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The State of Early Mental Health & Developmental Data in Ontario: Opportunities for Research and Collaboration

Knowledge Institute
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Infant and Early Mental Health Promotion
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The views expressed herein are those of the authors and do not necessarily reflect those of the Province.

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Disclaimer

While the meeting participants contributed to the meeting discussions and Participant Catalogue, this document was prepared by the contributing authors. As such, the summaries and themes presented here are solely their reflection of the meeting.

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Executive Summary

While Canada collects some data on infant and early years mental health and development (MHD), there is no standardized system of routine data collection for children under six years of age (Carsley et al., 2020). Further, early MHD data that is stored in electronic health records may be inaccessible to decision-makers when it is not extracted, analyzed, and reported (The College of Family Physicians of Canada, 2017). There is a need to identify the early MHD data that is currently available, discover where gaps exist in data collection, and foster inter-sectoral collaboration on the collection and use of data.

Two meetings were held in November 2024 and May 2025 to address these needs within Ontario with researchers, service providers, and decision-makers. This report summarizes the discussions from both meetings, and is intended for a broad audience, including researchers, policymakers, healthcare practitioners, and advocates.

In November 2024, 69 individuals from federal, provincial, and community organizations attended an inaugural meeting. Participants discussed the following three topics.

1. **Challenges in accessing and using early MHD data**
   Participants noted a general lack of early MHD data, along with limited knowledge regarding available data, resources, and relevant policies. There is a lack of standardized definitions and data collection methods, which may contribute to variances in data quality. Participants also noted limited collaboration between researchers and children, families, and communities. As well, there is a lack of linked data between data sets, which limits the use and meaningfulness of data.
2. **Strengths and weaknesses of equity, diversity, and inclusion (EDI) data collection**
   In recent years, there has been an increased focus on the importance of collecting EDI data. However, several weaknesses were also reported. There is limited understanding of what data is collected and by whom, and an identified need for improved training and education for researchers. Important data is often missing, such as outcome, longitudinal, and qualitative data. Communities facing or experiencing systemic inequities may not be involved to any degree in important research decisions. There is a need for greater engagement and communication with communities regarding knowledge dissemination.

3. **Gaps in early MHD data collection to be addressed through future research**
   Participants identified a need for greater standardization of definitions, assessments and measures, data-sharing agreements, reporting, and knowledge translation. There are also research gaps related to longitudinal and lifespan data; population-level data; Canada- and Ontario-specific data to inform programs and services; pre-natal development data; and data on family, community, environmental, and cultural contexts. Additionally, there is a need for greater connection between research, policy, and practice. Participants reported an overall lack of resources and funding for early MHD research.

In May 2025, 54 individuals (27 returning) from federal, provincial, and community organizations participated in a follow-up meeting to identify actionable steps to the challenges identified at the November 2024 meeting. Participants proposed actionable steps that included the following.

1. **Environmental scan and data inventory**: Conduct an environmental scan to identify ongoing data collection efforts and create a detailed inventory to promote data accessibility and linkage.
2. **Cross-sectoral collaboration**: Increase engagement between ministry partners, researchers, service providers, and public health to reduce siloed data collection, promote data-sharing and linkage, and improve knowledge.
3. **Standardization**: Create standardized indicators and definitions, data collection methods, and training. Promote the use of standardized, reliable, and valid tools for infants and young children, but consider individual needs when deciding which tool(s) to use. Address the absence of standardized EDI data collection.
4. **Data linkage**: Use unique identifiers to link data across data sets to follow individuals through their care journey and connect family data.
5. **Guidelines and legislation**: Increase legislation and guidance from ministries and government agencies concerning best practices in data collection, including new or improved policy regarding developmental surveillance, pathways, mandatory implementation, data linkages, and data-sharing.
6. **Family and community collaboration**: Increase collaboration with those families and communities impacted by research but typically excluded from decision-making. Prioritize collaboration that includes trust-building and self-determination. Develop family advisory committees, co-design data collection initiatives, embed data collection within communities, and co-create knowledge-sharing strategies.

Background

Mental health and development (MHD) from birth through age five can critically impact mental and physical health, socioemotional outcomes, and economic productivity, throughout a person's life (Boivin & Hertzman, 2012; Irwin et al., 2007; Shonkoff, 2010; Zero to Three, 2017). Early MHD includes physical and mental well-being, as well as linguistic, cognitive, and socio-emotional development, and relies on appropriate and safe relationships, environments, and nutrition (Center on the Developing Child, 2010).

Within Canada, there are initiatives to collect data related to early MHD. These initiatives include the Canadian Health Survey on Children and Youth (Statistics Canada, 2025), the Child Maltreatment Surveillance Indicator Framework (Centre for Surveillance and Applied Research, Public Health Agency of Canada, 2020), and the First Nations and Inuit Health and Wellness Indicators (Health Canada, First Nations and Inuit Health Branch, 2018). Within Ontario specifically, the Institute for Clinical Evaluative Sciences collects and maintains datasets related to population health and healthcare delivery, such as the Discharge Abstract Database and the National Ambulatory Care Reporting System (Institute for Clinical Evaluative Sciences [ICES], 2025).

These initiatives provide important insights into early MHD. However, the current landscape of early MHD, throughout Canada and within Ontario, remains unclear. There is no dedicated survey focused exclusively on the well-being of infants and children under six years old. Early childhood development data is collected in Canada, but the data is limited (United Nations Children's Fund [UNICEF] & Countdown to 2023 Women's, Children's and Adolescent's Health [Countdown to 2023], 2023). The data available on mental health for children under four years old is also limited, and there is currently no standardized system to routinely collect data for children younger than six (Carsley et al., 2020).

Background

At present, data captured in electronic health records may be difficult for decision-makers and policymakers to access when data is not extracted, analyzed, and reported (The College of Physicians of Canada, 2017). As well, the field of early MHD involves individuals from various sectors (healthcare, community mental health, education, social services, research, and government) and is not well-defined, and there are known inter-sectoral collaboration difficulties (Carsley et al., 2020; Clinton et al., 2014; Kulkarni et al., 2019).

Encouragingly, researchers, advocates, and health professionals have recommended increased data collection and cross-sectoral collaboration (Carsley et al., 2020; Clinton et al., 2014; Hertzman et al., 2011; Infant and Early Mental Health Promotion [IEMHP], 2017; Janus et al., 2018; Kulkarni et al., 2019; Mental Health Commission of Canada, 2021). This suggests there is momentum to move this work forward.

Measuring early MHD indicators is a crucial step in providing evidence-informed care that impacts health, well-being, and economic productivity across the lifespan. It is important that we identify data that is currently available, where gaps exist, and whether existing sources of data may be leveraged for new purposes like population assessment and surveillance. There is a need to foster collaborative research to support integrated analysis, gain a more holistic understanding of early MHD, and promote data accessibility to leaders and decision-makers.

November 2024 Meeting

Objectives

A meeting was held on November 20, 2024 at The Hospital for Sick Children in Toronto to address gaps in early MHD data collection and inter-sectoral collaboration within Ontario. The meeting had three objectives: 1) better understand what data is currently collected; 2) identify gaps, including gaps in equity, diversity, and inclusion, that could be addressed through future research; and 3) discuss opportunities for further collaboration between policymakers, services providers, and researchers.

Participants

Sixty-nine individuals attended from 35 organizations at the community, provincial, and federal levels. Participants included content experts, leadership, and decision-makers. See Appendix 1 for a list of the organizations that attended the meeting.

Roundtable

The meeting started with a roundtable of introductions, where each organization provided a brief overview of its mandate and some high-level information about the early MHD data they collect or use. Participants shared information on their data collection timelines, current number of records, social determinants, French language variables, and whether raw data or findings are typically shared. A complete overview of this information can be found in the Participant Catalogue.

Meeting Discussion Themes

Participants engaged in three break-out groups to discuss each of these questions:

1. What are the challenges you experience when accessing and using early MHD data?
2. What are the strengths and weaknesses of the equity, diversity, and inclusion data collected on Ontario children under age six?
3. What are the gaps in early MHD data collection and research that should be addressed through future research?

Following the meeting, notes from each break-out group discussion were synthesized to identify emergent themes within each question. Themes are presented here.

What are the challenges you experience when accessing and using early MHD data?

Knowledge

Challenges

- Staff turnover contributes to lost knowledge over time
- Currently, there is a lack of knowledge on:
  - Available data, who holds data, where to find data, and how to access data
  - Which individuals are missing or excluded from datasets
  - Data linkage (linking individuals' data between data sets)
  - Collaboration opportunities, available resources, and relevant policies

What is needed

- More knowledge and training on early MHD, including risk identification and management
- More knowledge of validated measures (e.g., InterRAI Early Years, HEADS-ED Under 6)
- Plain language of research and/or data reporting to improve understanding and accessibility

Meaningful and linked data

Challenges

- Data exists in silos, but there is a lack of linked data
- Meaningful and appropriate data collection includes identifying the concepts and questions that should be assessed. However, because data is not linked, we aren't able to get a fuller picture of context, needs, and outcomes

What is needed

- Identify how data should be appropriately used
- Collect and analyze locally and clinically meaningful and relevant data
- Increase the use of strength-based approaches during mental health assessments and data collection

Collaboration

Challenges

- Linkage and collaboration opportunities are largely unknown
- Data governance structures are siloed
- There is a lack of pooled resources and services, along with a shortage of experienced resources to support data extraction and analysis

What is needed

- Greater collaboration with those who are impacted by the data (children and families)
- A plan to create pathways — with providers and within the health system — to collect data during children's first year of life; for example, at immunization appointments and well-baby checks

Standardization

Challenges

- There is a lack of standardization in data collection and definitions
- There are inconsistencies in overall data collection: collection methods, software, data formats, age groups, and collection and reporting of mandatory vs. non-mandatory data
- More publicly funded data is available than private sector data

What is needed

- Setting standardized definitions is an important first step of overall standardization
- Standardization is needed to compare datasets and outcomes, and to build infrastructure

Data quality

Challenges

- Data quality is varied and/or lacking
- Poor quality data leads to poor results; there is a need to maintain standards and sustained quality
- Specific issues are noted related to reliability, validity, and missing or invalid diagnostic codes in datasets

What is needed

- Standardization is needed to improve data quality

Lack of data

Challenges

- Overall, there is a lack of data, and in the limited data that is available, there are gaps
- Specific concerns include:
    - Limited system integration data
    - Lack of family integration and parent-child dyad data
    - Lack of early-years mental health data
    - Limited measurement of protective factors
    - Important variables are missing in data collection
    - There is a lack of ongoing data collection and aggregation

What is needed

- Funding is needed to support data aggregation initiatives and activities

Community involvement

Challenges

- Communities have limited knowledge of, and access to, their own data.

What is needed

- Involve relevant communities in data collection (local, Indigenous)
- Gain trust and consent
- Share data and knowledge in easily accessible ways
- Generate well-formulated plans to present for feedback
- Use plain language to improve understanding and accessibility

Funding and resources

Challenges

- There is a lack of funding to support data collection and reporting
- High costs limit new data collection, access to existing datasets, and data aggregation
- Other resources are lacking, including time, staffing, capacity, and technology
- Technology barriers exist, including use of different and incompatible electronic medical records

What is needed

- Explore ways to leverage technology such as:
    - EMHware
    - Business intelligence
    - Artificial intelligence
    - Measures with integrated software systems (e.g., InterRAI Early Years)

What are the strengths and weaknesses of the equity, diversity, and inclusion (EDI) data collected on Ontario children under age six?

Strengths

- Importance and value: Commitment to better understand diverse needs and experiences. Individuals with diverse perspectives and backgrounds are increasingly involved in data collection and use
- Data collection: In recent years, there has been an increase in organizations collecting demographic and EDI data including income/socio-economic status, gender, Indigeneity, risk data for birth parents, family violence data

The following themes identify weaknesses regarding EDI data collection.

Knowledge

Challenges

- Currently, there is no clear understanding of what EDI/demographics data is collected, and by whom
- There is a lack of information of which groups are successfully represented, missing, or underrepresented in data collection.

What is needed

- Greater education and training on appropriate data collection and use of EDI and demographic data
- Strategies and initiatives to help children, families, and communities understand why their data is collected and how it will be used

Standardization

Challenges

- Overall, there is a lack of standardization in collecting EDI data
- There is inconsistency in the questions asked, and in data format and definitions
- Variables are incorrectly reported — for example, sex reported as gender
- There are inconsistencies in documenting and reporting demographic variables

What is needed

- Standardize options for demographic variables presented in checklists or drop-down lists

Data limitations

Challenges

- EDI data and demographics are not routinely collected
- Information is missing on justice and children's aid and outcomes
- Longitudinal and qualitative data collection is limited
- Data is collected from multiple perspectives — children, all parents/caregivers, early childhood educators — but representation is missing in data, services, and policy
- Data is missing from commonly underrepresented groups including inter-sectional identities, vulnerable individuals, young females, and those with low literacy or understanding of English

What's needed

- Identify which respondents can accurately disclose EDI information

Appropriateness

Challenges

- Overall, there is a lack of appropriate and meaningful data being collected
- Individuals or groups may be resistant to providing data due to discomfort, lack of trust, or uncertainty in how the data will be used

What is needed

- Design research questions that are well considered to support individuals to answer specific questions
- Train and inform researchers and frontline staff to be mindful of biases
- Strategize and implement ways to ensure researchers and participants/clients understand why questions are asked, why data is being collected, and how the data will be used

Lived expertise and community involvement in research

Challenges

- Currently, collaboration and mutually beneficial partnerships between research organizations and people with lived expertise are limited or non-existent

What is needed

- Involve communities that are facing or experiencing systemic inequities; involve them in research, data collection, and data use, including research question development and important decision-making
- Generate collaboration between academics and communities
- Allocate funds from grants to directly benefit the group(s) involved
- Capture environmental and contextual factors

- Capture more fully the care journey narratives and how services fit diverse experiences/backgrounds
- Consider children's outcomes from culturally relevant perspectives

Knowledge dissemination

Challenges

- Currently, communication is limited when it comes to how data will be used and what data will be shared with communities and the public

What is needed

- Increase community engagement
- Expand knowledge translation activities, with a focus on how data will be used at the forefront of projects
- Provide actionable data in a timely manner

What are the gaps in early MHD data collection and research that should be addressed through future research?

Data collection and measurement

Challenges

- At present, there is no way to ensure accurate and consistent measurement through standardization, systematic evaluation, and uniform tools
- Limited standardized assessments appropriate for infants and young children (attachment measures, transdiagnostic tools), or limited knowledge of these tools

What is needed

- Agreement on what data should be collected, and who should collect which variables
- Longitudinal and lifespan data connecting infancy and early years to prenatal and middle years data

Standardization

Challenges

- Greater standardization needed of definitions, assessments and measures, data-sharing agreements, reporting, and knowledge translation

What is needed

- Systematic evaluation, data governance, and data hubs

Actionable data

Challenges

- Gaps in actionable data overall, as well as Canada- and Ontario-specific data that informs programs and services

- Limited population-level and actionable qualitative data
- Limited understanding regarding children's outcomes and which pathways/services have positive impacts
- Lack of investment into interventions and services that respond to children's identified needs

What is needed

- Better address wait times for assessments and clinical services
- Better connections between research, policy, and practice

Funding and resources

Challenges

- Lack of resources: funding, time, large-scale databases, data hubs, labour
- Lack of data scientists and physicians

Collaboration

Challenges

- Sectors work in silos
- Gaps in system integration, data linkage, multi-purpose data
- No inter-sectoral agreements on values and desired outcomes

What is needed

- Inter-sectoral collaborative pathways to care
- Policy and data governance
- Legislation that considers needs identified through research
- Family engagement and collaboration in research

Environment and context

Challenges

- Failure to consider children's contexts and environments in data collection
- Limited considerations of MHD as beginning prior to conception and of a whole-family approach
- Contextual knowledge gaps when considering MHD's impact: COVID-19 pandemic, substance use medical emergencies, housing and food insecurity

What is needed

- Better understanding of the impact of foster care
- Better understanding of how children and families engage with their communities
- Better understanding of cultural contexts, including how MHD is understood/measured

May 2025 Meeting

Objectives

A follow-up meeting was held in May 2025 in Toronto. This meeting aimed to: 1) review the common challenges and gaps regarding data collection, access, and use that were identified during the November 2024 meeting; and 2) generate actionable steps to address the identified challenges.

Participants and theme topics

Fifty-four individuals from 30 organizations attended the May 2025 meeting, 27 of whom also attended the November 2024 meeting. Participants included representatives from public health, community MHD services, hospitals, universities and research institutes, funding agencies, and government departments and agencies. Each participant was pre-assigned to a single break-out group to ensure that all eight groups included perspectives from research, practice, and policy. See Appendix 2 for a list of the organizations that participated.

At the start of the meeting, the group was presented with an overview of the discussions from the November 2024 meeting. Each break-out group identified actionable steps that addressed the challenges and gaps highlighted within their sub-set of themes. When creating actionable steps, participants were asked to consider the scope of their actionable steps (provincial vs. local level, for example), as well as resource needs and collaboration opportunities. Themes and actionable steps are presented in Tables 1, 2, and 3.

Table 1. Actionable Steps to Address the Challenges of Accessing and Using Early MHD Data

Theme	Theme Topics	Actionable Steps
Knowledge	Lack of knowledge: available data, where to access data, relevant policies Staff turnover contributes to lost knowledge over time Need for knowledge and training on early MHD, including validated measures, risk identification, and risk management Plain language needed to improve understanding and accessibility	Increase public and multisectoral knowledge of the purpose of data collection and how data will be used to inform community care Establish a database for data collection Set up common, agreed-upon standardized indicators Establish universal screening with tiered tool administration Engage Ministry of Health, Ministry of Education, and Ministry of Children, Community and Social Services Engage Ontario Health Teams, Community Health Centres, and primary care providers
Meaningful and linked data	Data exists in silos and there is a lack of linked data Linking data would allow for fuller picture of context, needs, and outcomes Need to identify how data should be appropriately used Lack of locally and clinically meaningful data collection and analysis	Monitor regional and community data trends Identify and develop best practices for data collection Establish greater data linkage and use unique identifiers to follow individuals through the care journey Collect family-level data
Collaboration	Unknown linkage and collaboration opportunities Siloed data governance structures Lack of pooled resources and services Need for greater collaboration with individuals and groups who are impacted by the data (e.g., children and families)	Collect family, social, and security data. Allow families to self-report their own data Build connections and knowledge-sharing with families and communities Build connections with universities and university hospitals Expand the use of standardized assessment tools (e.g., Ages and Stages Questionnaire, HEADS-ED, InterRAI Early Years)
Standardization	Lack of standardization regarding data collection and definitions Need for standardization to compare datasets and outcomes Inconsistencies include collection methods, data formats, software	Charge ministries and government agencies to define the standards and definitions for data collection Establish a centralized data repository with dashboards to view and filter data

Theme	Theme Topics	Actionable Steps
Data quality	Data quality that is varied and/or lacking Poor quality data leads to poor results. Need to maintain standards and quality Standardization is needed to improve data quality	Collaborate with practitioners and direct service staff to review and revise indicators used for children under six years old Implement regular review cycles for indicators
Lack of data	Overall lack of data and gaps in the limited data that is available Important variables are missing Lack of ongoing data collection and/or lack of data aggregation Need funding to support data aggregation Specific concerns: limited system integration data, lack of family integration, lack of early-years mental health data, limited measurement of protective factors	Use existing screening programs (e.g., Newborn Health Screening) Expand existing programs to improve accessibility Advocate for longitudinal surveys and datasets and highlight the importance of understanding trends over time Improve data-sharing and data-linking across ministries and sectors to reduce silos and improve connectivity Address data privacy and security
Community involvement	Need to involve relevant communities in data collection Gain trust and consent Communities have limited knowledge of and access to their own data Need to share data and knowledge in easily accessible manner Need to generate well-formulated plans to present for feedback Use plain language, to improve understanding/accessibility	Increase data literacy Prioritize early years Engage key partners (e.g., community mental health agencies) Create an inventory on major data projects that are underway Seek opportunities to leverage the data and work that is currently ongoing Increase policy on developmental surveillance, pathways, data, and mandatory implementation Standardize inter-sectoral data collection
Funding and resources	Overall lack of funding High costs limit collection of new data, access to existing datasets, and data aggregation Other lacking resources: time, staffing, capacity, technology	Secure dedicated funding Find examples of where resources are currently shared Present collective solutions to ministries Identify opportunities to collaborate and share the responsibility of data collection and analysis

Table 2. Actionable Steps for Equity, Diversity, and Inclusion (EDI) Data

Theme	Theme Topics	Actionable Steps
Knowledge	Better understanding of what EDI and/or demographics data is collected by whom Awareness of which groups are successfully represented in data collection and which groups are missing or underrepresented Greater education and training of appropriate data collection and use of EDI and/or demographic data Children, families, and communities should understand why their data is collected and how it will be used	Create a communications campaign for caregivers and families, as well as for clinicians and providers Standardize ethics training Provide education on transparency and power dynamics in data collection Co-create messaging with individuals who have lived expertise Set up a partnered plan for Indigenous data sovereignty Establish an Indigenous-led data plan
Standardization	Overall lack of standardization regarding EDI data collection Inconsistency in the questions asked and in data format and definitions Lack of standardization in options for demographic variables presented in checklists or drop-down lists Incorrectly reported variables (e.g., sex reported as gender) Inconsistencies in documenting and reporting demographic variables	Determine why there is a lack of standardization (culture differences, language, location, shifting identities, other) Develop a strategic plan for why standardized data is needed. Lack of standardization may actually be ethical in cases where standardization does not capture diverse cultural backgrounds, lived expertise, or evolving identities to be reflected Train practitioners on how to ask questions appropriately Add definitions to response options in questionnaires Translate questionnaires into as many languages as possible Promote increased appointment times with clinicians and providers to facilitate relationship- and trust-building and reduce missing context

Theme	Theme Topics	Actionable Steps
Data limitations	EDI data and demographics not routinely collected Missing justice and children's aid information and outcome information Limited longitudinal and qualitative data collection Need to collect data from multiple perspectives Need to identify which respondents can accurately disclose EDI information Missing representation in data, services, and policy	Determine where data is going and what it is being used for Develop a data literacy course: Understanding Data 101. Include the following topics: terminology, Indigenous data ownership, research ethics, top-down vs. bottom-up data Identify community champions
Appropriateness	Appropriate and meaningful data collection is necessary Need trained and informed researchers and frontline staff who are mindful of biases Researchers and participants should understand why questions are being asked, why data is being collected, and how the data will be used	Ensure thoughtful steps are taken to co-design research across all cultures Include deep learning about *why* we are collecting data Build on the evidence-based practices of community-based research
Lived expertise and community involvement in research	Communities facing or experiencing systemic inequities should be involved in research, data collection, and data use Collaborations should be generated between academics and communities Mutually beneficial partnerships are required Funds from grants should be allocated to directly benefit the group(s) involved Need to capture environmental, contextual, and cultural factors	Embed data and research activities within the community Create data collection and data-sharing plans with communities, including a shared vision of why data is collected and how data is best used Use artificial intelligence scraping and advancing data technology to analyze big data, lived expertise, and social media
Knowledge dissemination	Greater community engagement Better communications with communities about how data will be used Awareness of knowledge translation and consideration for how data will be used at the forefront of projects Actionable data provided in a timely manner Use of data to dispel misinformation	Use multiple means to communicate results/knowledge (storytelling, infographics, others) Ensure a sense of ownership and self-determination when working with individuals and communities Establish shared vision, transparency, and trust. Explain why data is being collected Leverage artificial intelligence to expedite data cleaning

Table 3. Actionable Steps to Address Gaps in Early MHD Data Collection and Research

Theme	Theme Topics	Actionable Steps
Data collection and measurement	Need agreement on what data should be collected and who should collect what variables Need to ensure accurate and consistent measurement through standardization, systematic evaluation, and uniform tools Limited standardized assessments appropriate for infants and young children (e.g., attachment measures, transdiagnostic tools), or limited knowledge of such tools Limited capture of social demographics and social determinants of health Overall lack of longitudinal and lifespan data	Conduct an environmental scan of existing data: who is included in the data, what data/variables are included, when the data was collected and where, why was the data collected, and how is it/was it used Determine how to capture and link existing data, systems, clinics/hospitals, and institutions Encourage group-up data Research other countries for examples of early years surveillance Create an engagement strategy that acknowledges all levels of decision-makers across all relevant sectors
Standardization	Greater standardization needed of definitions, assessments and measures, data-sharing and agreements, reporting, knowledge translation Need for systematic evaluation, data governance, data hubs	Move away from standardization as a term. The word “standardize” is exclusionary language and one size does not fit all There can be standardized methodology, but tools should depend on needs and requirements
Actionable data	Gaps in actionable data Gaps in Canada- and Ontario-specific data that inform programs and services Limited population-level data Need for actionable, qualitative data and better use of data Lack of understanding regarding children’s outcomes and what pathways/services have positive impacts Need investment into interventions and services that respond to children’s identified needs Need to better address wait times for assessments and clinical services Better connections needed between research, policy, and practice	Collaborate with the Child and Youth Mental Health Lead Agency Consortium to develop and use consistent definitions and determine how data can be collected using specific tools Use data that is already collected or reported to the Ministry of Health Encourage the integration of outcomes tracking, both child and parent Collect and analyze predictors for the type of resources a child will need or access in 3 to 5 years Generate evidence to show that investing during the early years will save money in the long term Conduct studies demonstrating the long-term outcomes and forecasting of early intervention (clinical, social, educational outcomes) and how data compares to typically developing children

Theme	Theme Topics	Actionable Steps
Funding and resources	Lack of resources: funding, time, large-scale databases, data hubs, labour Shortage of data scientists and physicians	Advocate for dedicated support for data reporting Create programs that support data collection Advocate for transparent and accessible ministry-reported data for all provincial programs Establish a working group to house an inventory of ministry-reported data Identify clinical tools and resources that capture specific data/variables for children under six years of age Conduct research with community agencies
Collaboration	Sectors work in silos Gaps in system integration, data linkage, multi-purpose data Require inter-sectoral agreement on values and desired outcomes Lack of inter-sectoral collaborative pathways to care Lack of policy and data governance Lack of legislation that considers needs identified through research Lack of family engagement and collaboration in research	Conduct an environmental scan or inventory of what data is available, how it is collected, and at what level. Determine how to make this data available, to avoid duplication Create a data repository that includes data linkages between various sectors. Use unique identifiers to achieve this Create a family advisory committee Reduce siloed data collection by engaging different organizations, groups, and sectors Identify a sponsor to champion and leverage this work Conduct an analysis to identify data and collaboration gaps Determine how to capture early years data before school entry Generate legislation to promote data linkage and data-sharing

Theme	Theme Topics	Actionable Steps
Environment and context	Failure to consider children's contexts and environments in data collection Need to consider MHD as beginning prior to conception and consider whole-family approach Limited understanding of how children and families engage with their communities Need to better understand cultural contexts, including how MHD is understood and measured Need to examine other contextual knowledge gaps when considering MHD impact: COVID-19 pandemic, substance use medical emergencies, foster care, housing, and food insecurity	Use unique identifiers to link families (mother, father, child) Identify the organizations and services that families are accessing in their communities. Determine how to acquire data from these services Understand what other countries are doing to collect environmental and contextual data Conduct a case study with a community or region to identify how data is collected and shared. Use this information to inform long-term actionable steps Collect qualitative and quantitative data using AI

Themes

Six themes were identified from the actionable steps generated during the break-out group activity:

- Conduct an environmental scan and create a data inventory
- Promote cross-sectoral collaboration
- Standardize data collection
- Improve data linkages
- Increase guidelines and legislation
- Prioritize family and community collaboration

A summary of each theme is provided below. These summaries reflect the discussions held during the break-out group activity.

Conduct an environmental scan and create a data inventory

Seven (of eight) break-out groups proposed solutions to address the lack of knowledge and access to early MHD data in Ontario. Ideas included conducting an environmental scan to identify ongoing data collection and use, as well as creating a data inventory to promote data accessibility and linkage. Additionally, four of the break-out groups highlighted the importance of minimizing duplicate projects and leveraging existing work. Both an environmental scan and a data inventory could help inform service- and system-planning.

Promote cross-sectoral collaboration

Six (of eight) break-out groups identified actionable steps to help promote cross-sectoral collaboration. Many of these steps focused on increasing engagement between various partners such as Ministry of Health; Ministry of Education; Ministry of Children, Community and Social Services; researchers; healthcare providers; and community mental health agencies. These actions were proposed to reduce siloed data collection, promote data-sharing and linkage, and improve knowledge.

Standardize data collection

Five (of eight) break-out groups proposed actionable steps to address gaps in standardized data collection. Proposed steps included standardizing indicators and definitions, data collection methods and procedures, and training, as well as promoting the use of consistent, reliable, and valid tools for infants and young children. Alternatively, two groups warned against over-standardization, explaining that data collection tools, such as screening tools, should not follow a "one size fits all" approach, and that individual needs should be taken into consideration. Participants noted that the absence of standardized EDI data collection raises ethical concerns if diverse cultural backgrounds, lived expertise, and personal identities are not reflected or accurately captured.

Improve data linkages

Five (of eight) break-out groups brainstormed ideas to promote data linkages, primarily through greater use of unique identifiers to link individuals' data between data sets. Greater data linkage would allow researchers and service providers to connect individuals across databases and services, allowing individuals to be followed through their care journey. Additionally, unique identifiers may help connect family data and provide additional contextual information, allowing researchers and service providers to implement whole-family approaches to care.

Increase guidelines and legislation

Four (of eight) break-out groups suggested the need for increased legislation and guidance from ministries and government agencies on data collection best practices. This could include new and improved policies related to developmental surveillance, pathways, mandatory implementation, data linkage, and data-sharing.

Prioritize family and community collaboration

Four (of eight) break-out groups proposed solutions to increase collaboration with families and communities. Suggested solutions included creating family advisory committees; co-designing data collection initiatives and embedding data and research activities within communities; creating data collection and data-sharing plans with communities that highlight trust and self-determination; and co-creating knowledge-sharing strategies.

Emerging Opportunities

Both meetings allowed cross-sectoral partners to discuss gaps in early MHD data collection and identify actionable steps to begin to address these gaps. Conducting an environmental scan of ongoing data collection initiatives within Ontario was identified as a valuable first step. The information summarized in the Participant Catalogue provides some preliminary information to inform this scan. Participants also noted that it may be helpful to create an inventory of the early MHD data collected throughout the province and have it updated regularly. This approach would allow for ongoing knowledge exchange of ongoing work, reduce duplication, and promote collaboration. Overall, these initial steps will help provide direction for future data collection initiatives that can be explored by leaders in the field of early MHD.

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Participant Catalogue: Data holders and users

This section includes information about the organizations in attendance at the November 2024 meeting that hold or access early MHD data. Information was submitted by participants. The Participant Catalogue can be used to understand organizations' focus and mandates, gain preliminary information about specific early MHD data collection initiatives, and to better understand what initiatives may exist throughout Ontario.

1Call1Click.ca

1Call1Click.ca is a coordinated and collaborative access service that helps connect children, youth, and families to mental health, addictions, substance use health, and neurodevelopmental services in the Eastern Ontario region. For more information, please visit https://www.kidscomefirst.ca/en/index.aspx.

What data are you currently collecting on children six and under, and what is the data used for?

1Call1Click.ca collects variables such as mental health care resources (primary care provider, past services received), demographic information, presenting problems, screening data, level of need and recommended interventions, and services referred. 1Call1Click.ca data is used for quality improvement and monitoring in the form of clinical and operational dashboards. Data is also included in research publications and conference presentations to support broader knowledge transfer.

What is unique about your data?

1Call1Click.ca captures a large portion of mental health needs within the Eastern Ontario community.

What equity, diversity, or inclusion data or social determinants of health have you collected?

Demographic variables include guardian information, age, language (language of service, spoken at home, mother tongue), sex/gender, family income, residence type, disability, racial/ethnic background, and education. 1Call1Click.ca's services are available in French and English.

Canadian Institute for Health Information

Canadian Institute for Health Information (CIHI) provides comparable and actionable data and information used to accelerate improvements in health care, health system performance, and population health across Canada. For more information, please visit https://www.cihi.ca/en.

What data are you currently collecting on children six and under, and what is the data used for?

CIHI hosts extensive linkable, pan-Canadian data across the health care continuum. We have 28 databases in total, many of which will include data for children 6 and under (Discharge Abstract Database (DAD), National Ambulatory Care Reporting System (NACRS), Patient Level Physician Billing (PLPB). The databases are used by multiple audiences, including policy- and decision-makers, clinicians, and others.

What is unique about your data?

Databases are pan-Canadian (coverage varies by province) and usually include a unique patient identifier so data can be linked. The data is standardized, with regularly checked data quality, and there are continuous efforts to improve coverage and data quality.

What equity, diversity, or inclusion data or social determinants of health have you collected?

Database dependent. Some demographic variables such as age and sex are routinely collected. Postal codes are also generally collected, and we use them to derive variables such as neighborhood income quintile or rurality using the Postal Code ^{OM} Conversion File Plus (PCCF+) algorithm from Statistics Canada. Variables such as race, language, or education may not be routinely available in our larger databases.

Canadian Primary Care Sentinel Surveillance Network

The Canadian Primary Care Sentinel Surveillance Network (CPCSSN) is a federated network of practice-based research and learning networks (PBLRNs). Each PBLRN has agreements with local primary care providers to contribute clinical patient data to a national electronic medical record (EMR) data repository. For more information, please visit https://cpcssn.ca/.

What data are you currently collecting on children six and under, and what is the data used for?

CPCSSN holds the medical records on over 1.8 million patients. This would include records for patients under six years, if they saw their primary care provider during those years.

What is unique about your data?

It contains the primary care records of children including well baby checks, diagnoses, prescriptions, physical measurements, labs, and referrals.

What equity, diversity, or inclusion data or social determinants of health have you collected?

CPCSSN does not contain direct measures of equity, diversity, or inclusion data or social determinants of health as primary care providers are poor documenters of these data types. However, CPCSSN links the EMR data to postal code and has neighborhood level measures including the Canadian Index of Multiple Deprivation, the Pampalon Index, and the Canadian and Ontario Marginalization Index.

Children First

Children First (Essex County) provides services for families with children up to six years of age who are at risk for or are experiencing mental health challenges or developmental concerns. We use a family-centred approach based on the principles of respecting every family's beliefs, values, and culture. For more information, please visit https://www.children-first.ca/.

What data are you currently collecting on children six and under, and what is the data used for?

HEADS-ED Under 6 data is collected at intake for all referrals. It is used for screening needs, level of need, level of support, prioritization and triage. Aggregated data is reviewed to inform program decisions. This data is provided to Lead Agency as part of the B.I. Solution CYMH.

InterRAI Early Years is used primarily as an initial assessment at present. Data is used to inform clinical decision making and family-led service plans. Data is reviewed at the management level to inform knowledge-building regarding those served and ways to improve service delivery, identify patterns and trends, and convey relevant information to community and partners for continuous improvement. As we progress, the data will be used to inform overall outcome measurement through multiple time point analysis.

The Measure of Processes of Care (MPOC) is a 20-item measure to assess parents' perceptions of the care they and their children receive from children's treatment centres. It is a means to assess family-centred behaviours of health care providers. MPOC is administered at a minimum of two times per year to families randomly. The data is shared with staff, management, the Board, and families with the opportunity to inform service delivery and program improvements as identified by family.

What is unique about your data?

Parental engagement — sharing data with caregivers — can help parents understand their child's development and engage more effectively in their learning. Aggregate data is used to inform waitlist management strategies, as well as program and policy changes. Our data has been used as a community to create pathways and community of practices.

The data we collect on the caregiver, the child, and their environments informs care planning and service coordination.

What equity, diversity, or inclusion data or social determinants of health have you collected?

The data collected through the InterRAI reflects social determinants of health. We also collect the number of families receiving services in French and their perspective of the quality of services offered and how family-centred their services are.

Children's Hospital of Eastern Ontario, Early Connections

The Children's Hospital of Eastern Ontario (CHEO) is an academic pediatric hospital located in Ottawa, Ontario. The Early Connections service provides specialized mental health care to treat children 0 to 6 with complex emotional and behavioural concerns and provides expert consultation supports to community-level agencies.

What data are you currently collecting on children six and under, and what is the data used for?

A rigorous data collection process has been implemented since 2023. All families seen through our program receive a series of questionnaires to complete throughout their service journey, at Choice, New Partnership, and at transition to community. Measures include a demographic intake survey, psychometric measures relating to both the child and the caregivers' mental health (Parent Reflective Functioning Questionnaire, Rugged Resilience Measure, Child Behaviour Checklist, Parental Stress Scale, Patient Health Questionnaire-9, SNAP-IV for ADHD, Devereux Early Childhood Assessment, Weekly Assessment of Child Behaviour, and others) and client service satisfaction. Data on program uptake and service utilization is collected via chart review by the team. The data collected by our team helps us understand symptom improvement, family satisfaction, and service delivery metrics, and is used to assist in guiding any changes to optimize delivery of care within our service. This measurement-based data is intended to be used as a secondary database to evaluate quality improvement initiatives and research-based questions. We are currently in the process of conducting a broader program evaluation project which includes an extensive chart review of all patients referred and seen through Early Connections dating back to 2019. This data is intended to map onto our program's logic model which was developed prior to the clinic's implementation. The logic model includes components of Provision of Services (increasing access to specialized care, decreasing need for emergency services), Collaboration with Community Agencies (uptake and satisfaction of community-based partnerships/pathways), and Prevention and Education (satisfaction and change in knowledge/skills after delivering training workshops to other mental health professionals). The data collected in all of the above initiatives is also projected to be used in a future economic evaluation to determine the gaps and potential improvements which can be made to change policy and increase funding at the government level for services for this population.

What is unique about your data?

To our knowledge, we are the only hospital-level program that has the resources to conduct such a rigorous evaluation and research initiative.

What equity, diversity, or inclusion data or social determinants of health have you collected?

Our demographic intake questionnaire collects information about gender/sex, language, racial/ethnic background, family income, education/daycare attendance/supports, caregiver demographic information, Adverse Childhood Experiences, attachment to child protection service(s), and others. Most of our questionnaires are administered in French and English, but the majority of our families complete the questionnaires in English.

Hôpital Montfort

What data are you currently collecting on children six and under, and what is the data used for?

Dre Valérie Giroux collects the following information: measure of attachment relationship between mother and children, standardized measures via scales (Devereux Early Childhood Assessment (DECA), Ambiance Brief, and Weekly Assessment of Child Behavior (WACB)).

What is unique about your data?

It is the first longitudinal study on mothers with borderline personality disorder and their children, a vulnerable and high-risk population.

What equity, diversity, or inclusion data or social determinants of health have you collected?

Demographic variables include guardian information, age, language, sex/gender, source of income, residence type, medical and psychiatric comorbidities of the mothers, and education.

Infant and Early Mental Health Promotion

Infant and Early Mental Health Promotion (IEMHP) is a national organization which improves outcomes across the lifespan through translating and promoting the science of early mental health into practice with families during pregnancy, infancy, and early childhood. For more information, please visit https://www.iemhp.ca/.

What data are you currently collecting on children six and under, and what is the data used for?

We are currently collecting Ages and Stages Questionnaire (ASQ) information for children up to six months of age. The data is used for research and program decisions, with the potential to be used for policy decisions as well. The ASQ information collected includes: child’s birthdate; child’s sex; whether the child is on a waitlist for any intensive services and, if yes, which ones; whether the child has a diagnosis at the time of screening and, if yes, the diagnosis; whether child is premature and, if yes, how many weeks; communication score total and interpretation; gross motor score total and interpretation; fine motor score total and interpretation; problem-solving score total and interpretation;

personal-social score total and interpretation; additional questions collected by the ASQ; whether a developmental support plan (DSP) was developed and, if yes, the domains of development that the DSP targets; the follow-up action taken following the ASQ screening.

Additionally, we collect demographic information from the caregivers of the under 6 children. The demographic information includes postal code; age of caregiver; family structure; number of children in family's care; languages spoken at home; years lived in Canada; current employment status; ethnicity; household income; education level; if the child is involved with any programs; and if the child is currently receiving any services.

This data has been entered into the Nurturing the Seed (NTS) Database and the Canadian Database of Development, Infancy to Six (CanDDIS) since 2019.

What is unique about your data?

The CanDDIS is a unique opportunity to learn about child development for children under the age of six across diverse Canadian contexts, such as Indigenous communities, child welfare, public health units, schoolboards, and community-based organizations. The NTS Database is a unique opportunity for Indigenous communities in Canada to learn about the development and social-emotional well-being of the children in their local communities.

What equity, diversity, or inclusion data or social determinants of health have you collected?

We collect information related to age, sex, ethnicity, primary language spoken at home, household income, education level, employment status, postal code, service waitlists, and service access.

Institute for Clinical Evaluative Sciences

The Institute for Clinical Evaluative Sciences (ICES) is a not-for-profit health research and data analytics institute. ICES leads cutting-edge studies that evaluate healthcare delivery and outcomes. For more information, please visit https://www.ices.on.ca/.

What data are you currently collecting on children six and under, and what is the data used for?

ICES has over 100 different data holdings. They are grouped into people and geography, health services, providers and facilities, registries, and social data (ICES Data Dictionary). The vast majority of ICES' data holdings have information about children six and under. The datasets focused on children are: Better Outcomes Registry Network, Newborn Screening Ontario, Target Kids!, Pediatric Oncology Group of Ontario data, and Ontario Paediatric Inflammatory Bowel Disease data.

In addition, some identity and social data that may be of interest includes permanent resident and temporary resident data (from Immigration, Refugees and Citizenship Canada), Indian Register System (under strict First Nations governance), Métis Citizenship Registry and household surveys (under strict governance by Métis Nation of Ontario).

Other data that we are currently working to bring to ICES includes the Early Developmental Instrument and the child welfare data.

What is unique about your dataset?

ICES holds over 100 individual-level data holdings that are linkable, which allows ICES to track the trajectory of individuals interactions with the health system and beyond from birth to death. Further, ICES has models to support the access of the data it holds by various types of researchers. Finally, ICES data encompasses much of the publicly funded administrative health services records for the Ontario population eligible for universal health coverage since 1986, and is capable of integrating research-specific data, registries, and surveys.

What equity, diversity, or inclusion data or social determinants of health have you collected?

ICES collects and has developed algorithms related to the following equity data: immigration data, neighborhood-level income, Ontario Marginalization Index measures, rurality of residence, violence-related healthcare, homelessness, hospitalization, maternal age at first birth, community health centre data, Aboriginal health access centres, social assistance, disability support program, Indian Registry System (under strict First Nations governance), Métis Citizenship Registry and household surveys (under strict governance by Métis Nation of Ontario), environmental data, and school readiness data. Although not population-based, several of ICES' data holdings include contact information about race and ethnicity. ICES has also developed a Guidance Document and Framework for Anti-Racist Approaches to Research and Analytics at ICES (ICES | Health Equity at ICES). ICES does not specifically collect French language variables.

Linck Child, Youth & Family Supports

Linck Child, Youth & Family Supports (Linck) is the lead agency for child and youth mental health services for children aged 0 to 18 years in Chatham-Kent. Linck also provides municipal developmental services for children aged 0 to 6 years, childcare support services, child welfare, and youth justice mental health services. For more information, please visit https://linck.org/.

What data are you currently collecting on children six and under, and what is the data used for?

Client demographics and service use data are used for program evaluation and service planning.

What is unique about your data?

Our data reflects the developmental and/or mental health needs of those living in a rural community. Client and service use data spans 26 years of service.

What equity, diversity, or inclusion data or social determinants of health have you collected?

We collect postal codes. Equity data collection is otherwise not consistent. French language variables are not consistently collected; however, Chatham-Kent is a French-designated community.

Lumenus Community Services

Lumenus offers a broad range of high-quality mental health, developmental, and community services for infants, children, youth, adults, and families across Toronto. For more information, please visit https://www.lumenus.ca/.

What data are you currently collecting on children six and under, and what is the data used for?

For our clinical services, we are currently collecting basic demographic data, number served, number of visits, cost per client, duration of service, wait times, client satisfaction, and experience and outcomes (self-reported). We are moving toward assessing outcomes and the impact of services more deliberately in the coming years, which is connected to our new strategic plan where client outcomes are a key goal. Our data is not currently easy to assess for clients under six years.

What is unique about your data?

Our kids under six years could be included in our mental health, developmental, autism, and other early years services. With 4 data systems coming into the amalgamation, it has been challenging to integrate the data in meaning ways. With the new client information system recently launched, we will be able to use data very differently moving forward.

What equity, diversity, or inclusion data or social determinants of health have you collected?

We recently transitioned to a new client information system and included a standardized data set for client self-identifying information. French language variables are not collected.

Ministry of Children, Community and Social Services

The Children with Special Needs Division (CSND) at the Ministry of Children, Community and Social Services (MCCSS) leads policy development and program design and provides operational oversight and accountability in support of a family-centred, data-informed and effective integrated service system for children and youth with special needs. This division also promotes effective and individualized support for families, infants, and children with risk to healthy development, and children and youth with special needs. CSND works collaboratively across the Ministry and in partnership across the government and broader public sectors to transform service delivery models for children, youth, and their families across the life course. For more information about MCCSS, please visit https://www.ontario.ca/page/ministry-children-community-and-social-services.

What data are you currently collecting on children six and under, and what is the data used for?

CSND collects and analyzes data in regard to the Early Child Development programs in Ontario: Healthy Babies Healthy Children (HBHC), Young Parent Services (YPS), Preschool Speech and Language (PSL) Program, Infant Hearing Program (IHP), Blind Low Vision (BLV) Program, and the Infant Child Development Program (ICDP). It includes demographic and service delivery data, such as wait times, screening forms, intervention, assessments, and outcome measurement tools. The data is used to monitor the delivery of these programs against their set targets, and data is managed to run custom queries to respond to targeted research questions and produce analytical reports.

The CSND uses a system that is called the Healthy Child Development – Integrated Services for Children Information System (HCD–ISCIS). HCD-ISCIS is a multi-tier case management system that captures results from screening and a variety of assessment tools to evaluate risk in families and their children (up to age six). This system gathers information from HBHC, IH, BLV and PSL. Data can be extracted from the HCD-ISCIS system using pre-defined or custom reports in ISCIS Reporting Sub-System (IRSS), a web-based decision support system that consolidates, transforms, and summarizes the data entered in HCD-ISCIS so that users can produce analytical reports.

CSND also integrates a strategic approach to develop and implement research, evidence, and data to inform CSND programs and policies, including a dynamic research agenda aligned with Ministry and divisional policies, strategies, and frameworks.

What is unique about your data?

The data collected captures information on conditions that affect the physical, communication, cognitive, emotional, and social and/or behavioural development of children. This includes data captured via screens that are universally offered to all babies born in Ontario.

What equity, diversity, or inclusion data or social determinants of health have you collected?

Demographic variables collected includes age, language, birth weight, sex/gender, income, geography, and education. Language variables collected includes the percentage of home languages spoken that are neither English nor French.

Ministry of Health, Digital Analytics Strategy Division & Office of the Chief Officer of Health

The Health Data Branch manages data assets for the Ministry of Health (MOH) and the Ministry of Long-Term Care (MLTC), including management of data standards; data development; acquisition and collection of data; access to authoritative, business-driven data; and integrated data solutions.

The Office of the Chief Medical Officer of Health (OCMOH) safeguards the health of Ontarians and provides advice on public health matters to the health sector, the division, MOH, other Ministries, and the provincial government. The OCMOH provides oversight and takes appropriate steps to promote and protect the health of Ontarians.

For more information about the MOH, please visit https://www.ontario.ca/page/ministry-health.

What data are you currently collecting on children six and under, and what is the data used for?

The MOH collects the following datasets that contain health data pertaining to children under six years of age:

Discharge Abstract Database (DAD): Quarterly hospital inpatient data acquired from Canadian Institute for Health Information (CIHI) and includes inpatient mental health hospitalizations for children in designated mental health units.

National Ambulatory Care Reporting System (NACRS): Quarterly data on hospital-based and community-based ambulatory care. These include surgical day/night care, outpatient clinics, and emergency departments. Contains data on mental health visits for children.

Claims History Database (CHDB): A repository of medical claims submitted by providers of health care services. Includes mental health claims for children primarily related to mental health related assessments.

MOH also has the following: Ontario Mental Health Reporting System (OMHRS) dataset includes information submitted to CIHI about all individuals receiving adult mental health services in Ontario. Information on children and youth can be found in this dataset if these individuals received services in adult mental health beds, as well as some individuals receiving services in youth inpatient beds and selected facilities in other provinces.

Ontario oversample of the 2019 and 2023 Statistics Canada Canadian Health Survey on Children and Youth (CHSCY): See Statistics Canada section for more information.

What is unique about your data?

DAD: Administrative data regarding inpatient care in acute hospitals, including Ontario Mental Health Act designated children's mental health units. Selection criteria are applied to identify mental health-related inpatient stays.

NACRS: Administrative data regarding ambulatory visits in emergency departments, day surgery, ambulatory oncology and ambulatory dialysis. Selection criteria are applied to identify mental health-related emergency department visits.

CHDB: Administrative data regarding physician claims for health services. Selection criteria are applied to identify mental health-related visits (fee schedule codes and fee schedule codes in combination with diagnosis codes).

What equity, diversity or inclusion data or social determinants of health have you collected?

DAD: Indigenous identity and racialized groups were added to the data collection in 2022/23; however, these are optional data elements.

NACRS: Indigenous identity and racialized groups were added to the data collection in 2022/23; however, these are optional data elements.

CHDB: Not available.

Ministry of Health, Mental Health and Addictions Division

The Mental Health and Addictions Division in the Ministry of Health (MOH) is responsible for a range of policy, program development and implementation, working in close collaboration with partners to advance government priorities related to mental health and addictions. Improving the mental health and well-being of Ontario's children and youth continues to be a priority for the government.

What data are you currently collecting on children six and under, and what is the data used for?

The Child and Youth Mental Health (CYMH) BI Solution is a system that collects client service data from agencies and provides performance indicators used by the Ministry and agencies to inform policy development, program design, service planning, and evidence-based decision making. CYMH BI currently collects quarterly data from approximately 90 agencies across the sector. Some of these agencies provide services to clients aged six and under. There is also the Transfer Payment Ontario (TPON) system that collects aggregated data for financial purposes. This system has close to complete coverage of Ontario, but the only data that is available in this system is the Number of Children and Youth between ages 0–5 for each agency.

What is unique about your data?

CYMH BI captures a large portion of data for CYMH core services within Ontario.

What equity, diversity or inclusion data or social determinants of health have you collected?

CYMH BI data has gender and race. Note that the race data is of low quality and has not been reported or validated. French language variables are not collected.

Peel Public Health

For information about Peel Public Health, please visit https://peelregion.ca/health/peel-public-health.

What data are you currently collecting on children six and under, and what is the data used for?

Collected data: Peel Infant Feeding Survey (PIFS) is a cross-sectional survey conducted with mothers between 26 to 33 weeks postpartum on the start date of the survey period. PIFS assesses infant feeding practices in hospital and at home, exclusive breastfeeding rates, duration of breastfeeding, and the introduction of other liquids and solids. We also collect demographic information about the mother. This survey is an enhanced surveillance initiative. It is used to monitor infant feeding practices over time in Peel Region. Public Health Units are required to collect local data related to infant feeding and monitor health behaviour and outcomes as per the Population Health Assessment Foundational Standard of the Ontario Public Health Standards (2021). Peel Region-specific infant feeding data is used to increase our understanding of infant feeding practices and help inform Peel Public Health's infant feeding programs and services.

Acquired data:

Canadian Survey on Children and Youth (CHSCY): We are able to look at data from both the Public Health Unit level (Peel Region) and Ontario-wide. For more information, please see the Statistics Canada section.

Early Development Instrument (EDI): This data is collected in Peel by various school boards, the Offord Centre for Child Studies, Ministry of Education, and the Peel Early Years Data Analysis Coordinators. EDI collects data on children's vulnerability in five developmental domains: physical health and well-being, social competence, emotional maturity, language and cognitive development, and communication skills and general knowledge. This questionnaire is completed by kindergarten teachers for every student in their Senior Kindergarten class. The EDI is an outcome measure of children's early development. The purpose of the dataset is to allow for population-based analysis, which is intended to allow communities to assess how well they are doing in supporting young children and their families and assist in monitoring changes.

Administrative health data (live births – birth weight, emergency department visits, hospitalizations, deaths). Data collected across a variety of settings and made available through the Ontario Ministry of Health's data portal (Intellihealth). Allows for analysis at the overall and cause-specific level using International Classification of Disease (ICD) codes.

Ontario Cancer Registry (OCR) (cancer incidence and mortality). Provincial database of information about all Ontario residents' diagnoses with cancer and those who have died of cancer. Combined multiple data sources.

What is unique about your data?

PIFS: Fills a data gap regarding infant feeding from hospital discharge to approximately 6 to 8 months of age. This allows us to look at any and exclusive breastfeeding for the first 6 months of life, as well as timing for introduction of other liquids and solid foods. In addition, PIFS collects information about programs and services accessed by new mothers.

CHSCY: CHSCY 2019 has allowed us to fill a data gap for children aged 1 to 11 as there is no other data source that provides data on health behaviours of children of this age. CHSCY allows us to fulfill Ontario Public Health Standards requirements around chronic diseases, healthy growth and development, school health, and more. We hope to use the data to continue to assess the health and well-being of children and youth in Peel region and provide our Family Health and Chronic Disease and Injury Prevention Divisions with population health assessment data to contextualize their work, including program planning, policy development, and advocacy.

EDI: EDI allows us to measure age-appropriate development before children enter the first grade and assess what proportion of children entering the first grade are vulnerable in one or more domains.

Administrative health data: Allows for custom age groupings and cause-specific analyses.

OCR: Allows for custom age groupings and cause-specific analyses.

What equity, diversity, or inclusion data or social determinants of health have you collected?

PIFS: Collects data on infant's age, sex, and birth hospital. For the mother, it collects information on parity, marital status, education, immigration, ethnic and cultural origin, and income. In addition, we collect data on if an interpreter was used to assist the participant in completing the survey over the phone in a language other than English. Participants can take the survey over the phone with an interpreter in a different language, such as French, if they choose, and we have data on what languages the survey was taken in.

EDI: Geographical location, gender, age, first language, attendance to junior kindergarten, and attendance to early immersion program. Language variables include if first language is English, French, bilingual, or other, French Second Language status, and if the child is in French Immersion.

Administrative health data & OCR: Minimal beyond basic demographic information.

Provincial Council for Maternal and Child Mental Health

The Provincial Council for Maternal and Child Health (PCMCH) is a provincial organization that provides evidence-based and strategic leadership for perinatal, newborn, and child and youth services in Ontario. For more information, please visit https://www.pcmch.on.ca/.

What data are you currently collecting on children six and under, and what is the data used for?

PCMCH works on projects where we use de-identified and aggregated data collected from other sources to inform our work. Much of the data PCMCH does collect is hospital or program-level data. PCMCH collects data on children aged six and under for a variety of projects, programs, and networks that are not developmental and mental health specific.

Ontario Paediatric Bariatric Network (OPBN) collects variables such as demographic information, general visit data, patient status at follow-up assessment timepoints, and other conditions/diagnoses. In fall 2024, PCMCH implemented an expanded data collection template that encompasses the following additional variables: current medications, metabolic, mechanical, and mental health. This data aims to inform a performance measurement framework for paediatric bariatric care in Ontario, providing insights into care quality, identifying system gaps and excellence, and driving quality improvement.

The Complex Care for Kids Ontario (CCKO) program collects data on CCKO patient volumes, referrals, waitlists, intake, transition to adult care, and care delivery and coordination. We also collect the FSA (first three digits of postal code) of patients that reside in Northern communities that are under the care of a complex care clinic. This data is used to inform quality improvement, program planning, and decision-making to identify how the program is developing along with system gaps and opportunities. CCKO program metrics are also used for accountability purposes, ensuring the program is on target.

What is unique about your data?

For OPBN, the data captured are de-identified at the patient-level for all patients enrolled in Ministry of Health-funded paediatric bariatric programs. For CCKO, all data is de-identified and reported by each CCKO clinic on a quarterly basis. To address health system gaps. PCMCH collects data on patient volumes, referrals, waitlist, intake, transition to adult care, and care delivery and coordination.

What equity, diversity, or inclusion data or social determinants of health have you collected?

For OPNN, demographic variables include age, sex assigned at birth, and FSA (first three digits of the patient's postal code). Additional social determinant of health measures are currently being considered to be collected in the near future. For CCKO, PCMCH collects data on FSA of patients from Northern communities. French language variables are not specifically collected.

Public Health Agency of Canada

The Centre for Surveillance and Applied Research leads the development and implementation of epidemiological activities to support national surveillance of health and chronic conditions across the life course, including among children and youth. For more information about the Public Health Agency of Canada, please visit https://www.canada.ca/en/public-health.html.

What data are you currently collecting on children six and under, and what is the data used for?

The Laboratory Centre for Disease Control (LCDC) supports provinces and territories in the collection of data. LCDC also funds Statistics Canada for specific national population health surveys.

Canadian Health Survey of Children and Youth (CHSCY): See information in Statistics Canada section.

Canadian Chronic Disease Surveillance System (CCDSS): The CCDSS is a collaborative network of provincial and territorial surveillance systems, supported by the Public Health Agency of Canada. The system collects data on all residents who are eligible for provincial or territorial health insurance. It can generate national estimates and trends over time for over 20 chronic diseases and conditions and other selected health outcomes. To identify people with chronic diseases and conditions, provincial and territorial health insurance registry records are linked using a unique personal identifier to the corresponding physician billing claims, hospital discharge abstract records, and prescription drug records.
With respect to mental health data, the CCDSS collects the following

information on those over the age of 1: use of health services for mental illness and alcohol/drug induced disorders, use of health services for mood and anxiety disorders, use of health services for schizophrenia.

Canadian Health Measures Survey (CHMS): The CHMS is administered by Statistics Canada. It is a nationally representative survey that collects self-report and direct health measures in Canadians aged 3 to 79. There have been 6 cycles of the CHMS collected between 2007 and 2019. For children under six there are some measures of mental health (self-reported mental health [3 to 6 years] and Strength and Difficulties Questionnaire [4 to 6 years]). There are also questions on diagnosed developmental disorder, ADHD, and learning disabilities (3 to 6 years). In addition, the first 5 cycles of the CHMS have been linked by Statistics Canada to hospital administration data to obtain information on follow-up diagnosed conditions. Linkages have been completed up until 2023.

What is unique about your data?

CCDSS: This is the only system which uses a unique personal identifier to link physician billing claims, hospital discharge abstract records, and prescription drug records to identify people with chronic diseases and conditions. CCDSS has almost 20 years of data.

CHMS: This is a large nationally representative survey with physical measures, linked to administrative databases including the Discharge Abstract Database, National Ambulatory Database, and the Ontario Mental Health Reporting System.

What equity, diversity, or inclusion data or social determinants of health have you collected?

CHMS: There are a number of variables related to gender, ethnicity, place of birth, family income, Indigenous status, French and English language use, and others.

CCDSS: As the CCDSS relies on health administrative data, sex, age group, and province/territory are available.

Starling Community Services

For information about Starling Community Services, please visit https://starlingcs.ca/.

What data are you currently collecting on children six and under, and what is the data used for?

There is a small amount of data collected specifically to children under six through the HEADS-ED Under 6 Tool through Camino, and some specialized assessments completed by Grand River Hospital for their pre-school diagnostic program. There is not a focus on this demographic either in data or program decisions regionally.

What is unique about your data?

The preschool diagnostics program at Grand River Hospital would have some potentially rich data beyond demographics that is typically collected. However, we need to explore this further with them if there is a clear identified purpose.

What equity, diversity or inclusion data or social determinants of health have you collected?

The data is not reliable at this time. French language variables are not specifically collected, beyond the client data set.

Statistics Canada

For more information about Statistics Canada, please visit https://www.statcan.gc.ca/en/start.

What data are you currently collecting on children six and under, and what is the data used for?

Statistics Canada is current collecting data on children and youth 1 to 17 years old through the Canadian Health Survey on Children and Youth (CHSCY). It explores issues that have an impact on the physical and mental health of children and youth, such as physical activity, the use of electronic devices, time spent in school and extracurricular activities, mental health, childhood experiences, suicidal thoughts, substance use, and impact of the COVID-19 pandemic. Additionally, the 2023 iteration of CHSCY follows respondents from the previous cycle (2019), assessing changes over time in health and well-being outcomes of Canadian children and youth. Information from the survey will be available to support the development of appropriate programs and policies to better serve Canadian children and youth, as well as promote physical activity and good physical and mental health.

We also collected vaccine data through the Childhood National Immunization Survey (CNICS) every two years from 2021 to 2021. Information on early learning and childcare arrangements are collected through the Survey on Early Learning and Child Care Arrangements (SELCCA) and the Canadian Survey on Early Learning and Child Care (CSELCC). Data is used by Federal-Provincial-Territorial (FPT) government, policymakers, and researchers to monitor, plan, implement and evaluate programs to improve the health of Canadian children and youth.

What is unique about your data?

The survey results provide reliable data at the national, provincial, and territorial levels, on factors affecting the health and well-being of Canadian children and youth, helping guide policymakers and decision-makers create programs and policies to help improve the lives of Canadian children and youth.

The longitudinal component of the 2023 CHSCY is particularly valuable in assessing changes in the health and health determinants of children and youth over time, as it contains data collected from the same individuals in both 2019 and 2023 on topics such as physical activity, the use of electronic devices, time spent in school and extracurricular activities, mental health, and substance use, among others. The longitudinal data was collected for the provinces only. The upcoming CHCSY annual program will continue to gather comprehensive data on the health of children and youth. This initiative is the result of the announcement by Federal, Provincial and Territorial governments to work towards improving health care for Canadians. This commitment acknowledged that strong data and common Shared Health Priorities indicators are essential for measuring and sharing progress with Canadians. The CHSCY annual program will collect health characteristics, determinants of health and outcomes, such as physical and mental health, substance use, access to health care, and health care needs.

The CNICS collects information on national immunization coverage for vaccines administered to children and pregnant women, as well as knowledge, attitudes, and beliefs about vaccination.

The SELCCA was the first national survey of childcare in more than 20 years. It provides valuable information to inform the Multilateral Framework on Early Learning and Child Care and progress of the Canada Wide Early Learning and Child Care program. The addition of the CSELCC provides even more detailed information about childcare participation as well as parental work arrangements.

What equity, diversity, or inclusion data or social determinants of health have you collected?

In line with Statistics Canada's Disaggregated Data Action Plan, our survey data contains sociodemographic characteristics such as age, sex at birth, gender identity, sexual orientation, race and ethnic origin, immigration status, Indigenous identity, for the child, personal most knowledgeable (PMK), and their spouse. Other data includes household income, household food insecurity, housing, school, and childcare. We also collect language information, and our survey questions are available in both official languages.

TARGet Kids!

What data are you currently collecting on children six and under, and what is the data used for?

Please see targetkids.ca.

What is unique about your data?

Parent and child reported outcome measures, health measures collected, and trials within cohort design.

What equity, diversity, or inclusion data or social determinants of health have you collected?

Income, education, ethnicity, experiences of discrimination, weight bias. French language variables are collected.

Toronto Public Health

Toronto Public Health (TPH) reports to the Toronto Board of Health and is responsible for the health and well-being of Toronto residents. For more information, please visit the website.

What data are you currently collecting on children six and under, and what is the data used for?

TPH offers a wide range of programs and services to families with children six and under, including Healthy Babies Healthy Children (HBHC) program, breastfeeding and infant feeding support, and parenting education workshops. Much of the data is collected as part of service documentation, which includes a mix of observation notes and structured data collected using assessment tools (e.g., NCAST Parent-Child Interaction Scales) and surveys.

Variables that we collect data for include demographic information, limited information about birth and family/parenting characteristics, infant feeding and breastfeeding practice, perinatal mental health, recommended interventions, and services referred. All of TPH's program data is used for quality improvement and performance measurement in the form of accountability reports and operational dashboards. Data is sometimes used in research publications and conference presentations to support broader knowledge transfer.

What is unique about your data?

The HBHC postpartum screening data captures approximately 50–60% of the babies born to Toronto residents. A subset of these families then goes on to receive additional services from TPH, and additional data will be collected for these families.

What equity, diversity, or inclusion data or social determinants of health have you collected?

Demographic variables generally collected from families and clients receiving services include: name, age (date of birth), and residential address. Select specialized programs for high-risk families collect additional sociodemographic data such as mother's education level, race/ethnicity, Indigenous identity, and family income. All of our services are offered in multiple languages, including French, either through service providers who speak the language or through language interpretation services. However, there is no language variable in the client profile and service record.

Waypoint Centre for Mental Health Care, Family, Child & Youth Mental Health Program

Waypoint Centre is a regional outpatient mental health consultation program in Simcoe-Muskoka serving patients under 18 years old. We work in a shared-care model with primary care providers. For more information, please visit https://www.waypointcentre.ca/.

What data are you currently collecting on children six and under, and what is the data used for?

We are a new program (established in 2020) and so have only recently started collecting HEADS-ED and HEADS-ED Under 6 as of fall 2024. We will be tracking this data to inform our triaging process. We also started using a patient questionnaire developed in-house, but this is only used for clinical decision making by the physician. We use Meditech as an electronic medical record (EMR) and therefore do have the ability to track demographics, diagnoses, wait times, etc. to assist in resource planning. HEADS-ED has been formatted within Meditech EMR.

What is unique about your data?

It represents a patient population with identified mental health or developmental concerns.

What equity, diversity, or inclusion data or social determinants of health have you collected?

Our Meditech system just formalized a social history dataset which includes demographics on gender identity and ethnicity, amongst other things. French language variables are collected.

Appendix 1: Organizations at the November 2024 Meeting

- Bloorview Research Institute
- Canadian Institute for Health Information
- Canadian Institutes for Health Research, Institute for Human Development, Child and Youth Health
- Canadian Primary Care Sentinel Surveillance Network
- CanChild
- Children First
- Children's Hospital of Eastern Ontario, Early Connections
- Children's Hospital of Eastern Ontario Research Institute
- Edwin S. H. Leong Centre for Healthy Children
- EMHware
- Empowered Kids Ontario
- Hamilton Health Sciences
- Happy Roots Foundation
- Holland Bloorview
- Hôpital Montfort
- Infant and Early Mental Health Promotion
- Institute for Clinical Evaluative Sciences
- Knowledge Institute on Child and Youth Mental Health and Addictions
- Linck Child, Youth & Family Supports
- Ministry of Children, Community and Social Services
- Ministry of Health
- Offord Centre for Child Studies
- Peel Public Health
- Provincial Council for Maternal and Child Mental Health
- Public Health Agency of Canada
- Public Health Early Years
- Public Health Ontario
- Starling Community Services
- Statistics Canada
- TARGet Kids!
- The Hospital for Sick Children
- Toronto Public Health, Public Health Early Years
- Waypoint Centre for Mental Health Care

Appendix 2: Organizations at the May 2025 Meeting

- Algoma Public Health
- Canadian Institute for Health Information
- Children First
- Children's Hospital of Eastern Ontario
- Children's Hospital of Eastern Ontario Research Institute
- Children's Mental Health Ontario
- Children's Mental Health Services, Hastings and Prince Edward County
- EarlyON Child and Family Centres, City of Windsor
- EMHware
- Empowered Kids Ontario
- Georgian Bay Native Women's Association
- Hands the Family Help Network
- Happy Roots Foundation
- Infant and Early Mental Health Promotion
- John Bright Foundation
- Knowledge Institute on Child and Youth Mental Health and Addictions
- Lumenus Community Services
- Ministry of Health, Digital & Analytics Strategy
- North Hastings Children's Services
- Offord Centre for Child Studies
- Peel Public Health
- Provincial Council for Maternal and Child Mental Health
- Public Health Agency of Canada
- Reach Out Centre for Kids
- Tampere University, Faculty of Medicine and Health Technology
- The Phoenix Centre for Children and Families
- Toronto Public Health
- University of Toronto
- Waypoint Centre for Mental Health Care
- York Region Public Health

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