every two years. It did not include First Nations children living on reserve. Parents and caregivers completed the surveys for children aged 0 to 17 in the child component of the study. The youth component of the survey was completed alone by youth aged 16 and older. Children aged 10 to 17 years were provided with an additional questionnaire, called the self-report, which they completed themselves. These different surveys addressed different issues. Between 11,000 and 17,000 children across Canada participated in over six survey cycles (Statistics Canada, 2008). The study employed a cohort sequential design, where different cohorts were introduced at each study wave, enabling both cross-sectional and longitudinal comparisons. They started

with one cohort and added three new cohorts over the study period (one on the third wave, one on the fourth and one on the fifth) (Statistics Canada, 2008). The first wave included children aged 0 to 11, and subsequent waves returned to these children if possible. The intention was to follow participants until age 25, but, in the end, the study only followed them for 15 years over seven cycles before the program was cancelled in 2009. Additional cohorts were added following Wave 1 to account for children born since the initial wave. The data from these surveys have also been linked to the T1 Family File of income tax returns from 1993 to 2015, extending the life of these surveys and adding new information (Statistics Canada, 2020). Though this study provides a rich dataset about the health and well-being of Canadian children during the study period, it provides limited information about First Nations children since it was not conducted on reserve, and it does not provide current information for First Nations leadership.

## Canadian Incidence Study on Reported Child Abuse and Neglect

One source of data about the health and well-being of First Nations children comes from the First Nations component of the 2008 Canadian Incidence Study on Reported Child Abuse and Neglect (FNCIS-2008) (Sinha et al., 2011). The CIS-2008 was the third phase of a national study of Canadian children's experiences with the child welfare system, and the research team notes that a fourth phase is currently in development (First Nations Incidence Study, n.d.). In this study, the CIS research team reports on the analysis of an extensive dataset about the health, well-being and family environments of children experiencing child welfare services in Canada. These data came from standardized data collection forms that child welfare workers filled out over the course of child maltreatment investigations. The forms asked workers to report on the type of investigation (e.g., unfounded, suspected, substantiated, future risk), the type of placement children received (e.g., no placement, informal care, kinship care, foster care, group home), the type of maltreatment investigated (e.g., physical abuse, sexual abuse, neglect, emotional maltreatment, exposure to intimate partner violence), checklists about indicators of risk among two primary caregivers and within the home environment, whether the case remained open after investigation, and the degree of physical and emotional harm to the children that was known to be caused by the maltreatment. The CIS research team suggests that when it is linked with data from the previous two phases, the CIS-2008 dataset provides "a unique opportunity to describe changes in child maltreatment investigations across Canada over the last decade" (Public Health Agency of Canada, 2010, p. 5). They encourage researchers to utilize these rich datasets.

The First Nations component of the CIS-2008 study (FNCIS-2008) was initiated as an attempt to provide a First Nations-specific lens on the analysis and interpretation of CIS-2008 data regarding child maltreatment investigations involving First Nations children (Sinha et al., 2011). The FNCIS-2008 report was written through a collaboration between members of the CIS-2008 research team and an advisory committee that consisted of representatives from major organizations supporting First Nations child and family service agencies, First Nations agencies themselves and the Assembly of First Nations. This collective effort was focused on providing data and conducting analyses to better understand and address concerning findings in the CIS datasets such as the overrepresentation of First Nations children within the child welfare system as well as findings that this overrepresentation is "driven primarily by cases of neglect rather than other forms of child maltreatment" and that these incidents of neglect are "associated with poverty, poor housing and caregiver substance abuse" (Sinha et al., 2011, p. 1).

The major goals of the FNCIS-2008 report were to “generate new knowledge about the nature of and response to maltreatment of First Nations children in Canada and to increase capacity for future research on child maltreatment in First Nations communities.” (Sinha et al., p. xi). In service of these goals, the research team reports on a number of major findings about child maltreatment investigations with First Nations children, which speak to the unique experiences of First Nations children beginning from their first entrance into the child welfare system. In addition, the FNCIS-2008 report provides extensive evidence of why it is necessary to interpret these data within the context of the colonialism of the Canadian child welfare system that does not acknowledge factors such as: the diverse family structures of First Nations families and extended kinship networks (Greenwood, 2005; Muir & Bohr, 2014; Sinha et al., 2011), the ancestral and historical experiences of First Nations children (Blackstock, 2009), as well as the distinct epistemologies and the cultural and spiritual support systems that exist within First Nations communities about caring for and raising children (Blackstock, 2009). After analyzing the data available from the CIS-2008 study, the FNCIS research team suggests that attempts to work with First Nations to address the difficulties that are facing First Nations families involved with child welfare agencies “may require programs offering longer term, comprehensive services designed to help them address multiple factors ... which pose chronic challenges to ensure the well-being of First Nations children” (Sinha et al., 2011, p. xxi).

First Nations in Quebec commissioned a similar regional study, which focused on First Nations youth subject to the Quebec *Youth Protection Act* (FNQLHSSC, 2013). Using administrative data from ISC and the Government of Quebec, the participating First Nations were able to compare circumstances between First Nations and other youth in the province.

The data available to First Nations through the CIS datasets or other administrative datasets have many strengths, yet they also leave open a number of gaps in terms of the information First Nations can access and utilize to understand and support their children’s development and well-being.

Strengths include:

- Comprehensive data about First Nations children at risk of adverse childhood experiences is gathered when they come in contact with First Nations child welfare agencies.
- Standardized reporting forms from child welfare workers provide quantitative data and information about a number of aspects of these children’s home and family environments.
- Various phases of data collection can provide opportunities to explore relationships between the incidence of child maltreatment and changes in policies and practices used by child welfare agencies.
- Through the FNCIS-2008 report, data and analyses are contextualized within First Nations’ lived experiences of the child welfare system as well as the history of child welfare in Canada.
- The FNCIS-2008 report provides strong and relevant data that First Nations are using in advocacy and policy development focused on ensuring the child welfare system better serves their children.

Despite these strengths, there are a number of limitations and gaps in the data available to First Nations through these datasets:

- These datasets only include children and families who come in contact with child welfare agencies.
- As these data come from child maltreatment investigations, they focus on assessing risk factors for

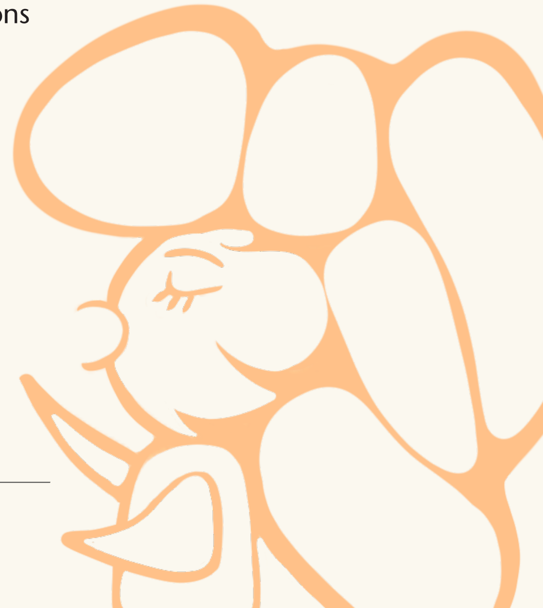
adverse childhood experiences, and they do not assess strengths and resilience within First Nations families and communities.

- First Nations scholars (e.g., Blackstock, 2009) have pointed to numerous ways that Canadian child welfare systems and the assessments used by child welfare agencies have been developed based on Western, colonial and assimilative systems that fail to consider First Nations' perspectives about raising and caring for children and supporting their well-being.
- Though CIS data are comprehensive and national in scope, there are long gaps between data collection periods, which limit the utility of the data and analyses for supporting evidence-based policy change.
- The research does not employ a longitudinal design that follows the same cohort of children over time, which limits the inferences that can be made about understanding and supporting First Nations children's development and well-being.
- The datasets do not provide information about the everyday experiences of First Nations children who are not in contact with child welfare agencies, which leaves large gaps in the knowledge First Nations have available to them to support the development of programs, policies and interventions for First Nations children and families.

## Human Early Learning Partnership (HELP)

The Human Early Learning Partnership (HELP) is a research network based at the School of Population and Public Health at the University of British Columbia that monitors population-level changes in the well-being of BC children over time (HELP, n.d.a). The HELP team is focused on building "a comprehensive population health monitoring system" that provides data on experiences of children across BC from their early years into adolescence (HELP, n.d.a). Through partnerships with school boards, HELP works to provide province-wide developmental data by administering research and monitoring tools within BC schools. With this methodological approach, the research focuses on exploring "developmental change or trends in populations [emphasis added] of children at varied geographies (provincial, regional, neighbourhood)" (HELP, n.d.a). In the majority of studies conducted with the data from HELP, the research is considered longitudinal at the population level, and comparisons are made between different regions in BC. That is, trends are tracked within different regions as a new cohort of students is assessed with the various instruments during the early years, when they enter kindergarten, and recently in grades 4 and 7. This allows researchers to track changes in children's well-being at school "across time and location," and the data is used by researchers, educators and policy makers to identify regional areas with particular vulnerabilities, and to support decisions about funding and interventions (HELP, n.d.a.).

The HELP team utilizes several instruments to assess the children's well-being and school readiness. The Childhood Experiences Questionnaire (CHEQ) reports information gathered from parents and caregivers about children and the environments in which they live during their early years, prior to kindergarten (HELP, n.d.b.). This survey is completed by the caregivers of incoming students in the first few weeks of the school year. The Toddler Development Index (TDI)



is a new measurement instrument for children aged one to two years that is currently being piloted in a few select regions. The TDI is completed by parents or caregivers online and provides information about their child's family, home, and community life. (HELP, n.d.c.). In kindergarten, teachers complete the Early Development Indicator (EDI) for each child in the class. This questionnaire has been designed to measure several "core areas of early childhood development" that, based on past research, are thought to be "good predictors of adult health, education and social outcomes" (HELP, n.d.d.). Finally, a self-report middle years development instrument (MDI) is administered to children and youth in grades 4 and 7. This survey asks children about "their thoughts, feelings and experiences in school and in the community" (HELP, n.d.e.). The MDI has been developed as an attempt to give children a voice in reporting on their own well-being, which can inform decisions about early years and educational policies that affect them. Data is shared through various means, including provincial-level data, community-level profiles, and interactive maps. Data is not shared at the individual level.

An Aboriginal Steering Committee (ASC) has contributed to the design and reporting of various HELP instruments, taking into account Indigenous perspectives and cultural frameworks (HELP, n.d.f.). The ASC has commissioned an independent assessment of the EDI for potential bias against Indigenous Peoples in the survey design or in its completion by teachers, as Indigenous children tended to receive lower scores than their non-Indigenous peers. This commissioned research found no evidence of bias in the representative sample of teachers completing the form, but did recommend that teachers receive training on how to complete the questionnaire to ensure they do not introduce unconscious bias into the collection of data or the interpretation of results (Directions Evidence and Policy Research Group, LLP, 2016). The EDI is a prominent measure of children's well-being that has been used in public schools across Canada for a number of years (Guhn et al., 2016). In addition, the HELP team reported that a number of First Nations in BC are making use of the EDI in First Nations-run schools and that HELP has recently begun collaborating with Manitoba First Nations around use of the MDI in First Nations schools (Schnort-Reichl, K., personal communication). In light of this extensive use, Ktunaxa scholar Sam (2011) has presented a number of considerations about validity in the use of the EDI with First Nations children. She emphasizes the need to integrate local Indigenous knowledges into research, data collection and knowledge sharing processes to help make meaning of EDI scores in ways that are relevant to First Nations worldviews, and in ways that support First Nations in social justice and decolonizing work as well as Nation building and self-determination. With these considerations and protocols in mind and through extensive work in building relationships with partnering First Nations, Sam (2011) sees potential for the EDI to be used "as a tool that begins to de-colonize research, by contributing to a research culture of self-determination and empowerment, through supporting local Indigenous inquiries" (p. 322).

At the time of writing, HELP reported that almost 300,000 kindergarten children in British Columbia have participated in over seven waves of data collection from the EDI, beginning in 2001 (HELP, n.d.a.). Approximately 40,000 children are evaluated each wave. Schools with small student populations conduct the survey annually, whereas larger schools conduct it less frequently. The EDI has also been utilized by several research teams in Canada and internationally to investigate children's well-being and school readiness in kindergarten. It provides indicators of children's physical health and well-being, language and cognitive development, social competence, emotional maturity, community skills, and general knowledge, as assessed by kindergarten teachers.

The MDI has been administered in more than half the schools in BC since 2010, with over 86,000 children participating. It has also been used in other provinces, including Alberta, Manitoba, Ontario, Yukon, Nova Scotia and the Northwest Territories (HELP, n.d.e). The MDI includes questions about physical health and well-being, connections with peers, family, and community, social and emotional development, school experiences, and after-school activities. A unique component of the MDI is that the children respond to the survey themselves, thereby giving them a voice to comment on their health and well-being. When combined with data from the CHEQ and EDI, results from the MDI enable the HELP research team to investigate how children in various regions of BC gradually develop an understanding of their own health and wellness through interactions that occur within the early environments where they spend the majority of their time.

Research using EDI data in BC and other regions has yielded several findings relevant to local policy on child and youth well-being. For example, one study made use of EDI results from schools in Saskatoon, Saskatchewan over three years and explored relationships between regional EDI scores and measures of neighbourhood socioeconomic disadvantage (Cushon et al., 2011). This study reported evidence of declining EDI scores over the three years in the domains of physical health and well-being, as well as communication and general knowledge. In addition, correlations with census data suggested that these decreases were not uniform across all Saskatoon neighbourhoods. Specifically, neighbourhoods with the highest neighbourhood disadvantage also showed the most marked decline in physical health and well-being. In linking these results with policy decisions, the authors suggest that their findings support the conclusion that "neighbourhoods matter for school readiness" and that there is evidence of a need for "flexible and adaptive" policy solutions to meet the "evolving needs" of local communities (Cushon et al., 2011).

## Aaniish Naa Gegii: Aboriginal Children's Health and Well-Being Measure (ACHWM)

The First Nations-led project, Aaniish Naa Gegii: Aboriginal Children's Health and Well-Being Measure (ACHWM), was developed to identify and assess culturally relevant conceptualizations of health and well-being for an Anishinaabe community (Young et al., 2016a; Young et al., 2017). Although the measure was developed for a cross-sectional study, one community has used it for longitudinal analysis, following up with the same children one year later (Young, N., *personal communication*). The survey is administered to children and youth aged 8–18 years for self-reporting.

A partnership between Wikwemikong Unceded Territory and Laurentian University launched the project on the reserve. Their approach included several innovations that fostered community support for the survey. For example, they engaged the children and community in helping to develop the survey instrument questions by involving children in a community bicycle tour to collect photos and identify key issues to address in the survey. The research team then used the Medicine Wheel to organize the various health issues the children identified (Young et al., 2013). In this way, the questions for the survey were developed from the issues children identified during discussions of their photos, and these questions were then brought back to the community for verification (Young et al., 2013).

Additionally, the methodology used to administer Aaniish Naa Gegii includes a mechanism to screen for children who may be at risk, enabling timely intervention (Young et al., 2016b). The researchers conclude that they have:

> demonstrated a feasible system to screen survey responses and act on them immediately. The process was designed by local mental health experts in one First Nation, facilitated by a tablet-based approach, and enabled the mental health team who met with all children who required support on the same day as the survey. This is a key innovation, supporting ethical research practice, and is essential when working with a high-risk population (Young et al., 2016b).

Finally, the data is collected at the community level, and although it is stored on a university server away from the communities, it is still considered to be owned by the communities. The communities are entitled to access this data, analyze it on their own accord, and control who else has access to it, thus respecting the First Nations' Principles of OCAP®. This process has further helped to strengthen communities' commitment to the research.

The ACHWM is a survey tool, not a longitudinal study, although it has been employed in some small studies to collect longitudinal data. In addition, the research team has recently received additional funding to expand its use (Ulrichsen, 2020).

# INTERNATIONAL STUDIES

In the course of this literature review, FNIGC examined several international examples of longitudinal or other relevant research designs. This search began with examples of studies involving Indigenous Peoples, one in Australia and one in New Zealand. From there, FNIGC explored examples of studies operating under circumstances somewhat similar to those of some First Nations. This section begins with a discussion of the Australian "Footprints in Time" longitudinal study.

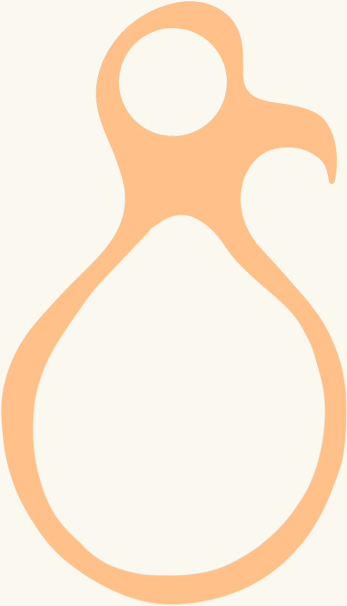
## Footprints in Time Survey

A notable example of a longitudinal study conducted with Indigenous children is the Australian project Footprints in Time, or the Longitudinal Study of Indigenous Children (LSIC). This study began in 2008 and had launched six waves of data collection as of 2019 (Department of Social Services, n.d.a). The survey of Aboriginal and Torres Strait Islanders follows two cohorts, one aged 6–18 months in the first enrolment and a second aged 3.5–5 years. In describing how the choices were made in the study methodology, the research team notes that following two cohorts, what they call "an accelerated cross-sequential design" had several advantages (Thurber et al., 2015). First, it allowed them to gather and report on data relevant to the first eight years of life over only four years of annual data collection. Additionally, it reduces the potential for cohort effects by enabling data users to compare two cohorts of children of the same age, thereby increasing the sample size for statistical analysis. Over 1,680 parents or primary caregivers were interviewed in the first wave, and over 1,200 families from the first wave continued to participate at wave six. Data is collected annually through face-to-face interviews, often in the family home. The survey content covers a wide range of topics about children's health, learning, and development, and data collectors also gather information about the participating child's family and community environment. A "purposive sampling" strategy was employed. The sample represents 5–10 percent of the Aboriginal and Torres Strait Islander population in the cohort age ranges. It is focused on 11 different regions in Australia, including urban, rural, and remote communities. This sampling strategy has some limitations. For example, due to pragmatics and community interest, neither the selection of sites nor the selection of children within sites employed random assignment; as such, the study results are not interpreted to be representative of all Aboriginal and Torres Strait Islander children. Instead, the study was designed “to provide a picture of life within a range of environments and communities in which Aboriginal and Torres Strait Islander children are concentrated” (Thurber et al., 2015).

The choices made regarding the content and methodology of the Footprints in Time Study were influenced by discussions with representatives of Indigenous communities in Australia. This community consultation process resulted in several choices and modifications to the study design. For example, the research team notes that their research methods focused on collecting both quantitative and qualitative data about the Indigenous children and that data collection involved speaking with multiple informants who were relevant in the children’s lives (Thurber et al., 2015). The Footprints in Time study team chose this design “to best reflect the meaning of ‘family’ for Indigenous Australians” (Thurber et al., 2015) because the mainstream Australian idea of the nuclear family did not reflect their lived realities. In addition, the study team has invested significant effort in building relationships with participating families, which they attribute as a major reason for their ability to maintain high levels of participation. For example, members of the study team have taken great care to document the experiences of the families when they participate in interviews. In one report, the authors note that when families were asked about why they continued to participate in the surveys year after year, participants listed the following reasons:

- The chance to tell their story;
- Benefits to the community;
- Satisfaction with the study methods and learnings;
- Chance to track an individual child’s progress;
- Study processes are respectful;
- Receiving study gifts;
- Valuing what the study stands for;
- Reciprocity; and
- Trust in and connection with the surveyors (Thurber et al., 2018).

To make sure families and communities are respected and engaged in the process, the results are provided to them in multiple formats, including booklets, videos, and key summary reports (Thurber et al., 2015). To encourage research with this unique dataset, the study has been set up so that data are made available to data users through a registration process. Data are available to approved researchers from governments, academia, and non-government organizations (Department of Social Services, n.d.a.). The National Centre for Longitudinal Data (NCLD) maintains the data on its Dataverse. Researchers seeking to access the data must register, sign a confidentiality agreement and make an application through the NCLD (Department of Social Services, n.d.b.).



Research using Footprints in Time data has yielded several findings relevant to supporting child health and well-being within Aboriginal and Torres Strait Islander communities. For example, researchers have reported an association between carers' experiences of major life events and decreases in their social and emotional well-being over time (Thurber et al., 2015). Others have reported decreased preschool attendance over time among children whose carers experienced feelings of racial discrimination (Thurber et al., 2015). Finally, a recent study has linked carers' emphasis on their children's participation in cultural activities with higher social and emotional well-being in their children later on (Dockery, 2020). This ability to track the association between changes in family dynamics and environmental experiences and changes in child well-being is an important advantage of longitudinal research that can support data-driven directions in policy, priorities, investments and decision-making by Indigenous Peoples.

## Growing Up in New Zealand

Recently, New Zealand has undertaken a longitudinal study of health and development in early childhood that includes both Indigenous Peoples and non-Indigenous people. The Growing up in New Zealand Study (GUiNZ) was designed to be representative of the diversity of the New Zealand population, with an emphasis on sampling Māori, Asian heritage, and Pacific Islander families (Morton et al., 2013). Data collection for the study began with interviews with mothers and fathers before the participating children were born. The intention is to continue data collection until the children reach the age of 21. Parents and children have been interviewed face-to-face five times as of January 2021: at pre-birth, nine months, two years, four years, and eight years. Additionally, brief telephone calls have been conducted six times during the study period, and two online data collection waves have been completed as of January 2021. The interviews cover a wide range of topics related to children's health and well-being, their social, cognitive and emotional development, as well as the environments and family dynamics that the children experience. Interviews are conducted with mothers, fathers, partners, and, starting at age two, observations are conducted with the children themselves. Data collection typically occurs within the family's home. Multiple methods of data collection are employed, including self-report surveys, child and home observations, and qualitative survey questions. Computer-assisted personal interviews (CAPI) and computer-assisted telephone interviews (CATI) were both employed as data collection tools. Approximately 7,000 children were recruited for the first wave, following extensive collaboration to establish a foundation for long-term relationships throughout the 21-year survey. Approximately 81 percent of the original sample participated in the eighth face-to-face data collection wave.

The GUiNZ Study has employed various strategies for sampling, recruitment and participant retention to establish a cohort that is "broadly generalizable" to the diversity of the contemporary New Zealand population, and that can inform public policy aimed at closing health gaps among these diverse communities. In terms of sampling, the GUiNZ Study built a cohort of participants by sampling from a defined geographical region of New Zealand that included a population representative of diverse ethnicities, different socioeconomic status markers, and a mix of urban and rural home environments. A key consideration was ensuring that large enough sub-samples of families with different ethnic backgrounds were available to allow for comparative analyses. In describing this choice, the research team notes that sampling from only one specific geographical region

"provided the most cost-efficient and effective strategy for cohort recruitment and retention for future data collection" (Morton et al., 2013). Specifically, they suggest that focusing recruitment efforts on a limited geographical region allowed for investments in a wide variety of different recruitment strategies (e.g., engaging Lead Maternity Carers, direct engagements with participants at hospitals and antenatal clinics, and engagement with local community organizations) that would have been more difficult over a wider geographical range. In addition, the study team notes that this sampling strategy may have also helped develop a strong "local identity" for the study, which built interest in the study at both the regional and national levels and encouraged participant retention.

The GUiNZ research was designed in such a way that longitudinal research results could have clear relevance to national policy supporting health, well-being and early childhood development within New Zealand Families. In particular, longitudinal data are being collected to provide insight into the "developmental trajectories" of New Zealand children and to inform ideas about the multiple "causal pathways" relevant to supporting children's health and development, as well as the ways that different causal factors interact over time. Considerable efforts have been made to share findings and results in ways that are informative to various stakeholders, including public servants, policymakers, medical professionals, educators, as well as families and caregivers with young children, including participant families. Recent reports from the GUiNZ research team point to a number of key findings that have emerged from this research, which have clear policy implications. For example, one study explored whether experiences of maternal stress, both prenatally and postnatally, were associated with a child's BMI score at 54 months (4.5 years). By exploring longitudinal data that tracked changes in both maternal stress indicators and children's standardized BMI scores over the early years of life, the research team was able to report evidence supportive of a "cumulative stress model" where children whose mothers experienced "chronic" stressors in both the pre- and post-natal periods had significantly higher BMI scores when compared to children who experienced no maternal stress at both time points, or who experienced maternal stress only prenatally or only postnatally. In interpreting these results, the authors make clear links to policy, stating that the most impactful programs for stress reduction for children and families in New Zealand are likely to be those that target both the pre- and post-natal periods together (Farewell et al., 2018).

## Mexican Family Life Survey

The Mexican Family Life Survey and the ones that follow were selected for review because they operate under sometimes challenging conditions that may be similar to some First Nations realities. This included challenges such as a lack of street names, house numbers or telephones, migration within a country, and/or remote locations.

The Mexican Family Life Survey was launched in 2002 with two additional waves of data collection in 2005–6 and 2009–12 (Rubalcava & Teruel, n.d.). The survey was a comprehensive study that included 35,000 individuals from 8,400 households across 150 different communities. Participants were questioned about a range of issues, including education, housing, and family planning. Information on community characteristics was collected through interviews with public officials, including the availability of services such as schools, hospitals, electricity, water, and sanitation, as well as natural disasters, enterprises, and factories, and community welfare, i.e., violence and the cost of living.

Of particular interest with this survey was the commitment by the survey organizers to track the participants who had migrated domestically or internationally to the United States. Researchers were particularly interested in the impact of migration on Mexican families. Even with participants moving, the organizers still managed to track and interview 90 percent of the original households. Tracking processes included asking participants in the surveys to provide a contact for a friend or close relative in case the family moves. The subsequent waves of the study then used the original contacts for the participants, or, if no response was received, followed up with the contact information provided by friends or close family members. The project team collaborated with researchers in the United States, located individuals, and conducted the surveys. Mexican researchers followed up with individuals and families who had migrated within Mexico. In addition, the study team has utilized advancements in statistical methods for analyzing longitudinal data to mitigate issues arising from attrition due to migration. For example, one analysis of the results from the three waves of surveys examining the health of Indigenous Peoples who migrated domestically or internationally utilized multilevel models to address missing or incomplete data resulting from attrition. Models were adjusted to control for the number of waves in which participants participated, addressing potential bias from attrition or mortality (León-Pérez, 2019).

## Cebu Philippines Longitudinal Health and Nutrition Survey

The Cebu Philippines Longitudinal Health and Nutrition Survey was a long-running longitudinal study that took place in the Philippines (Adiar et al., 2011). It began in 1984 to study infant feeding. In subsequent years, it expanded to include child development, schooling, reproductive health, family dynamics and intimate partner violence, among other issues of health and well-being. The research team notes that the study makes use of a health determinants model:

> which posits that underlying community-, household- and individual-level variables affect a set of proximate health behaviours which, in turn, influence health outcomes such as growth and infectious disease morbidity and mortality. (Adair et al., 2011).

Single-stage cluster sampling was used to randomly select 17 urban and 16 rural sub-administration units from which to launch the survey. Pregnant women in these areas were identified and invited to join the survey. Over 96 percent agreed to participate, and those who gave birth between May 1983 and April 1984 were included in the study. The children born were a representative sample of births in the metro Cebu area. Cebu is the second-largest urban centre in the Philippines. In describing data collection plans, the research team notes:

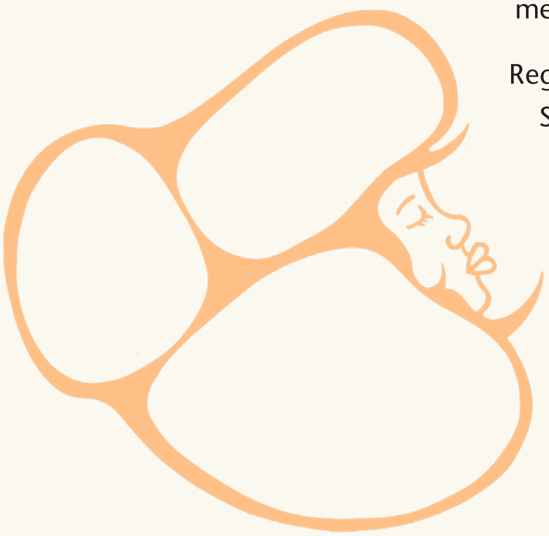
> Surveys were conducted in the second to third trimester of pregnancy, immediately after birth and then every 2 months for 24 months. Subsequent follow-up surveys took place in 1991–92, 1994–95, 1998–99, 2002 and 2005. A more limited tracking survey of mothers was completed in 2007, and [the original] children and their offspring were tracked in 2009 (Adair et al., 2011).

In the initial stages of the survey, the focus was on environmental, demographic, social, access to health services, and nutrition that may have influenced the health and well-being of the babies born. The next waves of the survey focused on infant feeding, mothers' health, nutrition and growth. In 1991, the survey investigated issues related to stunting, intellectual development, and school entry success. As the children reached adulthood, the focus shifted to reproductive health, academic achievement, obesity, and cardiovascular disease. Community surveys were also conducted to gain a better understanding of the environment in which the children were growing up. This included the availability of healthcare services, drinking water, sanitation, the cost of food and other commodities, and community infrastructure, among other things. In 2009, interviews and surveys were still being conducted with the original cohort, except now the researchers were also studying the children of the first cohort's child participants, making this an intergenerational study. In 2008, the researchers reported that they were still in touch with approximately 60 percent of the original mothers and children. Attrition was largely attributed to families moving out of the survey area. Generally, the more highly educated and urban segment of the cohort migrated out of the region, leaving a less representative sample over the years. Refusal rates were initially high but decreased substantially as researchers and participants became more familiar with each other. The data collection process included both in-home and health clinic visits, and researchers have published more than 125 reports on the results and methodology (Adair et al., 2011).

## Mandela's Children (The Birth to 20 Study)

A longitudinal survey was conducted in South Africa, following 3,273 children born shortly after Nelson Mandela's release from prison in 1990 (Richter et al., 2007). The 1990 Birth to Twenty Study became known as "Mandela's Children" as a result. The original intention was to study children of Soweto for the first ten years of their lives in what turned out to be a time of rapid political and socioeconomic change in South Africa, with the collapse of apartheid. The study was extended to twenty years at the ten-year mark. In the early years of the survey, the researchers focused on environmental influences, access to health services, child development and nutrition. Once the children reached school age, the researchers added cognitive ability and school performance to the list. Physical and physiological measurements were taken at various stages. When the children turned 16, data were collected on sexual and reproductive health, early metabolic syndrome challenges, and social marginalization. The challenge of following these many children under difficult social and political circumstances was significant. The researchers noted they:

> had to innovate in a number of areas, such as establishing tracking systems under circumstances where few people had a street address or telephone, create a flexible dataset because names were inaccurately translated and transcribed from record to record, translating and adapting questionnaires developed in the West and establishing norms for many of the measures used (Richter et al., 2007).



Regarding attrition from the survey, the researchers found that White South African families tended to drop out more frequently, as they were generally better off financially and socially, and likely perceived that they had less to gain from their participation (Richter et al., 2007). Three reasons for attrition were described, including absolute attrition, where, for example, the child died. Second was intermittent attrition, as families often followed a circular migration pattern between urban and rural settings, meaning they were sometimes available for surveys and sometimes not. The researchers noted that approximately one-quarter of the families relocated during each data collection period. Finally, children were lost to the study because they could not be traced after the previous survey wave. To address the issue of attrition, the researchers began by building strong relationships with the community, including the creation of a Community Advisory Board whose membership evolved as the focus of the surveys shifted. Staff and field workers were recruited from local communities, and some have remained with the study since it began, creating stability in the relationships with the community (Ritcher et al., 2007). Regular updates were provided to families participating in the surveys, participants' travel costs were paid for if they had to travel for health clinic visits associated with the survey, and contact was maintained through birthday cards to the children, newspaper and radio advertisements, a toll-free telephone line, and referral services if health or other problems were identified in the course of the surveys.

## The Young Lives Longitudinal Survey

The Young Lives Study is a mixed-methods longitudinal study that is currently running in four countries: Peru, Ethiopia, India and Vietnam (Young Lives, n.d.a.). This study follows 12,000 children in these four countries to explore the impact of child poverty. The researchers are following two cohorts of children: one born in 2001–02 and the other born in 1994–95. Over 400 papers have been produced from this study, including 150 on methodology. They have also produced extensive guides to their research methodology, which covers their sampling process, research ethics, managing fieldwork, and dealing with attrition (Young Lives, n.d.b.). A recent report, published in March 2019, explored the consequences of child poverty identified through this longitudinal survey. In this report, the researchers:

> synthesized evidence from across the study and combined it with life course longitudinal analyses that permit examination of the cumulative influence of sources of risk, protection, and opportunity from across childhood and through adolescence. This approach has allowed us to consider the implications of these findings for child-focused policy and programmes as low- and middle-income countries strive to overcome intergenerational poverty and inequality and meet the challenges of the Sustainable Development Goals (Boyden et al., 2019).

This collaborative research project made several advancements in research methodology, process and the dissemination of research findings. Similar to the Footprints in Time Study, the approach to sampling in the Young Lives Study involves following two separate cohorts of children, which allows data users to explore changes within each cohort over time and to make comparisons between cohorts when they reach the same age. Young Lives has employed a complex sampling strategy, where participating children are randomly selected from 20 different regional sites to represent the diversity of social groups in each of the four countries. This strategy has allowed the research team "to identify commonalities and differences not only within, but also, between the national samples" (Boyden et al., 2019). In addition, the Young Lives research project has employed a multifaceted and mixed-methods approach to collecting data to "track children's developmental trajectories across the early life course" and "untangle the complex relationship between poverty and child outcomes" (Boyden et al. 2019). Data collection techniques include household surveys with multiple informants (children, caregivers and community representatives), longitudinal qualitative research with children and caregivers, surveys about school experiences, as well as qualitative sub-studies on focused topics. Surveys and qualitative instruments covered a wide range of topics related

to children's lives and the complex environments in which they lived. In addition, the content assessed at each study wave both maintained sufficient continuity with earlier waves and incorporated some changes informed by topics of interest that emerged in earlier waves. For example, early waves revealed how central schooling was to participants' lives in the four countries, and subsequent waves then included specially designed school surveys to investigate the influence of school-related factors on learning.

This complex research design has allowed the Young Lives research team to highlight a number of research findings that have clear relevance to national and international policies focused on reducing childhood poverty. For example, by exploring a wide array of factors and health indicators relevant to children's lives, researchers found that intersecting inequalities were the most challenging for children and youth. In multiple regions, youth were challenged with intersections of poverty, less educated parents and membership in a disadvantaged group (e.g., caste, ethnicity) (Boyden et al., 2019). In addition, longitudinal evidence has enabled the Young Lives research team to make several policy recommendations that challenge prevailing thinking about child poverty. For example, while research on the association between nutrition and child stunting (being much shorter than expected for age) suggests that, though the first 1,000 days are integral to a child's growth and development, there is also evidence that significant changes in nutrition into middle childhood and adolescence are associated with recoveries from early stunting (Boyden et al., 2019). In this way, longitudinal evidence from the Young Lives project suggests that nutritional experiences in infancy do not solely determine children's developmental trajectories in physical growth. As such, there could be significant benefits from extending investments in nutritional interventions beyond infancy, and into the childhood and adolescent years.

## LEARNINGS FROM THESE LONGITUDINAL STUDIES

Numerous learnings can be drawn from exploring these various longitudinal studies. First, it is possible to conduct longitudinal and representative cohort studies over multiple years, even in challenging circumstances such as political upheaval, migration, impoverishment and funding uncertainty. Attrition is a significant concern in longitudinal studies. Participants drop out, move, lose motivation to participate or even die. High attrition rates can lead to bias in the study because there are insufficient people to serve as a representative sample, making generalizability difficult.

It will be challenging to track First Nations children and youth over time and reduce attrition, particularly if the survey is confined to children and youth living on reserve. A large initial cohort size could help ensure a viable cohort group by the study's conclusion, ensuring the size is sufficient for statistically relevant outcomes. Furthermore, careful consideration must be given to deciding whether a proposed longitudinal survey studies only children on reserve or if it tracks First Nations children both on and off reserve. Even in challenging circumstances, the reviewed research suggests it is possible to keep attrition low, particularly when participants see the value in the work for themselves, their family members, and their communities. In many of the longitudinal studies we examined, building strong relationships between the data collectors and the families being surveyed played a role in keeping families involved. Migration out of the country or at least the geographical limits of the survey was an issue with many of these longitudinal research projects, but using a variety of methods allowed the researchers to track the majority of participants over many years.

Another key lesson from these examples of longitudinal research is the importance of employing flexible data collection instruments that allow researchers to measure, assess and track multiple aspects of children's lives and experiences, as well as the ecological contexts in which they live. Many studies employed diverse methodologies, including self-report surveys with multiple informants, child, home and environmental observations, as well as qualitative questions and interviews. Through these diverse methodologies, the different research teams were able to construct complex portraits of the lives of the participating children, highlighting the importance of various factors in their everyday environments for their health and wellness. These complex pictures of child well-being may resonate well with holistic perspectives on health and wellness advanced by First Nations people, which are discussed further below. In this way, collecting similar kinds of longitudinal data could be highly relevant for First Nations in making decisions about policy and funding for child and family wellness.

Secure funding was identified as a challenge for the reviewed longitudinal studies, many of which were uncertain how long their funding would last and thus how long they could follow the children and youth. In some cases, surveys were extended as funding was received; however, this approach creates significant uncertainty, as well as staff turnover, loss of corporate memory, and considerable time and effort required to secure the next round of funding. Most of the longitudinal studies explored were planned for a period of approximately 10 to 20 years, aiming to investigate both short-term and long-term patterns of change over time among participating children. Many of the studies made significant investments in relationship building with participant communities and often reached out to community organizations, building steering committees or advisory boards that were representative of diverse communities within their sampling frame. For example, the HELP team has invited an Aboriginal Steering Committee to provide input into their research process and the use of their measurement instruments (HELP, n.d.f.). The planning and development of the GUiNZ Study involved reaching out to community organizations that represented the diverse ethnicities targeted in the study (Morton et al., 2013). In the Footprints in Time Study, both the primary research questions being addressed and the content choices for the interview were developed and modified through consultations with Aboriginal and Torres Strait Islanders (Department of Social Services, n.d.a.). Finally, to enable continued participation of the different cohorts in four different countries as well as actionable policy recommendations in the diverse regions, the Young Lives research team emphasizes the importance of their decision to employ the same field supervisors since the beginning, which has helped build relationships and trust (Boyden et al., 2019).

## Adverse Childhood Experiences (ACEs)

Research shows that chronic exposure to adverse experiences can have a detrimental effect on an individual's health and well-being throughout their life (Felitti et al., 1998). The ACE Study, developed in the United States, has demonstrated an association between ACEs and health and social problems, including youth suicide, autoimmune diseases, heart disease, lung cancer, diabetes, depression, alcohol and drug abuse, and violence and victimization. The greater the number of ACEs that participants reported experiencing, the higher the risk of developing each of these problems later in life.

The initial ACE studies identified several childhood experiences that have a strong potential to negatively influence health and wellness in later life (Felitti et al., 1998). These experiences included:

- Physical abuse;
- Verbal abuse;
- Sexual abuse;
- Physical neglect;
- Emotional neglect;
- Parent is an alcoholic or drug user;
- Mother is a victim of domestic violence;
- Family member in jail;
- Family member diagnosed with mental illness; and
- Loss of a parent through divorce, death or abandonment.

It is essential to note that the ACEs surveys described in the original ACE studies are retrospective — they examine past events, rather than current circumstances. These types of surveys are delivered to adults, not children (Felitti et al., 1998). As we have seen in the example of longitudinal studies reviewed so far, surveying parents and caregivers about aspects of children's lives, their behaviours and aspects of their early environments is a common approach to learning about development and well-being in the early childhood years (Adair et al., 2011; HELP, n.d.a; Rubelcava & Teruel, n.d.). To learn more about children's lives and experiences, researchers often supplement these caregiver surveys with data from other sources, including child observations, observers of interactions between children and adults, as well as various tests and assessments of children's skills and competencies (Adair et al., 2011; Rubelcava & Teruel, n.d.; Thurber et al., 2015). There has also been recent work that has attempted to capture children's own perspectives on their experiences through interviews or surveys, though these methods are not typically used with children during the early childhood years (ages five and under). (HELP, n.d.a; Varni et al., 2007; Wikwemikong Unceded Territory and Laurentian University, n.d.). Additional concerns could arise from asking parents or caregivers to report on ACEs in their children's lives. Specifically, asking parents questions about physical, sexual, or emotional abuse of their own children may not be answered at all, or accurately, as parents may be concerned about possible consequences if they answer truthfully.

The most commonly identified ACEs by participants in the initial Kaiser Permanente study were listed above; however, the population participating in that study was primarily white and middle class. There are, of course, many other stresses that a child may experience. In the context of Indigenous Peoples in Canada, distressing experiences that children may often experience include racial discrimination and the historical trauma associated with colonialism including malnutrition, residential schools, relocation of communities, and loss of land, self-government, and self-determination (National Inquiry into Murdered and Missing Indigenous Women and Girls, 2019; Royal Commission on Aboriginal People, 1996; Truth and Reconciliation Commission, 2015). A recent review of research conducted with Indigenous People in Australia reported that exposure to chronic stress can lead to high allostatic load, or wear and tear on the body, which in turn may help to explain the high rates of metabolic, cardiovascular and mental health problems experienced by Indigenous individuals in Australia (Ketheesan et al., 2020). Similarly, a small American study of the impact of historical trauma and discrimination on the mental wellness of American Indian adolescents and young adults found that historical loss was associated with increased risk of depression, poly-drug use, and PTSD, and high levels of discrimination were associated with higher rates of poly-drug use and PTSD (Brockie et al., 2015).

Research conducted with Indigenous Peoples suggests that the trauma from these kinds of adverse experiences is cumulative, building on the suffering experienced by previous generations (Aguiar & Halseth, 2015). There is also evidence of an intergenerational impact of ACEs. Research suggests that children who suffer a high number of ACEs can pass biological damage to their offspring (Aguiar & Halseth, 2015). A Canadian study explored how the impact of residential schools could lead to intergenerational trauma (Chief Moon-Riley et al., 2019). This research reported evidence that residential school attendance by either the mother or father generally raised the number of ACEs among their children. The researchers interpret these results to suggest that "colonial residential school experiences may have become biologically embedded, passed to subsequent generations" (Chief Moon-Riley et al., 2019, p. 1), which in turn leads to a higher likelihood of health and wellness problems later in life. A review of literature on the intergenerational transmission of trauma conducted for the National Collaborating Centre for Aboriginal Health in 2015 reports three ways that historical trauma is passed to successive generations: psychological, physiological, and social pathways of transmission (Aguiar & Halseth, 2015).

Another small study, conducted by a master's student at the University of Waterloo, examined the limitations of current ACEs surveys in addressing the adversity experienced by certain social or cultural groups, including Indigenous Peoples (Luther, 2019). The researcher invited Indigenous Peoples at the university to participate in a focus group to consider ACEs experienced by Indigenous Peoples in Canada and then to explore resiliency and healthy coping mechanisms that individuals and communities could use to counter the influence of ACEs. The participants in the focus group were asked to first list ACEs they may have experienced, as opposed to the typical approach of responding to a preconceived questionnaire. Thirty-three different ACEs were described by the participants, which were then sorted into five main themes. These include some of the standard ACEs explored in Kaiser Permanente surveys, but some are clearly in addition to them. These are:

- Historical trauma, including residential schools, child welfare policies and programs, cultural and community disruption, cycle of poverty, and suicide;
- Lack of infrastructure, including water, health services, and housing;
- Household dysfunction, including loss of a family member, abuse, addictions, lack of parenting and neglect, and exposure to serious crime;
- Gender-based adversities, including missing and murdered Indigenous women, sexual harassment, sexual assault, domestic violence, and gender discrimination in other settings, including employment, education, athletics, etc.;
- Racial discrimination, including ethnicity-based bullying, public experiences of racism, community racism and familial prejudice (lateral violence), and devaluing identity and lived experience (Luther, 2019).

Interestingly, the study also asked participants to identify the coping mechanisms they had adopted to build resiliency. Again, there was no preconceived list from which to select; the participants came up with these examples of coping mechanisms independently. Four main themes of coping mechanisms were identified:

- Addressing trauma, including healing through helping, accessing counselling, embracing identity, and a growing societal awareness of Indigenous issues;
- Cultural connections, including integrating ceremony, Indigenous-based programming, connecting to traditional teachings, and language, music and dance;
- Social network, including being part of a caring community, building relationships, and acceptance and belonging; and
- Personal attributes, including willingness to connect, confidence, mindfulness, optimism and laughter, and gaining new skills (Luther, 2019).

Another common concern about addressing ACEs in research involves the sensitivity of ACEs questions for survey respondents. In one study, Mersky et al. (2019) explored the concerns of respondents who completed ACEs tests as part of survey research. Using data collected between 2013 and 2018, participants completing the ACE survey were also asked about their discomfort in answering the questions. This study found that more than 80 percent of respondents reported experiencing no discomfort or only slight discomfort when answering the questions. However, those with higher ACEs scores and those with a history of depression reported higher levels of discomfort. Interestingly, high levels of unease were associated with how the home visitor delivered the test. Specifically, if the home visitor was uncomfortable with delivering the test, the respondents also reported higher levels of discomfort (Mersky et al., 2019). Extensive training of survey administrators would be required to ensure they are equipped to conduct the interviews in the deployment of an ACEs survey with First Nations people. In addition, it is important to note that the study by Mersky et al. (2019) did not involve First Nations people, who may or may not react the same.

## CULTURAL FRAMEWORKS AND STRENGTHS-BASED INDICATORS

For many years, First Nations have emphasized the need to incorporate Indigenous values and cultural frameworks of health and well-being into the research and survey design to help ensure that the results accurately capture and reflect Indigenous perspectives and realities (First Nations Information Governance Centre, 2020). The concern is that without Indigenous perspectives informing the research questions and objectives, surveys end up measuring the degree to which Indigenous Peoples are different from the majority population, but not necessarily how Indigenous Peoples are faring in their health and wellness. The problem is that,

> [f]undamentally, deficit-based measures focused on disease and illness do not reflect Indigenous worldviews of well-being, which are not based on the Western medical model framework of illness and disease, but are holistic and grounded in balance and harmony in human relationships and the natural and spiritual world. Indigenous worldviews require a description of child well-being based on

> strengths, reflecting the web of connections among the child, family, and community; cultural and spiritual practices; and individual health and stability (Rountree & Smith, 2016, p. 207).

This problem arises in cross-cultural circumstances when researchers from outside the community apply their own preconceived notions to the ways health and well-being are conceptualized in a research project, rather than seeking to understand how these concepts are understood by the community being studied. Even researchers from the community can be indoctrinated into the dominant frame of discourse, for example, through the school system or to meet the demands of their employer and likewise fail to take Indigenous perspectives into account. In an article describing examples of culturally based research with Indigenous children from Central America, Rogoff and colleagues (2017) note how:

> Even with good intentions, people who are familiar only with dominant cultural ways commonly make the unfounded assumption that there is "One Best Way"—only one way that works. Alternative ways are assumed to be deficient and in need of fixing. This deficit approach treats cultural practices of nondominant communities as problems that account for the difficult life circumstances often faced by families from nondominant communities (e.g., poverty or difficulties in middle-class institutions such as schools) (Rogoff et al., 2017, p. 877).

For many researchers and members of the nondominant community, Rogoff and colleagues suggest that one solution could be to examine and incorporate the cultural framework of the community being surveyed into the design of the research project, starting from the formation of the guiding research questions.

Cultural frameworks and strengths-based indicators are two sides of the same coin. The cultural framework helps to identify issues and concepts valued by that community. The indicators of health and well-being are then chosen based on that community's perception of what is valuable for health and well-being, or those things considered to be strengths in that community.

Judging the health and well-being of First Nations children from a deficit perspective, rather than from a strengths-based perspective, does little to inform First Nations people, perpetuates notions of superiority of non-Indigenous people, and offers little insight on which to build improvement (Hyett et al., 2019).

Some researchers working to understand and describe cultural frameworks for health and wellness among Indigenous communities have discussed the need for more research, particularly in terms of studies that collect high-quality data encompassing holistic models of health and that are led by Indigenous communities. A worldwide review of published research from 1997 to 2017 on the impact of Indigenous cultures on health and well-being was conducted by Bourke et al. (2018). They considered research that looked at language, self-determination, cultural expression, family and kinship, country and caring for country, and knowledge and beliefs. "Country and caring for country" are concepts that concern the relationship each Indigenous culture studied had with its own territory. They found that the reviewed studies generally concluded that connection to culture serves to reduce risky behaviour and has positive impacts on physical, social and emotional health. However, they found that the "strength of evidence from most publications was assessed as moderate or low quality, and was limited by a lack of reliable and valid measures, population-level studies, and longitudinal studies" (Bourke et al., 2018). The researchers acknowledge the problems associated with the process they used, but because the literature generally pointed to a positive relationship between connections to Indigenous culture and health and well-being, they recommend continued research efforts to design valid measures of culture, health and well-being, as well as studies that use mixed methods — qualitative and quantitative approaches.

Below, we review some examples of cultural frameworks that have been used to design successful research projects with Indigenous community partners. Following this, we discuss some examples of how First Nations-led research projects have approached the idea of strength-based indicators.

## Examples of Cultural Frameworks

Multiple First Nations' cultural frameworks were considered in the course of this literature review. This included cultural frameworks supporting past and ongoing FNIGC research projects (FNIGC, 2005), the First Nations Mental Wellness Continuum Framework (AFN & Health Canada, 2015), a cultural framework for First Nations on health delivery in Saskatchewan (Federation of Saskatchewan Indian Nations, n.d.), and a First Nations' Wholistic Approach to Indicators of Well-Being (Secretariat of the Permanent Forum on Indigenous Issues, 2006) from Canada, as well as a few frameworks from Indigenous communities in the United States (Barraza et al., 2016.; Kelley & Small, 2016; Rasmus, Allen, Connor & Freeman, 2016; Rountree & Smith, 2016). It is not possible to review each of these frameworks in detail here, as many are exceedingly complex. Instead, some commonalities are identified that may be helpful to consider in developing a potential longitudinal study.

First, many of the First Nations cultural frameworks reviewed speak about balance between the physical, mental, emotional, and spiritual elements of the individual as an indicator of well-being (FNIGC, 2005). For example, Thunderbird's Mental Wellness Continuum Framework identifies these four elements of wellness to assist First Nations in understanding and assessing "culture as treatment" within the context of substance use and mental wellness programming, policy and interventions (AFN & Health Canada, 2015). By recognizing these diverse elements of mental wellness, this cultural framework points to corresponding "outcomes" that could be assessed among First Nations people seeking treatment and support for mental wellness; these include purpose, meaning, belonging, and hope, respectively.

The Medicine Wheel is a common symbol used by many First Nations to illustrate the balance between different elements of health and well-being (AFN & Health Canada 2015; FNIGC, 2005). For example, in the RHS cultural framework, FNIGC has utilized the Medicine Wheel teachings to inform its surveys and data collection initiatives.

In another example of a cultural framework, the Fresno American Indian Health Project also relied on the Medicine Wheel imagery to develop a cultural framework that focused on belonging, mastery, interdependence and generosity as key elements of personal growth and balance (Barraza et al., 2016). In this study, the

Medicine Wheel was utilized by the youth participants to develop a "Personal Balance Tool" that assisted young people in navigating challenges and finding ways of moving towards balance within their lives.

Many of the cultural frameworks reviewed also discussed a connection to the land as an essential element of First Nations' well-being and, conversely, the loss of this connection as detrimental to people's well-being. Different frameworks examined opportunities for hunting, fishing, trapping and gathering medicines, as well as access to sacred places, as key elements of Indigenous health (AFN & Health Canada, 2015; Rasmus et al., 2016; Rountree & Smith, 2016). For many First Nations people, relationships with the land and the indigenous flora and fauna are fundamental elements of their well-being, not just for nourishing their bodies, but also for nourishing their minds, souls, cultures and communities.

Relationships with family, extended family and community were also frequently mentioned as critical to the well-being of First Nations people. A study by Rasmus and colleagues (2016) conducted in partnership with Coastal Salish peoples in the Pacific Northwest, identified family and community relationships, as well as individual and spiritual sources of well-being. In this framework, family includes one's lineage, extended family, role and place in the family, parenting and grandparenting, and family traditions. Community relationships include cultural traditions and resources, community education activities, and access to tidelands, hunting grounds and sacred places.

While these cultural elements are helpful to consider in developing a longitudinal study with First Nations, it is also important to bear in mind that there are cultural differences between First Nations across Canada. It is unlikely that a particular research project will be able to, nor should it, identify or suggest a pan-First Nations cultural framework. However, it may be possible to design a research project with sufficient flexibility in terms of the methodologies and indicators employed to address diverse cultural practices, values and epistemologies within First Nations communities. Additionally, this may be an area where the regions can help inform and tailor the cultural framework of the research project to the needs of the First Nations in their region.

For example, the First Nations-led work, Aaniish Naa Gegii: Aboriginal Children's Health and Well-being Measure (ACHWM) (Young et al., 2017), discussed above, is a community-based and collaborative research study that was developed with input from children, parents, other caregivers and community leaders. The authors report that the survey has since been adapted, using the same process of community input for two additional First Nations communities, a First Nations child welfare agency serving 10 First Nations communities, and the Ottawa Inuit Children's Centre. This approach has allowed for the inclusion of culturally relevant issues, perspectives, words and symbols in the survey design. Local staff were trained to deliver the survey to a cohort of children from the community, further building community support. Based on their successes, the Aaniish Naa Gegii research team recommends the following to achieve a high degree of cultural relevance for a research project:

1. Ensure that the voices of communities, as well as the words of the children and their caregivers and guardians, are prioritized;
2. Adopt a collaborative approach that ensures:
   - Engagement of a local champion (preferably a manager or director) who can navigate the required approvals and support the implementation at a local level;
   - Access to appropriate health resources (e.g., mental health workers) to support implementation;

- Flexibility within the team to adapt to the local context;
- An understanding of cultural protocols;
- Commitment by all team members to collaboration and capacity building; and
- Several face-to-face meetings with excellent ongoing communication to achieve success (Young et al., 2017).

## Strengths-Based Indicators

Many reports emphasized the importance of utilizing positive language and strengths-based indicators as part of the Indigenous cultural framework that guides a particular project. (Oré et al., 2016; Rasmus et al., 2016; Rountree & Smith, 2016; Young et al., 2017). Strengths-based indicators, derived from cultural frameworks, may help in crafting research questions, identifying issues for research, and interpreting results. Overall, the research reviewed here suggested that employing strengths-based indicators within appropriate cultural frameworks has the potential to provide a more accurate picture of the health and well-being of First Nations children and youth from the perspective of First Nations people themselves.

Within the context of strengths-based indicators, two different elements of the concept were identified. The first is the use of positive language in surveys, that is, asking questions about positive activities instead of negative ones. Examples of positive questions include, "I feel I have healthy friends/peer group that make good decisions/stay out of trouble" or "I take time to volunteer at school or in my community" (Rountree & Smith, 2016). Asking questions in ways that use positive language honours many Indigenous Peoples' values of using constructive speech to reflect caring and respect.

The second element of the strengths-based indicators is the opportunity such surveys provide to identify factors contributing to the resilience of Indigenous Peoples in the face of sometimes overwhelming colonialism and imposed cultural hegemony. As Rountree and Smith (2016) suggest:

> Mainstream child and family well-being indicators continue to reflect the Western framework of illness and disease. These indicators are almost universally used to describe the physical, social, and economic welfare of children. Their use is of particular concern in communities facing social inequities that are largely driven by structural or systemic, institutionalized bias, because the Western framework underlying these indicators assumes that the means to improving child well-being is to treat "symptoms" with an individual "cure," and does not acknowledge that well-being is also a product of social inequities...While the Social Determinants of Health movement has helped to shift some of the "blame" off individuals to political and economic systems, the focus is still on what is deficient—what is missing or wrong with the community and how those deficiencies negatively affect children and families (Rountree & Smith, 2016, p. 206).

Alternatively, researchers have suggested that strengths-based approaches could be particularly helpful when working with Indigenous people as a counter to this deficit-based language. In discussing a project that made use of a strengths-based approach when working with First Nations youth, Crooks and colleagues (2010) note:

> A strengths-based approach is especially important for First Nations youth, because it takes the Canadian historical context into account. By placing the high rates of violence, substance abuse, and poverty experienced by First Nations families into the appropriate context of colonization and assimilation policies, it shifts the perceived deficits away from the individual and allows us to focus instead on the resilience many of these youth have demonstrated (Crooks et al., 2010, p. 161).

A global review of the literature on strengths-based indicators offers insight into various Indigenous perspectives on what sustains resilience (Rountree & Smith, 2016). The review considered research conducted to identify the perspectives of Māori, First Nations, Sami, Native Hawaiians and Aboriginal peoples in Australia. It is notable that, again, different Indigenous Peoples selected different indicators to represent strengths in their communities, although there are some similarities. This further supports the need for regional engagement to identify appropriate indicators of strengths in child development and well-being for the different First Nations being surveyed. For example, in the global review, Māori identified the well-being of the extended family as an element of individual health and well-being. They also identified five interconnected elements that support health and well-being, including mind, body, spirit, family and land (Rountree & Smith, 2016). This community-led identification of strengths is supported by child development research with Māori families, which suggests that many Māori children may grow up in a "richer narrative environment" that supports earlier "first memories," more detailed memories of their "birth story" (Reese & MacDonald, 2008) as well as a greater emphasis on ancestral ties in their personal life stories as adolescents when compared with European heritage families in New Zealand (Reese et al., 2017). In this way, collaborative work with Māori communities has highlighted particular skills, practices and competencies as "strengths" that are not often considered in more mainstream child development research.

In their review, Rountree & Smith (2016) describe numerous examples of research projects where Indigenous communities have broadened understandings of how different strengths contribute to health and well-being. Specifically, First Nations in Ontario and BC have identified social, cultural and land-use factors as essential to their well-being. Native Hawaiians look to family, ancestors, culture and harmony with nature as key elements to explore. Sami also identified a connection to land as critical to their health and well-being, as well as language competency, the use of natural resources, and traditional ecological knowledge, and the interconnectedness between community members and the environment. Finally, Aboriginal peoples in Australia focus on a strong culture and strong children, which encompasses individual characteristics of each child, as well as a strong environment that includes safety, access to services and meeting material needs. Perhaps in response to Western researchers' disregard for broader societal circumstances, Aboriginal people in Australia also identified historical, social and political strengths and challenges as part of their consideration in determining health and well-being.

Regional input on the concepts and strengths to be included in a longitudinal study will be essential to identify First Nations-appropriate cultural frameworks and strengths-based indicators. Collaborative projects with Indigenous Peoples, such as the ACHWM project, may offer some valuable lessons in how to achieve this when working with First Nations communities.

# CONCLUSIONS

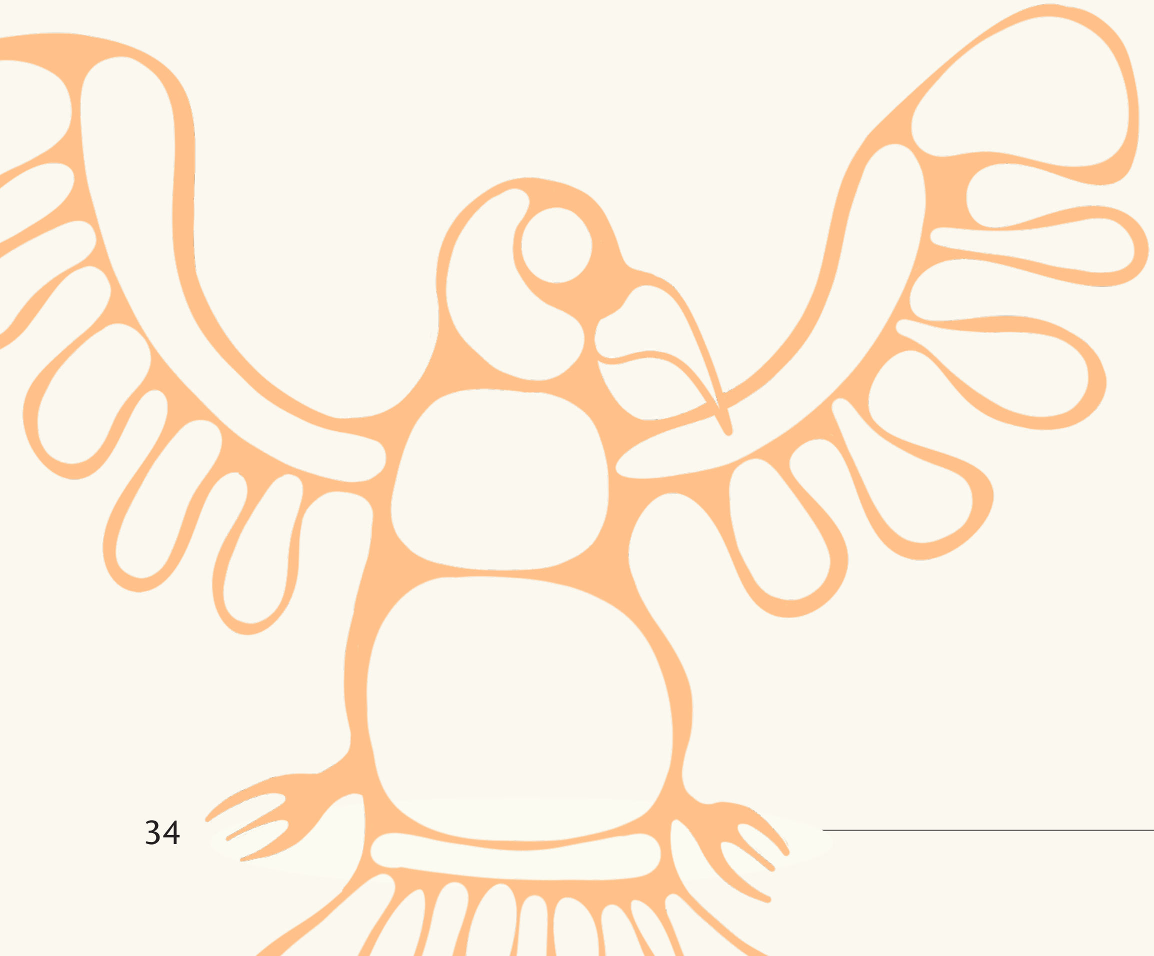
This literature review was conducted as part of a larger study to assess the feasibility of conducting a longitudinal study of First Nations child development and well-being with First Nations communities across Canada.

The work of this feasibility study involved several interrelated activities, including an analysis of results from a literature review, engagement with recognized subject-matter experts and FNIGC regional partners, and the integration of lessons learned from FNIGC's experience with longitudinal surveys across different phases of the Regional Health Survey (RHS).

A summary of the key findings from this literature review is included in the *Feasibility Study on Longitudinal Research with First Nations Children*. A comparison table of methodologies and sampling, as well as key learnings from the nine most informative studies that were consulted in the literature review, is also available in Appendix A.

All information gathered for the feasibility study was analyzed to determine potential challenges, considerations and options for conducting this research, as well as to capture First Nations' views on ways of examining child and youth development in their communities.

The feasibility study concludes with a set of recommendations consolidating the overarching themes identified through regional engagement sessions, subject-matter expert interviews, FNIGC's past experience and the literature review.



# REFERENCES

Adair, L. S., Popkin, B. M., Akin J. S., Guilkey, D. K., Guitiano, S., Borja, J., Perez, L., Kuzawa, C. W., McDade, T., & Hindin, M. J. (2011). Cohort profile: The Cebu Longitudinal Health and Nutrition Survey. *International Journal of Epidemiology*. 40 (3), 619–625.

Aguiar, W. & Halseth, R. (2015). *Aboriginal Peoples and historic trauma: The processes of intergenerational transmission.* National Collaborating Centre for Aboriginal Health.

Assembly of First Nations. (2018a). Special Chiefs Assembly Resolution #76/2018: *First Nations Child Development and Well-being Longitudinal Survey*, Adopted at the Special Chiefs Assembly, December 2018. Retrieved from: https://www.afn.ca/wp-content/uploads/2019/01/Combined-Final-2018-December-SCA-Resolutions_EN.pdf

Assembly of First Nations (2018b). *Auditor General report shows need for government to make better use of data, work with First Nations to make faster progress on closing the gap*. [website]. Retrieved from: https://www.afn.ca/auditor-general-report-shows-need-government-make-better-use-data-work-first-nations-make-faster-progress-closing-gap-2/

Assembly of First Nations. (2018c). *Accessing Jordan's Principle: A resource for First Nations parents, caregivers, families and communities.* Retrieved from: https://www.afn.ca/uploads/Social_Development/Jordan%27s%20Principle%20Handbook%202019_en.pdf

Assembly of First Nations & Health Canada. (2015). *First Nations Mental Wellness Continuum Framework.* Retrieved from: https://www.thunderbirdpf.org/wp-content/uploads/2015/01/24-14-1273-FN-Mental-Wellness-Framework-EN05_low.pdf

Barraza, R., Bartgis, J., & Fresno Native Youth Council (2016). Indigenous youth-developed self assessment: The personal balance tool. *American Indian and Alaska Native Health* 23(3), 1– 23.

Beedie, N., MacDonald, D., & Wilson, D. (2019). *Towards justice: Tackling Indigenous child poverty in Canada.* Retrieved from: https://www.afn.ca/wp-content/uploads/2019/07/Upstream_report_final_English_June-24-2019.pdf

Blackstock, C. (2009). Why addressing the over-representation of First Nations children in care requires new theoretical approaches based on First Nations ontology. *Journal of Social Work Values and Ethics*, 6 (3), 24–45.

Bourke, S., Wright, A., Guthrie, J., Russell, L., Dunbar, T., & Lovett, R. (2018). Evidence review of Indigenous culture for health and well-being. *The International Journal of Health, Wellness, and Society*, 8 (4), 11–27.

Boyden, J., Dawes, A., Dornan, P., & Tredoux, C. (2019). Tracing the consequences of child poverty: *Evidence from the Young Lives Study in Ethiopia, Indian, Peru & Vietnam.* Bristol. UK: Policy Press

Brockie, T., Dana-Sacco, G., Wallen, G., Wilcox, H., & Campbell, J. (2015). The relationship of adverse childhood experiences to PTSD, depression, poly-drug use and suicide attempt in reservation-based Native American adolescents and young adults. *American Journal of Community Psychology*, 55 (3–4), 411–421.

Canadian Institute of Child Health. (n.d.). *The health of Canada's children: A CICH profile.* [website]. Retrieved from: https://cichprofile.ca/

Chan, L., Batal, M., Sadik, T., Tikhonov, C., Schwartz, H., Fediuk, K., Ing, A., Marushka, L., Lindhorst, K., Barwin, L., Berti, P., Singh, K., and Receveur, O. (2019). *FNFNES final report for Eight Assembly of First Nations Regions: Draft comprehensive technical report.* Assembly of First Nations, University of Ottawa, Université de Montréal. Retrieved from: http://www.fnfnes.ca/docs/FNFNES_draft_technical_report_Nov_2__2019.pdf

Chief Moon-Riley, K., Copeland, J. L., Metz, G. A. S., and Currie, C. L. (2019). The biological impacts of Indigenous residential school attendance on the next generation. *SSM – Population Health* 7,100343.

Crooks, C. V., Chiodo, D., Thomas, D., & Hughes, R. (2010). Strengths-based programming for First Nations youth in schools: Building engagement through healthy relationships and leadership skills. *Aboriginal Policy Research Consortium International (APRCi)*. Paper 229.

Cushon, J. A. (2011). Neighbourhood poverty impacts children's physical health and well-being over time: Evidence from the Early Development Instrument. *Early Education and Development*, 22(2), 183–205.

Department of Social Services, Australian Government. (n.d.a.). *Footprints in Time: The longitudinal study of Indigenous Children.* Retrieved from: https://www.dss.gov.au/long-term-research/footprints-tice-longitudinal-study-indigenous-children

Department of Social Services, Australian Government. (n.d.b). Access to DSS longitudinal datasets. Retrieved from: https://www.dss.gov.au/national-centre-for-longitudinal-data-ncld/access-to-dss-longitudinal-datasets

Directions Evidence and Policy Research Group, LLP. (2016). *Assessing potential bias in population level research with Aboriginal children: Literature review, Psychometric, and Administration Report.* Retrieved from: https://earlylearning.ubc.ca/app/uploads/2022/06/edi_assessing_bias_final_report_2016Jan.pdf

Dockery, A. M. (2020). Inter-generational transmission of indigenous culture and children's well-being: Evidence from Australia. *International Journal of Intercultural Relations*, 74, 80–93.

Farewell, C. V., Thayer, Z. M., Puma, J. E., & Morton, S. (2018). Exploring the timing and duration of maternal stress exposure: Impacts on early childhood BMI. *Early Human Development,* 117, 15–19.

Federation of Saskatchewan Indian Nations. (n.d). *Cultural Responsiveness Framework.* Saskatoon. Retrieved from: https://www.saskhealthauthority.ca/sites/default/files/2021-06/FSIN-cultural-responsiveness-framework.pdf

Felitti, V., Anda, R., Nordenberg, D., Williamson, D., Spitz, A., Edwards, V., Koss, M., & Marks J. (1998). Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults: The Adverse Childhood Experiences (ACE) Study. *American Journal of Preventive Medicine*, 14, 245–258.

First Nations Child and Family Caring Society of Canada. (n.d.) *Canadian Human Rights Tribunal decisions on First Nations child welfare and Jordan's Principle.* Case Reference CHRT 1340/7008, October 31, 2016. Retrieved from: https://fncaringsociety.com/sites/default/files/Info%20sheet%20Oct%2031.pdf

First Nations Health Authority. *First Nations Perspective on Health and Wellness [website].* Retrieved from: https://www.fnha.ca/wellness/wellness-for-first-nations/first-nations-perspective-on-health-and-wellness

First Nations Incidence Study. (n.d.). Retrieved March 27, 2020, from: https://cwrp.ca/first-nations-incidence-study

First Nations Information Governance Centre. (2005). *RHS cultural framework.* Retrieved from: https://fnigc.ca/wp-content/uploads/2020/09/rhs_cultural_framework.pdf

First Nations Information Governance Centre. (2012). *Report on the findings of the First Nations Oral Health Survey (FNOHS) 2009-10.* Retrieved from: https://fnigc.ca/wp-content/uploads/2020/09/fn_oral_health_survey_national_report_2010.pdf

First Nations Information Governance Centre. (2020). *Strengths-based approaches to Indigenous research and the development of well-being indicators.* Retrieved from: https://fnigc.ca/wp-content/uploads/2021/05/FNIGC-Research-Series-SBA_v04.pdf

First Nations of Quebec and Labrador Health and Social Services Commission (2013). Analysis project on the trajectories of First Nations youth subject to the Youth Protection Act analysis report: Summary report. Retrieved from: https://cssspnql.com/en/produit/analysis-project-on-the-trajectories-of-first-nations-youth-subject-to-the-youth-protection-act/

Greenwood, M. (2005). Children as citizens of First Nations. *Paediatric Child Health, 10 (9)*: 553–555.

Guhn, M., Janus, M., Enns, J., Brownell, M., Forer, B., Duku, E., Muhajarine, N., & Raos, R. (2016). Examining the social determinants of children's developmental health: protocol for building a pan-Canadian population-based monitoring system for early childhood development. *BMJ open*, 6(4), e012020.

Halseth, R. (2019). *The prevalence of Type 2 diabetes among First Nations and considerations for prevention.* Prince George, BC: National Collaborating Centre for Aboriginal Health.

Human Early Learning Partnership, University of British Columbia. (n.d.a). Human Early Learning Partnership home page. Retrieved from: http://earlylearning.ubc.ca/

Human Early Learning Partnership, University of British Columbia. (n.d.b). Childhood Experiences Questionnaire (CHEQ). Retrieved from: https://earlylearning.ubc.ca/monitoring-system/cheq/cheq-overview/

Human Early Learning Partnership, University of British Columbia. (n.d.c). Toddler Development Instrument (TDI). Retrieved from: https://earlylearning.ubc.ca/monitoring-system/tdi/tdi-overview/

Human Early Learning Partnership, University of British Columbia. (n.d.d). Early Development Instrument (EDI). Retrieved from: https://earlylearning.ubc.ca/monitoring-system/edi/edi-overview/

Human Early Learning Partnership, University of British Columbia. (n.d.e). Middle Years Development Instrument (MDI). Retrieved from: https://earlylearning.ubc.ca/monitoring-system/mdi/mdi-overview/

Human Early Learning Partnership, University of British Columbia. (n.d.f). Indigenous initiatives. Retrieved from: https://earlylearning.ubc.ca/about/indigenous-initiatives/

Hyett, S., Gabel, C., Marjerrison, S. & Schwartz, L. (2019). Deficit-based Indigenous health research and the stereotyping of Indigenous Peoples. *Canadian Journal of Bioethics / Revue canadienne de bioéthique, 2* (2), 102–109.

Jetty, R. (2021). Tuberculosis among First Nations, Inuit and Métis children and youth in Canada: Beyond medical management, *Paediatrics & Child Health*, 26, 2. e78–e81.

Justice Canada. (2019). *Spotlight on Gladue: Challenges, experiences, and possibilities in Canada's criminal justice system, part 2 statistical overview on the overrepresentation of Indigenous persons in the Canadian correctional system and legislative reforms to address the problem.* Retrieved from: https://www.justice.gc.ca/eng/rp-pr/jr/gladue/p2.html

Ketheesan, S., Rinaudo, M., Berger, M., Wenitong, M., Juster, R. P., McEwen, B. S., & Sarnyai, Z. (2020). Stress, allostatic load and mental health in Indigenous Australians. *Stress, 23*(5), 509–518. DOI: 10.1080/10253890.2020.1732346.

Kelley, A., and Small, C. (2016). Establishing the reliability and validity of the sources of strength in one American Indian community. *American Indian and Alaska Native Health*, 23(3), 84–92.

Kumar, M. and Tjepkema, M. (2019). *Suicide among First Nations People, Metis and Inuit (2011-2016): Findings from the 2011 Canadian Census Health and Environment Cohort (CanCHEC).* Retrieved from https://www150.statcan.gc.ca/n1/pub/99-011-x/99-011-x2019001-eng.htm

León-Pérez, G. (2019). Internal migration and the health of Indigenous Mexicans: A longitudinal study. *SSM - population health*, 8, 100407.

Luther, A. (2019). *Developing a more culturally appropriate approach to surveying adverse childhood experiences among Indigenous Peoples in Canada [unpublished dissertation].* Retrieved from: https://uwspace.uwaterloo.ca/bitstream/handle/10012/14478/Luther_Alexander.pdf?sequence=5&isAllowed=y

Menard, S. (2002). *Longitudinal research. SAGE: Research methods.* Thousand Oaks: CA, SAGE Publications, Inc.

Mersky, J., Lee, C., & Gilbert, R. (2019). Client and provider discomfort with an adverse childhood experiences survey. *American Journal of Preventative Medicine,* 57 (2), e51–e58.

Monnat, S. M., & Chandler R. F. (2015). Long term physical health consequences of adverse childhood experiences. Sociol Q. 56(4), 723–752.

Morton, S. M. B., Atatoa Carr. P. E., Grant, C. C., Robinson, E. M., Bandara, D. K., Bird, A., Ivory, V. C., Kingi, Te Kani R., Liang, R., Marks, E. J., Perese, L. M., Peterson, E. R., Pryor, J. E., Reese. E., Schmidt, J. M., Waldie, K. E., & Wall, C. (2013). Cohort profile: Growing up in New Zealand. *International Journal of Epidemiology*, 42, 65–75.

Muir, N., & Bohr, Y. (2014). Contemporary practice of traditional Aboriginal child rearing: A review. *First Peoples Child & Family Review*, 9 (1), 66–79.

National Inquiry into Missing and Murdered Indigenous Women and Girls. (2019). *The final report of the National Inquiry into Missing and Murdered Indigenous Women and Girls.* Retrieved from: https://www.mmiwg-ffada.ca/final-report/

O'Brien Institute for Public Health. (2018). *Raising Canada: A report on children in Canada, Their health and well-being.* Retrieved from: https://childrenfirstcanada.org/wp-content/uploads/2021/04/RaisingCanadaReport-2018.pdf

Office of the Auditor General of Canada. (2018). Report 5 – *Socio-economic gaps on First Nations reserves – Indigenous Services Canada.* Retrieved from: https://www.oag-bvg.gc.ca/internet/English/parl_oag_201805_05_e_43037.html

Oré, C., Teufel-Shone, N., & Chico-Jarillo, T. (2016). American Indian and Alaska Native resilience along the life course and across generations: A literature review. *American Indian and Alaska Native Mental Health Research,* 23 (3): 134–157.

Park, J., Tjepkema, M., Goedhuis, N., and Pennock, J. (2015). *Avoidable mortality among First Nations adults in Canada: A cohort analysis.* Retrieved from: https://www150.statcan.gc.ca/n1/pub/82-003x/2015008/article/14216eng.htm

Public Health Agency of Canada, Ottawa. (2010). *Canadian incidence study of reported child abuse and neglect – 2008: Major findings.* Ottawa, 2010. Retrieved from: http://cwrp.ca/sites/default/files/publications/en/CIS-2008-rprt-eng.pdf

Rasmus, S., Allen, J., Connor, W., Freeman, W., Native Transformations Community Action Board, & Skewes, M. (2016). Native transformations in the Pacific Northwest: A strength-based model of protection against substance use disorder. *American Indian and Alaska Native Health, 23 (3)*: 158–186.

Reese, E., Hayne, H., and MacDonald, S. (2008). Looking back to the future: Māori and Pakeha mother-child birth stories. *Child Development, 79(1)*: 114–125.

Reese, E., Fivush, R., Merrill, N., Wang, Q., & McAnally, H. (2017). Adolescents' intergenerational narratives across cultures. *Developmental Psychology, 53(6)*: 1142–1153.

Richter, L., Norris, S., Pettifor, J., Yach, D., & Cameron, N. (2007). Cohort profile: Mandela's children: The 1990 birth to twenty study in South Africa. *International Journal of Epidemiology, 36 (3),* 504–511.

Rogoff, B., Coppens, A. D., Alcala, L., Ruvalcaba, O., Lopez, A., & Dayton, A. (2017.) Noticing learners' strengths through cultural research. *Perspectives on Psychological Science, 12(5)*: 876–888.

Rountree, J. & Smith, A. (2016). Strength-based well-being indicators for indigenous children and families: A Literature review of indigenous communities' identified well-being indicators. *American Indian and Alaska Native Mental Health Research*, 23 (3), 206–220.

Royal Commission on Aboriginal Peoples. (1996). *Report of the Royal Commission on Aboriginal Peoples.* Retrieved from: https://www.bac-lac.gc.ca/eng/discover/aboriginal-heritage/royal-commission-aboriginal-peoples/Pages/final-report.aspx

Rubalcava, L. and Teruel, G. (n.d.). Mexican Family Life Survey. Retrieved from: http://www.ennvih-mxfls.org/english/ennvih-1.html

Sam, M.A. (2011). An Indigenous Knowledges perspective on valid meaning making: A commentary on research with the EDI and Aboriginal Communities. *Soc Indic Res* 103, 315–325.

Secretariat of the Permanent Forum on Indigenous Issues. (2006). *Meeting on Indigenous Peoples and indicators of well-being.* Retrieved from: http://caid.ca/AFNUNIndWelBei2006.pdf

Sheppard, A. J., Shapiro, G. D., Bushnik, T., Wilkins, R., Perry, S., Kaufman, J.S., Kramer, M.S., & Yang, S. (2017). *Birth outcomes among First Nations, Inuit and Métis populations.* Retrieved from: https://www150.statcan.gc.ca/n1/pub/82-003-x/2017011/article/54886-eng.htm

Sinha, V., Trocmé, N., Fallon, B., MacLaurin, B., Fast, E., Thomas Prokop, S., Petti, T., Kozlowski, A., Black, T., Weightman, P., Bennett, M., Formsma, J., Brascoupe, P., O'Brian, S., Flette, E., Gray, R., Lucas, L., Hoey, S., Levi, J., Montgomery, H. M., & Richard, K. (2011). *Kiskisik Awasisak: Remember the children: Understanding the overrepresentation of First Nations children in the child welfare system.* Ontario: Assembly of First Nations.

Statistics Canada. (2008) *National Longitudinal Survey of Children and Youth.* Retrieved from: https://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&Id=4632

Statistics Canada. (2017). *Census in brief: Diverse family characteristics of Aboriginal children aged 0 to 4.* Retrieved from: https://www12.statcan.gc.ca/census-recensement/2016/as-sa/98-200-x/2016020/98-200-x2016020-eng.cfm

Statistics Canada. (2020). *Extending the relevance of the longitudinal files (ERLF).* Retrieved from: https://www.statcan.gc.ca/en/microdata/data-centres/data/erlf

Thurber, K. A., Banks, E., & Banwell, C. (2015). Cohort profile: Footprints in Time, The Australian Longitudinal Study of Indigenous Children. *International Journal of Epidemiology*, 44(3), 789–800.

Thurber, K.A., Olsen, A., Guthrie, J., McCormick, R., Hunter, A., Jones, R., Maher, B., Banwell, C., Jones, R., Calabria, B., & Lovett, R. (2018). "Telling our story ... creating our own history": Caregivers reasons for participating in an Australian longitudinal study of Indigenous children. *International Journal for Equity in Health*, 17, 143–160.

Truth and Reconciliation Commission of Canada. (2015a). *Truth and Reconciliation Commission of Canada: Calls to Action.* Retrieved from: http://trc.ca/assets/pdf/Calls_to_Action_English2.pdf

Truth and Reconciliation Commission of Canada. (2015b). The final report of the Truth and Reconciliation Commission of Canada. Retrieved from: http://nctr.ca/reports.php

Ulrichsen, H. (2020). *App developed locally to connect Indigenous kids to health services is going national.* [news report]. Retrieved from: https://www.sudbury.com/local-news/app-developed-locally-to-connect-indigenous-kids-to-health-services-is-going-national-2009132

UNICEF Canada. (2017). UNICEF Report card 14: Canadian companion, *Oh Canada! Our kids deserve better.* UNICEF Canada, Toronto. Retrieved from: https://www.unicef.ca/sites/default/files/2017-06/UNICEF%20RC14%20for%20youth.pdf

Varni J.W., Limbers C. A., & Burwinkle, T. M. (2007). Parent proxy-report of their children's health-related quality of life: An analysis of 13,878 parents' reliability and validity across age subgroups using the PedsQL 4.0 Generic Core Scales. *Health Qual Life Outcomes,* 5, 2. DOI:10.1186/1477-7525-5-2

Young N., Wabano M. J., Blight, S., Baker-Anderson, K., Beaudin, R., McGregor, L. F., McGregor, L. E., & Burke TA (2017). Relevance of the Aboriginal Children's Health and Well-being Measure beyond *Wiikwemkoong. Rural and Remote Health,* 17, 3941. (Online).

Young, N., Wabano, M., Burke, T., Ritchie, S., Mishibinijima, D., & Corbiere, R. (2013). A process for creating the Aboriginal Children's Health and Well-being Measure (ACHWM). *Canadian Journal of Public Health. Revue canadienne de santé publique.* 104, e136-41. DOI: 10.1007/BF03405677

Young, N., Wabano, M., Usuba, K., Mishibinijima, D., Jacko, D., and Burke, T. (2016a). Reliability of the Aboriginal Children's Health and Well-Being Measure (ACHWM). *SpringerPlus, 5*, 2082.

Young, N., Jacko, D., Wabano, M., Hawthorne, L., Seabrook, S., Wabanosse, S., & Usuba, K. (2016b). A Screening Mechanism to Recognize and Support At-Risk Aboriginal Children. *Can J Public Health*, 107: 399. DOI:10.17269/cjph.107.5539

Young Lives, University of Oxford. (n.d.a). *Young lives: A longitudinal study into children and youth around the world.* Retrieved from: https://www.younglives.org.uk/

Young Lives, University of Oxford. (n.d.b). *Methodological lessons and learning.* Retrieved from: https://www.younglives.org.uk/research-project/methodological-lessons-and-learning

# APPENDIX A

## Table 1: Summary of Methods and Key Learnings from Longitudinal Studies

| Survey Title and Location | Research Design | Sampling | Study Length & Attrition | Key Learnings | Impact |
|---|---|---|---|---|---|
| Canadian National Longitudinal Survey of Children and Youth (NLSCY)[1] | National representative survey; cohort sequential design; data has been linked to income tax returns | 26,000 Canadian children and youth 0–17 years old; designed to be representative of the Canadian population; did not include First Nations children on reserve | Seven waves of data collected between 1994 and 2009; through complex sampling and participant tracking procedures, it was reported that 60.4% of the total participants in Cycle 1 were maintained[2] | A rich dataset about the health and well-being of non-Indigenous Canadian children, but did not include First Nations on reserve; maintaining a cohort that was nationally representative was very resource intensive and challenging | Data from the NLSCY continues to be accessed and used by researchers and government agencies in Canada; there are concerns about the age of the data, and it is not relevant to current and pressing concerns |
| First Nations Component of the Canadian Incidence Study on Reported Child Abuse and Neglect (FNCIS)[3] | Repeated cross-sectional design; three phases have been reported on so far; in the third wave, the First Nations component provides a specific, culturally relevant lens to the analysis and interpretation of CIS-2008 data | Data comes from standardized data collection forms that childcare workers fill out in relation to child maltreatment investigations | Three phases of data collection and analysis have been completed for the CIS study; a fourth wave is currently underway; data comes from administrative forms, and attrition is not relevant | The First Nations component reports on a number of major findings about child maltreatment investigations with First Nations children, which speak to their unique experiences; data is limited to First Nations children and families who come into contact with the child welfare system | The study has had a wide-ranging impact for scholarship and policy on child welfare for First Nations children; there are recognized limitations of the data and calls for a more holistic and culturally relevant picture of First Nations child well-being |

---

[1] https://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SDDS=4450

[2] Calculations of the overall attrition rate are provided in: Statistics Canada. n.d. Microdata User Guide, National Longitudinal Survey of Children and Youth, Cycle 7, September 2006 to July 2007. http://www.statcan.gc.ca/imdb-bmdi/document/4450_D4_T9_V7-eng.pdf (November 9, 2010).

[3] https://cwrp.ca/first-nations-component-canadian-incidence-study-reported-child-abuse-and-neglect-fncis-2008

| | | | | | |
|---|---|---|---|---|---|
| Human Early Learning Partnership (HELP), British Columbia[4] | Repeated cross-sectional design; new cohorts are assessed every year as children enter kindergarten, grade 4 and grade 7; built as a comprehensive system for monitoring population-level changes in the health and well-being of BC children over time; most reporting is focused on tracking trends in "populations" over time; some longitudinal data is available through tracking by personal ID and data linkage | Data has been collected from approximately 300,000 children over the seven waves of study thus far; the project is built as a population monitoring system where data is collected from families through schools in BC; new schools and communities are added each wave | Seven waves of data collection so far; participation is targeted and organized at the level of individual schools to maintain sufficient participation across BC regions | HELP has reported success in building and maintaining a province-wide child health and well-being monitoring system with considerable impacts on research and policy discussions; an Aboriginal steering committee (ASC) is active on the HELP team to integrate Indigenous perspectives with the project; data linkages are occurring but there are limitations in the kinds of data HELP collects and its relevance and validity within First Nations communities | HELP produces province-wide reports as well as regional reports for each data collection wave, peer-reviewed publications and numerous other KT initiatives are produced; the knowledge-to-action program seeks to support significant impacts on public policy for BC children and youth; through the ASC HELP strives to better integrate Indigenous perspectives in the project |

---

[4] http://earlylearning.ubc.ca/

| | | | | | |
|---|---|---|---|---|---|
| Footprints in Time, Australia[5] | Accelerated cross-sequential design; quantitative and qualitative data collected every year with participating families; two cohorts, one aged 6–18 months and one aged 3.5–5 years old in the first wave | Sampling captures 5% to 10% of the Aboriginal and Torres Strait Islander population; original cohort had 1,680 families; used a purposive sampling strategy that is not meant to be representative, but rather to provide a picture of life within a range of environments and communities | The study maintained a minimum 70% retention rate by Wave 6 and was funded by the Australian Government as one of a suite of longitudinal studies in Australia that are overseen by a National Centre for Longitudinal Data | Study was designed through an extensive community consultation process with Aboriginal and Torres Strait Islander communities; involves flexible methods to track associations between changes in family dynamics and environmental experiences and changes in child well-being; significant efforts put into building relationships with participating families | Reports are published for every study wave; multiple KT products are published with reports; data is available to outside users through a registration process; Indigenous and non-Indigenous researchers use data and interpret results in high-impact, peer-reviewed publications; participating families have reported numerous benefits from their participation |

---

[5] https://www.dss.gov.au/long-term-research/footprints-time-longitudinal-study-indigenous-children

|  |  |  |  |  |  |
|---|---|---|---|---|---|
| Growing up in New Zealand, New Zealand[6] | Longitudinal single-cohort study, started with interviews of pregnant women; quantitative and qualitative data collected; data collected from both mothers and their partners and in later waves from children themselves; participants have been asked and given permission for data linkages with administrative data about health and education | 6,853 Māori, Pacific Islander, Asian and European heritage children, sampling focused on building a cohort from a defined geographical region where the population was broadly generalizable to the New Zealand population in terms of ethnicity, SES, and rural/urban living; a focus was placed on recruiting large sub-samples of Indigenous and other ethnically diverse people | Approximately 81% of the original sample participated in the most recent wave of the study; the study is funded through the Ministry of Social Development in New Zealand and is planned to continue until child participants are 21 years old | Research design places emphasis on collecting data with clear relevance to national policy; focused on providing insight into the developmental trajectories of New Zealand children and to provide information about the multiple causal pathways relevant to children's well-being; emphasis is placed on providing a comprehensive picture of life in New Zealand by collecting a wide range of data from multiple informants | Reports and data sharing occur after every wave; extensive KT activities to share data with multiple audiences, including public servants, policy makers, medical professionals, educators, as well as families and caregivers with young children; Māori communities have used study data to track, report on and advocate for language revitalization programs and policy |

---

[6] https://www.growingup.co.nz/

| | | | | | |
|---|---|---|---|---|---|
| Mexican Family Life Survey[7] | Longitudinal single-cohort survey; data collected at the individual, household and local level to explore different dimensions of well-being for the Mexican population | 35,000 individuals from 8,400 households, including Indigenous people from Mexico; households were located within 150 different localities in Mexico | Currently contains information for a period of 10 years, collected over three surveys; the study has tracked the migration of participants as they moved domestically and internationally to the US; recent waves have accounted for close to 90% of original participants | Noted by the research team as the first longitudinal study in Mexico designed to be representative of the Mexican population; a single instrument has been designed to collect information on various socio-economic and demographic indicators at the individual, household and local levels; designed to provide information to help evaluate the impact of social programs and policies | Publications, presentations and reports have targeted many topics, including the experience of migration, evaluations of government programs, inequalities, gender and many other social dimensions of well-being |
| Cebu Philippines Longitudinal Health and Nutrition Survey[8] | A longitudinal single-cohort study of Filipino women who gave birth in 1983 and their children; began as a study of infant feeding patterns in natural environments and expanded to cover a wide range of maternal, child health and demographic issues | Baseline sample included 3,327 women from 33 randomly selected communities in the Cebu Metropolitan area; has included seven follow-up surveys with mothers and with children themselves | Of the 3,327 women included at baseline, 3,080 remained in the study and had singleton live births during the one-year eligibility period; in the latest tracking survey, 63% of these 3,080 mothers who were present at the birth information survey were located and interviewed, and 59% of the 3,080 children were located and interviewed | Detailed data were collected at the community, household and individual levels, allowing for a wide range of analytical approaches; CLHNS index children are now becoming parents, offering opportunities for three-generation studies; time gaps between the follow-ups limit the relevance to important aspects of child and adolescent growth | More than 125 scholarly works based on the CLHNS have been published in demography, economics, epidemiology, biomedical sciences, human biology, nutrition, public health and women's studies journals |

---

[7] http://www.ennvih-mxfls.org/english/index.html
[8] https://www.cpc.unc.edu/projects/cebu

| | | | | | |
|---|---|---|---|---|---|
| Mandela's Children (The Birth to 20 Study)[9] | A birth cohort study in South Africa designed to track the effect of rapid urbanization on children's health and development; originally planned on tracking the cohort for 10 years, but was expanded to a 20-year study (from 1990 to 2010); last published work in 2012 | The study followed 3,273 children who were born in 1990, shortly after Nelson Mandela was released from prison; data were collected annually from participants on a wide variety of physical and mental health indicators, as well as socioeconomic and demographic factors | Tracking the participants was challenging due to a lack of infrastructure and regular migration for work, but the research team used several techniques to stay in touch; reports at the end of the study in 2012 noted that 64% of the original sample was maintained | A committed core research team and strong relationships with health services, schools and community were able to maintain the study through challenges in funding; considerable efforts went into tracking and cohort maintenance, resulting in a low attrition rate; there were struggles to find the appropriate level of statistical expertise needed to do justice to the longitudinal data | Study researchers noted that the study has been a source of reference for several major policy decisions in the country, particularly in the absence of other data |

[9] Richter, L., Norris, S., Pettifor, J., Yach, D., & Cameron, N. (2007). Cohort profile: Mandela's children: the 1990 Birth to Twenty study in South Africa. International journal of epidemiology, 36(3), 504–511. https://doi.org/10.1093/ije/dym016

| | | | | | |
|---|---|---|---|---|---|
| Young Lives Longitudinal Survey[10] | A multi-country longitudinal two cohort study with quantitative and qualitative data collection; two cohorts allows for both cross-sectional and longitudinal comparisons; data is collected from children and other members of their households (e.g., parents and siblings) and communities (e.g., teachers) to address six major themes; data collection instruments include household surveys, school surveys and qualitative interviews with sub-samples of children; collaborative research initiatives link young lives data with other data sets | Sample includes approximately 12,000 children in Peru, Ethiopia, India and Vietnam; data is collected from two cohorts, one starting at age eight (born 1994–5) and one starting at age one (born 2001–2); Sampling involved selecting 20 sites in each country to illustrate diversity in rural and urban location, ethnicity and religion; sample includes approximately 2,000 children from the younger age group and 1,000 children from the older age group in each country; sampled children were randomly selected from children of the right age in each study site | Long-term core funding (15 years) has been provided by the UK government and other governments, agencies and NGOs; goal of the project is to track all of the children in the cohort even if they change location; recent reporting notes a 5% total attrition rate between rounds 1 to 4; analysis separates attrition by cause (e.g., mortality, refusal, untraceable); a tracking system (using contacts outside the household) was established to update basic information about participants between survey rounds; continuity of field workers has helped keep attrition low | Key findings focus on understanding the ways that intersecting inequalities (i.e., poverty, less educated parents, membership in racially disadvantaged group) are challenging for children and youth; a wide variety of data uses are reported including understanding the effects of poverty at various life stages, monitoring the impact of macro-economic changes, and tracing the effect of poverty across generations, among others; data collection continued in 2020 with a COVID-19 phone survey to explore the impact of international COVID policies | Wide-ranging dissemination strategy involving regular reports (aggregate and country specific) and updates, high-impact publications, accessible fact sheets and reports on key findings, online blogs and social media, impact case studies of policy relevant data as well as presentations, capacity building workshops and discussions of data and research methods with diverse audiences; data and survey planning has been linked to the Sustainable Development Goals to influence international policy |

---

[10] https://www.younglives.org.uk/

FNIGC CGIPN
First Nations Information Governance Centre
Le Centre de gouvernance de l'information des Premières Nations

**Head office:** 34 McCumber Road, Unit 13 | Akwesasne, Ontario K6H 5R7
**Ottawa office:** 180 Elgin St., Ste. 1200 | Ottawa, ON K2P 2K6

**T:** (613) 733-1916 or toll-free at 1-866-997-6248