National Child Data Strategy: Results of a Feasibility Study

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INTRODUCTION

This report presents the results of a feasibility study to determine the need for a national child data strategy. It was undertaken on behalf of the Lawson Foundation, which has a long-standing interest in the healthy development of children and youth.

In November 2016, the Lawson Foundation hosted a forum in which a diverse group of academics, representatives from charities and non-profit organizations, and governments were invited to reignite a pan-Canadian conversation across sectors about how to support young children. Feedback from participants at that session pointed to the need for additional work on child data, in particular.

METHODOLOGY

The feasibility study consisted of three major activities:

- a preliminary environmental scan of major initiatives on child well-being and sources of child data in Canada, presented in Appendix A

- interviews with selected key informants (Appendix B) using an interview guide (Appendix C)

- participation in webinars with *l'Observatoire des tout-petits* and the Canadian Council on the Social Determinants of Health, and in a Round Table on the Middle Years Strategy convened by the Government of Ontario.

For the purposes of this study, child well-being was defined broadly to include its physical health, mental health, cognitive, social and economic dimensions. Children were defined as young people from birth to age 18. This definition is consistent with the *United Nations Convention on the Rights of the Child* ratified by Canada in 1991.

However, several respondents pointed out the importance of collecting data on child well-being even before birth because of the powerful links between prenatal health and positive outcomes in child well-being. In fact, a number of researchers are already collecting this data in their own work and are continually seeking new measures and sources of information at the pre-birth stage.

While this study focused on children up to age 18, it is important to note that most researchers select a subset of this broader group, such as the early or middle years. *La Commission sur l'éducation à la petite enfance*, for example, explored services for children ages 0-16. Ontario has developed a strategy to support the well-being of youth ages 12 to 25.

In fact, one key informant felt that any child data strategy should target children under age 12. Currently, there are numerous data sources, such as the Canadian Community Health Survey and Health Behaviour in School-aged Children, which focus on youth ages 12 and over. But there are serious data gaps for children younger than age 12. A child data strategy that encompasses the entire spectrum up to age 18 would likely require a subdivision of groups, such as preschoolers, school-aged and older. Policy questions and associated methods of data collection differ for these distinct age groups.

Another key informant challenged the notion of a wide-ranging child data 'strategy,' which appears to be too broad and amorphous in its current conceptualization. A more helpful and strategic approach might be to identify the specific topics that would comprise a child data initiative (e.g., education, child welfare, health and

child care) and to determine the data components to include in each area. Decisions would have to be made as to whether to focus exclusively upon children or to capture relevant data on families, mothers and other demographic information as well.

On the whole, however, all key informants were supportive of the effort to focus more attention on high-quality child data and to encourage conversation about and financial investment in this policy area. One respondent noted: "Without an ability to collect good data, including the use of standardized measures and surveys, we will not be able to truly understand the strengths, needs and risks of our children, youth, families and communities." Another pointed to the "huge mass of data gaps that need a focused approach as well as better connections, increased funding, more information-sharing, and education about research design, and the uses and misuses of data and research."

KEY FINDINGS

This preliminary environmental scan and initial set of interviews together identified five core challenges related to:

- data architecture and governance
- knowledge gaps
- methodological limitations
- data collection
- contextual issues.

Data architecture and governance

The environmental scan and interview process found a wide range of research efforts under way throughout the country involving the collection of data on children. The work listed in Appendix A gives some sense of the broad scope of these pan-Canadian initiatives.

Many charitable and non-profit organizations, such as UNICEF Canada and the Canadian Institute of Child Health, are involved in the curation or collection of data on children. There are also a number of research collaboratives or networks in which researchers, primarily within and between universities, are pooling their respective sources of data and expertise in order to develop new data and instruments, such as surveys. Most of this work involves some form of engagement with charitable and non-profit organizations and sometimes provincial governments, such as Manitoba and BC.

Statistics Canada and its provincial/territorial statistical counterparts are key sources of data on children and Canadian families. The First Nations Information Governance Centre has been collecting data on Indigenous Canadians.

In addition, all governments in the country have embarked upon some type of work related to enhancing child well-being and collecting associated data. However, some provinces – notably New Brunswick, Québec, Ontario, Manitoba and BC – were cited by various respondents as having progressed further than others in their data collection efforts and their reporting on healthy child development.

New Brunswick produces *State of the Child* reports, Québec is actively engaged in *l'Observatoire des tout-petits*, Ontario has developed an Early Years Policy Framework and a Strategic Framework for Ontario's

Youth[1] (it is currently crafting a Middle Years Strategy), Manitoba hosts Healthy Child Manitoba and BC publishes a *Growing Up in BC* report. One respondent referred to "massive IT developments" that are enabling some provinces to fundamentally transform their data systems.

Finally, there are several initiatives in Canada that are acting as both hub and portal of child data.[2] These include *l'Observatoire des tout-petits*,[3] the PrevNet research network on bullying and the substantial new data initiative being launched by the Canadian Centre on the Social Determinants of Health.[4]

Considerable work is being undertaken on various aspects of child well-being by diverse researchers and organizations across the country. The preliminary data scan confirmed that this is, indeed, the case. One respondent described the field as a "cornucopia" in order to capture the richness of efforts currently under way. That's the good news.

The not-so-good news is the fact that many researchers, representatives from charities and non-profit organizations, and government officials are not aware of the scope of existing work. Despite the wide range of efforts and sources of data, the initiatives tend not to be coordinated on a formal basis or even set up informally to share information.

One key informant referred to the current landscape as "pockets" of data collection efforts. It is simply not possible for individual researchers and non-profit organizations, to keep up with this active landscape. At a recent event on child well-being, for example, a participant identified the need for assembling the relevant research on bullying in Canada – with no knowledge of the PrevNet research network working in precisely this area.

There may be duplication of effort or several initiatives may be struggling with the same challenges related to data collection or the ownership, curation and privacy of data. But there is no single or even ongoing conversation among these diverse efforts. Moreover, there appear to be few opportunities for information exchange, let alone deep learning to explore possible application of methodologies to other communities or jurisdictions.

Because of scarce time and resources, it makes no sense to continue functioning as ships that pass in the night. It is wasteful to continually reinvent the wheel when we can build on good efforts and scale up through the application of existing knowledge.

The work throughout the country effectively is being conducted in discrete clusters. No recognized organization currently enables the ongoing exchange of information and there are relatively few efforts to pull together existing information into a coherent framework or data infrastructure. Fortunately, the work of *l'Observatoire des tout-petits* in Québec is a notable exception (though it focuses explicitly on young children) and the upcoming project of the Canadian Council on the Social Determinants of Health will also help change the data landscape considerably.

L'Observatoire des tout-petits, housed at the Chagnon Foundation in Montréal, produces an annual table of available statistics on children between the ages of 0 and 5. Its mandate is to ensure that the well-being of children is considered as a priority for Québec. In order to achieve that goal, *l'Observatoire* compiles rigorous data on the well-being of young children and communicates this information in a publicly accessible way.

The repository was developed in association with 11 researchers and more than 200 professionals from different fields to identify the best indicators to include in the database.[5] The database itself is organized into

five major domains: health, child development, family environment, physical and social environment, and early childhood services and supports. These domains are broken down, in turn, into 20 sub-domains that touch on 46 themes and produce 87 indicators. The statistics derive from data collected by various Québec ministries as well *l'Institut de la statistique du Québec* (ISQ), which assembles information from all the provincial government ministries. *L'Observatoire* has signed a protocol agreement with *l'Institut de la Statistique du Québec*, which helps ensure that the data is valid and reliable.

L'Observatoire also plays an active role in communicating and sharing relevant information. In order to inform media, Québec and municipal politicians, and key influencers, it publishes an annual report on the overall findings as well as thematic reports that explore a specific subject in depth.[6] It creates opportunities for dialogue among decision-makers, members of the business community and workers engaged in health, education and the community sector about the implications of the data for child well-being and its policy implications.

Few respondents outside Québec are aware of the wide-ranging activities that this initiative plays with respect to the collection, curation and animation of data on early childhood. Several key informants felt that there is a need for a similar process of gathering, consolidating and curating data elsewhere in the country. One key informant noted that UNICEF Canada had, in fact, convened a conversation several years ago in which participants discussed this observatory role. While participants generally agreed on the need for this approach, no organization was in a position at the time to assume that vital data intermediary function. It should be noted that UNICEF Canada has since launched the One Youth initiative, discussed below.

The initiative about to be announced by the Canadian Council on the Social Determinants of Health (CCSDH), in partnership with the Canadian Institute of Child Health, will help address the problem that numerous respondents have identified. The project is guided by a rigorous governance process, including expert advisory panels, to ensure quality control. It is being launched in English in the spring of 2017, with the French launch to follow three months later.

The purpose of the initiative is to pull together into one repository the major sources of data in Canada on all aspects of child well-being and child-related services. To date, the project has populated eight sections on child development, each of which includes a set of indicators. A total 320 indicators currently comprise the database. There is also a separate web area devoted specifically to data on Indigenous children. It is based on a determinants of health model and focuses on several core areas of well-being.

Despite the extensive work under way on various aspects of child well-being, clear gaps exist in our knowledge of and data on child and youth well-being as well as associated programs and services for children and families.

Knowledge gaps

There are three different types of information required for the study of children. While these areas are linked, they are in fact quite distinct.

Outcome data enables us to make conclusions about how well children are faring along multiple designated domains. *Program data* provides information about access to and the effectiveness of various child and youth interventions. *Social environment data* highlights the impact of key environments (notably, the family, school, community and governments through their respective public policies) upon the well-being of children.

A major gap lies in the very foundations of this work. There is no consensus on the core set of questions that would help determine how well Canada's children are doing now – and over time. Canada does not collect many vital indicators that enable comparisons with international reports.

It is important to get back to basics in defining the central questions to ask, how best to answer these questions and what is missing from a data perspective. Canada even lacks basic demographic information – "first order" questions, which are foundational for understanding the profile of the child population and fundamental aspects of child development.

Neither is there general agreement on who should determine which measures are relevant and which indicators are particularly meaningful to users. Not surprisingly, diverse users such as academics, policy-makers and program providers, often have distinct information needs.

Potential users of information and the targets of research studies (i.e., young people and their families) are rarely asked about the factors they would select to assess their own health and well-being. There are notable exceptions in the country, such as the work of UNICEF Canada, which will help shift this practice. The Human Early Learning Partnership (HELP) has actively engaged knowledge users in the design and coverage of the Middle Years Development Instrument (MDI),[7] Childhood Experiences Questionnaire (CHEQ)[8] and Toddler Development Instrument (TDI).[9] In each case, an extensive and time-consuming consultation process fundamentally shaped the structure of each tool.

It may not be possible to arrive at consensus on the issue of basic questions, given the wide-ranging diversity of views and current work. There will never be a single or correct approach to the fundamental questions and associated data requirements. The questions to be asked will always be coloured by the needs of various users and by the work of researchers and non-profit organizations with different missions. However, a substantive conversation on this issue would sharpen our collective thinking by challenging certain assumptions and practices.

At the same time, one respondent cautioned that waiting for a new conceptual framework or "grand scheme" to be carefully developed and implemented would be years in the making. While these overarching conversations are important, they should not get in the way of incremental actions that can and should be taken right away to tackle the substantive and contextual issues identified in this report.

While figuring out the bigger picture, it is essential to proceed with the many actions that need to be taken right now to address the myriad gaps in child data, identified below. One respondent argued that, given the seven-year gap in data due to the loss of the National Longitudinal Survey of Children and Youth (NLSCY), new data collection must take place now using data instruments currently in place.

While the data gaps identified here pertain generally to Canada as a whole, there are some nodes of excellence that can act as a model for other parts of the country. The exemplary work can be the subject of knowledge transfer and exchange (discussed below under Next Steps). Research in these identified areas would also help fill major knowledge gaps.

First, there are gaps in our understanding of the correlations among variables rooted in distinct fields, such as genetics and other biological factors and markers, including epigenetics,[10] environmental factors and the economic status of the household, on the one hand, and the physical health, mental health and social well-being of children and youth, on the other.

It was noted that the Canadian Health and Measures Survey collects many direct measures on children, family socioeconomic status and child outcomes. While the data is adequate to address correlations among variables, the sample size is limited as are the outcomes that are collected on children, which are primarily parent-reported behaviour problems. Experimental and quasi-experimental/longitudinal designs are required in order to get a sense of causal pathways. Pockets of work are under way in the country, such as the pan-Canadian CHILD study, which are trying to bridge the knowledge gaps in some of these areas.[11]

There is a lack of data on very early childhood, including the impact of prenatal health and care. While most data collection begins at birth or shortly thereafter, several respondents argued that it should begin pre-birth. We know about links of prenatal health and its associations with child outcomes but we lack good lifespan or longitudinal data to track effects over time.

Canada also lacks data on specific populations, notably Indigenous children. A key informant who works actively with Indigenous children noted that there are information gaps in virtually every domain of child well-being. Rates of child mortality, numbers of children in care and numbers participating in licensed child care were identified as a few examples.

Sometimes, the information is available but is outdated. For instance, the *Early Childhood Education and Care* report produced by the Childcare Resource and Research Unit (CRRU) presents a wide-ranging provincial and territorial review of child care and other early childhood education services, accompanied by associated demographic data. The report includes figures on the numbers of children and working parents in every jurisdiction. While the last report published in 2015 used rounded numbers from 2014, the data for Indigenous children derives from numbers gathered in 2011.

For Indigenous children, the problem involves not only a lack of data. There are also knowledge gaps on the cultural appropriateness of certain types of information, the relevance of this data to the group in question and the sensitivity with which information is collected. Fortunately, there is some positive work under way in the country, such as efforts at the University of Northern British Columbia. The DEVOTION (Manitoba DEVelOpmenTal Origins of chronic diseases In children Network) initiative includes in its study an Indigenous birth cohort and a unique Indigenous statistical research centre.[12]

Canada lacks data on children with disabilities and the nature of their condition. Because these children and their families may require special attention and extra supports, it is vital to have some sense of the numbers. A respondent pointed out that the federal government had also cut a major national source of information on disability, known as the Participation and Activity Limitation Survey (PALS).

There are data gaps with respect to children's mental health and self-perceived well-being. The Mental Health Commission of Canada noted in its national strategy that up to 70 percent (one key informant pegged this figure at 75 percent) of young adults with mental health problems report that their symptoms started in childhood. This is crucial preventive information. While some data is available in the form of diagnostic information in medical records, it may be difficult to access and link this information. The University of Manitoba has just released a major report on children's mental health and associated data challenges [Chartier et al. 2016].

We have limited understanding of the numbers and needs of refugee and immigrant children. The culturally sensitive collection of data was raised with respect to newcomer children as well.

Canada lacks good data on the numbers of children in care. The figures in some jurisdictions are years out of date; the Canadian Child Welfare Research Portal posts figures on numbers of children in care dating

from 2007 in some provinces. Key data is also lacking on Indigenous children in care – a gap that is particularly problematic because of the disproportionately high numbers of Indigenous children in the care of the child welfare system.

There is relatively little information and data on children living in military families. These children face unique mental health pressures given long absences of a parent, frequent moves and lack of family-based resources on military bases.

Gaps were identified with respect to early childhood education programs and child care services. In fact, an entire report highlighted the many problems in this area alone [Cleveland et al. 2003]. While the report was released in 2003, many of the concerns regarding data collection (discussed below) have still not been resolved 14 years later.

Concerns were raised about the lack of data with respect to the type, quantity, quality, effectiveness and affordability of early childhood development services, broadly defined. Use of and access to these services are also key, but are neglected issues.

One respondent identified specific service-related questions around which we lack data. They include:

How many low-income children go to what kinds of early childhood education and care (ECEC) programs? What is the nature of the programs, such as their quality? What happens to migrant children when they come to Canada in terms of ECEC programs? How many Indigenous children on and off reserve participate in what kinds of ECEC programs? What kinds of links are there between ECEC programs and families with children with disabilities to connect them to needed services? What happens when these families get into the school system (i.e., early learning in kindergarten)?

These issues are important given that *quality interventions*, not just any programs, make a fundamental difference in children's lives. In fact, one respondent noted that the question of quality interventions is a concern related to all interventions for children and families – not just those targeted toward early childhood.

The recent report of the *Commission sur la petite enfance* framed its entire report around the issue of quality. It set out the key criteria to help make this assessment, including such factors as staff/child ratio, staff training and staff/parent relationships [Commission 2017: 12]. Lacking, however, is extensive on-the-ground observational data with a detailed tracking of quality indicators regarding the provided services. These kinds of observational studies are time-intensive and expensive, resulting in a shortage of reliable research and data on quality.

The federal government is focusing on questions related to the quality and affordability of early childhood development services and child care, more specifically. This interest relates to the fact that Ottawa is working with the provinces and territories on an Early Learning and Child Care Framework, announced in Budget 2017.

Canada generally lacks high-quality, scientifically rigorous evaluative data on child and youth interventions. There are lots of program descriptions but not many rigorous studies that can be considered statistically reliable and valid. It is essential to develop evaluable programs from the get-go and to embed a rigorous evaluation component right into program design.

Another gap identified by key informants was the relative value and contribution of various child data methodologies and instruments. We lack information on the application of data results and knowledge translation activities to help potential users and stakeholders understand the significance of selected data and its

relevance to their group, neighbourhood or community. The Human Early Learning Partnership in BC has invested considerable energy in this area.

Several respondents noted that there are often discrepancies between national data used to identify certain trends in child well-being and international data seeking to measure the same problem. Most jurisdictions and non-profit organizations, for example, employ the Low Income Measure (LIM) to assess child poverty. The Low Income Measure before tax is a fixed percentage (50 percent) of median adjusted total household income.

A report published in 2014 by the United Nations Children's Fund raised questions when it used a modified version of this standard measure of poverty. *Children of the Recession: The impact of the economic crisis on child well-being in rich countries* ranked the change in child poverty in 41 EU and/or OECD countries between 2008 and 2012. The change was calculated by computing child poverty in 2008 using a poverty line fixed at 60 percent of median income rather than the 50 percent typically employed in Canada.

What is not well known in Canada is that LIM60 is employed internationally because it is the standard in the European Union Statistics on Income and Living Conditions (EU-SILC) survey. It is the *de facto* global standard covering most OECD countries.

This is just one example of a broader challenge: when data at the national level does not line up with the methodology employed in the calculation of international measures and, not surprisingly, the associated results. In the poverty example, the challenge was to reconcile the results presented at home with those presented on the international stage. Data discrepancies can often create political challenges, especially for charitable and non-profit organizations trying to explain the differences.

Statistics Canada can provide leadership by participating in efforts to develop and align data with international initiatives. While Canada needs to collect data that is relevant to national priorities, it must also consider the need to collect data in a manner consistent with international indicators.

One respondent expressed concern about the lack of alignment between investments, programs and policies intended to support child and youth well-being, on the one hand, and the data to identify where some of the most intransigent and inequitable outcomes lie. Indices and international comparisons can assist in identifying what UNICEF Canada calls the "Possibility Gap" – i.e., the difference in an outcome between one population (e.g., the Canadian average) and a comparator population (e.g., the average achieved by the best-performing country). The indicators in which the gaps are widest, such as child homicide or immunization, ideally should spark discussion as to whether they are overlooked in the policy and service landscape.

Similarly, "Progress Gaps" refer to indicators that point to areas where limited progress has been made over time. These areas include obesity, low birthweight and bullying. "Equity Gaps" are the indicators in which the outcomes across a child population are excessively wide and inequitable.

Methodological limitations

Two basic types of data are employed to assess child well-being and child interventions. *Administrative data* represents the set of information derived from an administrative source. It is collected primarily by government departments for the purposes of registration, transaction and record-keeping in such areas as health, education, welfare and tax collection. *Survey data*, by contrast, derives from information gathered about a population's characteristics; self-reported and observed behaviour; awareness of identified programs; or needs, attitudes and opinions.

Five major methodologies are employed to collect child-related data. This classification was developed by the late Dr. Clyde Hertzman in collaboration with colleagues from across Canada [Monitoring Committee 2009]. Dr. Hertzman led a group of researchers within the Forum on Early Child Development Monitoring where these views were further formulated.

Cross-sectional surveys are a type of study that analyzes data collected from a population, or a representative subset, at a specific point in time. Successive snapshots taken over time create trend data that help determine the direction and extent of change on the variable(s) being tracked. This type of data can be used to describe characteristics that exist in a community and possible links between these variables − though not necessarily causal relationships. The Early Development Instrument (EDI) is the most widely-employed cross-sectional survey to assess child well-being in Canada.[13]

Longitudinal surveys involve the systematic follow-up of a representative sample of a population of children and their families over a period of time, sometimes lasting many years. These surveys help identify the factors (i.e., genetic, environmental, social and economic) that appear to have a key influence on health outcomes and well-being. The results can provide direction regarding the factors or interventions that should be introduced, modified or removed in order to generate positive outcomes. Four Canadian examples are the Québec Longitudinal Study of Child Development,[14] the Québec Study of Newborn Twins,[15] the Canadian Healthy Infant Longitudinal Development (CHILD) initiative and the National Longitudinal Survey of Children and Youth (NLSCY),[16] which was inactive as of 2008-09. The NLSCY began in 1994 and was developed jointly by Statistics Canada and the former Human Resources and Skills Development Canada (HRSDC).

Linked data approaches seek to join routinely-collected administrative data from health, education, tax and other sources, including surveys already populated by data (thereby making use of existing information). By linking datasets across time, children can be followed from birth through adolescence and into adulthood. This method enables the identification of the factors (e.g., birth weight, region of residence) deemed to be the best predictors of various outcomes, such as high school completion or health conditions like asthma or diabetes. Healthy Child Manitoba and the Human Early Learning Partnership (HELP)/Population Data BC employ a linked data approach. But they go beyond administrative data alone to include information from cross-sectional surveys using the Early Development Instrument and other related indices. The DEVOTION (Manitoba DEVelOpmenTal Origins of chronic diseases In children Network) initiative also links various types of diverse data.

Social indicators approaches are based on the creation of composite indices. The individual indicators derive from a variety of sources, including surveys or administrative data, such as birth statistics from vital statistics. The approach seeks to present a profile of a given issue or concern by looking for patterns among the distinct measures. The individual pieces together comprise a story about how well a certain group – or even the nation – is faring. The Canadian Index of Well-Being, for example, paints a picture of how well Canadians are doing along multiple domains. UNICEF Canada is developing a new Index of Child and Youth Well-Being, discussed below.

Environmental scans seek to collect consistent and comparative information and data on programs related to children and families involving prenatal and postnatal care, family support, early learning and development, and cross-sectoral community initiatives. The data gathered includes what programs exist, how they are being used by families, how they operate and how much they cost. The Atkinson Centre for Society and Child Development, for example, employs an environmental scan approach in its collection of data on early childhood education services and child care [McCuaig and Akbari 2014]. The methodology involves a rigorous process of data identification, screening and collection.[17]

In order to assess and monitor child well-being, a nation ideally should have a solid data infrastructure that combines various elements of these distinct methodologies. It should have the capacity for multiple linkages both within and between jurisdictions and, ideally, at the community level where possible.

Unfortunately, Canada's data infrastructure on children falls short from several perspectives. Most respondents felt that the withdrawal of the National Longitudinal Survey on Children and Youth (NLSCY) left significant gaps in our knowledge of child well-being (fortunately, Québec managed to maintain its Québec Longitudinal Study of Child Development). Environmental scans are difficult because of data collection challenges, discussed below.

Respondents also identified gaps in existing measures and instruments. The Early Development Instrument (EDI) is the most widely employed tool in the country to assess child well-being. Despite its widespread use, its coverage is not complete and its data is not national. There has been no large-scale funding to collect data at national/provincial/community levels simultaneously. Moreover, there is no single instrument that represents consensus on what we need to know about children in the very early years and beyond the early years.

On a positive note, significant efforts are under way to fill key data gaps by developing scientifically rigorous and valid methodologies, including cross-sectional surveys, longitudinal surveys, data linkage and an index of child and youth well-being. For instance, there is no commonly employed Middle Years Index though several researchers and organizations have designed – or are working on the formulation of – a new measure for this age group.

The Human Early Learning Partnership (HELP), for example, has designed a monitoring system to assess the healthy development of children at five different stages of their lives:

- birth to 18 months
- 3 to 4 years
- 5 years (Early Development Instrument)
- middle years
- adolescence.

In 2013, HELP devised the Childhood Experiences Questionnaire (CHEQ) to respond to the lack of a widely-accepted population-level mechanism for measuring the quality and nature of children's experiences in their early environments. CHEQ is a companion document to the Early Development Instrument. HELP has crafted a Middle Years Development Instrument (MDI), which is a self-report questionnaire completed by children in Grade 4 and Grade 7. It intends to create a Youth Development Instrument that is modelled on the Middle Years Development Instrument. A Toddler Development Instrument (TDI) is also being formulated by a group of experts from across Canada. The TDI is an 18-month measure that gathers information about the contexts in which children are being raised as a companion set of data to existing developmental screens.

UNICEF Canada is the process of designing a Canadian Index of Child and Youth Well-Being, which will soon be ready for beta testing to assess the relevance and validity of the proposed domains and associated indicators. It is working on the Index in association with research partners at the Canadian Index of Well-being, University of Waterloo, and outside expert advisors. The new instrument will help "domesticate" the UNICEF Index of Child Well-Being and improve how we understand the state of children and youth in the country.

In fact, UNICEF Canada embarked upon a unique methodology for the development of this instrument. First, it carried out an environmental scan in which it gathered and documented all the child and youth well-

being indices being employed throughout the world [Walker and Smale 2017]. It actively engaged young people in the selection of the general domains and specific indicators of well-being that are relevant to them. For example, the young people involved in the process are interested in knowing why Canada placed only 17th in 2015 in the international UNICEF Index of Child Well-being.

The targets of surveys are rarely seen as users of the information or have an opportunity to select barometers of well-being that are meaningful to them. These indicators typically are selected by professionals and 'experts' on their behalf. Certain indicators may be chosen simply because of the availability of the administrative or survey data designed for other purposes.

UNICEF Canada is also trying to address the fact that the domains generally employed in various indices are constructed as though they are unique entities in which the factors within one domain have no impact on the factors in another stream. But the reality is that children's lives are complex with all key factors linked to each other. For example, household level of income will affect the ability to afford nutritious food which, in turn, influences both child health and the ability to learn. The activity within the separate domains are not neat and clean as current indices typically imply.

There is a need for fulsome discussion on the role and contribution of various methodologies and associated instruments along with their relative appropriateness, strengths, weaknesses and even potential risks. The latter point had to do with whether any of the instruments, their measures and behavioural expectations could have negative consequences for some children who may be judged prematurely to be failing on certain key developmental outcomes.

Several respondents raised questions about the relative strengths of longitudinal and cross-sectional surveys when it comes to assessing the well-being of children. In the absence of the NLSCY, researchers have devised new methodologies or novel ways of linking data that provide information on child well-being. It was noted, however, that this linking is no replacement for a long-term national survey.

Cross-sectional surveys typically provide detailed information and may be a good way to assess the impact of certain interventions. Cross-sectional studies are easier and quicker to perform, especially if information is required in the near term. Longitudinal surveys, by contrast, tend to be more costly and resource intensive. By their very nature, these surveys may not be able to provide policy-relevant answers in the short term.

One respondent argued that the lack of solid methodologies and good data have left the door open to the application of economic methodologies to assess the quality of early childhood interventions. This approach was deemed inappropriate and has resulted in misleading conclusions about various child interventions.

Fortunately, there are noteworthy efforts under way in Canada to tap into and combine existing data in new ways in order to derive novel insights on child health and well-being. The governments of Manitoba and BC, for example, are cross-referencing various types of information in order to find new correlations and relationships between and among variables.

Québec is also leading the way in its representative, population-based longitudinal studies. *L'Étude longitudinale du développement des enfants du Quebec (ÉLDEQ)* has been going on for 20 years and is into its fourth phase (20-25 years of age). *L'Institut de la Statistique du Québec* is planning a new longitudinal cohort (ÉLDEQ2) to start next year with 4,000 families to be followed from birth into adulthood. The data from these studies can be publicly accessed through the *Centre d'accès aux données de recherche de l'Institut de la Statistique du Québec* (data access centre for research purposes of the Statistical Institute of Québec).

Healthy Child Manitoba and the associated Manitoba data repository represent an exemplary data linkage model as does the work of the Human Early Learning Partnership, which is engaging actively with the BC government in the data linkage process. Several non-governmental initiatives involving researchers from a wide range of disciplines, such as CHILD and DEVOTION, are combining data from various sources to explore the possible correlations among key variables.

Manitoba appears to be the most well developed example, to date, of a province engaged in data linkage. Its Population Research Data Repository, housed within the Manitoba Centre for Health Policy, contains anonymized records of individuals' interactions with several systems. There is data from the health care system, including the Manitoba Health, Seniors and Active Living insurance registry, which is updated every six months. The Repository contains numerous population-based records, including data from the Office of Vital Statistics (birth, death and cause of death), provincial surveys such as the Manitoba Longitudinal Study on Aging and national surveys (e.g., the Canadian Community Health Survey).

The Repository also includes primary and secondary education data, such as enrollment information on all students in kindergarten to grade 12, course marks for high school students, standard test scores and special education funding. Province-wide data from the Healthy Child Manitoba Office on the Early Development Instrument (EDI) is collected as well. The database includes provincial social service information, notably use of employment and income assistance benefits, contact with the child welfare system and use of child care services.

In short, more than 90 administrative, survey and clinical databases are contained in the Repository, making it a powerful research resource for studying child health and development. As just one illustration, the ability to link datasets (e.g., high school standard tests scores and the population registry) allows the examination not only of high school outcomes of students still in school but also of all the young people who have repeated a grade or dropped out of school. Manitoba First Nations are developing a new First Nations Statistical Institute similar to the Population Research Data Repository.

However, many challenges are embedded in the data linkage approach. It requires provinces to share information internally – both within and between departments. This is not always easy. Departments often collect information independently of each other, making it difficult to link the data in order to track progress of selected individuals or populations. Governments need to devise and employ a coding system that tracks individuals across departments in order to collect personal information regarding physical health, mental health, education, family income and other factors.

Some jurisdictions are already linking data through use of various identifiers, such as personal heath or social insurance data. But governments tracking information across departments also need to ensure its confidentiality in order to protect the privacy of citizens, discussed below under Contextual Issues.

Data collection

Services for families and children are funded primarily by provinces and territories, resulting in a unique set of programs in each jurisdiction. Certain provinces and territories gather more data than others on the state of healthy child development.

Basic information on the use of services is often not kept. Caseloads are counted in different ways. It is not easy to get an accurate read on how many children are enrolled in which type of child-related program, how

long they have been there and whether they are receiving subsidy. One respondent noted that the lack of good data on the positive impact of quality services has left the door open to commercialization in the child care field, in particular.

Moreover, these data gaps make it difficult to assess the impact of child-related programs on child development. It is not possible to conclude that a certain intervention has had a positive effect if there is no identifier attached to a given child and no way to consistently follow his or her progress over time. Lack of data on the inputs to an intervention make it hard to know where to attribute the outcomes.

The Atkinson Centre for Society and Child Development, for instance, faces challenges in conducting its scans of provincial and territorial early childhood services and supports. Because every jurisdiction employs a unique approach in collecting child data, researchers must make numerous assumptions in order to ensure relative comparability of the information. For example, it may be necessary to estimate an end-of-month caseload calculation if a given jurisdiction produces only a mid-month count. Data about the Territories can be incorporated in cross-country studies of early childhood services only if the jurisdictions themselves provide the information because of data suppression due to sample size and other technical considerations.

Other challenges include the fact that some provinces use data from programs that may require families to register or pay an associated fee. If costs are involved, many families are unable to participate in the program and are left out of the count – even though these families would likely benefit most from a given program or intervention.

Administrative data on fees varies widely across the country so it is hard to assess the affordability of child care services, in particular. Higher fees typically are paid in larger urban centres with greater demand.

Similarly, questions were raised about the current data on affordability. How best to assess whether a given service is affordable or not? Is affordability determined relative to income, a basket of goods that a household must purchase on behalf of its members or the costs that a family must incur on behalf of its children? The presence of a special need, for example, may involve high costs for a household.

Not surprisingly, affordability is also a function of jurisdiction and whether subsidies for lower-income households are available in a given province or territory. It is also determined by the presence of services in a specific community and the associated demand for services. The data derives from administrative sources, which are maintained in distinct ways by different jurisdictions. Even within municipalities, the boundaries for certain services may be different, making it difficult to line up potentially linked information like child care, education, health care and recreation.

Several respondents identified a capacity problem with respect to data collection, especially when survey instruments are employed. Training may be needed before staff in community-based organizations are deemed sufficiently qualified to gather information on children and youth, taking into account scientific rigour, privacy and cultural appropriateness. This capacity issue is particularly critical in certain child and youth interventions, like SNAP® – the Stop Now And Plan "behaviour model" – which require adherence to clear intervention protocols in order to ensure effective impact.[18]

Fortunately, there have been notable improvements in recent years. More jurisdictions are collecting program information and the co-location of child care and kindergarten within one ministry in some jurisdictions has helped. For example, since child care was moved into the Ministry of Education in Ontario, the province has started to collect relevant data. A 2015 Operators Survey can now provide information on both prices and subsidies.

Some provincial governments have truly advanced the data collection agenda on child well-being, and how they are accessing various databases and cross-tabulating the data across sources and even jurisdictions (i.e., with federal data). These provinces have grappled with complex issues, such as data consistency across government, methodologies for coding and sharing information while protecting privacy, and cross-tabulating data gathered through diverse sources.

As noted, Manitoba has designed a model system for collecting and linking administrative data in a systemic way. Its Population Research Data Repository contains anonymized records of individuals' interactions with several systems. BC is also involved in data linkage work through the Human Early Learning Partnership (HELP) and Population Data BC, both located at the University of British Columbia. Québec has integrated many of its data sets and makes this information publicly available through *l'Observatoire des tout-petits*. Exploratory discussions are under way among the Atlantic provinces on the possible joint collection of child data, which would ensure the comparability of results across the region as well as address the small sample size challenge.

Finally, one respondent noted that provincial/territorial differences are not necessarily a bad thing when it comes to testing new models of delivery. The diversity of approaches can be made into a strength, rather than a weakness, under three conditions. First, jurisdictions agree to learn from each other and not shy away from interjurisdictional comparisons. Second, jurisdictions agree on standards for evaluation of outcomes and commit themselves to evidence-informed decision-making. Third, jurisdictions commit themselves to support a cross-country monitoring system that can be used to track progress at the population level over place and time.

This respondent noted:

> In Canada, social services, health and education are the responsibility of the provinces, resulting in high levels of variability in the type, level and cost of service provision across the provinces. Although these circumstances could be seen as a challenge for the application of a uniform and coherent set of policies and programs toward early childhood across Canada, they also provide multiple testing grounds for various policies and services. Each province has actually been experimenting with different arrangements for supporting children and families in the early years. This has led some Canadian researchers to propose pan-Canadian learning indices regarding the strengths and weaknesses of each approach to policy [McCain, Mustard and McCuaig 2011]. These initiatives should be encouraged, improved and advocated for in the various constituencies, with the goal of providing a fertile basis for policy innovation and emulation across Canada.

Contextual issues
Challenging environment

The past few years have been especially difficult in terms of the collection and production of and access to child data. The temporary withdrawal of the long-form Census represented a serious problem in critical population data for researchers in virtually all social and economic fields.

While the current government has restored the Census, there will always be a gap in the trend data – at least regarding a consistent picture over time. As noted, the National Longitudinal Survey on Children and Youth was dismantled and has not been reinstated, leaving a gaping hole according to many respondents.

Federal-provincial/territorial collaboration

It was noted that, for nearly a decade, the federal government had retreated from interaction with provinces and territories other than on a bilateral basis. There was a move away from collaborative federalism toward bifurcation in which Ottawa assumed certain roles and the interaction played other distinct roles.

The apparatus of federalism and associated relationships are "rusty" and will need to be rebuilt with considerable time, effort and resources in order to enable federal-provincial/territorial collaboration around child well-being, child/youth services and child data. It may take some time to get those relationships back on track. Fortunately, there are noteworthy developments, such as the Early Learning and Child Care Framework, which will involve active conversations between the federal and provincial/territorial governments.

Lack of adequate funding

Not surprisingly, several respondents raised concerns about the availability of funding for the collection and interpretation of data on children. Funding is scarce relative to the need for information on various aspects of child well-being and the cost of certain research efforts, especially longitudinal studies. By definition, this methodological approach requires a significant investment of funds over a period of years.

There is lack of adequate funding for all types of data collection on child well-being, including longitudinal studies, environmental scans and data linkage. There are insufficient funds for the rigorous evaluation of child and youth programs and services, such as randomized control trials, making it difficult to assess the effectiveness and impact of many interventions. There is relatively scant financial support for the interpretation and application of data to ensure that it is meaningful and relevant to communities. We lack information on the use of early childhood development services and their associated social determinants.

It was also noted that there are fewer research dollars than in the past. As a result, the broader research environment has become increasingly competitive and less collaborative. Instead of encouraging and enabling collaboration, government funding requirements effectively create pressures for researchers and organizations to compete against each other rather than work together.

Funding coherence

Another funding problem identified by one respondent involves the lack of coordination at the federal level, in particular. The various departments within a single order of government appear to make financing decisions independently of each other. There are few opportunities for information exchange or joint decision-making between and sometimes within departments.

Neither does there appear to be much collaboration between government departments and the various federally-supported funding bodies, such as the Social Sciences and Humanities Research Council, whose mandate is to support research. It is not clear whether there is any consultation or coordination involved in the selection of research projects or any expectation to ensure that the work financed through one funding stream builds upon and does not duplicate the research supported through another funding stream.

There is a need for more coherence in funding decisions. Careful alignment and planning regarding what and how to measure, and the storage and linkage of data, would save a lot of money, reduce duplication and create synergies.

Yet another issue relates to the fact that various funders have unique requirements associated with the receipt of a grant. In most cases, academic researchers are expected to publish the results of the work for which they received support. As a result, they may not be in a position to share data until they have gone through various phases of peer review.

Questions were also raised about proprietary issues. If a government department or national funding body finances a data collection project, some respondents asked who owns the information. Does it belong to the academic or researcher who carried out the work or is it considered within the public domain because the research was conducted with public funds?

Quality control

Quality concerns were raised in several areas, including the lack of rigorous evaluation of child and youth programs. Quality assurance is also a concern when methods employed in one jurisdiction are applied elsewhere; underlying assumptions to ensure comparability and validity of the data must be clearly stated and carefully respected.

For example, researchers may employ cost data from the largest city in every jurisdiction if they are trying to get a consistent sample of relatively comparable data. Or they may assume certain proportions of two-parent and one-parent households within the population. They may do calculations on the basis of a two-child household and may assume specific ages of the children – again for comparative purposes. Researchers employing the methodology for their own study must be sure to cite these assumptions and apply them to any new calculations.

Privacy concerns

It is essential to protect the privacy of children and families when government departments or researchers share personal information through various research methodologies, including the linkage of administrative data or use of longitudinal studies that track selected individuals over time. University-affiliated bodies were identified as a good place for doing this type of linkage work as there are strict and transparent privacy regulations to which researchers must adhere.

Another set of challenges involves the collection of data from young people themselves. It has become increasingly difficult to get access to schools because of safety protocols, privacy concerns and other barriers. Researchers may need to consider non-traditional methods for gathering information that must still be considered reliable and valid.

Several respondents, however, did not consider privacy issues to be an obstacle to data collection and analysis. In fact, they believe that the privacy caveat is often used as an unnecessary excuse not to collect, release access to or share data.

While the protection of privacy is vital, it is becoming increasingly difficult to conduct rigorous evaluation and research due to the various legislation and privacy laws. There are ways to gather and store data to minimize such risks and still conduct ethically sound research and data collection.

It was also noted that some researchers and certain jurisdictions did an excellent job of protecting privacy through confidential coding systems and other methods developed for this purpose. On an international basis, Australia was identified as an exemplary jurisdiction. BC has done extensive work on the cross-tabulation of data through numeric identities. Manitoba employs a scrambled algorithm for this purpose.

Statistics Canada's website also sets out guiding principles on the use of administrative records when these present a cost-effective alternative to survey methods of data collection.

> The use of administrative records may raise concerns about the privacy of the information in the public domain. These concerns are even more important when the administrative records are linked to other sources of data. The Policy on Informing Survey Respondents (Statistics Canada, 1998) requires that Statistics Canada provide all respondents with information such as the purpose of the survey, the confidentiality protection measures, the record linkage plans and the identity of the parties to any agreements to share the information provided by those respondents. Record linkage must be in compliance with the Agency's Policy on Record Linkage.

It should be noted that the First Nations Information Governance Centre (FNIGC) has set out key guiding principles regarding the collection of data. The First Nations principles of OCAP® are a set of standards that establish how First Nations data should be collected, protected, used or shared.

Indigenous stakeholders need to be involved in all steps including identifying data gaps, data collection, interpretation and implications of results. In fact, one respondent noted the importance of getting much better at the process of "pre-engagement ethics," which involves working with First Nation communities to generate research questions and designs.

While these principles represent the *de facto* standard for how to conduct research with First Nations, their relevance appears to be applicable to other research initiatives. The following description is cited directly from the FNIGC website.

> Standing for ownership, control, access and possession, OCAP® asserts that First Nations have control over data collection processes in their communities, and that they own and control how this information can be used. There are four components of OCAP®: Ownership, Control, Access and Possession.
>
> *Ownership* refers to the relationship of First Nations to their cultural knowledge, data and information. This principle states that a community or group owns information collectively in the same way that an individual owns his or her personal information.
>
> *Control* affirms that First Nations, their communities and representative bodies are within their rights in seeking control over all aspects of research and information management processes that impact them. First Nations control of research can include all stages of a particular research project from start to finish. The principle extends to the control of resources and review processes, the planning process, management of the information and so on.
>
> *Access* refers to the fact that First Nations must have access to information and data about themselves and their communities regardless of where it is held. The principle of access also refers to the right of First Nations communities and organizations to manage and make decisions regarding access to their collective information. This may be achieved, in practice, through standardized, formal protocols.
>
> *Possession* While ownership identifies the relationship between a people and their information in principle, possession or stewardship is more concrete: It refers to the physical control of data. Possession is the mechanism by which ownership can be asserted and protected.

FUTURE WORK

While there was strong support for continued work on child data, the notion of a child data 'strategy' seemed too broad and amorphous for some. It appears to touch on too many areas and, as a result, risks not achieving concrete results in specific areas of immediate need.

A wide-ranging agenda could also get bogged down in trying to craft a perfect plan around which there is consensus. This would be a time-consuming task and highly unlikely in any case. One respondent pointed

out that every researcher and project has a unique data wish list and "it will never be possible to please everyone."

A preferable approach is to break down the broader agenda into specific components of child data and to ensure that the people engaged in those areas play a role in defining the precise information needs. Subsequent work should consist of a coherent set of activities in support of diverse efforts under way throughout the country. Future work should also build on data recommendations put forward in earlier work, such as the Report of the Royal Society of Canada-Canadian Academy of Health Sciences Expert Panel [Boivin and Hertzman 2012].

Mapping key data initiatives

There is a need for a repository of information on various data collection initiatives that can act as a resource for researchers, charitable and non-profit organizations, and governments. Such repositories do exist in some provinces and a jurisdiction-based approach may work better than a national approach, especially when it comes to data linkage.

As noted, *l'Observatoire des tout-petits* fulfills this role to a large extent with respect to young children and the pending initiative of the Canadian Council on the Social Determinants of Health will act as an important hub and portal for child data. Ideally, its role will be coordinated with the work of Statistics Canada.

The mapping process could start by documenting the efforts highlighted in this report and expand to other projects, including the work of international organizations like UNICEF, the World Health Organization (WHO) and the Organisation for Economic Co-operation and Development (OECD). A major health-related national data strategy is emerging called SPOR (Strategy for Patient Oriented Research), which is grappling with many of the same data challenges.

As part of its development of a Canadian Index of Child and Youth Well-Being, UNICEF Canada carried out an environmental scan in which it documented all major child indices, both at home and abroad [Walker and Smale 2017]. Its ongoing work in this area can serve as a foundation for the mapping activity proposed here. A visual representation of the major nodes of activity may be helpful.

Creating opportunities for conversation

There are few opportunities in Canada to come together as a community to identify data needs and gaps, or for in-depth discussion and debate on data issues, in general, and child data issues, more specifically. Neither are there many options for sharing good practice or exchanging ideas on the resolution of data challenges.

A dialogue between academic researchers and governments might help highlight the challenges involved in collecting vital pan-Canadian data. Another conversation could engage only governments and would provide an opportunity to share ideas on common issues, such as consistency and linkage in the collection of child data. While provinces and territories typically do not like comparative studies, they know that this information is important and, in fact, use these studies to determine how well they are doing relative to their counterparts.

It may also be worth convening a small and focused conversation about specific problems, such as the loss of the National Longitudinal Survey on Children and Youth (NLSCY). More specifically, what capacity have we lost with no NLSCY and what we have done in its place to provide good information? What can we no

longer conclude because of its loss and what are we now able to infer because we have designed new forms of data collection and associated instruments? What have we gained through the development of new measures?

There is a need for frank and open discussion on funding and how decisions are made to support various forms of data collection. This conversation should take place within and among diverse orders of government and the major research funding bodies.

Conversations among groups of interest should be supported as well. For example, researchers and communities collecting information and data on the health and well-being of Indigenous children should be supported to convene and sustain their own conversations, based on OCAP® principles. Significant work is being done in Manitoba and BC on the culturally relevant data indicators for assessing the well-being of Indigenous children and families, and translating the results into appropriate community interventions.

Creating opportunities for learning

There are few opportunities for deep or sustained learning on data-related issues. In-person or webinar-based sessions can be organized on selected areas of interest. Topics include the major data collection initiatives currently under way in Canada and their respective strengths, weaknesses and challenges.

A set of webinars can be organized that profile the data collection efforts highlighted in this report, including *l'Observatoire des tout-petits*, UNICEF Canada, Healthy Child Manitoba, the Human Early Learning Partnership and the Canadian Council on the Social Determinants of Health (this is not an exhaustive list). The key investigator from each of the selected initiatives would be responsible for the design and delivery of the webinar. Presenters could be asked to include material on how they have handled data collection challenges. Webinars could be recorded as podcasts and be made available to researchers across the country.

Opportunities for learning need to be created for content on healthy child development and the use of population, large-scale data. In the absence of the NLSCY, fewer and fewer academics who are interested in children are using population-based data, resulting in a significant lack of trained child experts who have content expertise and who can do research and analyses on population-based/secondary data sets.

Federal and provincial/territorial officials can participate in learning sessions in which they share information on data collection, storage and linkage. While officials exchange information on data needs related to children, another group needs to think about how needs will be met. Officials can exchange information on common concerns, such as ensuring privacy while sharing data across programs and departments.

Supporting data collection

There is a need to ensure adequate funding for various child data efforts. Governments and other partners, such as foundations and the private sector, should be involved in these discussions as the latter are vital supporters of this work. A funding consortium could also engage the private sector in providing technical assistance in such areas as data collection, coding, cross-tabulation, and the curation, linkage and management of large data sets.

Supporting engagement and knowledge translation

The collection of data on child well-being and on child and youth programs is only one part of the process. There is an equally important need to engage current and potential users of the data to help them understand the results and their relevance in improving child well-being. It was noted that initiatives like the Encyclopedia on Early Childhood Development could play a role in this regard.

Knowledge translation involves the engagement of potential targets and users of data in the following processes:

- determining key indicators and data collection methodologies and instruments
- gathering the data
- interpreting its relevance
- identifying its policy implications
- developing appropriate programs or interventions, as required.

While the knowledge translation approach has not generally been applied to child well-being, there are some promising developments. As noted, UNICEF Canada is formulating and testing a new Index of Child and Youth Well-Being.

Through a structured and monitored process, young people have been actively engaged over time in selecting the measures that they consider relevant to positive health and wellness. In fact, the UNICEF Index is part of a larger One Youth initiative, which consists of three pillars: Measure, Design and Influence. The data will be one component of a three-pronged strategy that will design solutions and mobilize knowledge in an effort to influence change.

Significant work is being done in Manitoba and BC on the culturally relevant and appropriate indicators for Indigenous children and families. The DEVOTION project, for example, is animating the members of the Indigenous community around the collection, interpretation and application of the data.

One successful knowledge translation method involves the creation of data maps, which serve as an educational tool to help communities understand their respective child-related strengths and challenges. These maps illustrate the relevance of population-based data for communities as well as programs.

Using a knowledge translation approach similar to that designed by the Canadian Institutes of Health Research (CIHR), the Human Early Learning Partnership (HELP) engages with 140 collaborative tables across the province. It has a network of 60 Early Development Instrument/Middle Years Development Instrument trainers, and works with a range of organizations on the interpretation and application of data. It also maps data results in order to show neighbourhoods how well their children are doing and to determine the specific domains that require attention.

CONCLUSION

This feasibility study was a preliminary exploration to identify the need for ongoing strategic work on child data. There is strong support for continued work in this area so long as it is clearly defined, does not duplicate existing efforts and is shaped by key players in the field. While a 'strategy' may be too broad, there are nonetheless a wide range of areas around which focused efforts are required – sooner than later. Future initiatives should enable, enhance and help scale up the many excellent data initiatives currently under way in Canada.

Endnotes

1. In its strategy for youth, for example, Ontario has set out seven key themes in *Stepping Up: A Strategic Framework to Help Ontario's Youth Succeed*. They include health and wellness; strong supportive friends and families; education, training and apprenticeships; employment and entrepreneurship; diversity, social inclusion and safety; civic engagement and youth leadership; and coordinated and youth-friendly communities. Each of the seven areas incorporates priority outcomes as well as associated indicators [Government of Ontario nd].

2. Two other initiatives are important to note. The Encyclopedia on Early Childhood Development, a knowledge transfer tool, provides up-to-date syntheses on the state of knowledge in early childhood development. While this knowledge tool is international and not about Canadian children specifically, it enables information on early childhood development in Canada to be shared/compared with similar information from other countries. ReACH (Research Advancement through Cohort Cataloguing and Harmonization) is an initiative funded by the Canadian Institutes of Health Research aimed at harmonizing large longitudinal birth cohorts across Canada, including *l'Étude longitudinale du développement des enfants du Québec* (the Longitudinal Study of Child Development) and the Québec Newborn Twin Study (QNTS).

3. It was noted that prior to the establishment of *l'Observatoire*, several organizations including the Research Unit on Children's Psychosocial Maladjustment (*Groupe de recherche sur l'inadaptation psychosociale chez l'enfant*), Centre of Excellence in Early Childhood Development, Early Childhood Learning Knowledge Centre and Strategic Knowledge Cluster in Early Childhood had created over the last 20 years a hub of early childhood development research and knowledge mobilization initiatives. Among them were the platform for the Encyclopedia on Early Childhood Development, longitudinal studies spanning more than 30 years and many early childhood intervention studies.

4. The Canadian Council on the Social Determinants of Health is working in partnership with the Canadian Institute of Child Health to create portals of data on children and Indigenous children in Canada. The sections include contextual/demographic data; income and labour market characteristics of families; family context; community context; health services; environmental risks and conditions; health outcomes; and developmental outcomes. The latter section presents information on the Early Development Instrument including scores for physical well-being; emotional maturity; language and cognitive development; communication and general knowledge; vulnerability; and social competence. Additional development measures are presented with respect to vocabulary, number knowledge, empathy, literacy and school readiness.

   The module on Indigenous Children and Youth employs a Determinants of Health Model. The module is broken down into component sections that present data on the structural, systemic, community and family enablers of well-being. There is also material on individual health and well-being related to the early years, middle childhood and youth.

5. Four steps were taken in the development of its 'data dashboard.' Research was carried out to identify the main themes and associated indicators employed throughout the world to measure child well-being and development of children ages 0 to 5. A total 37 international sites were consulted. The preliminary selection of themes and indicators were examined according to selected criteria – a total of 147 indicators across 99 themes. A conceptual validation of the data dashboard was carried out with child development specialists (11 Québec researchers and *l'Institut de la Statistique du Québec*). The preliminary dashboard was tested with managers and service providers from health, social services and early childhood education.

6. In the first year, the report presented all the indicators answering the question: In what kind of environment are young children living? For the second year, the report will present indicators that focus on how young children are faring. For the third year, the objective is to create an indicator of young children's well-being. The process involves a three-year cycle to provide enough time to work with new data. *L'Observatoire* also publishes theme-based reports on specific issues, such as early child development, child abuse and food security.

7. The Human Early Learning Partnership (HELP) has devised the Middle Years Development Instrument (MDI), which is a self-report questionnaire completed by children in Grade 4 and Grade 7. It asks them how they think and feel about their experiences both inside and outside of school. The instrument includes questions related to the five areas of development linked closely to well-being, health and academic achievement: physical health and well-being, connectedness, social and emotional development, school experiences and use of after-school time.

8. The Childhood Experiences Questionnaire (CHEQ) was developed by an interdisciplinary team of researchers in children's developmental outcomes in collaboration with teachers, administrators and community stakeholders from across British Columbia. The CHEQ is a population-level research tool designed to gather information on the experiences of children from birth to kindergarten entry in the following areas: physical health and wellness; early language and literacies; social and emotional well-being; and family, neighbourhood and community.

9. The national Forum for Early Childhood Development Monitoring has created the Toddler Development Instrument (TDI) to collect data on the social context and the early experiences of children during the toddler years (about 18 months of age). The TDI is a caregiver- or parent-completed survey. It contains questions about children's early experiences (child-caregiver interactions sleep, nutrition, play, screen time), access to resources in the community (e.g., child care/day care; facilities, health and education services) and social context (e.g., social support for the caregiver, well-being of the caregiver, financial resources and neighborhood safety). The questions on the TDI have been identified as predictors of child development outcomes during the developmentally critical period of the early years. TDI questions are mostly actionable – i.e., the questions address contextual factors or resources that can be affected by policies or initiatives at the individual, family, school or community level.

10. "Epigenetics is the emerging evidence of how early experience can 'get under the skin' to influence brain and biological development. It has built upon the prospect that the environments of stimulation, support, nurturance and participation in early childhood can speak to our genes through identifiable, credible biochemical and physiological mechanisms. In turn, genes may then express themselves differently according to the quality of early experience, and do so in ways that will influence our life chances, up to and including risks of addiction and mental health problems. We believe that this epigenetic perspective, when combined with insights on life course development from birth cohort studies, and with the emerging developmental neurobiology of the brain, forms a new science. The new science has the potential to transform the way we understand the challenges raised by various developmental health problems, including addictions and mental health problems; changing our ideas of how these problems emerge and calling into question how and when society should act to address them" [Boivin and Hertzman 2012: 124].

11. The purpose of the Canadian Healthy Infant Longitudinal Development (CHILD) initiative is to explore how genes and the environment influence child health and development. It seeks to understand the origins of childhood health and disease. The effort is a collaboration among 40 researchers, representing more than 20 scientific disciples, based in Toronto, Hamilton, Winnipeg, Edmonton and Vancouver. The study is following 3,600 children born between 2010 and 2012 in four sites in Canada. The time frame is prenatal recruitment through to age 5.

12. The Manitoba DEVelOpmenTal Origins of chronic diseases In children Network (DEVOTION) received $500,000 a year for five years from Research Manitoba. DEVOTION's mission is to focus on the early life determinants of chronic diseases and develop novel strategies to overcome them in order to reduce the burden and costs associated with non-communicable chronic disease in Manitoba. It is linking data from wide-ranging sources to identify the early life determinants of chronic disease. The initiative includes 40 scientists, policy-makers and stakeholders with expertise ranging from cell-based science to community-based intervention research. It has four key pillars related to basic science and cell biology, clinical populations, population-based data sets and policy implementation.

13. The Early Development Instrument (EDI) is a questionnaire filled out by kindergarten teachers on each of their students in approximately one working day. It reports on five key domains of children's early development: physical, social, emotional, language/cognitive and communication skills. When collected on all kindergarten children in a jurisdiction, the EDI provides detailed information at the local community and neighbourhood levels, where the key determinants of early child development and the best opportunities for intervention are found. The EDI has now been used extensively in most regions of Canada, which has led to an emerging understanding among policy-makers of how it can be employed as a population measure of the state of child development, rather than just as an individual educational assessment.

14. Funded by the Québec Government, the Chagnon Foundation and the Research Unit on Children's Psychosocial Maladjustment (GRIP), the Québec Longitudinal Study of Child Development (QLSCD) is a study over time of a sample of children, starting at the age of 5 months. They were sampled to be representative of the population of infants born in Québec. The primary goal of the QLSCD is to understand the impact of early child development and experiences upon the later developmental course of emotional, cognitive, behavioural, social and school adjustment in childhood and adolescence.

15. Childhood development is partially influenced by both environmental and biological factors. The Québec Study of Newborn Twins (QSNT) gathers data on childhood development in order to distinguish between the two categories of influence as well as to identify future interactions between environmental and biological influences. Children are met with at age 5, 18 and 30 months and evaluated through a series of behavioural and physiological measures. Parents are also evaluated through measures of parental behaviour and attitude. The QSNT is funded by the National Program for the Research of Health Development, Health Research Fund of Québec and Québec Council for Social Research.

16. Prior to its cessation, the National Longitudinal Survey on Children and Youth (NLSCY) was Canada's major source of longitudinal data on young people. The NLSCY tracked the progress and development of children from birth through early adulthood, and was meant to identify factors influencing each child's development. Specific areas of study included emotional, social and behavioural development and their implications for the child in adulthood. The NLSCY involved observations of physical development and overall health, learning ability, behavioural tendencies, family and friend structure, and the type of school and community in which the child was raised.

17. The benchmarks for the Atkinson Centre *Early Childhood Education* report were established following an extensive review of monitoring tools developed in Canada and internationally, and in consultation with experts involved in the development of these measures. Nineteen benchmarks were selected and populated using available data compiled from past environmental scans, an analysis of government publications and reports, Statistics Canada data and custom runs from the National Longitudinal Survey of Children and Youth, and the Labour Survey. Provincial/territorial profiles were created using the above data, supplemented by a survey of and interviews with provincial and territorial officials. Draft profiles were provided to officials for comment. Four seminars also helped inform the content of the report.

18. SNAP,® which stands for Stop Now And Plan, is an evidence-based, cognitive behavioural, gender-specific model. It provides a framework for teaching children struggling with behaviour issues, and their parents, effective self-regulation (emotional regulation, self-control and problem-solving skills). The primary goal of SNAP® is to keep children and youth in school and out of trouble by helping them make better choices "in the moment."

    SNAP® seeks to:

    - increase emotion-regulation and self-control skills in children and their parents
    - reduce aggression, bullying, anxiety and antisocial behaviour
    - increase social competency
    - improve academic success by reducing behavioural issues at school
    - connect children and parents to community-based resources
    - prevent delinquency, school drop-out and teen pregnancy.

    Thirty years of rigorous SNAP® research has achieved the highest standard of scientific and clinical excellence with more than 15 years of implementation experience.

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Appendix A
Major Data Initiatives

- Atkinson Centre for Society and Child Development
- Canadian Child Welfare Research Portal
- Canadian Council on the Social Determinants of Health
- Canadian Healthy Infant Longitudinal Development (CHILD) Study
- Canadian Institute of Child Health
- Centre of Excellence for Early Childhood Development
- Childcare Research and Resource Unit (CRRU)
- DEVOTION (Manitoba DEVelOpmenTal Origins of chronic diseases In children Network)
- Encyclopedia on Early Childhood Development
- First Nations Information Governance Centre
- Healthy Child Manitoba
- Human Early Learning Partnership (HELP)
- *L'Observatoire des tout-petits*
- Offord Centre for Child Studies
- PrevNET
- SNAP®
- Strategic Knowledge Cluster on Early Child Development
- UNICEF Canada

Additional sources of data
- Statistics Canada
  - Census
  - General Social Survey
  - income data
  - poverty data
- Canadian Institute for Health Information (CIHI)
- Public Health Agency of Canada
- provincial/territorial statistical agencies
- provincial/territorial strategies on child health and well-being

Appendix B
Key Informants

Key informants from across the country, including federal officials and from Indigenous organizations, were interviewed for this study. In addition, the following key informants participated in interviews and provided invaluable feedback and comments on a draft document. As this was a limited feasibility study, the key informants reflect a broad range of work and opinion but do not represent an exhaustive list of researchers working on child data in Canada.

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Appendix C
Feasibility Study Questions

Selected key informants were interviewed around the following issues:

- stakeholders' current work with respect to child data
- identification of other organizations and researchers collecting data related to child well-being
- the need for a national child data strategy to consolidate information and determine gaps (e.g., Indigenous children; child welfare)
- how a national child data strategy might dovetail with and contribute to work currently under way in Canada
- the scope of the initiative in terms of the age of children and substantive content areas
- major gaps in data
- problems in data collection and/or comparability.