



# Performance Measurement in Infant and Early Childhood Mental Health and Well-Being in Canada

Key Messages and Resources from a Rapid Scoping Review

Mental Health Commission of Canada mentalhealthcommission.ca

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## **Executive Summary**

In the fall of 2020, the Mental Health Commission of Canada (MHCC) conducted a rapid scoping review (as part of its early childhood mental health project) to examine population-level performance measurement on mental health and well-being for the infancy and early childhood (IEC)\* period in selected high-income countries and Canadian jurisdictions. A key project aim was to describe the state of policy and practice around performance measurement and to identify opportunities for pan-Canadian population-level performance measurement for this group. Information was synthesized systematically from scientific and grey literatures with a focus on the past five years. The project was designed to build on the broader work reported in *Measuring Progress: Resources for Developing a Mental Health and Addiction Performance Measurement Framework for Canada*, which the MHCC published in 2018.¹ In addition to some special considerations, brought about by the COVID-19 pandemic on the measurement of mental health and well-being in this age group, the following broad messages emerged from the materials reviewed.

#### Key messages

- The knowledge base about the associations between mental health-related states, behaviours, and adversity in the IEC period, on the one hand, and poor outcomes at subsequent life stages, on the other, is solid and is informing the design and refinement of interventions.
- 2. Effective interventions for the prevention, early intervention, and treatment in the IEC age group are available, and related knowledge about implementation is also accumulating daily. However, myths to the contrary persist on both counts, and policy and practice implementation is falling far behind the science.
- 3. Population-level performance measurement in child and youth health, and well-being more broadly, has a long history in many countries. The number of indicators used (and proposed) for child and youth health and well-being is very large, and "indicator chaos"<sup>2</sup> is evident.
- 4. Despite the large number of indicators, even for IEC, serious gaps in indicator sets are being reported in most jurisdictions, which effectively makes mental health and well-being-related issues for this age group invisible. Arguably, the most glaring gap is the lack of measures for the early IEC-parent relationship despite the strength of science on this aspect of IEC mental health and well-being.
- 5. Serious gaps in IEC measurement are present for important subgroups of infants and children as well as for the quality of interventions and their outcomes.
- 6. Emerging issues (including the COVID-19 pandemic) were noted that will need to be considered and planned for in any pan-Canadian performance measurement initiative for the IEC group or for child and youth mental health and well-being more generally.

<sup>\*</sup> The initial focus for this work was ages 0 to 6, but since the views in the literature were that the antenatal and perinatal periods were also critically important, we included them. There was variation on the upper bounds for IEC mental health as well, with 0 to 3, 0 to 4, 0 to 5, 0 to 6, and 0 to 8 years categories all used in the literature reviewed.

- The scarcity of mental health- and well-being-related indicators for the IEC age group is not due to
  a lack of possible measures on the concepts of interest or a deficiency of knowledge about how to
  collect the data.
- 8. Provincial and territorial mental health policy documents recognize the importance of mental health, both for the IEC age group and performance measurement more broadly. Yet only a minority of jurisdictions have current and specific child and youth mental health policies (that include Indigenous perspectives), which are necessary for advancing a population health approach to performance measurement. This lack of visibility on measurement for the IEC age group can make it a low priority for resource allocation decisions.
- 9. In Canada, there is an outstanding knowledge capacity for monitoring and measuring child and youth mental health and well-being. We have several centres of excellence and world-leading research teams working on child and youth mental health and well-being, as well as on IEC mental health and well-being and measurement.
- 10. Recently, several data-related advances and comprehensive initiatives in child health and well-being in Canada have provided important capacities, potentials, and opportunities for the progression of performance measurement in child and youth mental health and well-being (including the IEC group). Other than a few pockets of collaboration, these efforts are fragmented.
- 11. For nearly two decades, multiple research and practice leaders from human service sectors in Canada have stressed the importance, value, and need to have better performance measurement in child and youth mental health (including in the early years). Further, it is well understood that IEC mental health and well-being is critically contingent on the parent-child relationship; consequently, performance measurement should be as well.
- 12. Having a comprehensive performance measurement framework for child and youth mental health and well-being in Canada is overdue. Such a framework would need to leverage research, practice excellence, and advocacy networks and be developed in partnership with people with lived and living experience (including children, youth, and parents\*), policy makers (including provinces and territories), and Indigenous peoples.
- 13. The full potential of a pan-Canadian child and youth mental health and well-being performance measurement framework can only be achieved if an infrastructure and capacity for connecting existing stakeholders (including children, youth, and parents) and initiatives across the country is established for conceptualizing, sourcing, collating, analyzing, and reporting.

#### Summary and opportunities for the future

As a set of "big picture" findings, this rapid scoping review found an impressive knowledge capacity for performance measurement in child and youth mental health and well-being (including for the IEC age group). Also evident was a consensus among stakeholders that there are distinct gaps and we must do better for children and youth in Canada, especially for vulnerable and equity-deserving groups. There is an enormous potential to be among the most advanced countries in the world in this area if we broaden

<sup>\*</sup>The term "parent" refers to guardians/carers of all types, including people who are included by birth, marriage, kinship, or fostering. "Family" refers to close relatives of any persons included by birth, marriage, adoption, kinship, or fostering. "Father" refers more generally to the non-gestational parent.

collaborative efforts across organizations, provinces, territories, and communities and maximize our deep subject matter expertise in mental health and well-being measurement.

Recommended are (1) a collaborative pan-Canadian performance measurement *framework* for child and youth mental health and well-being (with balanced coverage of the IEC age group), (2) new data collection (either via national surveys and/or a longitudinal cohort study\*), and (3) a collaborative pan-Canadian performance measurement *system* that includes the capacity to focus advocacy, research, practice, and policy on improving the mental health and well-being of all Canadian children.

<sup>\*</sup> With Indigenous leadership of data collection for Indigenous families.

## Introduction and Background

Experiences in early childhood have lifelong implications for mental health, with increasing recognition that the failure to intervene has serious health and economic consequences.<sup>3</sup> Infancy and early childhood (IEC) mental health and well-being has risen to the top of public health and policy agendas in many countries.<sup>4,5</sup> For this age group, there are both striking similarities with older children (e.g., in prevalence of disorders\*,6-10) and striking differences (i.e., the greater degree of dependence on parents and greater challenges in measurement).<sup>11-13</sup> Despite the recognition of how important IEC mental health and well-being are for individual and societal outcomes, it has been generally observed that information to inform policy and practice in Canada is lacking.

This document reports on the findings of a rapid scoping review conducted in the fall of 2020 to examine population-level performance measurement on mental health and well-being for the IEC period in major developed countries and Canadian jurisdictions.

The project's main aims were to

- describe the state of performance measurement policy and practice for IEC
- identify opportunities for pan-Canadian population-level performance measurement for this group.

The information was systematically collected and synthesized from scientific and grey literatures published in Canada and similar countries, with a focus on the past five years. While the review was undertaken as part of the Mental Health Commission of Canada's (MHCC's) early childhood mental health project, it was grounded in the broader work reported in its 2018 report, Measuring Progress: Resources for Developing a Mental Health and Addiction Performance Measurement Framework for Canada.

#### Review methods in brief

Rapid scoping review methods were used to capture key information in alignment with six components:

- a rapid review of the recent scientific literature (666 abstracts, 81 articles, one textbook)
- a rapid review of the national and international grey literature (via general and jurisdiction-focused searches for Canada, Australia, New Zealand, the U.K., the U.S., and the EU) (143 documents or websites)
- a review of 19 provincial/territorial policy documents and indicator sets from the early childhood mental health project
- a quick poll of eight MHCC stakeholders for the IEC project, who had expressed an interest in performance measurement for this age group
- a quick poll of five international key informants, who the searches identified as leaders in their jurisdictions and as knowledgeable about other leaders and initiatives

<sup>\*</sup> The current prevalence of mental disorders for children and youth ages 4 to 17 from the 2014 Ontario Child Health Survey (OCHS) are estimated to be 18 to 22 per cent (see notes 6-8), worldwide, about 11 to 16 per cent (note 9), and for preschoolers, about 16 to 17 per cent (Norway, Denmark, and the U.S.) (note 10). Estimates typically do not include concurrent disorders and/or subthreshold conditions.

input on the draft report by seven research, parent, and policy-making experts

We defined *mental health* in a broad sense so that it includes well-being,\* in accordance with definitions by the World Health Organization (WHO)<sup>14</sup> and the *First Nations Mental Wellness Continuum Framework*. We defined *infant and early childhood mental health* as "the developing capacity of the child from birth to 5 years of age to form close and secure adult and peer relationships; experience, manage, and express a full range of emotions; and explore the environment and learn — all in context of family, community, and culture" (p. 1).<sup>†,16</sup> The analysis was guided by life course, population health, and social-ecological models. In keeping with the MHCC's early childhood mental health project, we defined *performance measurement* as the use of measures or indicators (qualitative or quantitative) to track change attributable to interventions with the aim of effecting positive improvements in meeting the needs of the population.<sup>17</sup> However, we acknowledge the lack of universal consensus on definitions and that other definitions with merit exist.

In terms of content, we included literature on performance measurement topics at policy, public health, service system, and practice levels across all child-serving sectors. Monitoring the health and development status of the IEC population was also included, as were IEC service system attributes such as quality and access. While we endeavoured to keep our focus on population-level performance measurement, much of the literature did not specify any level of measurement. Also, while socioeconomic status (specifically, poverty) were acknowledged as predominant overarching predictors of IEC mental health and well-being, we opted to concentrate on complementary performance measurement issues. In addition to the extensive coverage of socio-economic status elsewhere, <sup>18,19</sup> the MHCC and the Canadian Paediatric Society (CPS) are working on a policy brief about the impact of COVID-19 on young children, which will take this topic into account. <sup>20</sup>

The project's time frame and budget constrained the collection, collation, and review of materials. As such, while the broad findings reflect the materials reviewed, this report's coverage of the topic should not be considered complete.<sup>‡</sup>

Because the emphasis was on population-level IEC performance measurement, this report covers the international and national contexts and only the broadest provincial/territorial initiatives. These context sections are followed by an elaboration of each key finding. The final section summarizes and offers suggestions for advancing high-level performance measurement opportunities in Canada.

<sup>\*</sup> The conceptualization and measurement of "well-being" varies. While usually measured as a broad notion encompassing many life domains, including mental health, sometimes, particularly for the IEC age group, more direct indicators of mental or emotional health and development are absent. Well-being has also been operationalized as a single concept that is measurable at the individual level by either single- or multiple-item measures. Important distinctions between well-being, mental wellness, and mental illness must be addressed in any performance measurement initiative in children and youth, including the IEC age group.

<sup>&</sup>lt;sup>†</sup> The initial focus for this work was ages 0 to 6, but since the views in the literature were that the antenatal and perinatal periods were also critically important, we included them. There was variation on the upper bounds for IEC mental health as well, with 0 to 3, 0 to 4, 0 to 5, 0 to 6, and 0 to 8 years categories all used in the literature reviewed.

<sup>&</sup>lt;sup>‡</sup> See Resource A (published separately) for full details on the methods used.

<sup>§</sup> See Resource B (published separately) for more specific information on all the relevant provincial/territorial initiatives identified.

## International and national contexts for IEC mental health performance measurement

#### **Cross-country initiatives**

There has been substantial cross-country work in broader child and youth health measurement for decades. An index of child well-being for Europe, published in 2009, included 43 indicators in 19 groups. Yet very few indicators in these sets were specific to IEC mental health, other than perinatal (e.g., infant mortality and birth weight) or social-environmental measures (e.g., unemployment and poverty). Also in 2009, an OECD (Organisation for Economic Co-operation and Development) report on child and youth health data in 30 countries documented the paucity of data for both the prenatal period and early childhood for most nations, noting that the usual indicators for that age group are birth weight, immunization rates, mortality, and breastfeeding. It also identified the absence of breakdowns by Indigenous and other ethnic group status, which hampers efforts to improve equity. In addition, a 2009 UNICEF paper, describing further conceptual work on indicators of child well-being (and the need to balance positive and negative indicators), expressed the concern that, while "indicators are often collected within silos, such as education only or health only, it is widely recognized that well-being incorporates numerous domains" (p. 17). The report also mentioned that, since "young children in early childhood and of primary school age are under-represented in international data sources. . . . a portrait of positive well-being among young children is not available" (p. 24).

A later work (2016) examined developments in more direct measurement of child and youth mental health for cross-country comparisons, <sup>27</sup> but all measures described are for older children — since "measures are generally adolescent-focused and young children are under-represented in international data sources" (p. 107). <sup>28</sup> A 2018 report specific to early childhood well-being (defined as ages 0 to 4) by the Nuffield Trust and the Royal College of Paediatrics and Child Health exemplified this problem. <sup>29</sup> Indicators for 14 countries (including Canada), while packaged as reflecting health and well-being, included only perinatal health, mortality, immunization, breastfeeding, obesity, cancer, heart disease, injury, and neural tube defects; it contained no direct measures of IEC mental health or well-being.

Also in 2018, Alemán-Díaz et al. reported on broader child health data in 53 countries<sup>30</sup> while focusing on issues such as childhood obesity, immunization rates, and exposure to violence. The authors noted that more than 3,500 indicators were available for them to consider. They also expressed much concern about the patchy nature of measurement for mental health (mostly in relation to youth), despite stating that it is an important issue. While many mental health-related indicators were reported from the multicountry <a href="Health Behaviour in School-Aged Children">Health Behaviour in School-Aged Children</a> (HBSC) survey, none covered the IEC period. This work also identified gaps in data for vulnerable groups (examples given were children in institutional care, ethnic minorities, and immigrant children).

Two relevant works from 2020 were also found. The first was an OECD report on cross-country data about five-year old children from Estonia, England, and the U.S. This study focused on aspects of development and learning that were able to predict later educational outcomes and well-being in four domains: literacy, numeracy, self-regulation, and social-emotional skills.<sup>31</sup> Using direct measurement as well as parent and teacher ratings, it demonstrated (in the context of a research project) that measures could be standardized and administered in very different cultural contexts.

The second study, from UNICEF, examined well-being with a stronger emphasis on mental health across 41 high-income countries (including Canada, for some indicators). The report identified "life satisfaction" as the closest available individual measure of well-being, but it was only reported for age 15, and many countries (including Canada) did not use it. The authors noted that there were "no reliable, comparable data on children's mental health across this set of rich countries" (p. 3), 33 with measurement focusing only on adolescents. They also identified gaps both in children's positive sense of well-being and flourishing and in mental ill-health (other than suicide). The study included several socioeconomic context indicators, but just one was both direct and specific to the IEC period (the proportion of children in early learning and care). It was the only report recent enough in the international materials to discuss early indications of the impact of the COVID-19 pandemic on children and youth. With respect to mental well-being, the authors noted that the "existing children's mental health crisis will probably intensify. The experiences of lockdown, bereavement and ongoing strains on family relationships of economic uncertainty can damage many children's mental well-being. Children may feel anxious, insecure and fearful for the future" (p. 57).<sup>34</sup>

In summary, even now, international comparison initiatives are very limited in terms of measures for child and youth mental health and well-being across all age groups — and extremely limited for the IEC period. While benchmarking with other countries would be ideal, choosing indicators based on their availability across countries will result in gaps and biases that can detract from pursuing the most meaningful indicators within a country. In any case, it will likely be a very long time before enough countries are measuring comparable and more direct indicators of mental health and well-being in the IEC age group.

#### Country-level initiatives in selected other developed countries

#### **AUSTRALIA**

Based on information found online, governments and research organizations in Australia have been very active at national and state levels in broader child and youth health reporting. The Australian Research Alliance for Children and Youth has been reporting health indicators since at least 2008, with the most recent report in 2018.<sup>35</sup> Their work includes several indicators relevant to early childhood, including those related to the early learning and care setting.\*

In 2011, the Australian government produced a *National Framework for Universal Child and Family Health Services* for ages 0 to 8.<sup>36</sup> This broader report covered services from the antenatal period (including father-inclusive services), promotion, and prevention and included very specific indicators for particular programs. For IEC, the measures were heavily weighted toward perinatal outcomes, but the overall framework was laudable for its integration of performance measurement. It also updated progress toward "national performance monitoring and the compilation of national population health data for the purposes of comparison across jurisdictions and subpopulations" (p. 13).<sup>37</sup> "Headline" indicators from this work were reported as recently as 2018, and in 2019 the current government released a *National Action Plan for the Health of Children and Young People: 2020-2030*.<sup>38</sup> The framework also strongly emphasized a life course approach, including early years and the importance of

\* These indicators, and those relevant to IEC from the materials found for all other countries (including Canada), are provided in a separate document (Resource C).

early intervention. In addition, it made reference to other strategies (e.g., early learning) and indicator sets.

A set of very comprehensive indicators, released in 2020 under the title *Australia's Children*, consisted of seven domains, including a few that are relevant to IEC.<sup>39</sup> This work also identified data gaps and priority groups while underscoring the need to revise existing indicator sets and also develop new indicators, data collection processes, and child-focused data platforms. With respect to measurement more specifically, Australia's recurring population-based survey of child and adolescent mental health and well-being only covered ages 4 to 17, which results in a blind spot with respect to IEC mental health.<sup>40</sup> One other Australian framework, specific to IEC mental health performance measurement, was a 2015 literature review by the Victorian state government, called *Assessment of Wellbeing in Early Childhood Education and Care*, which focused on the 0- to 5-year age group.<sup>41</sup> Its target audience primarily consisted of child-care providers, and while it was mostly applicable to service- or program-level performance measurement, it did cover measures in five domains that may also have utility at the population or system level.

During our brief poll of international key informants, Brad Morgan, the director of Emerging Minds reported that work is underway in New South Wales on a mental health service outcomes scale for infant mental health, based on HoNOS (the Health of the Nation Outcome scales). Their group is also currently reviewing possible national-level indicators for this age group.

#### **NEW ZEALAND**

New Zealand, like other countries, has been working on advancing the measurement of child and youth health more generally for many years. Still, in a 2007 Pediatric Society of New Zealand report on the development of a child and youth framework, besides the usual social environment measures (e.g., income and education, teen pregnancy, household crowding), the only direct mental health-related measures were self-harm and suicide, and these applied only to youth and older ages. <sup>42</sup> The authors noted the paucity of data for disability and mental illness relative to the public health importance of these conditions.

Specific to measuring the outcomes of mental health services, the Health Research Council of New Zealand reported some very laudable work (albeit dating back to 2004), that examined the use and acceptability of measures in mental health services. While mostly aimed at the service level, the work involved Indigenous perspectives in ways that are rarely seen. Not only did it examine the acceptability of common tools such as the Strengths and Difficulties Questionnaire (SDQ) and the Child Behavior Checklist (CBCL) for the Māori people, it also reported on the development and use of a health status-related outcome tool (the Hua Oranga), which aligns with Māori conceptions of health and well-being. While the Hua Organa is not specific to young children, this work offers valuable lessons on the use of culturally relevant and appropriate measures and indicators.

Developments in New Zealand in the past decade included a multi-stakeholder initiative called Every Child Counts, which emphasizes the importance of the first 1,000 days of life and seems to have arisen out of early nutrition initiatives.<sup>44</sup> The initiative advocates for investing early, especially with vulnerable children, and intervening to support positive development. The importance of collecting high-quality information on children's well-being is also emphasized. A report on applying 1,000 days concepts and principles at the community level on the South Island illustrates how a comprehensive set of indicators

can be embedded in a cultural context and be used to guide policies and programs. Progressive measures relevant to IEC mental health included SDQ screening, starting at age 3. The report's aspirational IEC mental health indicators included a measure of well-being under age 2, along with measures of positive parental mental health, secure attachment and loving family relationships, opportunity for play, baby-friendly environments, and quality of early childhood services. This report also referenced the ongoing New Zealand Health Survey, which includes some content for children ages 0 to 14, as reported by their parent or caregiver.

In our international quick poll, University of Auckland associate professor Trecia Wouldes noted that work is underway in the national Well Child program to advance the measurement of key indicators of infant mental health across the country. Work is also underway to refine New Zealand's guidelines for child and adolescent mental health services so as to include clinical skills specific to infant mental health.

#### **UNITED KINGDOM**

The U.K. has had an outcomes framework for their Every Child Matters policy dating back to 2005. As with other countries the proportion of indicators specific to the mental health and well-being in IEC was small and included the usual indirect measures common in developed countries at that time. In 2009, Action for Children and the New Economics Foundation produced *Backing the Future: A Guide to Measuring Children's Well-Being*. Its authors saw the widespread adoption of social and psychological measures for children as essential:

As well as the structural conditions affecting the circumstances of children's lives (e.g., poverty, inequality), the psychological and social aspects of children's well-being are also vital for improving outcomes. In order to effectively track the difference our services are making and the wider community benefits that they are generating, *Backing the Future* argues that more meaningful measures of progress need to be developed at [the] national level, at [the] local level and at the service or project level.<sup>47</sup> (p. 1)

The authors also contended that the measurement of childhood well-being had largely been based on objective (observable) measures like obesity rather than on how children experience their lives. Yet, while the report made important points, its solutions primarily related to the measurement of self-reported well-being in children ages 7 and up.

In a National Children's Bureau Research Centre's 2009 report, which covered the measurement of young children's well-being from birth to age 8, the proposed key domains were physical well-being; mental, emotional, and social well-being; cognitive and language development and school performance; and beliefs. While indicators related to mental health are included in more than one domain, for the mental, emotional, and social well-being domain they recommended trying to capture how children act, behave, feel, communicate their feelings, and get along with others, starting (at the youngest ages) with temperament and regulation. The authors noted that children are able to discuss themselves in simple terms beginning at age 4. The document also covered measurement instruments in extensive detail.

Public Health England published the *Measuring Mental Well-being in Children and Young People* report in 2015.<sup>49</sup> Although covering a wide age range, unlike others documents from the U.K. where early childhood is understood as ages 0 to 8, it defines the early years as 0 to 5. In addition, because it was focused on self-reporting, its list instruments were only suitable for ages 8 and up.

Several documents from other countries praised the national indicator set for children and young people's mental health developed in Scotland. Work on this framework and set of indicators began in

2011 with measures covering mental health problems and well-being as well as associated contextual factors (from individual to system levels).<sup>50</sup> In 2013, Scotland reported on most of the 109 indicators that had been developed and subsequently transferred reporting on some of them to ScotPHO (a collaboration of public health agencies).<sup>51</sup> Current indicators directly relevant to the IEC age group are collected only on ages 4 and up (most based on the SDQ).

#### **UNITED STATES**

In the U.S., a broad agenda to influence policy and practice for IEC mental health has been advanced by the Zero to Three initiative. This work has identified gaps in general understanding (e.g., the myth that mental health problems do not occur in this age group, along with the potential harms of "wait and see" approaches by providers), while clearly pointing out that effective interventions are available. The initiative has also identified system problems, such as the single-funding-silo approach that has hampered effective planning and intervention. While our quick review found several documents that recommended specific policy approaches, it did not find any that were more specific to performance measurement. Another organization with a high profile in championing the importance of early childhood mental health is the Harvard University Center on the Developing Child. Its focus is to conduct and summarize research on mental health and related developmental issues and program-level effectiveness for this age group and to advocate for relevant policies such as paid parental leave. However, quick searches of their website found no documents specific to population-level performance measurement.

The Federal Interagency Forum on Child and Family Statistics reports annually on a set of 41 national indicators on child well-being across seven domains: family and social environment, economic circumstances, health care, physical environment and safety, behaviour, education, and health.\*,52 Although the indicators for the IEC age group are quite traditional (e.g., socio-economic context and traditional perinatal statistics), a more direct indicator does exist: emotional and behavioural difficulties for ages 4 and up. Most indicator data are broken down by age, gender, race, and poverty status, a set which allows for some examination of equity issues.

In our brief poll of international key informants, University of Vermont professor William Copeland reported that there is a limited sense of the scope of mental health issues for the IEC age group. Currently, not only is there no nationwide surveillance for early childhood mental health, there are no nationally representative studies of the problem, no characterization of unmet needs, and no likelihood of receiving services consistent with best practice. According to Jennifer Boss and Kathleen Mulrooney, key informants from Zero to Three, leading edge practice initiatives in the U.S. include the use of mental health consultants and the Pyramid Model for Supporting Social and Emotional Competence in Infants and Young Children in state systems of early learning and care. They also pointed to the Maternal and Child Health Bureau's<sup>†</sup> work on mental health consultation, including how consultants can assist with maternal depression in child care and home visiting contexts, but did not comment on IEC mental health and well-being performance measurement specifically.

<sup>\*</sup> Data for 2020 were collected and reported before the COVID-19 pandemic.

<sup>&</sup>lt;sup>†</sup> The MCHB is part of the Substance Abuse and Mental Health Services Administration's (SAMHSA's) Center for the Study of Social Policy.

This brief scan of initiatives in countries like Canada revealed some progressive activities but not much advancement in the more direct measurement of mental health and well-being for infants and preschool children. While the indicators used are important, they are relatively traditional perinatal and socio-economic measures. Even within countries there appears to be no consensus either about the measurement of child and youth mental health and well-being or about framework parameters, domains, and indicators.

The Canadian policy context for IEC mental health and well-being performance measurement Federal-provincial-territorial child and youth mental health policy initiatives go back many years. Over the last decade, one distinct policy milestone was the MHCC's pan-Canadian policy framework for child and youth mental health (the Evergreen Framework), from its child and youth advisory committee in 2010.<sup>53</sup> The report provided high-level strategic directions for policy and practice based on extensive consultations, which included families and youth. It emphasized promotion, prevention, and early intervention and presented examples of progressive practice for the IEC age group, including screening in well-baby/child health visits and training for providers of health care and early learning and care services. While the report did not specify performance measurement approaches, it offered a pan-Canadian perspective and shared values that could be used as a foundation for a child and youth mental health performance measurement framework with relevant indicators for IEC mental health and well-being.

In the decade since the Evergreen Framework was released, relevant policies have evolved in all provinces and territories. Content relevant to mental health and addiction priorities, and performance measurement more broadly, was reviewed in depth in the Measuring Progress project. For the current project, that review of 19\* policy documents was updated and briefly revisited using an IEC mental health and well-being performance measurement lens. The following key findings reflect its recognition of the importance of mental health and well-being, policy actions, and IEC performance measurement:

- All 13 jurisdictions acknowledge the importance of healthy families and children and the importance of promotion, prevention, and early intervention.
- Only four jurisdictions had a recent child and youth mental health-specific policy; of those, only two were current (i.e., released in the past five years).
- Documents for 10 jurisdictions included mental health in the early years as a specific policy priority.
- Only four referenced Indigenous perspectives in relation to the early years age group.
- Ten named specific interventions for this age group, but in most cases they were provided as examples rather than specific actions to be taken.
- Where specific interventions were mentioned, there was little consistency across jurisdictions.
- Most documents noted the importance of performance measurement more generally, but none elaborated on more than one or two IEC-specific measurement aims.

<sup>\*</sup> The number of documents reviewed (19) exceeded the number of policies developed in the provinces/territories (13) because some provinces/territories had separate policy documents for child and youth and for adults, separate policy documents for Indigenous peoples, or companion strategy documents.

<sup>&</sup>lt;sup>†</sup> The list of documents is provided separately in Resource A.

Overall, only three jurisdictions had a more specific current child and youth mental health plan, saw
the IEC age group as an important or specific priority, and included an Indigenous lens in the
framing of the policy.

The mental health and addiction performance measurement indicator frameworks proposed or in use in the provinces/territories (and identified in the 2018 Measuring Progress project) were also revisited using the IEC mental health and well-being lens. At that time approximately nine per cent (16 of 182 indicators) were relevant to the IEC age group (other than general socio-economic indicators); of these, only six (3.3 per cent overall) were specific to that group.

PAN-CANADIAN INITIATIVES RELEVANT TO IEC MENTAL HEALTH AND WELL-BEING PERFORMANCE MEASUREMENT Important content relevant to the population-level measurement of mental health and well-being for the IEC group was found in many documents at the pan-Canadian and provincial/territorial levels. In this section pan-Canadian initiatives are described along with a few provincial/territorial initiatives judged to have broader relevance for countrywide advancements in performance measurement.\*

In 2011, the CPS early years task force released their recommendation that primary care providers and public health nurses provide an enhanced visit at 18 months of age (including potential screening instruments). The Among its specific recommendations was a "comprehensive system of measurement and monitoring that collects appropriate data on the progress of Canada's young children and their families" (p. 649). In a later report on broader child and youth health, the CPS recommended that the implementation status of the enhanced 18-month well-baby visit be a performance indicator across all provinces and territories. The task force also released a statement on measurement in support of early childhood development, which outlined four approaches: the Early Development Instrument (EDI) suite of measures, longitudinal surveys, longitudinal administrative data linked to EDI data, and broader well-being indexes. Aside from longitudinal surveys and well-being indexes (which still lack more direct measures of mental health for the IEC period), some progress has been made at the pan-Canadian level.

In 2014, the Royal College of Physicians and Surgeons of Canada called for increased funding for early life interventions, along with a recommendation similar to that of the CPS for a "robust collection, monitoring and reporting system on early childhood" (p. 2).<sup>59</sup> The Infant Mental Health Promotion team at Toronto's Hospital for Sick Children also advanced the country's discourse in its *Embedding the Science of Infant Mental Health in Practice and Policy* report, published in 2015.<sup>60</sup> The report identified concerns about the public and professional understanding of infant mental health as well as the gaps in care and information, including a lack of consistent screening across sectors and a lack of data on prevalence and program effectiveness. Also in 2015, a working paper by the Canadian Council on the Social Determinants of Health (CCSDH) on improving healthy child development summarized themes from 12 Canadian leaders with a focus on ages 0 to 3.<sup>61</sup> Among other strategies, it recommended standardizing screening tools and assessments and collecting longitudinal data on children ages 0 to 3.

<sup>\*</sup> A list of all relevant provincial/territorial initiatives is provided separately in Resource B.

<sup>&</sup>lt;sup>†</sup> The Early Development Instrument is a tool for systematic teacher ratings using items in five domains: physical, social, emotional, language/cognition, and communication skills/general knowledge. Developed collaboratively in Canada and widely used in provincial/territorial policy documents and in other countries, EDI allows for population-level reporting on readiness for school (and is not an individual-level diagnostic tool). Similar instruments have now been developed for toddlers (TDI), children in middle school (MDI), youth (YDI), and for parent reports.

Followup work by the CCSDH in 2017 outlined lessons learned from community-based interventions for this age group across the country.<sup>62</sup>

For many years an area of particular strength in Canada has been early childhood education policy. Highlights include an early learning accord across the provinces and territories among the Association of Canadian Deans of Education in 2013<sup>63</sup> and strong work toward connecting early learning to later learning in a coherent model and curriculum.<sup>64,65</sup> In terms of performance measurement, there were regular reports of policy progress on 19 early childhood education measures in areas such as governance structures, funding levels, access, quality of early learning environments, and accountability.<sup>66</sup> Across Canada, however, only 53 per cent of children under age 5 are enrolled in formal early childhood education,<sup>67</sup> which points to the importance of ongoing measurement in the IEC age group for those with and without access.

In 2017, the Caledon Institute of Social Policy released the results of a feasibility study on a national strategy for child data (with "child" defined as ages 0 to 18). The gaps identified in the report include data on early childhood (including the prenatal period), mental health and perceived well-being, children with disabilities, Indigenous children, refugee and immigrant children, children in care, and early learning and care programs and their quality. The report recommended building on the excellent data initiatives already present in Canada.

While not specific to early childhood, some recent Indigenous data initiatives have important implications for child and youth mental health and well-being performance measurement. In 2018, the First Nations Information Governance Centre released its most recent *National Report of the First Nations Regional Health Survey*. <sup>69</sup> A total of 24,000 people in 250 First Nations communities were surveyed, in alignment with OCAP principles,\* using the *First Nations Mental Wellness Continuum Framework*. <sup>70</sup> The survey included data on IEC (broader health) via parent/caregiver reports and many traditional indicators such as birth weight, immunization, and injury. Also included was content on early learning, in particular the collection of culturally relevant indicators such as traditional foods and the use of traditional medicine. The issues of population-based data collection in Indigenous communities and its historical harms have been well-articulated by leading researchers in Canada. In response, the report offers solutions that include changing how and what is measured. <sup>71</sup>

In 2019, the National Collaborating Centre for Indigenous Health published *Indigenous Early Childhood Development in Canada: Current State of Knowledge and Future Directions.* The report included statistics for a broad range of health and social indicators, including data for Indigenous children under 6. It also identified several gaps, such as a lack of disaggregated data for specific subsets of Indigenous peoples, longitudinal data, culturally-relevant indicators, and consistent Indigenous identifiers.<sup>72</sup> In addition, the report reviewed the intersectoral interventions for this age group that have been used with Indigenous communities. The movement toward Indigenous data sovereignty (defined as the right to govern the collection, ownership, and application of data) is also growing in Canada and among Indigenous groups around the world. The issues are complex, but the continuing dialog and process around everything from reconceptualizing datasets (e.g., away from the chronic deficit framing that has characterized past

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<sup>\*</sup> OCAP refers to a set of principles described by the First Nations Information Governance Council for First Nations' ownership, control, access, and possession of data.

efforts) to collection, management, and reporting-leadership<sup>73</sup> are important advancements for all Canadians.

A broad set of well-being indicators for all ages is reported on by the Canadian Index of Wellbeing Centre at Waterloo University, but there are no mental health-related measures for those under age 12.<sup>74</sup> UNICEF Canada also recently produced a similar index for children and youth: the Canadian Index of Child and Youth Well-Being.<sup>75</sup> Although their set has 125 indicators, only a small minority relate to measuring younger ages and even fewer link directly to IEC mental health.

The Public Health Agency of Canada (PHAC) has surveillance systems that track some indicators broadly relevant to IEC mental health and well-being. They include perinatal health indicators (the most relevant of which would be maternal alcohol consumption during pregnancy), the Child Maltreatment Surveillance Indicator Framework (with several IEC-relevant indicators), and the First Nations and Inuit Health and Wellness indicators (with a very small number that are relevant to IEC). 76,77,78 PHAC has also advanced the measurement of mental health status more broadly with the Positive Mental Health Surveillance Indicator Framework. Indicators have now been reported for ages 12 to 17,79 and the development of positive mental health indicators for ages 1 to 11 is underway.

The Canadian Institute for Health Information (CIHI) also reports on hospital health service use for mental disorders for ages 5 and up.<sup>80</sup>

Statistics Canada published the results of an online and phone survey (2018-19) on maternal mental health in Canada, as one example of its rapid response survey function.<sup>81</sup> While it reported on important indicators of the parenting context for IEC — such as rates of feelings consistent with postpartum depression and anxiety, thoughts of self-harm, the availability of confidantes, substance use during pregnancy, and life satisfaction — there were no measures of IEC mental health (which would have been possible in a survey like this). In its 2019 Canadian Health Survey on Children and Youth, Statistics Canada broke down the findings by age group (including ages 1 to 4) and also collected information on Indigenous status.<sup>82</sup> Parents' ratings of their children's mental health for ages 1 to 4 were far below known epidemiologic estimates (only one per cent rated their children as having fair or poor mental health; see footnote, p. 1), which suggests that there were issues with terms, definitions, and/or respondent understanding. Overall, the survey content was weighted toward youth health issues, yet important groups of children and youth were excluded (i.e., children and youth on First Nations reserves and other Indigenous settlements and in foster care and institutions). The report did note the need for more health data, especially for those under age 12. This survey may also provide an important baseline for the mental health impacts of the COVID-19 pandemic for older children and youth, since (mostly less rigorously collected, crowdsourced) information reported in 2020 indicated that there was a range of such impacts. It is not yet clear, however, if the survey's assessment of them will be repeated.

In 2019, a PHAC discussion paper by leading researchers on early child development from across Canada summarized the results of the Canadian Institute of Child Health's\* 2018 profile, while contextualizing it by the research literature and recent Canadian initiatives. 83 The broad range of indicators and topics discussed included maternal and perinatal health, substance use, breastfeeding, parenting style,

<sup>\*</sup>The Canadian Institute of Child Health (CICH) has a set of more than 400 indicators on broader child and youth health. The Canadian Perinatal Surveillance System also regularly reports on physical pregnancy outcomes statistics but also on one key indicator for IEC mental health: alcohol consumption during pregnancy.

immunization, the built environment, family violence, children in care, recreation and play, and child care. The report also updated the status of the enhanced 18-month visit, which is still varies in terms of its jurisdictional implementation and the types of tools and providers being used. It also reviewed effective interventions for this age group and emphasized the importance of the social determinants of health. The authors underscored the gaps in this area, noting that "complete and up-to-date information on child well-being is lacking in several areas, including, most notably, for children in care and children with disabilities; uniform and consistent data collection and regular reporting of outcomes are essential for building a solid evidence base" (p. 36).<sup>84</sup> They recommended new partnerships for connecting research centres of excellence and had several specific suggestions on the need for a conceptual framework to prioritize indicators.

A report for the Canadian Children's Literacy Foundation, published in 2020, provided an in-depth look at children's literacy and its related societal and economic impacts. First among the many data-related issues the authors identified was the need for better data (especially longitudinal data). They also emphasized the critical importance of supporting parents and caregivers in the enrichment of home literacy environments, alongside socio-economic and early learning and care interventions.<sup>85</sup>

## PROVINCIAL/TERRITORIAL INITIATIVES IMPORTANT TO IEC MENTAL HEALTH AND WELL-BEING PERFORMANCE MEASUREMENT

The following provincial/territorial organizations have made important contributions to child mental health and well-being measurement in Canada. Together, with other initiatives and partners, they demonstrate the capacity in Canada for significant advancement of pan-Canadian child and youth mental health and well-being performance measurement, including for the IEC age group.\*

#### Specific to IEC

- All Our Babies/Families and APron pregnancy cohort studies University of Calgary, Cumming School of Medicine and Faculty of Nursing. These population-based longitudinal studies<sup>†</sup> (3,300 families and 2,200 families, respectively) have advanced understanding of early risk and development outcomes for a range of mental health and well-being measures, including biospecimens and advanced methods for engaging and retaining parents over time. They have also demonstrated that having an ongoing infrastructure enables the rapid assessment of impacts on emerging issues, such as the 2013 Alberta floods and COVID-19.
- Atkinson Centre for Society and Child Development University of Toronto, Ontario Institute for Studies in Education. A research centre that produces and promotes the best available evidence on early childhood development for policy and practice, including regular early childhood education reports.<sup>86</sup>
- <u>British Columbia Aboriginal Child Care Society.</u> This centre of excellence for Indigenous early learning and child care offers a broad range of training, resources, and services. Its 2019 report, Beyond Survival: A Review of the Literature on Positive Approaches to Understanding and Measuring Indigenous Child Well-Being, provides a thorough discussion of Indigenous

<sup>\*</sup> Additional provincial/territorial initiatives are listed separately in Resource B.

<sup>&</sup>lt;sup>†</sup> Longitudinal/prospective cohort data are no longer collected at the national level in Canada since the cancellation of the National Longitudinal Survey of Children and Youth in 2009.

- conceptualizations of well-being in young children, deficits versus strengths, and rights-based approaches for measurement.<sup>87</sup>
- Human Early Learning Partnership (HELP) University of British Columbia. This research team has been a world leader in the collaborative development and implementation of population-level school readiness and social-emotional development in the Early Development Instrument (EDI), which has informed policy and practice. The group continues to innovate with the development of instruments for the toddler and middle-years age groups and for parent reports. It also collaborated on the Canadian Neighbourhoods Early Childhood Development (CanNECD) study, which has linked more than 700,000 EDI records from children across Canada with other public data sources to allow for population-based analyses of social and environmental determinants of development.<sup>88,89</sup> In addition, HELP collaborated on PHAC's early childhood development report <sup>90</sup>
- <u>Infant Mental Health Promotion</u>\* **Hospital for Sick Children (Toronto).** This group has been a leader in advancing awareness and practice in infant mental health, contributing to knowledge translation activities in Canada and advancing leading practice work in Indigenous communities.
- Observatoire des Tout-Petits. A Montreal-based research centre dedicated to collecting and reporting information on development and well-being (including mental health) for infants and children 0 to 5 years old. The organization has produced several excellent reports that include multiple relevant indicators.
- Quebec Longitudinal Study of Child Development. A birth cohort study that has followed more than 2,000 infants since 1998. It is now entering its fourth phase of data collection as the young people reach ages 19 to 25.

#### **Broader organizations/initiatives**

- Children's Health Policy Centre Simon Fraser University. This research team has led excellent work on the development of a child and youth mental health performance measurement framework. This document has several meritorious attributes: it is grounded in science, it is based on a population health model (with the full continuum of interventions), and it considers user perspectives. Work on the framework has included an examination of available indicators by age groups (including early childhood) and the identification of important gaps. The centre has also led longitudinal effectiveness studies on interventions, such as the Nurse-Family Partnership, and has developed an effective model for policy-maker partnerships in B.C. In addition, it has collaborated on initiatives elsewhere in the country, such as on the Ontario Child Health Study (OCHS).
- <u>Institute for Clinical Evaluative Sciences</u> (ICES). The work of this Ontario research institute is much broader than child health, but it has led important work on development of service- and system-level indicators for child and youth mental health, including new indicators.
- Our Health Counts: Urban Aboriginal Database Research Project University of Toronto, MAP
   Centre for Urban Health Solutions, Li Ka Shing Knowledge Institute, St. Michael's Hospital.
   Investigators at this centre have led a groundbreaking community collaborative longitudinal study in several Ontario municipalities, which advanced the development of Indigenous-led measures, their selection (including capturing strengths and resiliency), and innovative data-collection approaches.

<sup>\*</sup> In January 2021, Infant Mental Health Promotion (IMHP) became Infant and Early Mental Health Promotion (IEMHP).

- Manitoba Centre for Health Policy (MCHP) University of Manitoba. While the work of this
  research centre is much broader than child health, it has been a leader in using linked
  administrative data to examine child and youth mental health issues for Manitobans. It has also
  collaborated with other organizations across the country.<sup>91,92</sup>
- Offord Centre for Child Studies McMaster University. This is the lead research organization for the Ontario Child Health Study (OCHS). The OCHS is a major survey of the mental health of children and youth ages 4 and up (and related topics, such as service use) that provides much-needed trend data. The Offord Centre also collaborates on previously noted initiatives.<sup>93-95</sup>
- Ontario Centre of Excellence for Child and Youth Mental Health. 87-90 This centre has produced several high-quality and influential scientific reports on mental health and well-being for the IEC age group. 96-98 These documents make the case for investments in interventions and for advancing the understanding of key measurement concepts, including self-regulation, temperament, resilience, attachment, positive caregiving relationships, play, and cultural considerations. The centre has also synthesized evidence and expert advice on interventions (including the formulation of a case for screening) and culturally appropriate and community-led adaptations for Indigenous peoples.

## COVID-19 DEVELOPMENTS RELEVANT TO IEC MENTAL HEALTH AND WELL-BEING PERFORMANCE MEASUREMENT In 2021, no report on public policy can be tabled without acknowledging the impact of the COVID-19 pandemic, including reports about young children and their families. The rapid activity around collecting and reporting impact data also has important implications for future population-level performance measurement for mental health and well-being for the IEC age group. This review (and additional focused searches) identified the following studies and surveys:

- An online B.C. government crowdsource survey for its population received close to 400,000 responses by May 2020. Households with children reported poorer mental health overall, including less sleep, more alcohol consumption, and extreme stress. 99 The sample was large enough to allow for breakdowns by geographic areas and ethnic minorities.
- In April 2020, researchers at the University of Manitoba and the University of Calgary published data from an online survey of 641 mothers (including expectant mothers) of children ages 0 to 8, which covered a range of maternal impacts related to mental health, risk and protective factors, and service use. The results showed elevated levels of maternal depression and anxiety compared to prior population prevalence. The findings, which were presented by age group (0 to 18 months, 18 months to 4 years, and 5 to 8 years), did not include measures on the mental health or well-being of the children.<sup>100</sup>
- A collaboration between University of British Columbia, University of Regina, and U.S. researchers
  resulted in the development and initial validation of COVID-19 stress scales for adults for more than
  3,000 participants in each country. No mention was made of a parallel scale for younger ages, but
  the study demonstrates the ability to rapidly mobilize measurement tools for emerging issues.<sup>101</sup>
- In May 2020, Toronto's Maximum City conducted an online, countrywide survey of children and youth ages 9 through 15 on the impact of COVID-19 on their well-being, including their behaviours, feelings, and experiences. While this study is another example of the internet's enabling force for collecting data quickly, once again, the data gap for young children is apparent.<sup>102</sup>

- A rapid review of the literature on the mental health consequences of previous pandemics and natural disasters by the Children's Health Policy Centre at Simon Fraser University concluded that rates of anxiety, post-traumatic stress disorder, depression, and behavioural challenges may be expected to increase due to COVID-19. It also found that there are likely to be disproportionate effects on Indigenous peoples, Asian-Canadians, children with disabilities or special needs, and those with prior socio-economic disadvantages. The review emphasized that addressing the mental health needs of children and youth (including tracking outcomes for children) is even more urgent and critical because of the pandemic.<sup>103</sup>
- Findings released from a December 2020 survey of 2,000 families conducted by the All Our Families and APrON cohorts documented serious concerns about the economic impacts on families: 20 per cent had lost all income sources, 58 per cent had declines in income, and 40 per cent experienced relationship tensions. For mothers, up to 35 per cent reported elevated levels of stress, anxiety, or depression; 20 per cent expressed concern about their children's behaviour and mood; and 80 per cent had difficulties managing daily activities. While the children's average age is now beyond the preschool period, outside these COVID-19 impacts the study illustrates the ability to examine longitudinal outcomes for those most at risk during the preschool years and, because of the sampling and data collection infrastructure already in place, to respond quickly to emerging issues.
- In May 2020, the Canadian Mental Health Association (National) surveyed a representative sample of 3,000 Canadian residents ages 18 and up about the pandemic's effects on the mental health of vulnerable populations. Higher proportions of parents reported poorer mental health in several domains for themselves, while 24 per cent said their children's mental health was worse.\* Both stressful interaction (e.g., more yelling, shouting, and worries about domestic safety) and positive interaction (e.g., showing love and affection more, and spending more quality time) were reported. But no information was reported by age group of the children. 105
- Statistics Canada reports on (1) perceived mental health (June 2020)<sup>106</sup> from a (repeated) web panel survey and (2) six-month social and economic impacts (September 2020)<sup>107</sup> aimed at the broad population provide insights into the pandemic context for the IEC age group. The survey on perceived mental health was conducted among people 15 and over across all provinces. While family stress from confinement and violence in the home was associated with the respondent's perceived mental health, the simple presence of a child or children in the household was not (after adjusting for other factors). With respect to social and economic impacts, the crowdsource survey documented parents' concerns for their children and families. Findings included worries about balancing child care, schooling, and work, which were lower for children ages 4 to 11 compared to younger and older age groups. Sedentary activity and screen time were only reported for ages 5 and up, but the impacts were greater, as would be expected, for families without home internet and families who have children with disabilities.
- Statistics Canada's Survey on COVID-19 and Mental Health (SCMH) is in the field during the time this report is being written.<sup>108</sup> It is being conducted via probability sampling of 30,000 adults (over 18 years old) in the 10 provincial/territorial capitals (not collectives or reserves) via electronic questionnaire or phone interview. The content includes self-reported symptoms of major mental disorders, substance use, and COVID-19 diagnosis, plus self-rated mental health, the sense of community belonging, coping, life satisfaction, and work status. Respondents are also being asked

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<sup>\*</sup> The survey also included questions for parents with children under age 18 living at home.

- about dependent children in the home (and their ages), parenting stress and behaviours, and household violence. Indigenous and other ethnic identity is also being collected, along with other demographic variables. While the parenting information is an advancement, again, there is no direct information on IEC mental health or well-being.
- Some key implications of these studies on mental health and well-being performance measurement for the IEC age group are noted here. First, while this is a small and very recent set of studies, the gap in information for IEC is apparent. Second, the information is ad hoc and patchy and is missing coverage of some important issues about the impacts on young children and families. Third, the opportunity for planned and coherent, proactive measurement overall was also missed, as were specific opportunities to measure impacts for the IEC group in surveys that could have easily included them. For example, neither Statistics Canada survey (2018 and 2019) had enough content on IEC mental health and well-being to serve as a baseline for comparing COVID-19 impacts in 2020 and beyond. Fourth, concerns have been repeatedly raised about potentially serious sampling and response biases associated with crowdsourced online surveys, especially for mental health-related topics and populations. 109 All these issues could have been addressed with a conceptual framework for measurement in child and youth mental health, along with the infrastructure for populationbased samples and data collection that would lead to a more rigorous and balanced assessment of emerging issues like COVID-19. Notwithstanding these concerns, this small set of studies illustrates how powerful the internet is as a tool for rapid, large sample, and efficient data collection and how rapidly measurement and measures can be mobilized when there is a recognized imperative.

#### Key messages from the review of scientific and grey literature

In addition to these observations on the performance measurement implications of the COVID-19 pandemic, 13 key messages arose from the materials reviewed.

- 1. The knowledge base about the associations between mental health-related states, behaviours, and adversity in the IEC period, on the one hand, and poor outcomes at subsequent life stages, on the other, is solid and is informing the design and refinement of interventions.
  - Much has been learned from research that includes both population-based, prospective pregnancy and birth cohort studies and special population-based studies about early child development, mental health, and well-being. Many studies were found, even in our recent selection of literature, that add to the knowledge base on refining risk and protective variables and to their associations with later outcomes in selected and general populations. Not only are many risk factors modifiable, early interventions have been shown to have long-term benefits (including economic) for children, their families, and society. Two very recent total population studies are enough to illustrate these associations between the IEC period and later mental health outcomes. In a Denmark study by Nilsson et al., 117 a random sample of 210 children and their parents (drawn from the Copenhagen child cohort) were assessed for their exposure to psychosocial adversity and persistent stressors up to the age of 18 months, using comprehensive, standardized, and diagnostic measures. Those who had been exposed (43 per cent) were found to have poorer cognitive development, behavioural regulation, attention problems, and symptoms of anxiety and depression. In a Canadian population-based study, Thompson et al. 118 analyzed data from nearly 35,000 B.C. children ages 5 through 14 (made

possible by linking EDI data to records from the ministries of Health and Education). The measures used demonstrated that social-emotional functioning (social competence, internalizing, and externalizing symptoms) at age 5 was related to elevated odds of physician-diagnosed mental health conditions (including depression, anxiety, conduct disorder, ADHD, and multiple conditions) between ages 6 and 14. The study documented a high prevalence of vulnerabilities at school entry as well as older-age adverse outcomes.

- 2. Effective interventions for the prevention, early intervention, and treatment in the IEC age group are available, and related knowledge about implementation is also accumulating daily. However, myths to the contrary persist on both counts, and policy and practice implementation is falling far behind the science.
  - Our rapid scoping review found more than 110 specific interventions (either mentioned or described) in the literature, even though it was not designed to systematically identify them. These interventions were comprehensive, from the policy level to local clinical practice, across the full range of populations from health promotion (i.e., universal, targeted, and selective prevention, early intervention and treatment). It included public awareness and screening as well as primary care and community- and home-based programs. Innovation was evident in programs like (1) early literacy (including in primary care), (2) universal or targeted parenting programs (such as digital formats for ages that include the youngest infants and in-service settings like the neonatal ICU), (3) programs for staff training and quality improvement in early learning and care, (4) consultation models, (5) home visiting, (6) integrated service models, (7) parent-child treatment approaches, and others. We identified all individual studies, reviews of studies, and databases listing specific intervention details and evidence (including in the Canadian context). 119-143,\*

To mention just one example, McLuckie et al.'s scoping review of 162 articles on infants and preschoolers at risk for socio-emotional difficulties included all intervention types (universal, selective, indicated), prevention and treatment, and multiple modalities: parenting groups, educational, in-home, cognitive behavioural therapy, and child care/early learning-based interventions. <sup>144</sup> Increasingly, approaches use the parent-child relationship as the change mechanism. One key message was that the role of fathers has been neglected in this space, but several father-inclusive approaches were described in its set of abstracts.) <sup>145</sup>

Other comprehensive reviews of intervention effectiveness have been published by the National Academies of Science, Engineering, and Medicine in the U.S. and by Australia's National Health and Medical Research Council. 146,147 The U.S. report notes strong evidence of benefits to children for parenting skills, attachment programs, and depression treatment in the perinatal period. The Australian study lists perinatal education and support, parent sensitivity and attachments, and neonatal behavioural assessment interventions as suitable for universal implementation. Home visiting and parenting interventions for preterm and low birth weight infants were deemed suitable for targeted implementation. This review includes detailed recommendations on instruments and assessment practices for this age group. It also

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<sup>\*</sup> This set of intervention studies and reviews is by no means exhaustive. While a preliminary list of the interventions has been compiled, a more complete and detailed inventory was beyond the scope of the project.

identified a need to "standardise definitions and outcomes for assessing infant social and emotional development and wellbeing, along with a need for agreement on the preferred scales/tools to measure these outcomes" (p. 125).<sup>148</sup> While every review points out that not all interventions have fully documented effectiveness (especially recent innovations), an encouraging number do.

A notable depth of analysis was found on the topic of screening and early identification, including in primary care, broader health care, child care, preschool, and home settings. Screening has been recommended by the early learning and care sector and by the health sector. Concerns, as well as necessary and best practice screening solutions, are well articulated. These include ensuring the capacity for followup on positives (and access to effective interventions), the implications of false negatives, quality control, and ensuring equity, among other principles. Evidence from two population-based surveys in the U.S. showed that developmental screening with monitoring for well-child visits in early childhood improved the subsequent receipt of mental health services. Research is also illuminating the best tools and approaches and how to get beyond initial screening to secondary triage and family engagement in various settings. And the care of the topic of the settings and family engagement in various settings.

Although a disappointingly small number of interventions (including screening) have addressed cultural suitability or appropriateness, we found several models of Indigenous-led and/or culturally adapted interventions, including exemplary approaches in Canada and elsewhere that use more progressive co-design, resiliency, and strengths-based approaches. More is being learned from Indigenous community leaders and researchers about community engagement for successful implementation. Connections to international knowledge networks of culturally appropriate interventions are also increasing. As Smylie and Phillips-Beck note "there is a resurgence of Indigenous community-led models of maternity care and evidence supporting their effectiveness across multiple outcomes" (p. 207). 164

While no shortage of information exists to guide more active efforts to improve IEC mental health and well-being outcomes, several authors expressed concerns that myths persist about the lack of effectiveness of prevention and early intervention programs, even among health and education professionals and policy makers. <sup>165,166</sup> They repeatedly note how the evidence base is insufficiently reflected in public policy for mental health, early learning and development or for broader child mental health. <sup>167,\*</sup> In Canada and elsewhere, the current status of interventions for child and youth mental health is repeatedly described as falling short relative to needs for both prevention and treatment. <sup>168-174</sup> As Foreman concludes, "this makes clear that our impaired ability to successfully deliver early interventions . . . is a serious deficit in our mental health strategy, with significant long-term consequences" (p. 214). <sup>175</sup>

The reviews of intervention effectiveness provide important guidance for performance measurement by pointing to domains of interest as specific outcome measures. Collaborating on population-level performance measurement can play a key role in raising awareness and sharing effective interventions. It can also increase uptake and help monitor the equity of delivery. Indicators can be as simple as *structural measures of program implementation per* 

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<sup>\*</sup> See also Zero to Three.

unit population and process indicators of reach and timely access. While a pan-Canadian approach cannot imply the imposition of canned programs, the substantial advances in implementation science and community-led approaches over the past decade can guide context-appropriate adaptation.

- 3. Population-level performance measurement in child and youth health, and well-being more broadly, has a long history in many countries. The number of indicators used (and proposed) for child and youth health and well-being is very large, and "indicator chaos" is evident.
  - Despite a relatively constrained review focused on a narrow time period and only a few
    countries, we identified dozens of performance measurement-related initiatives and hundreds
    of indicators in sets for child and youth health and well-being that included references to
    hundreds more.\* Individual authors also pointed to the specific domains or indicators they
    considered essential for the IEC period.†

This abundance sets the broader context for a conversation about domains and measures of interest. Clearly there is no shortage of existing indicators, even for IEC. As noted in Measuring Progress (in relation to all mental health), with dozens of players in multiple jurisdictions proposing or reporting on hundreds of indicators on a given health policy issue, a state of "indicator chaos" exists that makes it very difficult to come to any collective understanding of the issues and direction. Without a conceptual framework to guide the selection of child and youth mental health and well-being indicators in Canada, it is nearly impossible to realize the potential for performance measurement to contribute to the improvement of mental health and well-being for infants and young children.

- 4. Despite the large number of indicators, even for IEC, serious gaps in indicator sets are being reported in most jurisdictions, which effectively makes mental health and well-being-related issues for this age group invisible. Arguably, the most glaring gap is the strength of the science on the importance of the early IEC-parent relationship and the lack of corresponding measures.
  - Because our review of the indicator sets for child and youth mental health and well-being was only a quick scan, specific counts and types of indicators were not systematically tabulated. However, several imbalances were readily apparent. The paucity of measures for IEC relative to other ages was both observed and commented on by several authors. As one example, Sampaio et al. observed that, in Sweden, "data on the mental health and well-being of preschool children is scarce and not routinely collected in health care" (p. 44).<sup>177</sup> A deeper look at the IEC-relevant indicators reveals a predominance of socio-economic context indicators (a broad range of poverty measures) and perinatal health indicators (birth weight, preterm birth, infant mortality, etc.).

It is not uncommon to read studies that indicate tracking for developmental and mental health outcomes throughout the preschool years, only to have them appear as preterm, "small for gestational age" births, Apgar scores, and pediatric transfers. <sup>178</sup> While these are very important indicator types to track, they are not sufficient for monitoring of IEC mental health and well-

<sup>\*</sup> The indicators most relevant to the IEC period are listed separately in Resource C.

<sup>&</sup>lt;sup>†</sup> Also listed in Resource C.

being. In a very recent comprehensive review of provincial and national public data sources for child and youth mental health (broader ages) in B.C., only one source was found for the early years age group: the EDI for ages 5 to 6.<sup>179</sup> The report noted that, while the existing administrative and public datasets are a start, they have many limitations. As a result these datasets were found to be insufficient for monitoring determinants, status, interventions, and service use for child and youth mental health more generally. This work, in the Canadian context, clearly demonstrates the need to identify new indicators and have new data collection efforts for child and youth mental health overall, and for the IEC age group in particular. The current review found no population-level measures of the critically important early years child-parent relationship. Since what is measured affects awareness — and often action — lifespan considerations, including balance across age groups and key gaps within the IEC age group, should be front and centre in any child and youth mental health and well-being performance measurement framework.

- 5. Serious gaps in IEC mental health and well-being measurement are present for important subgroups of infants and children as well as for the quality of interventions and their outcomes.
  - Across authors, a consistent set of additional gaps in measurement for this age group (and child and youth mental health and well-being more broadly) were recognized. These gaps were for Indigenous infants and children, refugee and newcomer infants and children, infants and children with disabilities, and children in care. Imbalances have also been identified in measurement sets with respect to strengths-based versus deficit-based indicators. The good news is that progress is being made in Canada and around the world, which includes principles for data collection (OCAP) on Indigenous peoples, It Indigenous-led, First Nations Regional Health Survey, It Is Community-led health measurement, and innovative methods for reaching and engaging vulnerable populations. While many of these initiatives do not include a large number of IEC indicators, they are a foundation for progress.

Equity is an essential aspect of any performance measurement system, and it requires demographic variables that are acceptable to specific populations and self-determined indicators that resonate with cultural and community wisdom. An Indigenous population health approach includes holistic definitions of health and well-being, the collation of data from multiple sources, and the inclusion of all Indigenous peoples, regardless of their residential location and status. It requires disaggregating specific groups; honouring principles of data governance and management; ensuring the cultural relevance and appropriateness of measures, infrastructure, and human resource capacity; and connection to policy for action. Concerns have also been raised about insufficient information on whether services and programs are having the desired outcomes in practice. 194,195

- Emerging issues (including the COVID-19 pandemic) were noted that will need to be considered and
  planned for in any pan-Canadian performance measurement initiative for the IEC group or for child
  and youth mental health and well-being more generally.
  - Aside from the COVID-19 pandemic and the current and future impacts previously discussed, other emerging issues were as follows:
    - screen time and its effects in the IEC age group 196-198

- the environment not just social but also the natural and built environments (including access to green spaces, play spaces, and other baby- and child-friendly community spaces), neighbourhood safety, and child-friendly urban planning 199-202
- the impact of extended and multi-generational involvement or lack thereof<sup>203-206</sup>
- the increasing recognition of early literacy as a strong protective factor and new literacyrelated interventions<sup>207-210</sup>
- increasing concerns about early trauma such as child abuse, parental perinatal mental health problems, intimate partner violence, and the importance of trauma-informed approaches<sup>211-215</sup>
- the increasing impacts of the opioid crisis (e.g., neonatal abstinence syndrome) and other perinatal drug use, including cannabis<sup>216</sup>
- the increasing focus on IEC regulation issues, including sleep, feeding, crying and related concepts (irritability), and interventions, and the importance of supports for early-stage and inhome parenting<sup>217-226</sup>
- the increasing importance of rights-based approaches to child and youth mental health and well-being<sup>227</sup>
- 7. The scarcity of mental health- and well-being-related indicators for the IEC age group is not due to a lack of possible measures on the concepts of interest or a deficiency of knowledge about how to collect the data.
  - Our review, which was designed specifically to capture research and practice on the measurement of mental health and well-being in the IEC age group, yielded an abundance of indicators and measurement tools. These indicators and tools related to the full range of relevant concepts from the antenatal period onward, including parenting and parent-child relationships, infants, and young children through age 6.\* While many of the tools may only be appropriate for clinical, research, and program evaluations, and not necessarily for measuring population-level performance, the measurement domains and concepts are foundational resources for further work. In addition, newer analytic approaches (e.g., item response theory) can be used to reduce item numbers to those most predictive of a given concept, which would enable their use for performance measurement purposes in large population-based surveys or cohort studies.<sup>228</sup>

The review and measures list illustrate that enormous advances have been made in measurement science for IEC mental health and well-being, and that the concepts of interest are reasonably well understood and can be measured with reliability and predictive validity from the earliest months. <sup>229-233</sup> The key concepts include social interaction and parent-child attachment/relationship quality, and the regulation of sleep, feeding, and emotional states. Issues of concern that can be identified are attachment disorders, anxieties, affective disorders (including depression), regulatory disorders (crying, sleeping, feeding), disruptive and aggressive behaviours, and autism. <sup>234-236</sup>

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<sup>\*</sup> Compiled separately in Resource C.

We have the expertise in Canada to address the differences among the "big bucket" concepts of mental/emotional health, broad well-being, and mental illness. Measures are also abundant for parent experiences, behaviours, states, social circumstances, and other measures that relate to the quality of learning environments and service outcomes.<sup>237</sup> There is also accumulating evidence that parents can report with validity on the behaviours of their infants and small children. In some studies, parent reporting has been found to be better than direct child assessments (providing that questionnaire items are well-designed and pre-tested).<sup>238,239</sup> In addition, there is recent, sound research on the best combinations of measures and modes of administration for screening.<sup>240</sup> A review of 11 studies on the predictive validity of preschool screening tools for language and behaviour documented which tools and combination of tools performed best at which ages.<sup>241</sup> The National Academies of Science, Engineering, and Medicine report noted that recognition of the importance of developmental indicators was growing, and that "some measures and monitoring devices may be useful for both individual tracking of the developmental status of children over time and, when aggregated, community-and societal-level tracking" (pp. 359-360).<sup>242</sup>

- 8. Provincial and territorial mental health policy documents recognize the importance of mental health, both for the IEC age group and performance measurement more broadly. Yet only a minority of jurisdictions have current and specific child and youth mental health policies (that include Indigenous perspectives), which are necessary for advancing a population health approach to performance measurement. This lack of visibility on measurement for the IEC age group can make it a low priority for resource allocation decisions.
  - As our review of provincial/territorial policy documents showed, an encouraging recognition of child and youth mental health (even IEC mental health) exists, but there is still room for improvement. According to surveys from the early 2000s, this has been the case for many years.<sup>243</sup> At that time, one-off reports about child health, which included mental health and well-being data, were tabled but not repeated. Many internal challenges to regular monitoring were described, including departmental coordination, a lack in funding and in human resources, competing priorities, difficulties in determining what and how to measure, collection and response burdens, and clinical- or program-level resistance to measurement. While program- and service-level performance measurement have also been well elaborated in other literature, including practitioner resistance, a lack of capacity, an inability to recognize its benefits,<sup>244</sup> these can and have been overcome in other systems and for other patient populations.\*

Essential aspects of a conceptual framework are, first, distinguishing what is being collected, who collects it, and at what level, and second, sharing the knowledge and practices across jurisdictions. With respect to IEC-relevant indicators, in the same set of surveys, provincial/territorial representatives listed 36 indicators as desirable for monitoring. Yet only four were specific to the IEC age group. <sup>245</sup> One organization that has recognized this continuing gap is Toronto Public Health, which noted in its 2019 *T.O. Health Check* report that there are "extensive data gaps in early childhood health in Ontario. Examples include but are not limited

<sup>\*</sup> This lack of capacity in many provincial/territorial policies was also found by the broader Measuring Progress project.

to: achievement of developmental milestones, exposure to adverse childhood experiences, childhood healthy weights, and positive parenting" (p. 61).<sup>246</sup>

- 9. In Canada, there is an outstanding knowledge capacity for monitoring and measuring child and youth mental health and well-being. We have several centres of excellence and world-leading research teams working on child and youth mental health and well-being, as well as on IEC mental health and well-being and measurement.\*
  - The range of necessary subject matter and methodological know-how is wide. It includes population-based, cross-sectional, and longitudinal surveys, pregnancy and birth cohorts, administrative data linkages, clinical-level data collection, instrument development and validation, stakeholder and rights-holder engagement, and policy research partnership processes. In the past, much of this know-how was applied to single jurisdiction initiatives or formal research projects, but each has a wealth of information to be tapped for the good of all Canadian children and families.

More generally, we have excellent models for the development of mental health performance measurement frameworks and a stellar model for performance measurement in child and youth mental health and well-being. This latter conceptual framework, developed by the Children's Health Policy Centre at Simon Fraser University in 2013, was grounded in the literature and used a population health model that balanced several important considerations such as age ranges (including early childhood). As such, it offered a higher than usual proportion of IEC indicators. Other dimensions used were strengths and difficulties, health status, determinants and interventions, risk and protective factors, and context. Gaps across these dimensions were systematically identified (e.g., prevention was identified as a striking gap), although the scope of the work did not allow for the development of new indicators and data collection processes to address them. This work is a great foundation for a pan-Canadian approach.

We also have excellent pan-Canadian organizations with the broader measurement infrastructure and policy perspective, including Statistics Canada, PHAC, the Canadian Institute for Health Information, the Canadian Institute of Child Health, and others.

- 10. Recently, several data-related advances and comprehensive initiatives in child health and well-being in Canada have provided important capacities, potentials, and opportunities for the progression of performance measurement in child and youth mental health and well-being (including in the early years). Other than a few examples of collaboration, these efforts are fragmented.
  - In the past two years alone, several broad public and professional organizational coalitions have elevated the level of discourse about these efforts. <u>#WeCANforKids</u>, a collaborative project from the CIHR Institute of Human Development, Child and Youth Health; Children's Healthcare Canada; UNICEF Canada; and Pediatric Chairs of Canada, has expressed concerns

<sup>\*</sup> These teams and centres with the experience and skills for performance measurement at the population level (and other levels) were listed in the previous section. They are also available separately in Resource B.

<sup>†</sup> See Resource D.

about Canada's relatively poor rankings on international health and well-being measures(e.g., UNICEF), as well as the exacerbation of inequities resulting from the COVID-19 pandemic. In response, the group has initiated public consultations to inform research priorities, advance innovation and policy, and produce a framework for improvement of the health and well-being of children, youth, and families.

<u>Children First Canada</u>, a multi-stakeholder partnership that includes the Canadian Red Cross, the University of Calgary O'Brien Institute for Public Health, and private sector supporters, produced a <u>Raising Canada 2020</u> report that listed the top 10 threats to Canadian children and provided some of the earliest information on the impact of the COVID-19 pandemic (from Statistics Canada surveys). The report also raised concerns about drops in UNICEF child health rankings. Along with other mental health-related issues, such as child abuse and bullying, poor mental health has been identified as a top threat. The report's recommended policy actions include new funding and a specific strategy to tackle the top 10 threats. A similar network with dozens of partner organizations, called the <u>Sandbox Project</u>, is also active on these issues.\*

While these recent developments are not specific either to IEC or mental health, they exemplify the increasing stakeholder and public concern for child and youth health and well-being overall. Such concern provides a critically important context for any advancements in mental health and well-being performance measurement for all age groups.

Advances in and across provinces and territories are also enabling a more sophisticated access, linkage, and analysis of secondary (usually administrative) datasets, which involves some linking of broader child and youth mental health-related data across child-serving ministries. Among these advancements are programs from Population Data British Columbia, ICES, the MCHP, the Alberta child and youth data laboratory, and the NB Institute for Research, Data and Training. A recent case study of four provincial models identified four categories of data for infancy and preschool: newborn screening, home visiting, immunization preschool program attendance, and EDI data. While, as expected, these new categories reflect more traditional data types, the capacity for linkage represents progress.<sup>250</sup>

The <u>Canadian Research Data Centre Network</u><sup>†</sup> and the <u>Health Data Research Network Canada</u><sup>‡</sup> are major countrywide initiatives that have shown progress on the capacity for crossjurisdiction linkage and analysis. However, since there is very little IEC mental health-related data to be linked, performance measurement for IEC mental health and well-being in Canada is unlikely to progress without a framework to guide the selection and pursuit of new data.

11. For nearly two decades, multiple research and practice leaders from human service sectors in Canada have stressed the importance, value, and need to have better performance measurement in child and youth mental health (including in the early years). Further, it is well understood that IEC mental health and well-being is critically contingent on the parent-child relationship; consequently, performance measurement should be as well.

<sup>\*</sup> These and all relevant stakeholder organizations identified in the review are listed separately in Resource E.

<sup>&</sup>lt;sup>†</sup> A partnership between a group of Canadian universities and Statistics Canada.

<sup>&</sup>lt;sup>‡</sup> A group that includes federal, provincial, and territorial organizations that hold health and health-related data for the country's whole population. This also includes all SPOR Canada data platforms.

• As with mental health performance measurement more broadly, Canadian experts have been calling for better measurement in child and youth mental health and well-being for many years. <sup>251</sup> Governments have also supported this need for improvement (described above in the provincial and territorial surveys). <sup>252</sup> Duncan et al. has cogently summarized this history while pointing out that such a system would need to be cross-sectoral and psychometrically valid and have the ability to provide feedback to stakeholders. Such data collection would allow for the monitoring of status, service use, and outcomes and enable comparisons across jurisdictions to support planning. Further, the creation of research and policy partnerships would help increase researchers' awareness of competing policy priorities to serve measurement initiatives more effectively. <sup>253</sup>

Other experts have noted that current measures are not well connected to policy action. Most jurisdictions do not have the capacity for provincial/territorial comparisons or to get beyond simple surveillance. Similar recommendations have been made by research organizations in other countries. The National Academies of Science, Engineering, and Medicine has called for strengthening the monitoring of mental, emotional, and behavioural health in children and youth and has noted the lack of consensus on indicators for key concepts. In the IEC group, specifically, Canadian research and practice leaders have also underscored the need for better measurement. The EDI initiative is a Canadian model for what is possible in some aspects of early childhood development monitoring, but gaps remain on the measurement of essential aspects of mental health and well-being at younger ages such as the early parent-child relationship.

- 12. Having a comprehensive performance measurement framework for child and youth mental health and well-being in Canada is overdue. Such a framework would need to leverage research, practice excellence, and advocacy networks and be developed in partnership with people with lived and living experience (including children, youth, and parents), policy makers (including provinces and territories), and Indigenous peoples.
  - Enns et al.'s extensive review of data needs for early childhood notes that a simple catalogue of indicators is not enough to allow discussions on the most meaningful measures and determining priorities (which implies that there is a need for a conceptual framework to guide the work). As previously elaborated in the Measuring Progress project, simple indicator lists or sets also have many other limitations. A second problem regarding discussions about measurement and indicators is sector-specific thinking. But no age group needs to be considered more holistically than infants and young children. A third problem, which has been observed repeatedly, is the tendency for participants to "get into the weeds" too rapidly about data types and data access, mix levels of measurement, and confuse data for research purposes with data for monitoring purposes. While population-based research projects like longitudinal cohort studies can be a source of information for ongoing reporting, most one-off research projects are not well suited to performance measurement.

A conceptual framework for measures would help address such problems. It would focus the discussion on the *what* before the *how* and help avoid to the frequent mistake of "availability bias" (pursuing indicators where existing data is available rather than indicators that are most meaningful). It is an essential tool for making sense of the complexity of indicators, data

sources, and types, for identifying gaps, and for connecting findings to policy and practice, and for sharing knowledge capacity across jurisdictions. Without such a framework we also miss opportunities to capture important information, such as in surveys on closely related topics.

Any framework development process should be able to make explicit which principles and values are evident in the work. In addition to knowing what is measured, it is essential to know what is not measured and why. Stakeholders can consider the different types of frameworks<sup>263</sup> and how they fit with the overall aims of performance measurement. A lifespan approach requires that indicators for IEC be selected in light of other age groups and over time, as has been modelled in B.C.<sup>264</sup> Finally, while the increasing number of Canadian organizations and individuals in child health can be enormously beneficial, a potential hazard is that measurement efforts may be both duplicated and diluted by the fragmentation.<sup>265</sup> A collaborative and consensus-built framework can help focus the energy of multiple players with the same ultimate objectives.

- 13. The full potential of a pan-Canadian child and youth mental health and well-being performance measurement framework can only be achieved if an infrastructure and capacity for connecting existing stakeholders (including children, youth, and parents) and initiatives across the country is established for conceptualizing, sourcing, collating, analyzing, and reporting.
  - The National Academies of Science, Engineering, and Medicine has emphasized the need for investments in infrastructure for child and youth mental health in the U.S.: "Communities concerned with healthy development lack . . . resources or systems for collecting, analyzing, and reporting data on child development. Investments in shared infrastructure for data management will be essential" (p. 359). 266 The same sentiment has also been repeatedly expressed in relation to Canada, which "currently lacks a coherent approach to population monitoring as a crucial platform for improving children's mental health" (pp. 10-11). 267 There is a clear need not only for a framework but also a *system* for population-based epidemiologic studies (including surveys and cohort studies) that can provide estimates of prevalence and unmet need, including for IEC. In a recent review of data sources for monitoring in B.C., researchers "did not identify ongoing surveys providing parallel, detailed mental health data for younger children, suggesting that new surveys are needed" (p. 17). 268 This is also true for Canada as whole. Supporting infrastructure and capacity to connect and extend existing expertise would also allow for additional studies and a deeper understanding of indicators.

The Measuring Progress project identified a Canadian model for a performance measurement framework and a full system from the <u>Canadian Partnership Against Cancer</u> (CPAC). Not only does CPAC have a coherent pan-Canadian framework and infrastructure to combine data from sources such as CIHI, Statistics Canada, and provincial/territorial partners, they also support (through <u>CanPath</u>) a massive prospective cohort of over 330,000 participants (followed for 30 years) that includes detailed health assessments, surveys, and biospecimens. This cohort allows for the tracking of cancer outcomes and other chronic diseases, along with many types of sophisticated analyses. Multiple organizations, including governments, NGOs, and private partners, came together to make this world-class cohort a reality. Together, the performance measurement system and the cohort study allow for an in-depth understanding and high-level collaborative planning at individual, system, and population levels. They also provide an

infrastructure to support a rapid response to emerging issues like the COVID-19 pandemic. In addition to CPAC's work, Canada has a <u>longitudinal cohort study</u> on aging that has been following 50,000 participants for 20 years. Many other countries also have longitudinal pregnancy/birth cohorts.

There has been no compelling reason presented over the course of this or any prior work as to why an initiative with the scope of CPAC's work would not be appropriate for the mental health field, including child and youth mental health and well-being. Mental health has a similar population health burden and has been increasingly seen as an urgent public health issue, even more so in light of concerns about the impacts of the COVID-19 pandemic.

#### Summary and opportunities for the future

As a set of "big picture" findings, this rapid scoping review found an impressive knowledge capacity for performance measurement in child and youth mental health and well-being (including for the IEC age group). Also evident was a consensus among stakeholders that there are distinct gaps and we must do better for children and youth in Canada, especially for vulnerable and equity-deserving groups.

Knowledge about risk and protective factors and the effectiveness of intervention points to domains of interest as well as specific outcome measures. Collaborating on population-level performance measurement can play a key role in raising awareness and sharing effective interventions. It can also increase uptake and help monitor the equity of delivery. Indicators can be as simple as *structural measures of program implementation per unit population* and *process indicators of reach and timely access*. While a pan-Canadian approach cannot imply the imposition of canned interventions, the substantial advances in implementation science and community-led approaches over the past decade can guide context-appropriate adaptation.

There is a mounting imperative by professional, advocacy, and research organizations to do better, in keeping with the understanding that the identified barriers are surmountable. The COVID-19 pandemic has produced new concerns and has underscored the urgency of better measurement in this realm. In terms of opportunities, these are "good news" findings. An enormous potential exists to be among the most advanced countries in the world in this area if we broaden collaborative efforts across organizations, provinces, territories, and communities, and we maximize our deep subject matter expertise in mental health and well-being measurement. With the right collective will, leadership, and vision, the following initiatives are possible in Canada:

- A collaborative pan-Canadian performance measurement conceptual framework for child and youth mental health and well-being that
  - o includes a balanced set of indicators that cover important new and unmeasured concepts related to IEC mental health and well-being
  - o pays particular attention to gaps and equity
  - o covers status as well as service use, service quality, and outcomes
  - o complements existing high-quality data collection and reporting efforts.

- In terms of new data collection:
  - At minimum, a nationwide representative, population-based survey of parents of the IEC age group that includes measurement of ICE mental health and well-being and IEC-parent relationships using consensus, quality measures, and special sampling for important subgroups, while including resources and means for parallel or separate Indigenous-led survey(s) for First Nations, Inuit, and Métis families. Ideally, such a survey would include structure and process indicators to track the dissemination and adoption of appropriate evidence-informed interventions, as well as outcome indicators to document their impact. Doing so would require repeated surveys at reasonable intervals and the infrastructure to support their development and ongoing analysis.
  - A national longitudinal pregnancy cohort study could serve the functions of the survey above (with periodic waves) and provide a more dynamic understanding of the mental health and well-being of young children and families over time. The infrastructure for such a cohort would allow for better planning with respect to the measurement and tracking of child and youth mental health outcomes more broadly, in addition to the long-term impacts of the COVID-19 pandemic and rapid response to future emerging issues. While a representative sample for a cohort study is not inexpensive to set up, internet-based data collection has dramatically reduced the costs of ongoing data collection. There is a wealth of expertise in methods that can be tapped from lead investigators of pregnancy/birth cohorts in provinces and other countries, as well as pan-Canadian cohorts in other age groups.

These initiatives could form the initial activities for a collaborative pan-Canadian performance measurement system. Such a system could harness and integrate existing strengths in Canada and focus advocacy, research, practice, and policy attention on improving the mental health and well-being of all children in Canada in a sustainable way. Collaboration could also serve many other purposes, such as sharing performance measurement expertise across jurisdictions and communities, drawing from existing quality data sources for indicators, creating new consensus indicators, guiding discussions toward consensus tools (e.g., for screening), developing core datasets for quality care in various settings, and other collaborative initiatives.

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