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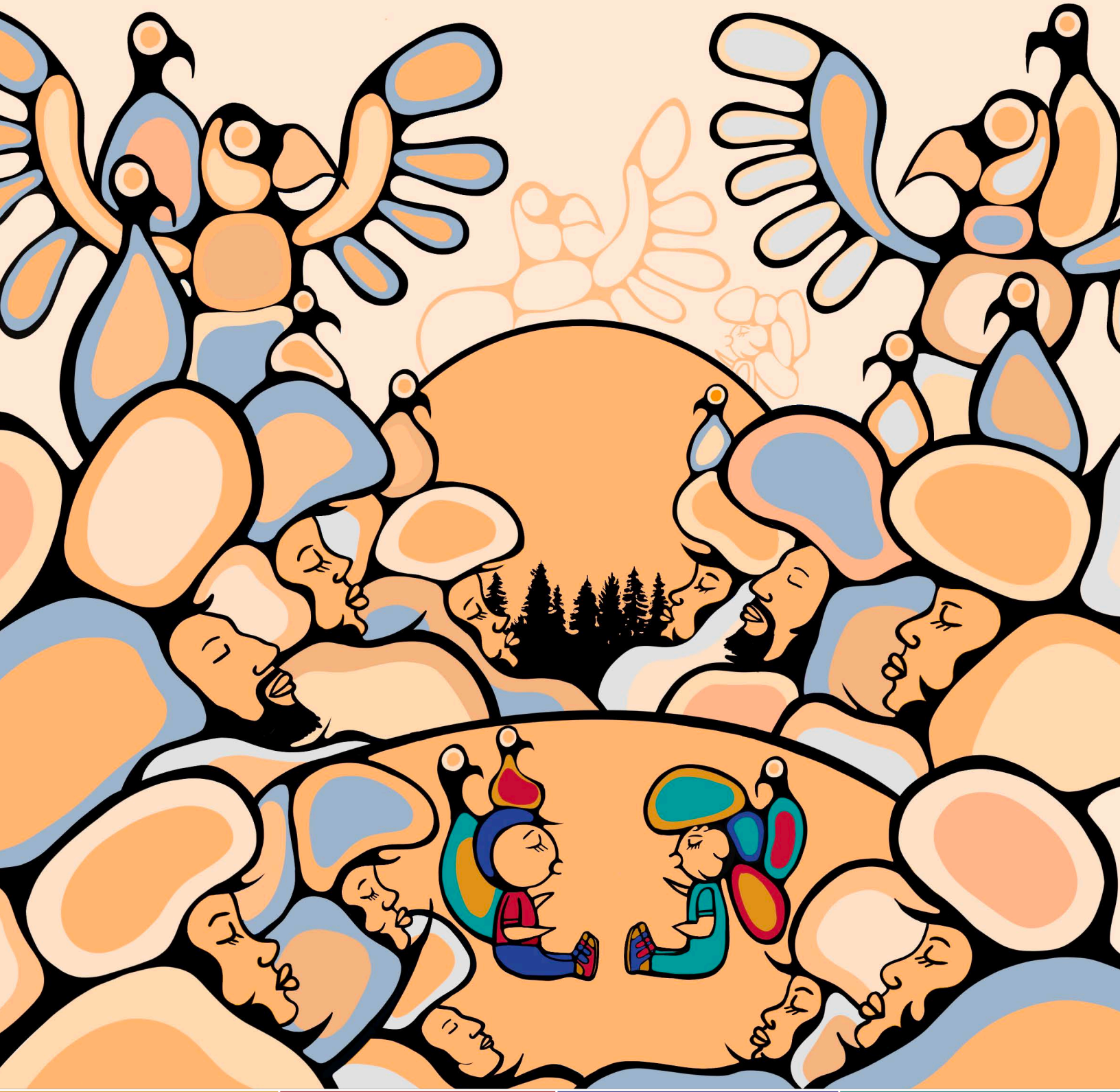
First Nations Information Governance Centre
Le Centre de gouvernance de l'information des Premières Nations

FEASIBILITY STUDY ON LONGITUDINAL RESEARCH WITH FIRST NATIONS CHILDREN



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This feasibility study 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 in First Nations children's 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.

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- The First Nations Health Authority

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- Kinwa BlueSky
- Margo Greenwood
- Michael McKenzie
- Nancy Young
- Pat Foster

We are grateful for the time, energy and knowledge that were shared by everyone who participated in this project.

EXECUTIVE SUMMARY

In December 2018, the Assembly of First Nations' Chiefs in Assembly passed a Resolution (#76, 2018), "First Nations Child Development and Well-being Longitudinal Study," 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, 2018). 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 *Feasibility Study on Longitudinal Research with First Nations Children* is a response to the AFN Resolution. The overall purpose of this feasibility study is to provide a well-informed analysis to determine whether longitudinal research is achievable and relevant to community priorities. As well as to determine the interest of First Nations to conduct, be involved with or participate in a longitudinal study.

The work of this feasibility study has involved several interrelated activities, including an analysis of the results from a literature review, engagement with recognized subject-matter experts and regional partner organizations, and the integration of lessons learned from FNIGC's experience with longitudinal surveys.

The report presents 17 recommendations, organized into four subject areas. They are derived from the study findings, including the literature review and the key findings from regional engagement sessions and subject-matter expert interviews. These recommendations provide important considerations for moving forward with the planning, development and engagement for a longitudinal study of First Nations children and youth.

Recommendations for employing a longitudinal research design

1. Planning for a longitudinal study should have strategies in place to address participant attrition
2. Commit to core funding for a long-term project
3. Consideration should be given to whether the sampling frame includes only First Nations people living on reserve and in Northern communities, or if it includes the off-reserve population
4. Consideration should be given to the current commitments of First Nations communities and First Nations regional organizations for surveys and research

Recommendations regarding collaboration and reciprocity

5. First Nations leadership, community organizations, Elders, Knowledge Holders, frontline workers and other community members should be at the table early on to provide input into project development and design
6. Governance and decision-making about the project should be aligned with processes, procedures and practices developed and endorsed by First Nations regional organizations
7. Invest in relationship building within the communities where participants live to be transparent and to build project relevance
8. Retain the same data collectors or field supervisors throughout the project to build relationships and trust

9. Build representative community steering committees and/or advisory boards to provide input to the research process
10. Specific and dedicated investments should be made in knowledge translation, dissemination and capacity building
11. Need for continued engagement

Recommendations regarding research design, research methods and the development of research instruments

12. Employ flexible data collection instruments, developed in collaboration with First Nations communities
13. Project goals, research questions and the design of research instruments should be based on, or founded on, First Nations worldviews, epistemologies and cultural frameworks
14. Data should be collected to present a balanced and culturally relevant picture of the lives, experiences and environments of First Nations children and youth
15. Research design should be targeted to provide evidence relevant to the influence of First Nations-led programs and services on First Nations children's development and well-being

Recommendations regarding research ethics and OCAP®

16. Research processes, data collection, data storage and data access guidelines should be developed in line with OCAP® principles as participating First Nations interpret them
17. Appropriate supports should be in place for data collection from children and about adverse childhood experiences

Four potential options for a longitudinal study are presented for consideration, informed by the analysis of literature review results, key findings and FNIGC's past experience. The potential benefits and challenges associated with each of these options are reviewed to support informed decision-making by First Nations leadership. Moving forward with any of these options will involve additional consultation and engagement with First Nations leadership and community members to determine which options best serve their data needs.

Option 1: A distinct longitudinal cohort study

- Potential for high-quality data relevant to First Nations data needs and research priorities
- Most resource intensive
- Challenges with large sample size, regional or national representativeness, and attrition

Option 2: Building a longitudinal cohort out of a cross-sectional sample

- Builds on existing research commitments and survey capacities
- Could provide quality longitudinal data with a sub-sample of participants and provide opportunities for scaling up
- Would require additional resources and may not be able to achieve the same levels of representativeness

Option 3: A small-scale, regionally focused cohort study with a region expressing interest

- Could provide high-quality data for participating regions about some research priorities and provide lessons about required resources and capacities

- Would not be representative of the First Nations population in Canada
- Challenges of attrition and tracking the cohort remain, and significant engagement would be needed to negotiate which region(s) choose to participate

Option 4: A retrospective adverse childhood experience study

- Could provide data comparable to the ACE study
- Could be integrated into existing survey programs like the Regional Health Survey (RHS)
- Less relevant to research priorities and data needs than longitudinal data

Overall, this report presents evidence of significant interest on the part of First Nations communities and regional organizations in accessible, First Nations-controlled longitudinal data regarding child and youth development and well-being. At the same time, numerous concerns were expressed about the required resources and potential challenges associated with developing a study of this nature.

Recommendations and potential design options should be seen as a starting point for further consultation and engagement with First Nations at the community, regional and national levels. Any project that moves forward needs to be beneficial for participating First Nations, support decision-making and the well-being of First Nation children and youth, and support First Nations' aspirations towards data sovereignty.

BACKGROUND

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, cease applying a narrow definition of Jordan's Principle and adopt measures to immediately implement its full meaning and scope. Based on the experience of Jordan River Anderson, who passed away during an inter-governmental 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, 2018, 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.

In December 2018, the Chiefs in Assembly passed Resolution no. 76/2018, *First Nations Child Development and Well-being Longitudinal Study*, 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, 2018). 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.

This *Feasibility Study on Longitudinal Research with First Nations Children* is the response to the AFN Resolution. The overall purpose is to provide a well-informed analysis to determine whether this research is achievable

and relevant to community priorities, as well as to assess the interest of First Nations in conducting, being involved with or participating in a longitudinal study. Collecting detailed longitudinal data on First Nations children provides an opportunity to assess program impacts and general measures of well-being, not only among First Nations children, but also against other Canadian children, with the ultimate goal of understanding and addressing cultural inequities.

METHODS

The work of this feasibility study involved a number of interrelated activities, including an analysis of the results from a literature review (full report, *Literature Review for The Feasibility Study on Longitudinal Research with First Nations Children*), engagement with recognized subject-matter experts and FNIGC regional partners, and an integration of lessons learned from FNIGC's experience with longitudinal surveys through different phases of the Regional Health Survey (RHS).

As a first step in the feasibility study, a literature review was conducted to explore the latest research and strategies for examining the development and well-being of First Nations children and youth, with a focus on longitudinal research approaches. The literature 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 feasibility study also included two main engagement processes. FNIGC and Firelight staff conducted interviews with select subject-matter experts (SMEs). Interviews were supported by interview guides collaboratively developed by Firelight and FNIGC. Regional engagement sessions were facilitated by Firelight, with support from FNIGC and representatives from the partner organization in each region. Details about the methods and procedures used in both the regional engagement sessions and the subject-matter expert interviews are presented in Appendix B. Additional materials created for the engagement processes can be found in Appendices C, D, E and F.

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

Following these various analyses, a number of recommendations for advancing a project like this were put forward, as well as an outline of several options for consideration, including a discussion of the potential strengths and challenges associated with these options.

KEY FINDINGS: LITERATURE REVIEW

This section will outline the key findings from the literature review. The complete literature review is available as a separate publication available in the FNIGC online library, titled Literature Review for *The Feasibility Study on Longitudinal Research with First Nations Children*.

Findings from the literature review were broadly organized around the following three objectives:

1. Key learnings about methods and research processes from existing longitudinal studies conducted with children and young people
2. Summary of research on adverse childhood experiences as it may apply in conducting research with First Nations communities
3. Summary of research on the use of First Nations cultural frameworks and strengths-based indicators to understand First Nations children's development and well-being

Objective 1 – Key learnings about methods and research processes from existing longitudinal studies conducted with children and young people

Various national and international longitudinal research projects related to child and youth development and well-being were examined. 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 available in Appendix A. Overall, these studies suggested that it is possible to conduct long-term longitudinal studies despite challenges surrounding political upheaval, migration, impoverishment, and funding uncertainty. However, these studies found specific challenges that should be addressed in the planning stages of potential longitudinal studies. Based on the literature reviewed, the following is a list of the most important considerations and challenges for conducting this research with First Nations communities.

Attrition

In the studies examined, attrition, when participants drop out of the study before it is completed, was explored. Participants dropped out, moved, lost motivation to participate or were lost to mortality. High attrition rates can lead to systematic differences in the data and interpretation between participants who leave the study and those who remain — this is known as attrition bias and can weaken the generalizability of the findings.

The literature review provided the following suggestions to address attrition bias and to keep attrition rates low:

- Starting with a large initial cohort to ensure there is a viable cohort by the end of the study, and that the size is sufficient for statistically relevant outcomes. Although large samples are preferable, it is worth considering that this comes with additional costs, particularly in terms of tracking and maintaining contact with participants over extended periods of time.
- Building strong relationships between the data collectors and the participating families can play an important role in keeping families involved. Research teams emphasized the importance

of employing the same data collectors or field supervisors throughout the project to build relationships and trust.
- The importance of significant investments in data dissemination, knowledge translation and knowledge mobilization strategies.

Through these strategies, study participants gained a deeper understanding of how participation in the study could be beneficial. Even in challenging circumstances, these projects suggest it is possible to keep attrition low, but participants must see the value in the work for themselves, their family members, and their communities.

Flexible data collection instruments

The literature also highlights the importance of employing flexible data collection instruments that allow researchers to measure, assess, and track multiple aspects of children's lives and experiences, including the ecological contexts in which they live. Many studies used multiple methods and instruments to collect data, including observation, self-report surveys and interviews. This enabled the research team to build complex and accurate pictures that highlighted a variety of important factors affecting the participants' daily health and well-being. In addition, flexible methods maintained the relevance and utility of the research data over extended periods, enabling new areas of focus to emerge. For example, in the Young Lives study (Boyden et al., 2019), researchers discussed how the study was modified after early waves of data collection to include a new area of focus on children's education. Several measures were maintained to ensure comparability with earlier waves, and new measures of school experiences were introduced.

Secured funding

Secure funding was identified as a challenge for the longitudinal studies examined. Many research teams 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 creates a great deal of uncertainty, staff turnover, loss of corporate memory, and time and effort to secure the next round of funding. Most of the longitudinal studies explored were planned for a period of approximately ten to twenty years, examining both short- and long-term patterns of change over time among participating children. Planning a project like this and building relationships based on respect with participating communities involves significant funding commitments. Some projects have been able to secure commitments of "core funding" for periods of up to 15 years, enabling research teams to plan for the future and commit to long-term relationships with participants and study communities.

Community representative steering committees and/or advisory boards

Many of the studies reviewed made significant investments in time, personnel and money devoted to relationship building within the communities where participants lived. Research teams reached out to community organizations to build steering committees and/or advisory boards representative of the communities involved. These organizations, advisory boards and steering committees provided input into multiple aspects of the research process, including the development of locally relevant questions, the development and use of measurement instruments, and storage and access to data. In many cases, research questions and interview and questionnaire content were developed and modified through consultations with community representatives or stakeholders. In the Growing Up in New Zealand (GUiNZ) study, the

research team notes that a regionally specific sampling strategy, combined with investment in relationship building with local community organizations, led to a strong "local identity" for the study, which built interest among participants and encouraged retention (Morton et al., 2013).

Importance of knowledge translation and capacity building

Many of the studies reviewed emphasized the importance of knowledge translation and capacity building within local communities and organizations for project success. Successful studies planned for comprehensive knowledge translation strategies involving reports, fact sheets, reports on key findings, and impact case studies of policy-relevant findings, among others. In addition, the Young Lives project has invested considerable effort in capacity building within participating countries, as well as in linking the project to international commitments related to poverty reduction, such as the UN Sustainable Development Goals.

Objective 2 – Summary of research on adverse childhood experiences as it may apply in conducting research with First Nations communities

The ACE study (Felitti et al., 1998; 2019), 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 study found that chronic exposure to adverse experiences can have a detrimental effect on an individual's health and well-being throughout their life. In addition, the greater the number of ACEs that participants reported experiencing, the higher the risk of developing each of these problems later in life.

It is important to note that ACEs surveys described in the work above are retrospective — they examine past circumstances, not current ones. These types of surveys are delivered to adults, not children (Felitti et al., 1998). Recent work has attempted to capture children's perspectives on their experiences through interviews or surveys; however, these methods are not typically used with children five years old and under (Varni et al., 2007).

Additionally, the original ACE studies were intended to be representative of the general population in the United States, and most participants were white, middle-class Americans. As such, the results of these studies cannot be generalized to First Nations communities in Canada.

The literature review revealed a substantial body of research focused on understanding the types of traumas and adverse experiences common within First Nations communities, as well as the impact of these experiences on the lives of First Nations people. In the context of Indigenous Peoples in Canada, adverse experiences include racial discrimination and the historical trauma associated with colonialism including malnutrition, residential schools, relocation of communities, and the 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). Research from Indigenous scholars and allied researchers suggests that the trauma from these kinds of adverse experiences is cumulative, building on the suffering experienced by previous generations (Aguiar & Halseth, 2015).

A recent study explored the impact of residential schools on intergenerational trauma. This research concluded that residential school attendance by either the mother or father generally raised the number of ACEs among their children (Chief Moon-Riley et al., 2018). 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., 2018), which leads to a higher likelihood of health and wellness problems later in life. A recent review of literature on intergenerational transmission of trauma conducted for the National Collaborating Centre for Aboriginal Health in 2015 reports that historical trauma is passed to successive generations through psychological, physiological and social pathways (Aguiar & Halseth, 2015). As these examples make clear, there is much evidence that adverse experiences early in life take a variety of forms for First Nations people, and that these early traumas can have intergenerational effects.

Challenges with ACE studies

Several challenges may arise in adapting the ACE study to a longitudinal study of the development and well-being of First Nations children and youth.

- ACE-type questions are generally asked of adults retrospectively about their childhood experiences. Adapting the original ACE study methodology would thus be very different from developing a prospective cohort study that follows First Nations children and their families over time.
- A study based on the original ACE study would have different kinds of research questions, funding requirements and types of relationship building with First Nations communities, organizations and participating families.
- Some research has developed methodologies for gathering information about ACEs through prospective cohort studies that involve parent or caregiver reports (Walsh et al., 2019a; 2019b). Further engagement with interested First Nations would be required to explore the cultural relevance and cultural safety of an approach like this.

Objective 3 - Summary of research on the use of First Nations cultural frameworks and strengths-based indicators to understand First Nations children's development and well-being

The literature review also examined research that incorporated First Nations cultural frameworks and strengths-based indicators to understand the development and well-being of First Nations children. Examinations of diverse cultural frameworks developed by First Nations scholars, organizations and communities suggest that complex pictures of children's and youth's development and well-being could resonate well with holistic perspectives on health and wellness advanced by First Nations people.

Cultural frameworks

Much of the review emphasized the need to incorporate Indigenous values and cultural frameworks into research and survey design to ensure that the results accurately capture and reflect Indigenous perspectives and realities. Cultural frameworks help identify issues and concepts valued by a particular community.

The indicators of development and well-being are then chosen based on that community's perception of what is valuable for health, wellness and well-being, or those things considered to be strengths in that community.

Key commonalities among the Indigenous cultural frameworks reviewed included:

- Balance between the physical, mental, emotional and spiritual elements of the individual as an indicator of well-being;
- Connection to land as an element of Indigenous well-being and, conversely, the loss of opportunity to connect with the land as damaging;
- Relationships with family and extended family were identified as critical to Indigenous Peoples' well-being. Family includes one's lineage, extended family, role and place in the family and community, parenting and grandparenting, and family traditions;
- Community relationships are supported by the availability and accessibility of cultural traditions and resources, community education activities, and access to hunting and gathering grounds and sacred places, all of which were identified as critical to Indigenous Peoples' well-being; and
- Developing strengths-based indicators, derived from cultural frameworks, to help in crafting research questions, identifying issues for research, and in the interpretation of results.

KEY FINDINGS: ENGAGEMENT

The key findings reported in this section summarize comments and perspectives from participants in two main engagement processes: 1) regional engagement sessions conducted in collaboration with FNIGC's regional partners, and 2) interviews with Knowledge Holders and subject-matter experts across Canada who were recognized for their knowledge of First Nations culture, history, social determinants of health and community well-being. Within this section, perspectives from both participant groups are presented.

CONSIDERATIONS FOR LONGITUDINAL STUDIES

Interest/Opportunities

When asked "*what would you hope to learn from a longitudinal study focused on child and youth development and well-being in your region?*" regional engagement participants expressed an interest in a longitudinal study with First Nations children, but noted it will be important to build a strong foundation for this work to ensure the study captures data that First Nations need.

Both regional engagement participants and subject-matter experts emphasized that longitudinal studies could have important benefits for First Nations in understanding child and youth development. For example, study participants expressed significant interest in how longitudinal studies can track changes in child and youth development and well-being over time. Additional benefits expressed were the ability to trace the relative impact of multiple factors over time, how they interact and how the "mix" or accumulation of stressors in children's lives influences developmental trajectories.

Some participants indicated that longitudinal studies could help disentangle the effects of multiple variables on child development, as well as help draw attention to broader structural challenges and

inequalities. Regional engagement participants suggested that experts and practitioners working with First Nations children possess a wealth of knowledge, which could be explored through longitudinal research. It was noted that a longitudinal study with First Nations children could help evaluate different ways of caring for and supporting children, which could ultimately improve programming. Also expressed was interest in associations between variables over time and exploring potential causal relationships.

This study identified a lack of longitudinal research on the early childhood experiences of First Nations children and youth, as well as the ways these experiences influence their well-being. Study participants noted that past projects could have benefited from the unique insight provided by longitudinal data. It was suggested that existing data focuses on negative outcomes for First Nations children, and this study could help to understand the diversity of experiences among First Nations children.

Overall, participants in regional engagements expressed an interest in the development of a longitudinal study. It was suggested by both regional engagement participants and subject-matter experts that a First Nations-led longitudinal study could provide better, outcome-focused data about children and youth development and well-being, grounded in First Nations perspectives.

Concerns/Challenges

Despite significant interest, some study participants expressed concern about the feasibility and relative utility of a longitudinal approach. Potential challenges were identified in various areas of the research process, including selecting the sample (i.e., who to include or exclude), determining how sampling would be undertaken and maintaining the sample integrity. Linked to this concern was the tracking of the cohort, as following children over time may become challenging due to the highly mobile nature of First Nations populations. The need to follow participants in and out of First Nations communities was noted as a significant challenge. In addition, some participants expressed concerns about the feasibility of ensuring the sample was sufficiently large for a successful longitudinal study involving First Nations children.

Additionally, regional engagement participants expressed concerns regarding the required resources and funding associated with the long-term commitments of a longitudinal study. Participants spoke about how commitments supporting long-term relationship building with participating First Nations would be an important part of building a respectful research collaboration. Some study participants questioned whether the data gathered from such a study would be worth the human and financial resources required. It was noted that a longitudinal study would necessitate a substantial budget and high staff requirements throughout all aspects of the study.

Of notable concern was whether a longitudinal study would have clear benefits for communities. Regional engagement participants noted that past projects have encountered issues due to data shortcomings. At the same time, this study heard that communities are experiencing survey and study fatigue. Interestingly, concerns were raised about funding being diverted from other programs, and some participants expressed doubts about whether this study would lead to action at the community level.

Some study participants suggested that a full longitudinal study may be less financially worthwhile compared to repeated cross-sectional studies. However, it was also noted that though some potentially less expensive options, such as repeated cross-sectional and retrospective studies, can be useful, they also have drawbacks, particularly in terms of the ways they can lead to false assumptions about causality.

RESEARCH TOPICS (RESEARCH GAPS AND PRIORITIES)

When asked about the research topics that should be explored in a longitudinal study focused on child and youth development and well-being, study participants provided a variety of responses. The research topics identified are presented below and organized into four categories: the well-being of First Nations children, structural challenges, protective factors and resilience, and research on adverse childhood experiences.

This section provides a detailed overview of the topics identified in each category, including considerations related to the importance of focusing on certain topics and the potential outcomes of doing so. These research priorities vary from national priorities to regional and community-specific priorities. The key findings presented here should be seen as a preliminary discussion of potential topics of interest. A more thorough engagement with interested First Nations is needed to refine these topics and determine areas of focus for a potential longitudinal study.

Well-Being of First Nations Children

Throughout the study, regional engagement participants were very clear that research on the well-being of First Nations children is a priority for their communities. Of particular interest was the idea of research that tracks changes in the health and well-being of First Nations children and that ties these changes to experiences with different kinds of programs and interventions. Participants emphasized the importance of exploring the relationships between well-being, language, culture and identity. As well, both regional engagement participants and subject-matter experts discussed the importance of foundational principles in developing study topics, such as doing "what is best for children" and putting "children's interests first."

Structural Challenges

Study participants identified a need for more data about the structural challenges First Nations children and youth face, especially compared to non-Indigenous children. The need for data linking child and youth development and well-being to social and structural determinants, such as inequities and discrimination, was also expressed. Most study participants often repeated this focus on structural risk factors. Of particular interest was research linking gaps in social, education and health outcomes among First Nations children to systemic factors, such as poverty, racism, and discrimination. It was also indicated that individual and family risk factors should be contextualized within structural and social dimensions of health, involving complex causal pathways.

This study identified a need to contextualize the challenges faced by First Nations families within broader structural factors. Participants expressed the need for clear and measurable data on structural inequalities, such as "state-based discrimination"; however, research needs to move away from framing and interpreting structural factors (e.g., high levels of poverty) as personal deficits (e.g., high levels of parental neglect).

It was noted that in much current research, risk and protective factors are defined too narrowly and do not consider structural factors. Instead, research should focus on how these kinds of structural factors contribute to the resilience of children, youth, and communities.

Protective Factors and Resilience

Research regarding protective factors was also identified as a priority focus for future research concerning the well-being of First Nations children and youth. Specifically, both regional engagement participants and subject-matter experts emphasized the need to focus research on the protective factors that enhance the strength and resilience of community members, as well as how communities contribute to and support child resilience and overall child well-being. Focusing on protective factors was emphasized as more important than focusing on risk factors. Study participants noted that emphasizing protective factors enables the development of strengths-based research and focuses on solutions.

Some of the protective factors and culturally appropriate wellness indicators that were identified as important to explore include the following:

- Language and culture
- Identity
- Connection to community
- Positive relationships and connection to family and support systems (presence of strong and healthy relationships)
    - ◊ Loving relationships
    - ◊ Intergenerational relationships
    - ◊ Relationships with parents
    - ◊ Relationships with extended family
    - ◊ Relationships with Elders
    - ◊ Relationships with adults
- Access to and participation in First Nations-driven community programs
- Access to supports and services (i.e., supports for families, early learning programs, etc.)
- Self-governance and awareness of good governance
- Measures of resilience and self-determination
- Participation in land-based learning

Regional engagement participants discussed the need for research to adopt a "whole-community" approach to develop a comprehensive understanding of the child's environment. A whole-community approach would address positive life experiences in the home, schools and community. Such an approach could provide a wealth of information about what is working well in communities and help in understanding why these approaches are effective.

Some regional engagement participants and subject-matter experts challenged Western conceptualizations of development and well-being, instead emphasizing the importance of developing indicators aligned with Indigenous values and worldviews. They stated that research should involve working with First Nations to clarify what constitutes healthy development in a First Nations context, as well as assessing child and youth development and well-being through a First Nations lens.

It was noted that there are few studies on the effectiveness of different interventions in providing culturally appropriate support and

helping children learn about their culture and language. Gathering data on the effectiveness of different interventions (where effectiveness is defined in terms of ensuring both that parents are supported and that the rights of First Nations children are honoured) was deemed important. Similarly, it was noted that few studies link outcomes to the presence or absence of specific community-based interventions, especially those developed by First Nations. Additional gaps exist in understanding differences in outcomes between First Nations and non-First Nations children and youth. Study participants noted that data specific to First Nations children, as opposed to pan-Indigenous data, is preferred.

ACE-BASED RESEARCH

When asked about the inclusion of ACE-based questions, the study participants were clear that a balanced approach would be needed in a longitudinal study focused on child and youth development and well-being. It was noted that the ability to track the long-term influence of ACEs is a significant benefit of longitudinal studies. It was also noted that a longitudinal study could shed light on both the impact of ACEs and the supports that foster child resilience throughout these experiences.

Some regional engagement participants and subject-matter experts indicated that ACE data could help highlight structural barriers and inequities, which could have legal, policy and funding implications. Exploring data on structural factors would be very important for contextualizing the findings. Additionally, ACE data could be useful in multivariate analyses, allowing researchers to control for the influence of different structural factors. Some study participants indicated that ACE data could help tell "the whole story" and aid in understanding the holistic mix of experiences that First Nations families are facing. Throughout the discussions, study participants stressed the importance of focusing on Indigenous perspectives and strengths-based indicators when exploring ACEs, which could help in avoiding pathological narratives.

Concerns About Including ACE-type Questions

Many concerns were discussed by the study participants about the inclusion of ACE-type questions. Such concerns included views that focusing on ACEs could deter participants, while others questioned the appropriateness of research looking at ACEs with First Nations children. Some study participants challenged the utility of this type of research, arguing that it would yield very little benefit to be involved in an ACE study that might confirm what First Nations communities already know, while also potentially exacerbating stereotypes. Some strongly expressed the view that an ACE-focused study was inappropriate and would perpetuate deficit-based research approaches, which communities are trying to move beyond. These participants suggested that a strengths-based approach would be more appropriate and would likely yield more beneficial data.

Additionally, participants in regional engagement sessions noted that ACE questions could have a high potential for re-traumatizing individuals. To mitigate these concerns, study participants emphasized the importance of designing the study carefully to minimize the potential for re-traumatization. This could involve being careful with question wording as well as providing appropriate aftercare supports to both field workers and study participants. These kinds of support would need to be accessible for any study, including ACEs. A longitudinal study would also need to collaborate with participants to develop culturally sensitive approaches to asking about difficult experiences.

It was expressed that research on ACEs without data on structural inequities risks placing blame on children and parents themselves. Additionally, drawing conclusions based on ACE data has limitations; it can paint an overly deterministic picture that neglects the role of structural factors.

ACE Topics to Explore

Participants identified a number of ACEs that could be important to explore, including addiction and the opioid crisis; intergenerational trauma; interpersonal, institutional and structural racism; bullying; poverty and housing difficulties; breakdown of cultural continuity; social isolation; youth suicide; influence of structural oppression; experiences in foster care; sexual violence; and stress.

Both regional engagement participants and subject-matter experts expressed particular interest in exploring the outcomes of experiences in foster care. Linked to this was a discussion around the "epidemic of child welfare" and how this is being exacerbated by the use of "colonial yardsticks" to measure child health and well-being.

There was also interest in exploring connections between poverty and other factors such as stress, nutrition and child apprehension, as well as relating outcomes like stress and depression to institutional barriers. Study participants identified intergenerational trauma as a topic of interest to explore. Specifically, the long-lasting effects of historical and intergenerational trauma and understanding the role of such trauma on social dimensions of health (e.g., housing, employment). The study participants also identified an interest in exploring the structural and personal repercussions of experiences with racism.

CULTURAL FRAMEWORKS AND STRENGTH-BASED APPROACHES

Study participants emphasized the importance of focusing on First Nations perspectives and strengths-based indicators throughout each phase of the study, from research design and implementation to dissemination and knowledge translation. It was suggested that any study with First Nations children should reflect the perspectives and conceptualizations of First Nations about child and youth development and well-being. Regional engagement participants and subject-matter experts noted that input from multiple community members, combined with the use of Indigenous methodologies, would help ensure the project is rooted in First Nations strengths-based and holistic worldviews. Some regional engagement participants stated that First Nations-led research would likely have more validity because non-First Nations-led research could receive inconsistent data from participants.

Study participants clearly expressed the need to avoid deficit-based approaches. Deficit-based approaches and past child welfare research have caused much distrust at the community level, especially for research "evaluating" parenting practices. Instead, there is a need to take a balanced approach and investigate both positive and negative factors that contribute to development and well-being.

Cultural frameworks are rooted in ancestral teachings and connections to the land and community. When developing or selecting appropriate frameworks and research instruments, study participants expressed that research frameworks should be anchored in these kinds of "teachings" about children. Some interest was expressed in building on the research frameworks used in past studies. As such, it was expressed that

conceptualizing child well-being should be rooted in First Nations worldviews, with an emphasis on the diversity of First Nations cultures.

A number of social dimensions of health were identified as important to consider when building cultural frameworks for research with First Nations, including connections to the land, culture and language; good governance; the presence of "natural helper systems," relationships with parents and other role models; and children's agency in social and community change, among others.

Both regional engagement participants and subject-matter experts expressed an interest in developing culturally appropriate indicators for distinct First Nations as opposed to a pan-Indigenous approach. A critical part of the work should be to establish culturally appropriate indicators and metrics; current tools are biased and deficit-based and not linked to broader systemic factors. Indicators should be actionable and linked to policy, programs and services.

COLLABORATION AND RECIPROCITY

Collaboration

Designing research in collaboration with community partners is a critical part of ensuring that it benefits participating communities, upholds the standards of OCAP®, and is carried out safely and ethically. If done in close collaboration with First Nations communities through an appropriate research framework, research can be designed in a way that benefits participating communities by gathering data needed to educate and build awareness, support healing, encourage evidence-based planning and programming, develop tools, garner funding, and influence policy. Ultimately, First Nations need to decide for themselves whether gathering this kind of data would be helpful.

Subject-matter experts and regional engagement participants both stated that taking the time to build trust with partner organizations and communities is a requirement for respectful, collaborative research. Without taking the time to build a strong foundation for such a project, it will be difficult to achieve community participation. Regional engagement participants suggested work needs to be done within and across First Nations to enable focused conversation about the design and delivery of a study like this.

Community-driven collaboration will be critical for the success of a longitudinal study focused on child and youth development and well-being. Throughout the study, it was clearly expressed that research should be community-driven and collaborative with direct input from community members, leadership, Elders, Knowledge Holders and children themselves. In addition, some regional engagement participants suggested forming working groups and committees comprised of representation from First Nations to do preliminary work on culturally appropriate measures and guide study and questionnaire design.

Many study participants expressed the need for Nation-specific data, rather than a pan-Indigenous approach. While some participants recognized the need for standardized measures, it was pointed out that there is also a need to understand and acknowledge the uniqueness and diversity of First Nations communities.

Regional engagement participants and some subject-matter experts expressed that a longitudinal study would be particularly useful if it provided access to data that enabled more culturally competent

assessments of First Nations child and youth development. Also expressed was the need for Indigenous Peoples, specifically First Nations people, to lead data collection and analysis of such studies. Regional engagement participants suggested that presenting examples of longitudinal data and its uses within First Nations communities could help to build support for the work. Additionally, regional engagement participants expressed a need to contextualize the data and share it with communities in meaningful ways. Research teams working on the study should clearly demonstrate how the data would be disseminated back to communities and how it could improve outcomes for First Nations children and youth.

Communication was also identified as an important factor in the success of a longitudinal study. An emphasis was placed on building a solid foundation for the study by clearly communicating its purpose and vision, as well as outlining the benefits of participation for both children and their families. It was also expressed by regional engagement participants that there is a need to focus on building awareness within First Nations communities about how study data could enhance and support community governance. More generally, study participants expressed the need for broad communication on data governance, the value of participation, the ways data can be used to support decision-making and good governance, cultural safety in assessment, and the identification of culturally relevant outcomes and measures.

Reciprocity

Participants discussed the need for reciprocity in a potential new study and greater emphasis on giving back to communities. Providing benefits back to communities requires working with community partners to understand their priorities and aligning and designing the research to support those priorities.

Subject-matter experts and regional engagement participants stressed the importance of respectful research processes and procedures. Such research involves communities having a clear understanding of, and control over, their own data. It involves returning research products and data back to communities in a way that is useful and meaningful, and respects data sovereignty by involving communities and allowing them to decide how the information is used.

Reciprocal benefits can also be provided to communities through support for capacity building. Regional engagement participants expressed a need to focus on building community capacity so that knowledge can be understood and used. Building capacity enables First Nations communities to better utilize data to advocate for and develop effective programs and services.

Last, both regional engagement participants and subject-matter experts discussed the importance of OCAP® and data governance in research. They expressed a need to adhere to OCAP® principles and develop low-barrier research deliverables. Due to some mistrust from historical research, it will be important to work with First Nations on data governance to ensure that a potential longitudinal study supports their aspirations and priorities and that it is conducted in a respectful and meaningful manner.

RESEARCH DESIGN

Discussions regarding the design of a future First Nations-specific longitudinal study focused on child and youth development and well-being involved considerations around community-driven design, Indigenous methodologies and mixed-method approaches. Study participants were asked general questions about research design, as the overarching research questions that will guide the study's design have not yet been determined. Decisions regarding research design for any potential longitudinal study will require further engagement and collaboration with First Nations once the study's goals and particular area of focus have been determined. As this study was a preliminary exploration of interest in and considerations for a potential longitudinal study, much more collaborative work with First Nations communities and leadership is needed to provide specific input into many questions about research design.

Despite these limitations, study participants emphasized the importance of community-driven design and building commitment to a common agenda among those participating in the longitudinal study. Participants explained how collaborative research design can help build trust and lasting relationships with communities. They also acknowledged the need to work with community experts and Knowledge Holders to collaboratively identify priorities and develop research frameworks, approaches, methods and tools. Flexible research designs were deemed important to enable research to be responsive to changing community priorities.

Regional engagement participants emphasized the importance of working with communities to determine what questions to ask and how to ask them. This should involve collaborating with multiple community members and may even involve working directly with children themselves.

There was a general interest in integrating Indigenous methodologies into a longitudinal study, as well as support for the use of a mixed-methods approach involving both qualitative and quantitative data. More specifically, numerous study participants supported the idea of a study that includes data on structural factors and inequities, as well as qualitative, contextualized data and quantitative, measurable data.

Regional engagement participants also suggested that an important step could be to first examine existing data from multiple sources, allowing new research to complement, rather than replicate, existing efforts. Some study participants suggested using a repeated cross-sectional approach as a potential alternative to a longitudinal study, allowing for long-term trend analysis with less risk of attrition. Others saw more use for data from a longitudinal study design that tracked individual changes in well-being, especially if these changes could be linked to participation in programs and interventions.

Gathering data on the effectiveness of various interventions was also discussed. However, study participants made it clear that effectiveness should be defined in culturally relevant ways, not through Western metrics. For example, some participants in regional engagements suggested defining effectiveness in terms of ensuring both that parents are supported and that the rights of First Nations children are honoured. It was noted by both subject-matter experts and regional engagement participants that few studies link outcomes to the presence or absence of specific community-based interventions, especially those developed by First Nations. Study participants would like to see data about the effectiveness of interventions on children's health and well-being, particularly those developed by First Nations themselves.

A final topic of discussion related to research design concerned the sampling and recruitment for a longitudinal study of child and youth well-being. Some participants expressed that the study would be most beneficial if it included First Nations children and youth living on and off reserve. Specifically, it was noted in some regional engagement sessions that many young people move off reserve or attend school off reserve and that failing to include these young people could leave important gaps in the research. In general, study participants suggested that design issues like this should be discussed and decided in collaboration with First Nations communities to ensure that the data collected from the study is relevant to their needs and priorities.

FUNDING (SECURED FUNDING) AND CAPACITY NEEDS

When asked about the supports or resources needed for a longitudinal study focused on child and youth development and well-being, regional engagement participants identified that such a study would require long-term, dedicated resources and staffing. Specifically, the need for long-term and secure funding was expressed throughout all sessions. It was acknowledged that considerably more resources would be required for a longitudinal study than those available for the RHS. A longitudinal study would require a significant time commitment from researchers, community leadership and participants.

Regional engagement participants acknowledged that, generally, communities have limited capacity and would need substantial financial and human resources for a longitudinal study to be successful. Several participants expressed concern about the existing community capacity to undertake this work, suggesting that First Nations communities and organizations would require dedicated resources for research to be effective and successful.

Additional concern was expressed about ensuring the current staff would not be burdened with additional responsibilities. Regional engagement participants indicated the need for additional analysts and coordinators, more resources and time for community engagement, and more staff generally.

Using existing regional organizations and training new community-based researchers to lead the project could help to address some capacity issues.

Linked to capacity concerns was the anticipated turnover. Regional engagement participants indicated that the study should anticipate high staff turnover and leadership changes, and work on ways to maintain relationships during such transitions.

FNIGC'S EXPERIENCE

Longitudinal Surveys: RHS 1 Lessons Learned

From the beginning, FNIGC had intended for the RHS to be a longitudinal survey. Following the First Nations and Inuit Regional Longitudinal Health Survey in 1997 (now known as the RHS pilot), FNIGC planned to conduct subsequent longitudinal surveys. The following wave of this survey was originally planned to follow the same individuals who completed the pilot. This plan was abandoned due to inadequate sample size in some regions for statistically healthy cohorts, lack of continuity in survey instruments, inadequate

or missing documentation of personal information in some regions, and insufficient consent. There was also the addition of new regions to the national sample — Yukon and Northwest Territories — to consider, and Inuit withdrew from the RHS process.

For these reasons, the next wave of the survey, now known as the Regional Health Survey (RHS) Phase 1 (2002/03), employed a cross-sectional research design. After the RHS Phase 1 collection was complete, a peer review of lessons learned was completed to assess the possibility of conducting future phases using a longitudinal approach. Some of the same issues with a longitudinal approach moving forward were identified, most importantly inadequate sample size for statistically healthy cohorts in certain regions. The original 2002/03 sample estimated to pursue a longitudinal sample was higher than the final sample achieved.

Another noted constraint was that, at the time, there were limited options for combining a longitudinal sampling design (to examine change in individuals over time) with a cross-sectional design (to describe the attributes of populations). Longitudinal samples become increasingly unrepresentative of the population over time, making them unusable as cross-sectional samples. This is a major reason why the Canadian Community Health Survey replaced the National Population Health Survey for describing the health of the non-Aboriginal Canadian population. For this reason, FNIGC determined that separate samples would be necessary to meet the requirements for both longitudinal and cross-sectional information.

During FNIGC's review process, the pros and cons of each method were considered and weighed along with a proposed combined method. Given cost and time constraints as well as considerations about the utility of the data, a cross-sectional approach was recommended. It was also noted that longitudinal designs are useful for describing changes among individuals within a cohort over time, not trends in populations. Therefore, the content of surveys for longitudinal and cross-sectional information will differ in many respects.

FNIGC revisited the issue in 2007 in preparation for the RHS Phase 2 (2008/10). This phase attempted to employ both cross-sectional and longitudinal design elements. However, its execution was challenging, yielding largely unsuccessful longitudinal results. Notably, insufficient consent to be contacted again for a subsequent wave, as well as a lack of contact information, limited the ability to follow up with participants. Moreover, funding constraints impacted the sample achieved, which in turn impacted the viability of the longitudinal component. Finally, attrition, administrative challenges associated with tracking and the general cost of conducting the longitudinal study were also noted as problematic. Given the above, FNIGC decided to discontinue the longitudinal design element, moving forward with only the cross-sectional approach for RHS Phase 3 and all subsequent waves of the RHS.

The goal of the RHS is to collect credible and timely data that could subsequently be utilized to present an accurate snapshot of the holistic well-being of First Nations people across Canada. A subsidiary goal was to compare trends at the national and regional levels between cycles, providing an evaluation of changes in health status at the level of the First Nations population. In its current state, as a cross-sectional survey, the RHS effectively fulfills the above goals.

FNIGC's Decision-Making Process

Research design and survey content

Any decisions on content and research design for FNIGC surveys must go through FNIGC's regional engagement process. For example, decisions regarding the inclusion or exclusion of content are based on collective feedback from all regional advisory committees and the communication of regional priorities. All regional priorities and feedback are weighed before decisions are collectively made by the group. These are the means by which FNIGC receives direction on how to proceed with national survey initiatives. FNIGC can suggest the addition of survey content and propose research directions for consideration, but all final decisions will be made collaboratively with regional partners.

Survey fatigue

FNIGC and its network of regional partners are committed to two existing national survey programs, the First Nations Regional Health Survey (RHS) and the First Nations Regional Social Survey (RSS). The two survey programs run concurrently, typically with one in the questionnaire design phase while the other is in the data collection phase.

Given that national data collection occurs every two to three years and typically spans 18 months on average in the field for each collection period, the introduction of an additional resource-intensive survey would present a significant burden on regional and community capacity to conduct survey work.

Recognizing this, FNIGC emphasized the importance of working closely with regional partners and federal funders to identify viable approaches should there be support for an additional proposed study. Notwithstanding these additional burdens, there remain opportunities to leverage existing survey infrastructure to accommodate a longitudinal study, which are discussed more fully in the following section.

Remaining unanswered questions

An examination of various study design possibilities is discussed below. There are still many unanswered questions regarding process, timelines, recruitment and retention strategies, and the frequency of follow up for each method discussed. Furthermore, the tools that need to be developed will be created through FNIGC's collaborative decision-making process with regional partner organizations. There is also the question of the study population of interest and whether it is desired that the sample be representative of the entire population of interest.

CONCLUSIONS

This study explored the feasibility of conducting a longitudinal study of First Nations child and youth development and well-being with First Nations communities across Canada. Moving forward, an efficient approach would be to work collaboratively with First Nations community partners in each region from the outset of the research process. This will ensure cultural safety and that the research is conducted respectfully and collaboratively, ultimately benefiting First Nations.

Developing a longitudinal study of First Nations child and youth development and well-being will not be an easy task. Next steps include presenting the study's findings to regional partner organizations and then refining the research objectives and questions. While this study provides considerable detail regarding community and regional preferences concerning research on child and youth development and well-being in First Nations communities, much work remains to narrow down the options, select an approach and develop a study.

With the considerations and recommendations detailed in this study in hand, future studies should be well-positioned to continue developing a collaborative longitudinal study focused on child and youth development and well-being in First Nations communities.

RESEARCH RECOMMENDATIONS

This study found that there is considerable interest in a longitudinal study of the development and well-being of First Nations children and youth. However, study participants also shared several concerns about becoming involved in a longitudinal study and whether the data collected would be worth the resources required. This section presents several key recommendations that should be considered for moving forward with the planning, development and engagement for a longitudinal study of First Nations children and youth in a good way.

These recommendations consolidate the overarching themes identified through regional engagement sessions and interviews with subject-matter experts. They should be viewed as best practice recommendations for conducting relevant, culturally safe research with First Nations about child and youth development and well-being.

Employing a Longitudinal Research Design

1. Planning for a longitudinal study should have strategies in place to address participant attrition
    - Planned cohort size should be tied to the goals of the study, interest in representativeness and needs for statistically significant results.
    - Planning should support relationship building with communities, participants and families to reduce attrition.
    - A dissemination plan should be developed so that participants can see clear benefits from their participation.
    - Consideration should be given to strategies that could account for frequent migration both on and off reserve.

2. Commit to core funding for a long-term project
    - Planning for a longitudinal study and building relationships based on respect with participating communities involves significant and long-term funding commitments.
    - Core funding is important for community support and capacity building within participating communities.
    - Core funding allows the research team to manage study challenges that could strain relationships.
    - Core funding supports a dedicated team of staff for the project, which enhances validity and the research process.
    - Core funding can support alignments with Indigenous perspectives on research methodologies, which emphasize the processes of respect, relevance, reciprocity and responsibility.
    - Planning should account for potential interruptions of the study and incorporate resources needed to successfully manage interruptions.

3. Consideration should be given to whether the sampling frame includes only First Nations people living on reserve and in Northern communities, or if it includes the off-reserve population
    - The current mandate of the FNIGC survey program is to serve First Nations people living on reserve and in northern communities.
    - Regional engagement pointed to the importance of involving the off-reserve population.
    - Considerations about the sampling frame should account for frequent patterns of migration in First Nations populations, both on and off reserve.

4. Consideration should be given for the current commitments of First Nations communities and First Nations regional organizations for surveys and research
    - Consideration should be given for how this study aligns with current work First Nations are committed to.
    - A number of regional engagement participants discussed feelings of survey fatigue and exhaustion by the number of other research projects that were present in First Nations communities.
    - Project planning should involve engagements with study partners about how commitments to other projects and data collection that is already underway could be leveraged to support this project.

Collaboration and Reciprocity

5. First Nations leadership, community organizations, Elders, Knowledge Holders, frontline workers and other community members should be at the table early on to provide input into project development and design
    - These strategies could help ensure the project is led by First Nations, which could support the project's success.
    - Multiple and diverse voices at the table can support the utilization of appropriate cultural frameworks so that data is meaningful and relevant for First Nations people.
    - First Nations community members should be involved in all decision-making including the development of research instruments and surveys.

6. Governance and decision-making about the project should be aligned with processes, procedures and practices developed and endorsed by First Nations regional organizations
    - Decision-making processes should build off collaborative work from FNIGC and regional partner organizations on data sovereignty and information governance.

7. Invest in relationship building within the communities where participants live to be transparent and build project relevance
    - Successful projects have invested heavily in relationship building and capacity development within participating communities.
    - Seek out opportunities to partner with local community organizations, service providers and early learning programs for participant recruitment and participation on advisory boards.
    - Involve community members in data collection processes and provide opportunities for research training.
    - Target knowledge translation initiatives to local community concerns so participants see the relevance of the data they provide.

8. Retain the same data collectors or field supervisors throughout the project to build relationships and trust
    - In many successful studies, strong relationships between the data collectors and the participating families played an important role in keeping families involved.
    - Staff retention reduces project interruptions, loss of corporate memory and expenses of training new staff.

9. Build representative community steering committees and/or advisory boards to provide input to the research process
    - Organized advisory boards and steering committees were an important part of project success and community support for many of the studies reviewed.
    - These organizations should advise on the development of locally relevant questions, the development and use of measurement instruments as well as storage and access to the data.

10. Specific and dedicated investments should be made in knowledge translation, dissemination and capacity building
    - Regional engagements highlighted a clear need for more knowledge translation and knowledge exchange so the research can be beneficial and useful for communities.
    - Training and capacity building within communities is essential for community support and project success.

11. Need for continued engagement
    - Support is needed for continued engagement with First Nations communities and regional organizations to build commitment to a shared vision for the project and/or shared priorities for overarching research questions.

Research Design, Research Methods and the Development of Research Instruments

12. Employ flexible data collection instruments, developed in collaboration with First Nations communities
    - Design instruments to address individual-level factors as well as structural and systemic factors in the surrounding context.
    - Consider the use of multiple informants to gather data about different aspects of children's lives and experiences.
    - Consider the potential of changing and modifying data collection instruments to address emerging priorities over the course of the study.
    - Consider ways and costs of maintaining research instruments across study waves to ensure comparability and validity of findings.

13. Project goals, research questions and the design of research instruments should be based in, or founded on, First Nations worldviews, epistemologies and cultural frameworks
    - Develop instruments relevant to diverse First Nations perspectives, as opposed to a pan-Indigenous approach.
    - Indicators should draw on First Nations conceptions of health, development, family and well-being to ensure the results capture and appropriately reflect First Nations perspectives and realities.
    - A solid foundation in terms of core research questions to guide the project could enhance support from diverse First Nations.
    - Data should be relevant to assessing structural and systemic inequalities for First Nations children.

14. Data should be collected to present a balanced and culturally relevant picture of the lives, experiences and environments of First Nations children and youth
    - It is important to avoid a deficit-based approach but also to tell the "whole story" about First Nations children's lives.
    - Data on protective factors and community strengths, according to First Nations worldviews, is important for developing culturally relevant portraits and for moving past a deficit-based approach.

15. Research design should be targeted to provide evidence relevant to the influence of First Nations-led programs and services on First Nations children's development and well-being
    - Key research priorities noted the influences of, and effects of, First Nations developed programs and services.
        - There are many programs and services running in communities but little data on the ways these programs and services influence First Nations children's lives.
            - Study design should consider the potential of data linkages to tie results with ongoing community programs.

Research Ethics and OCAP®

16. Research processes, data collection, data storage and data access guidelines should be developed in line with OCAP® principles as they are interpreted by participating First Nations
    - Interpretations of OCAP® can differ between First Nations; therefore, the project should involve appropriate consultations and decision-making processes in order to respect these differences in perceptions and interpretations.
    - Investments should be made in developing data sharing agreements with participating First Nations.
    - Data sharing agreements ensure data is accessible to First Nations leadership and community members so that it can be utilized to address community concerns.

17. Appropriate supports should be in place for data collection from children and about adverse childhood experiences
    - Subject-matter experts and regional engagement participants discussed the importance of "putting children first" in the design of data collection techniques (e.g., consent processes, supportive adult available).
    - Provision of supports and aftercare for participants is essential for research on "adverse" or "traumatic" experiences in childhood.
    - Careful consideration should be given to the use of "strengths-based" wording and questions on research instruments to avoid re-traumatization.
    - Consideration should be given to ways of collecting data and information about adverse experiences in childhood without directly questioning children and caregivers.

STUDY DESIGN OPTIONS

Below, several options are presented that could be feasible if a longitudinal study of the development and well-being of First Nations children and youth proceeds. These options are not presented as recommendations, and this report does not present a position about which of these options should be pursued. Support for each of these options can be found in the literature review, subject-matter expert interviews, and regional engagement sessions.

More work is needed to engage First Nations communities about these different options, determining which, if any, may be supported, and to compare the benefits and drawbacks of each option in relation to their specific data needs. These kinds of engagement processes are essential for developing community support for the overall project. Engagement processes and decision-making on study design should follow FNIGC's regionally based governance and decision-making processes.

A Distinct Longitudinal Cohort Study

The data from a longitudinal design deals with changes that occur to individuals, requiring continuous or repeated measures of the same people over a period of time. In a longitudinal cohort design, a group (or cohort) of individuals is sampled (could be a single or multiple cohort study). The sample can be designed to be representative of a population or to describe the experiences of a particular group with common characteristics. If a longitudinal cohort design is employed, one option could be to attain a large sample representative of the First Nations population in Canada. This approach could provide strong evidence of

changes in the development and well-being of First Nations children over time. However, following a large and representative cohort of First Nations children will be challenging and costly. Indeed, subject-matter experts interviewed in this study described extensive growth in the resources required for research instrument development, data processing, participant tracking and data analysis throughout the eight waves of data collection for the National Longitudinal Study of Children and Youth in Canada. It is also important to note that the more waves a longitudinal study design intends to have, the greater the chance for attrition over time. This presents challenges for analysis when comparing earlier waves to later waves of the study, as well as in maintaining representativeness across multiple waves. Additional considerations would involve negotiations and decision-making about whether representativeness is important at the national and/or regional levels, as well as whether sampling should include the off-reserve population. Each of these considerations will present different challenges in terms of capacity and resourcing.

Another option to pursue in terms of a distinct longitudinal cohort study could be to focus on collecting detailed descriptive data about the life experiences of the particular cohort being followed. This potential option would replace recruiting focused on a large and representative sample from First Nations in Canada. In this approach, the data could not be generalizable to First Nations as a whole but would instead be focused on describing the life experiences of the individuals in the cohort. This study design would focus on describing individual-level change, exploring individual developmental trajectories and could perhaps provide evidence relevant to understanding the influence of interventions.

A similar approach was taken in some of the longitudinal studies explored in the literature review. For example, the Footprints in Time study (Thurber et al., 2015) of Indigenous children in Australia has focused less on representativeness and more on building detailed pictures of the life experiences of Indigenous Peoples living in a number of different geographical regions in Australia. Through strong relationship building with participating families and communities, this research project has maintained a relatively low attrition rate.

Attrition will be a concern in any form of longitudinal cohort study. The *Literature Review for The Feasibility Study on Longitudinal Research with First Nations Children* pointed to several strategies that can be implemented to ensure sufficient retention of participants over many waves of a study. To limit sample attrition and attempt to encourage subsequent participation in later waves, strong relationships will need to be built with participants and their families. When there is trust and interest in the purpose of the research, participants are more motivated to participate in these types of studies. Knowledge translation was also an important factor in many of the successful longitudinal studies examined in the literature review. Time and resource dedication to these activities will be necessary to curb sample attrition should a longitudinal cohort design be pursued.

Building a Longitudinal Cohort Out of a Cross-Sectional Sample

Other FNIGC survey programs, inclusive of capacities and relationships, should be considered as potential vehicles for a longitudinal study. Established cross-sectional survey networks and processes could potentially be leveraged to attain a longitudinal cohort. This would involve partitioning the sample frame of a planned survey program into a cross-sectional survey with a longitudinal cohort as a sub-sample. This

could enable representative cross-sectional estimates, while retaining longitudinal capacity for a cohort of children and youth (age groups to be determined). This approach could also accommodate the differences in survey content required for longitudinal and cross-sectional surveys by adding a different subset, or module, of questions to the "core" survey questions for the longitudinal cohort. A tracking system would need to be established for the longitudinal cohort, allowing for migration follow up, and would require budgeting for additional costs.

In addition, leveraging existing cross-sectional vehicles could potentially avoid overburdening First Nations communities with another national survey initiative. There are concerns about how to determine the most appropriate sampling and weighting in combined longitudinal and cross-sectional samples. Further, the degree to which the initial longitudinal sub-sample could be representative will need to be explored, and engagement with regional partner organizations will guide this decision.

Another advantage of this option is that it provides space for scaling up a longitudinal cohort to reach greater levels of representativeness, while building on existing relationships and capacity in First Nations communities. Cohorts could begin with interested regions and be built upon over subsequent waves to be more inclusive and representative of diverse First Nations. This could also enable FNIGC to collaborate with regional partners to assess the resources and capacities necessary to successfully implement a longitudinal component across multiple waves.

Regional engagements and subject-matter interviews both highlighted significant challenges for longitudinal studies, including cost, required human resources, retaining project staff, data management and processing, revision of measurement instruments, and tracking participants over multiple data collection waves, among others. Participants noted that these considerations are important for building respectful and beneficial relationships with participating First Nations communities. Starting small could provide time and space for learning these kinds of lessons, which could support decision-making about a larger study across First Nations communities by providing evidence of successful research processes and procedures.

The literature review uncovered examples of longitudinal cohorts that achieved some level of representativeness and generalizability with relatively smaller or geographically focused samples. For example, the GUiNZ study has been collecting data from two cohorts (of differing ages) in a specific geographical region of New Zealand, where there is significant diversity among ethnic groups (Morton et al., 2013). This region was carefully chosen to be representative of the diversity present within the New Zealand population, and minority communities (Māori, Pacific Islander, Asian heritage) were oversampled within the sampling frame to allow for statistical comparisons. The success of this approach has been tied to extensive investments in relationship building with different cultural communities and organizations in the target region, which has led to high levels of motivation within the cohort.

A Small-Scale, Regional-Focused Cohort Study with a Region Expressing Interest

A nationally representative cohort study may be deemed too challenging and not fully supported by First Nations communities. Another option is a smaller regional cohort study of the development and well-being of First Nations children living within that region. This option would be less resource intensive

but would have drawbacks in terms of representativeness and generalizability. Key to the success of this option would be supporting appropriate levels of engagement and consultation with FNIGC's partner organizations to determine, together, where a small-scale, regionally focused cohort study could be conducted.

This option could address a number of the data gaps and research priorities described during regional engagement sessions and subject-matter expert interviews. For example, focusing resources on building long-term relationships with a particular region could support significant progress in capacity building within the participating region as well as community-led design of research instruments. A common theme emerged from both regional engagement sessions and subject-matter expert interviews regarding the need for culturally relevant data on child and youth development and well-being to better understand the experiences of children and families within distinct First Nations communities. In addition, there were strong calls for data about the influence of First Nations-led services and programs for children and youth, which differ among First Nations communities. A regionally focused study could support holistic and contextually relevant interpretations of the lives of children and youth within distinct First Nations communities. Success with one region could then provide transferable lessons to support capacity building in other regions. Regions may be able to build their own cohort study to provide comparative data relevant to their distinct cultural frameworks and worldviews, as well as their unique histories with different programs and services.

The literature review provided some examples supporting the effectiveness of locally scaled community-driven research about children's well-being within First Nations communities. For example, the Aanish-Naa Gegii (ACHWM) project was developed collaboratively with one First Nations community and has been successfully adapted for use by other First Nations and Indigenous communities in Canada to meet their specific data needs. Key lessons from this project have involved community-driven decision-making, research design and research processes, while integrating OCAP® principles (Young et al., 2013). Culturally relevant conceptions of child well-being were built into the measurement instrument using qualitative techniques that included children's voices. Results are shared in ways that resonate with First Nations worldviews in the form of medicine wheel teachings. Investing in this kind of meaningful relationship building at the community level could support long-standing calls to make data relevant and beneficial to First Nations communities themselves.

A Retrospective Adverse Childhood Experience (ACE) Study

The original ACE study was a retrospective study where adults reported on the extent to which they experienced different kinds of adverse experiences in their childhood. In this ACE study, the degree of exposure to adverse childhood experiences from these retrospective reports was found to be associated with a number of self-report measures of participants' current health status. This ACE study has provided strong evidence linking adverse early experiences with health and well-being in adulthood among adults living in the United States, but as the data is correlational and based on self-reports of experiences in the past, there are many limitations to the inferences that can be made.

Participants in this study expressed interest in learning more about adverse experiences occurring in the lives of First Nations children. However, there was much caution expressed about an ACE-based study and

the ways it could perpetuate a deficit-based understanding of First Nations children's development and well-being. Importantly, since the data from a retrospective study concern past experiences, it would have little relevance to identified data gaps and research priorities regarding the influence of First Nations-led interventions, programs and services, as well as the structural and systemic factors that pose challenges for First Nations children growing up today.

The engagement sessions, subject-matter expert interviews, and literature review provided little evidence that First Nations would support a new, separate, retrospective ACE-focused study designed to be nationally representative of the First Nations population. This would not address reported data gaps and research priorities as effectively as a prospective longitudinal study or the current surveys conducted by FNIGC. However, there was support for learning more about the kinds of challenges that First Nations children experience, particularly in terms of how these challenges are related to structural and systemic factors.

Instead of developing a stand-alone ACE study, there are possibilities for collecting similar data through FNIGC's current surveys in First Nations communities and/or the development of a prospective longitudinal study. One option could be to invest in further engagements with First Nations communities about the potential of including questions related to ACEs within future iterations of the RHS. Another possibility, if a longitudinal study is fully supported by First Nations, could involve finding ways of gathering data through surveys and other measurement instruments that assess adversities within children's environments. For example, this could include speaking with caregivers and/or other informants about challenges in parenting, issues related to food security and access to services, as well as other environmental conditions.

Some of the longitudinal studies reviewed employed similar procedures to investigate the impact of ACEs on children's developmental trajectories. For example, members of the GUiNZ study team developed proxy measures of ACEs experienced by children from questions about mental health, substance use and parenting that were asked on self-report questionnaires completed by study children's parents and caregivers (Walsh et al., 2019a). In addition to exploring the prevalence and influence of ACEs, GUiNZ researchers explored the role of a variety of protective factors in children's lives and how these factors contributed to the likelihood that "high risk" children would "beat the odds" (Walsh et al., 2019b). For either of these approaches to integrate ACE data, much more work is needed to engage with First Nations communities and leadership fully and to find ways of collecting data on these topics in culturally sensitive ways. All decisions regarding modifications to current survey programs must proceed through accepted procedures and decision-making processes employed by FNIGC and regional partner organizations.

Other Considerations

Phased approach beginning with qualitative focus groups

A clear recommendation from regional engagement and subject-matter experts was that the design of research instruments should be driven by First Nations communities, ensuring that indicators and measures are relevant to First Nations worldviews. A first step in finalizing a study design could be to start with qualitative focus groups (or sharing circles) with interested First Nations communities to build culturally relevant understandings of child development and well-being, which could guide the development of surveys and research instruments. Study participants pointed to a common criticism that dominant

Western models of child development do not fully reflect the conceptualizations of childhood, family, community and child well-being among diverse First Nations. It was evident that more work needs to be done to understand local conceptualizations of childhood before embarking on a large-scale longitudinal study. This is important in making the data useful and relevant for First Nations communities. Qualitative data from interested Nations, communities or regions could provide a solid bedrock for moving towards a longitudinal cohort study.

Data linkage

Engagement sessions with regions also referred to the data collection burden felt by First Nations communities. It was suggested that a scan of data available and accessible to First Nations communities be completed to better utilize existing datasets. Several examples of research projects utilizing datasets from the reviewed longitudinal studies also incorporated data linkages. It is important to point out that there are many limitations to the kinds of data that are collected or may be available in other datasets (e.g., self-report biases (memory, self-presentation), lack of relevant and strengths-based data for First Nations communities, lack of Indigenous identifiers). Additionally, it may be challenging to utilize this data to track the impact of interventions, which was identified as an important research priority by participants in the engagement session. However, working collaboratively with interested First Nations to better integrate linkages to existing data about First Nations children and youth could help support the success of a potential longitudinal study and its relevance to community priorities.

Inclusion of First Nations people living off reserve

Several study participants expressed interest in exploring ways to include the off-reserve First Nations population in a potential longitudinal study on the development and well-being of First Nations children and youth. For example, study participants noted that in many regions, a significant portion of the First Nations population resides off reserve; failing to include these individuals could result in a substantial data gap. Other participants discussed how many children and youth in First Nations communities leave the community to pursue education and employment, and they noted that methods and procedures would be needed to track these individuals so they could continue to participate in the study. Although clear interest was expressed in the idea of including the off-reserve population, several factors would need to be considered. Currently, FNIGC's survey program is designed to serve First Nations people living on reserve and in northern communities. Any decisions on expanding FNIGC's current survey mandate to include First Nations people living off reserve should be considered an exploratory effort and would require considerable coordination and resources at the regional level to ensure coverage and robust mechanisms for outreach and tracking.

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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/

APPENDIX B

METHODS

Approach

This feasibility study involved two key engagement processes: regional engagement sessions and key informant interviews with Knowledge Holders and subject-matter experts (SMEs) across Canada who were recognized for their expertise in First Nations culture, history, social determinants of health, and community well-being.

The approach undertaken for each of these engagement processes is described below, along with information about how the analysis was conducted following their completion. These engagements were conducted with support from Firelight Research Inc., an Indigenous-owned consulting firm (see *Appendix F*).

Regional engagement sessions

FNIGC arranged regional engagement sessions with support from Firelight and five participating regional partner organizations in New Brunswick, Nova Scotia, Quebec, Yukon, and British Columbia.

To ensure the engagement sessions were regionally driven, each participating regional partner organization:

- Engaged with FNIGC and Firelight to coordinate, plan, and implement their engagement sessions;
- Provided input on the engagement materials (e.g., participant agenda, facilitator's agenda, supporting visuals) and facilitation approach;
- Invited knowledgeable individuals to participate in their session, based on their understanding of their own regional context and who/what organizations to include;
- Supported facilitation during their session; and
- Reviewed and provided feedback on the summary reports that were produced following each session.

A total of four sessions were conducted with the five regional partner organizations between February 2020 and December 2020. The first engagement session was an in-person, all-day event in New Brunswick, co-hosted by the Union of New Brunswick Indians (UNBI) and the Union of Nova Scotia Mi'kmaq (UNSM). The subsequent engagements were conducted remotely using video conferencing technology due to the onset of the COVID-19 pandemic. The remote sessions were approximately two hours in length and were conducted with the First Nations Health Authority in British Columbia, the First Nations of Quebec and Labrador Health and Social Services Commission and with the Council of Yukon First Nations.

To structure each regional session, Firelight worked with FNIGC and the partner organizations to develop a detailed facilitator's agenda that included open-ended questions and opportunities for discussion. The questions that became the focus of each session are as follows:

1. What would you hope to learn from a longitudinal study focused on child and youth development and well-being in your region? What are the potential risks and benefits?

2. What kinds of strengths related to children, youth and their families, communities and relationships would be important to include in a longitudinal study in your region? What are some indicators or measures of these strengths?
3. What different kinds of childhood experiences should we be exploring to learn about child development and well-being in your region? What challenges or sensitivities may be involved in researching childhood experiences? How can these be mitigated?
4. Who should be involved, and when/how, to ensure this research is collaborative and community driven?
5. What support or resources would your region need from FNIGC to contribute to this research in the short term and the long term?

Participants received a project information sheet (Appendix D) in advance of each session. They provided their written and oral consent (Appendix C) for Firelight staff to take notes during the sessions and to audio record the remote sessions. Audio recordings taken during the remote sessions were relied upon as a backup for handwritten notes and were not transcribed. This report does not include direct quotes from participants in regional engagement sessions.

Subject-matter expert interviews

In addition to regional engagement sessions, FNIGC and Firelight staff conducted interviews with select subject-matter experts (SMEs) who live and work across Canada. A list of SMEs was compiled based on recommendations from FNIGC, participating regional partners and other First Nations organizations. Interview participation was requested by email and conducted over the telephone.

Subject-matter experts included professors, academics, researchers, and members of organizations, research bodies, and councils, either directly or indirectly involved in Indigenous and First Nations-specific child and youth development and well-being research. Interviews were supported by interview guides collaboratively developed by Firelight and FNIGC (See Appendix E for an example). Each of the interview guides was developed specifically for the SME's experiences and expertise; however, they all followed the same general themes. The SMEs provided verbal consent to have their words recorded via audio recording and notes, and to have their words and responses transcribed.

Analysis

Information collected through regional engagement sessions and SME interviews was systematically analyzed through a thematic coding process organized around the objectives identified in Section 1.1. The information was verified by participants in the analysis phase. Following each session, a "What We Heard" report summarizing the viewpoints shared during the session was circulated to all participants, who were given the opportunity to make changes, clarifications, or additions as needed. The summary reports, notes and transcripts from SME interviews were relied upon to write this report.

Limitations

Several limitations constrained this study. First, a cross section of regional SMEs was identified for both the interviews and regional engagement sessions. It is, therefore, important to keep in mind that the recommendations and preferences detailed in this study represent only a snapshot of First Nations' perspectives on this topic and are not fully representative. However, this study was always designed to be a preliminary step in scoping a national study, and FNIGC recognizes that additional engagement with First Nations will be required if this project progresses.

This study was approached broadly and openly, which encouraged respectful and collaborative conversations. It should be noted, however, that since participants were not asked to respond to a particular research design (or a specific type of longitudinal study), the conversations were, by necessity, less focused and specific, and it was difficult to identify concrete preferences or options with respect to different methodological approaches. This report, therefore, presents participants' perspectives on the different considerations, challenges and benefits of adopting a range of different approaches to longitudinal research. The study does not recommend a specific approach or research design; instead, it presents several options for consideration.

Finally, the onset of the COVID-19 pandemic, which occurred halfway through the study, presented unique challenges. Primarily, restrictions on travel and in-person contact shifted the method of regional engagement from in-person focus group sessions to online sessions utilizing videoconferencing technology. This shift in the engagement method also meant that the engagement sessions were shortened from full-day events to two to three hours in length. To accommodate this change, facilitators emphasized the need to provide more structure to the sessions while still allowing for open discussion. Overall, the quality of the sessions was not affected, but fewer people were able to participate.

APPENDIX C

CONSENT PROCEDURES (WRITTEN CONSENT FOR ONLINE ENGAGEMENT SESSION)

Engagement Session:

Feasibility of a Longitudinal Study of First Nations Child Development and Well-Being

Declaration of Informed Consent and Permission to Use Information

I (name), on (date), consent to participate in a key informant focus group regarding the Study entitled "Feasibility of a Longitudinal Study of First Nations Child Development and Well-being."

I understand that this project is being conducted by the First Nations Information Governance Centre (FNIGC), with the support of Firelight Research Inc. The purpose of this engagement session is to explore the feasibility of, and opportunities for, conducting a First Nations-driven longitudinal survey on child and youth health and well-being. As well as, assess the relevance and priority for First Nations to conduct, or participate in adverse childhood experience research.

Participants will have the opportunity to review the summary of information from the focus group in order to make additions or clarifications to collected information.

By signing below, I indicate my understanding that:

a) I consent to have my words and responses recorded via notes and through MS Teams videoconference.

b) I am free to NOT respond to questions that may be asked, and I am free to leave the session at any time.

c) I will have the opportunity to review the summary of information collected following this interview in order to make additions or clarifications to the information I provided.

d) I grant FNIGC the right to use any intellectual property that I choose to share as a participant in the Study, for purposes specific to the Study and not beyond that. FNIGC will ask for my consent for any additional use beyond those purposes.

e) I consent to have my name included in the report in a list of key informants and session participants. Words and responses will not be attributed to specific individuals.

For more information, please contact (name and contact details)

Signature of participant

_____

APPENDIX D

INFORMATION SHEET

Feasibility Analysis of a Longitudinal Study of First Nations Children and Youth

FNIGC is undertaking a feasibility study to determine the key issues, relevance, and interest of First Nations to conduct or participate in a longitudinal study focused on child and youth development and well-being in their communities.

The objectives of the feasibility study include the following:

- Explore the feasibility of conducting a First Nations-driven longitudinal study focusing on First Nations children and youth development and well-being;
- Identify the benefits and challenges of a longitudinal study focused on First Nations' child and youth development and well-being;
- Identify effective, culturally appropriate study designs and methods of measuring and assessing child and youth development and well-being;
- Assess the feasibility and appropriateness of assessing adverse childhood experiences;
- Assess the options for a research process; and
- Determine considerations for recruitment capability and sample characteristics, data collection methods, outcome measures, and available resources, in addition to other aspects related to the research process and community needs.

Engagement

A critical phase of the feasibility study involves meaningful engagement within each region with individuals and organizations who are recognized for their knowledge of First Nations culture, history, social determinants of health, and community well-being to gather their perspectives and experiences relating to First Nations child and youth development and well-being research. This includes reaching out to leaders, Knowledge Holders (including youth and Elders), and other subject-matter experts.

The Firelight Group, with support from FNIGC, will facilitate a regionally driven online engagement session using a videoconferencing platform called MS Teams, for a duration of 2-hours.

Microsoft Teams Meeting is a free application which allows multiple users to videoconference together. A "Join Microsoft Teams Meeting" link will be sent out prior to the scheduled meeting.

- Participants will receive a $300.00 honoraria in the form of a cheque.

Literature Review: In order to assess the existing knowledge and data gaps an initial literature review was completed that examined existing national and international longitudinal research projects and data collection efforts relevant to the health, development and well-being of First Nations and Indigenous children and youth, including adverse childhood experiences.

The literature review examined best practices and challenges, risks and benefits, effective methods, and culturally appropriate approaches for conducting longitudinal developmental and well-being research with First Nations children and youth.

A summary document of the literature review has been shared with the invitation in order to encourage engagement.

The Firelight Group: is an Indigenous-owned consulting group that works with Indigenous and local communities in Canada and beyond to provide high-quality research, policy, planning, mapping, negotiation, and advisory services. The Firelight Group focuses on culture, health, socioeconomics, ecology, and governance to support the rights and interests of Indigenous communities.

https://firelight.ca/

For more information, please contact:

FNIGC contact information inserted here

LONGITUDINAL STUDIES SUMMARY DOCUMENT FOR ENGAGEMENT: FIRST NATIONS CHILD AND YOUTH DEVELOPMENT AND WELL-BEING LONGITUDINAL STUDY

The following is a reference document to assist you throughout the session.

In this project, we are exploring the feasibility of using a longitudinal research design to help understand First Nation children's development and well-being.

What is a Longitudinal Study?

A **longitudinal** study follows and surveys the same group of people (a cohort) multiple times over a period of time (e.g., following one group of children and measuring their well-being each year over 10 to 20 years).

Longitudinal studies can be **retrospective** (looking back in time) or **prospective** (requiring the collection of new data).

What can we learn from longitudinal studies?

- They can help explain changes in health and well-being over time
- They can help identify the sequence of events in people's lives that influence their growth and development
- They can provide information about potential causes and effects
- They limit recall bias as individuals are not required to think back in time to remember an experience
- They can be flexible and allow for shifts in the focus of the research questions over time
- They help observe patterns, identify new trends, and analyze links between different factors
- They can provide evidence to help develop programs and policies

What are some challenges of longitudinal studies?

- Attrition rates, or participants dropping out of the study before it is completed
- Cost and resources
- Keeping in contact with participants
- Expectations about receiving results immediately
- Controlling for cohort effects (explanatory factors that are specific to the cohort of participants being followed)

Other relevant terms:

Cross-sectional study: Surveying people of different ages at the same point in time. Examples of cross-sectional surveys are the RHS, FNLED and REEES.

Strengths-Based Approaches

Strengths-based approaches focus on identifying and supporting the various strengths, motivations, ways of thinking and behaving, as well as the protective factors — within the person or the environment — that

support people in their journeys toward well-being. Strengths-based approaches to research have specific relevance to understanding and promoting health and well-being in Indigenous contexts.

In First Nations communities, strengths can include connections to the land, extended family connections, and resilience against colonialism. Strengths-based indicators show how strong and resilient First Nations communities are.

Research guided by a strengths-based approach can help bring forward strengths and create questions about the role of these strengths in health and well-being, instead of focusing only on weaknesses.

Adverse Childhood Experiences (ACEs)

This term is used to describe challenges people experience during childhood. The word "adverse" is used because these experiences may work against a person's well-being, and adverse experiences in childhood can create challenges in adulthood. Emotional, physical, or sexual abuse, violence between parents, or a parent suffering from addiction or mental health problems are examples of ACEs.

Large-scale research outside of First Nations communities has suggested that people who experienced more ACEs as children may have poorer health outcomes later in life. More recent research suggests that Indigenous children may experience particular kinds of ACEs more often than children from other communities. These experiences may include racial discrimination, historic trauma passed on from parents and grandparents, poor housing, lack of access to clean drinking water, and many more.

Information about ACEs can be gathered through both retrospective studies (asking people questions about previous events) and prospective studies (surveying and following the same participants over a period of time).

Examples of Longitudinal Studies

National Longitudinal Survey of Children and Youth (https://www12.statcan.gc.ca/census-recensement/2011/ref/92-135/surveys-enquetes/nationalchildren-nationaleenfants-eng.cfm)

- Conducted by Statistics Canada from 1994 to 2009 and included eight cycles of data collection
- Designed to collect information about factors influencing a child's social, emotional and behavioural development and to monitor the impact of these factors over time
- Surveys were conducted with parents/caregivers of children aged 0 to 17, and with youth themselves starting at age 14
- Did not include First Nations children living on reserve

Footprints in Time: A Longitudinal Study of Indigenous Children in Australia (https://www.dss.gov.au/long-term-research/footprints-time-longitudinal-study-indigenous-children)

- Following two cohorts of Indigenous children in Australia since 2008
- Data collection occurs through face-to-face interviews with multiple informants (parents, children, other caregivers), often in the family home
- Survey content covers a wide range of topics about children's health, learning, and development, as well as information about the participating child's family and community environment
- Choices in content and methodology are made through consultations with representatives of Indigenous communities in Australia

- Indigenous participants have noted many advantages to their participation, including: the chance to tell their story, benefits to the community, the chance to track their child's progress, valuing what the study stands for and trust and connection with surveyors, among others
- A recent study has linked a carer's emphasis on their child's participation in cultural activities with higher social and emotional well-being in their children at a later date (Dockery, 2020)

Growing Up in New Zealand (GUiNZ) (https://www.growingup.co.nz/)

- Following a cohort of children from before they were born until they reach 21 years of age
- Interviews are conducted with mothers, fathers, partners, and, starting at age two, with the children themselves, and they usually take place within the family's home
- 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
- Sampling has emphasized recruiting Māori, Asian heritage and Pacific Islander families to be representative of the diversity of the New Zealand population
- Māori-led research using GUiNZ data has reported significant growth in the interest and proficiency of te reo Māori within Māori families, and among non-Māori families (Simmonds et al., 2020), providing support for a variety of specific language revitalization efforts

Young Lives (https://www.younglives.org.uk/)

- A longitudinal study is currently running in four countries (Peru, Ethiopia, India and Vietnam) to explore the impact of child poverty
- Following 12,000 children from two cohorts to explore experiences at different ages of childhood
- The study has employed a multifaceted and mixed-method approach to collecting data to track children's developmental trajectories across the early life course, involving both quantitative and qualitative approaches
- Results from this study have provided evidence of the role of multiple and intersecting inequalities that influence the health and development of children and youth living in challenging circumstances in these countries
- Results have led to recommendations around issues like child nutrition, gender, marriage and parenthood as well as health and wellness that challenge prior thinking and policy (Boyden et al., 2019)

References:

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.* Policy Press.

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

Simmonds, H., Reese, E., Atatoa Carr, P., and Berry, S., & Kingi T.K. (2020). *He Ara Ki Ngā Rautaki e ora tonu ai Te Reo: Pathways to Retention and Revitalisation of Te Reo Māori.* www.msd.govt.nz/documents/about-msd-and-our-work/publications-resources/research/children-and-families-research-fund/he-ara-ki-nga-rautaki-e-ora-tonu-ai-te-reo-maori.pdf

APPENDIX E

STANDARD INTERVIEW GUIDE

Pre-Interview

Before formally beginning the interview, ensure the following steps have been completed.

1. Introductions:
    - Introduce yourself and the research team, who you work for, who you were hired by and who you report to.
2. Give the participant an overview of the project.
3. Explain the interview process and goals of the research. Read the following:
    - The purpose of this research is to support the First Nations Information Governance Centre in their ongoing work and research to determine the key issues, relevance, and interest of First Nations to conduct, or participate in, a longitudinal (or most effective research design) study concerning child and youth development and well-being. The results of this research will be shared with the federal government and will support FNIGC's recommendations about whether to proceed with a longitudinal survey, and if so, how.
        - From these interviews, we will be preparing engagement summaries and recommendations for FNIGC on the following topics:
            - ◊ First Nations' views on ways of examining child and youth development and well-being in their communities, including the influence of adverse childhood experiences and the social determinants of health;
            - ◊ National and international experience with longitudinal surveys, including benefits and challenges;
        - Effective and culturally appropriate study designs and methodologies in a First Nation context;
            - The feasibility and appropriateness of assessing ACEs for First Nations children, youth, or adults;
            - Methodologies for community-based research strategies that respect OCAP® principles; and
            - The capacity of First Nations to manage and implement the research agenda.
    - Provide an opportunity for the participant to ask questions.
    - Providing accurate answers to participants' questions is an important aspect of informed consent.
4. Review the consent form:
        - Read the consent form aloud to the participant.
        - Ask the participant if they have any questions.
    - Once the participant's questions have been answered, we will need to review the consent form

before beginning the interview. For obtaining verbal consent, ensure that the audio recorders are on, read through the consent form, and have the participant provide their verbal consent for the recording.

- If the participant does not provide recorded verbal consent, do not continue with the interview.

Introduction

[Read the text below with AUDIO RECORDERS ON at the start of each interview.]

Today is [date]. We are interviewing [participant name] for the FNIGC Child and Youth Development and Well-Being: Feasibility Study for a Longitudinal Study of First Nations Children and Youth. Thank you for your time today.

My name is [name] and my co-researcher(s) is/are [name]. [Participant name] has provided verbal consent, and we have explained the purpose of the study and interview plan.

Background and Experience

1. What is your current position (including position title, affiliations, etc.)?

2. Can you share a bit about your background as it relates to the subject matter, particularly in terms of your work on understanding and supporting early childhood development within First Nations families and communities?

Child and Youth Development and Well-being

1. Please share your thoughts on the importance of gathering new data and information concerning the development and well-being of First Nations children and youth within the context of their family and community environments.

- What data gaps do you see in the knowledge First Nations communities have available to them regarding child development and well-being?

2. We are interested in the work you have done that is focused on conceptualizing childhood as well as early childhood learning and care in ways that are based in First Nations worldviews and epistemologies. Could you tell us more about this work and about some of your key learnings?

- We are interested in exploring ways that a longitudinal research project could help us understand the strengths within First Nations communities in regard to child development and well-being, as opposed to past work that has focused on weaknesses and deficits. What are some of the important strengths and protective factors you have observed in your work with First Nations communities that are supportive of children's development and well-being?

Longitudinal Studies

1. This project began with a call for longitudinal data about the development and well-being of First Nations children and youth. What are your thoughts on the opportunities or advantages that data

gathered through a longitudinal study focused on First Nations children and youth development could offer?

2. What do you think may be some of the challenges involved in conducting a longitudinal study focused on First Nations children and youth development?
3. How can we be sure that a longitudinal study of child development and well-being provides data relevant to addressing the social determinants of health within First Nations families and communities?
4. In a social determinants of health framework, what kinds of data do you think could help us move beyond the proximal determinants of health to explore and influence the more intermediate and distal determinants of health for First Nations communities?

Research Focused on Adverse Childhood Experiences (ACEs)

1. Do you have any experience with research projects that have focused on assessing ACEs with First Nations children and families?
2. What are your thoughts on the feasibility of assessing ACEs through a longitudinal study conducted with First Nations children, youth, or adults?
   a. In your view, how could a study of ACEs incorporate the social determinants of health?
   b. Do you think there would be challenges or sensitivities involved in conducting longitudinal research on ACEs?
   c. Do you have any thoughts about how we could deal with these challenges and sensitivities?
3. What are your thoughts on the relationship between a strengths-based approach to research concerning First Nations child and youth development and well-being, and research focused on ACEs? Is it possible to take a strengths-based approach to this kind of research?

- What indicators are important to include in research concerning ACEs in a First Nations context? (i.e., what different kinds of childhood experiences should we be surveying?)

Cultural Frameworks and Collaborative Research

1. Can you tell us about some of the experiences you have had with collaborative and/or community-driven research projects with First Nations communities?

- Tell us about a collaborative and/or community-driven research project that you have been involved in that you feel was done in a good way.
  a. What stands out about this project?
  b. What steps did those involved take to ensure the research process was collaborative and/or community driven?

2. What do you think would be the most effective way to ensure that research focused on First Nations child and youth development and well-being is collaborative and community driven?
   a. Who should be involved and how?

- It is important that when research is undertaken in First Nation communities, it benefits those communities. What do you think needs to happen to ensure that if a First Nations-specific study on child and youth development and well-being goes ahead, it benefits the communities involved?

APPENDIX F

ABOUT FNIGC

FNIGC is an incorporated non-profit organization that has been mandated by the Assembly of First Nations' Chiefs in Assembly (Resolution #48, December 2009) to assert First Nations data sovereignty and support the development of information governance and management at the community level through regional and national partnerships. FNIGC envisions that every First Nation will achieve data sovereignty in alignment with their distinct worldview and is committed to producing quality research and information that will contribute to improving the health and well-being of First Nations across the country.

FNIGC is governed by a Board of Directors appointed by each of its ten (10) regional partners across Canada. Under the guidance of our regional partners, FNIGC helps build capacity and provide credible and relevant information on First Nations using the highest standards of data research practice. FNIGC does so while respecting First Nations' right to self-determination over research information and operating in true compliance with the First Nations Principles of OCAP®.

ABOUT FIRELIGHT

Firelight Research Inc. (The Firelight Group, Firelight) is an Indigenous-owned consulting firm with over forty staff and directors working from offices located in Vancouver, Victoria, and Edmonton. Firelight's staff members are dedicated research professionals with decades of combined experience providing facilitation, research, and technical support services to Indigenous organizations and communities across Canada and beyond. Firelight's work is focused on supporting the rights and interests of Indigenous Peoples across several domains, including culture, health and well-being, socioeconomics, ecology and the environment, and governance. Firelight strives to foreground Indigenous knowledge in everything they do.

FNIGC | CGIPN

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

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