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CHILDREN COUNT: TASK FORCE

RECOMMENDATIONS

CHILDREN COUNT

Acknowledgment

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CHILDREN COUNT PROVINCIAL TASK FORCE RECOMMENDATIONS

Introduction

Health seeking behaviors and risks for disease outcomes that occur later in life are often developed in youth and become harder to change over time. In order to make significant differences in chronic disease outcomes for a population, upstream approaches are needed that influence behaviours and the environment surrounding children and youth (Healthy Kids Panel, 2013). Focusing on children and youth and preventing or reducing poor health behaviours and risks before they start is the most direct way to improve overall population health and well-being (Cancer Care Ontario, Public Health Ontario, 2012).

Enabling children and youth to reach their full potential and reduce the burden of chronic diseases is a goal shared across multiple sectors including health and education. In their recent report, *Achieving Excellence* (Ministry of Education, 2014), the Ontario Ministry of Education (EDU) acknowledged the important interrelationship between health, well-being and educational outcomes. As well, the Ontario Ministry of Health and Long-Term Care (MOHLTC), in their release of the Ontario Public Health Standards (OPHS) (2018), underscored the importance of this connection with the inclusion of a School Health Standard that directly addresses health and well-being within the school environment. As such, Public Health Units in Ontario have a legislated responsibility for assessment and monitoring of child and youth health.

Addressing population health requires a comprehensive approach involving strategies built upon evidence and monitoring data. Monitoring, often referred to as 'surveillance' in the public health field, includes the systematic collection and analysis of health data for the purpose of planning, implementing and evaluating effective public health programs in local communities. In order to appropriately understand health behaviours of children and youth that influence well-being, and to properly measure health program investments over time, high quality assessment and monitoring data are needed at local levels. High quality data is accessible, reliable, accurate, consistent and comparable. In particular, it is important that sample sizes are large enough and representative enough to allow for valid analysis, ensure ethical standards for privacy and to draw solid conclusions to inform decision making.

The lack of a coordinated provincial system for the assessment and monitoring of child and youth health and well-being that meets local health assessment needs has been the focus of many reports, including: *Youth Population Health Assessment Visioning* (Public Health Ontario, Propel Centre for Population Health Impact, 2013) and *Child and Youth Health Sources Project* (Public Health Ontario, 2015). In a recent report to the Ministry of Education, *Unlocking Student Potential Through Data: Final Report (Quan, 2017),* the authors identify that improving monitoring of health and well-being for children and youth across systems would enable limited resources to be efficiently targeted to allow for the largest benefit to those most at risk of poor outcomes. Ontario's Chief Medical Officer of Health has also highlighted the importance of local data for planning and evaluating effective programs and services in the release of his report *Mapping Wellness: Ontario's Route to Healthier Communities* (The Chief Medical Officer of Health for Ontario, 2015).

Furthermore, the 2017 Annual Report of the Ontario Auditor General recognized that children are a public health priority population and that epidemiological data on children are not readily available to public health units for planning and measuring effective programming for this population (Office of the Auditor General of Ontario, 2017). Work must be done to coordinate and maximize resources that currently exists such that a cohesive approach can be developed to best capture and share information to enhance child and youth health and well-being that is accountable and fiscally responsible.

Improving Ontario's assessment and monitoring system would allow for:

- Greater impact and use of publicly funded dollars.
- Improved evidence in decision making at all levels (local, regional, provincial).
- Better efficiency, accountability, and collaboration between sectors.
- Improved health and wellbeing of children and youth.

Children Count LDCP

Building upon previous work, in the spring of 2017 the population health assessment and surveillance LDCP team released the results of its year of research in the report *Children Count: Assessing Child and Youth Surveillance Gaps for Ontario Public Health Units.* This report examined information gaps from the viewpoint of Ontario's public health units that were undocumented by earlier publications. The knowledge gained from public health units was further validated through stakeholder engagement with boards of education, federal and provincial government representatives, and child and youth health researchers in Ontario. The work of the LDCP resulted in key recommendations necessary for improving the assessment and monitoring of child and youth health and well-being in Ontario, as well as identifying priority health areas for action including physical activity, mental health and healthy eating.

This report is the outcome of the First Recommendation of the Children Count report to:

Establish a provincial task force: *The task force should include membership representing key stakeholders and leaders, with the aim to identify next steps for improving assessment and surveillance of child and youth health and well-being in Ontario.*

With continued support and funding through PHO, the Children Count LDCP team established the task force populated with leaders from public health units, non-governmental Organizations (NGO), education, government agencies, ministries, and researchers in this field. Invitations were sent in the spring of 2017 to identified stakeholders and organizations. The task force met four times (three in person and once via teleconference) from June 2017 to January 2018. Meetings of the task force included review and in-depth discussion of the Children Count reports recommendations and findings, review of current systems and their potential for monitoring in Ontario, and the crafting and refining of actions that need to be taken to improve assessment and monitoring of children and youth health and well-being.

The recommendations and action steps outlined in this report aim to improve the current state of health and well-being monitoring and assessment for children and youth in Ontario.

These recommendations are made specifically to the Ministry of Education, Ministry of Health and Long-Term Care and Ministry of Children, Community and Social Services; however, they will need to be applied with flexibility and a proper understanding of provincial and local conditions and capacities. Although the intended key stakeholders for these recommendations are the Minister of Education, Minister of Health and Minister of Children, Community and Social Services collectively, it is recognized that some recommendations may be directed to one Minister.

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RECOMMENDATIONS & ACTION STEPS

OVERARCHING RECOMMENDATION

Create a secretariat responsible for overseeing the implementation of the systems, tools and resources required to improve the monitoring of child and youth health and well-being. The secretariat shall be so enabled to:

1. **Guide the implementation of the five recommendations of the task force that are contained in this report.**
2. **Develop a process to ensure that assessment and monitoring systems remain effective, efficient, and relevant over time by addressing emerging issues and data gaps.**

Suggested Lead Ministries: Ministry of Children, Community and Social Services, Ministry of Education, Ministry of Health and Long-Term Care

The monitoring of health and well-being for children and youth is a shared priority of these three Ministries. In order to put children and youth at the forefront and ensure that programs and services are informed by local evidence based on high quality assessment and monitoring data, a secretariat is required. The secretariat should be formally enabled to work across Ministries to implement the following five recommendations.

Recommendation 1. Create an interactive web-based registry of database profiles resulting from child and youth health and well-being data collection in Ontario schools.

Suggested Lead Ministries: Ministry of Education, Ministry of Health and Long-Term Care
Suggested Supporting Ministry: Ministry of Children, Community and Social Services

Rationale: There is no coordinated or centralized system for data collection on the health and well-being of children and youth in Ontario schools. Instead, child and youth health and well-being is assessed by multiple data collection systems with a variety of methods, survey content, target populations, and purposes. A provincial registry of these systems would be an important step towards better and more consistent knowledge about the existence of child and youth health and well-being data across Ontario. The registry should document the data collection systems already in existence in Ontario to identify and reduce duplications to improve efficiencies that can increase the value of the information already collected, and ease the process of identifying knowledge gaps.

1.1 Identify and assign responsibility to a lead institution for the creation and maintenance of an electronic, interactive, and searchable registry.

1.2 Establish inclusion criteria for the registry, recognizing the large variability in size and quality of the data collected over time in Ontario schools, that will help optimize its value. The inclusion criteria may be based on principles related to:

- Collecting data in publicly-funded schools in Ontario
- Focusing on data regarding student health and/or well-being
- Determining a minimum sample size of study that should be included so that the data collected yield at a minimum, regionally representative estimates of student health and well-being indicators

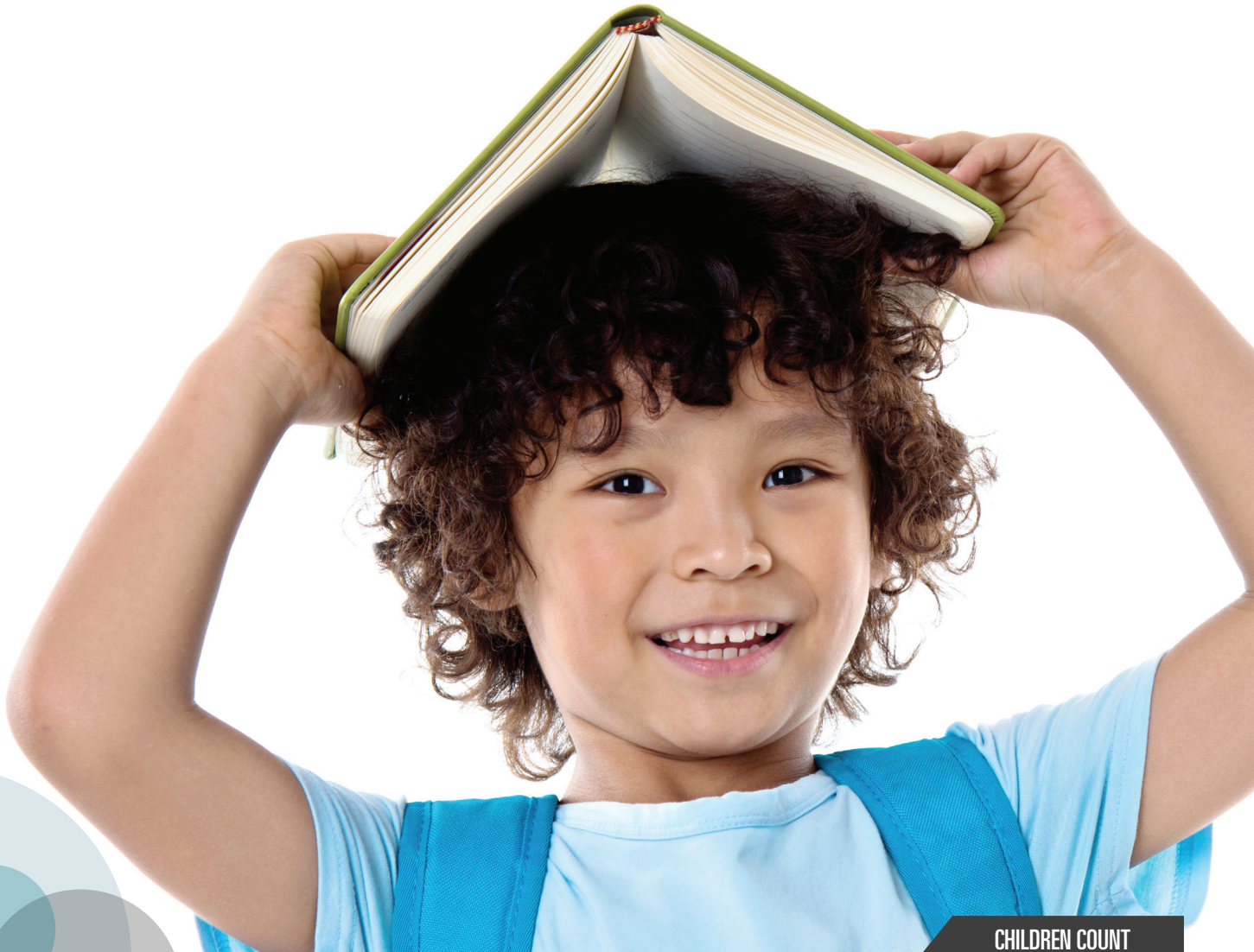
1.3 Determine the database characteristics and meta-data to be collected in the registry. The registry should provide a minimum set of publicly available information. The elements may include:

- Name, description, and purpose of the data collection system/survey
- The owner/administrator or principal investigator
- Methodological description (study design, sampling and data collection methods, consent process, etc.)
- Target student population description, (i.e., by age, sex, grade, school board, etc.)
- Geographic coverage, such as by school board or public health region and whether the system extends beyond Ontario (i.e., other provinces/territories or international)
- Data collection time period(s)
- Status of the database (active versus inactive)
- Survey content themes
- Detailed survey questions and response items, including socio-demographics and content relating to health and well-being
- Description of data quality, accuracy, and limitations
- Links to publicly reported results, as available
- Data release and access
- Contact information for the data

Recommendation 1. Create an interactive web-based registry of database profiles resulting from child and youth health and well-being data collection in Ontario schools. *CONTINUED*

1.4 Establish the necessary levels of user access and a process by which users can attain access to the registry database. As noted, there should be a minimum set of information for the registry that is publicly accessible; however, some elements (e.g., detailed survey questions) may not be appropriate for public access.

1.5 Secure agreement from the lead Ministries on the resources to establish and maintain the registry including the rules requiring monitoring activities involving Ontario publicly-funded schools to be included in the registry going forward.



Recommendation 2. Mandate the use of a standardized School Climate Survey template and a coordinated process across Ontario.

Suggested Lead Ministry: Ministry of Education

Suggested Supporting Ministries: Ministry of Children, Community and Social Services, Ministry of Health and Long-Term Care

Rationale: Monitoring of children and youth health and well-being is not well coordinated and the resulting reports/data are not or cannot always be shared, creating barriers for developing programs for children and youth. Mandating the use of a single School Climate Survey template for publicly-funded school boards would ensure that a standard set of data focused on health and well-being are collected regularly and consistently across the province. This standard template should include, at a minimum, the topics of mental health, healthy eating, and physical activity and be developed with appropriate stakeholder engagement and include space for individual school boards to ask questions on topics of local interest. Additionally, a coordinated reporting system that includes data sharing with public health units and other child service providers would improve coordination efforts with other data collection projects such as COMPASS, Health Behaviour in School-aged Children (HBSC), and the Ontario Student Drug Use and Health Survey (OSDUHS), and will increase the sharing of results with public health units, facilitated through the Ministry of Education.

2.1 Standardize frequency of School Climate Survey administration.

2.2 Consult with the Ministry of Health and Long-Term Care to coordinate concepts, terms and wording for standardized questions including, at minimum the topics of mental health, healthy eating and physical activity to ensure alignment with public health needs and definitions.

2.3 Coordinate with other large data collection projects such as COMPASS, HBSC and OSDUHS to use standardized health and well-being questions and to balance timing of all data collection systems (see 2.1) in Ontario publicly funded schools.

2.4 Require all school level data from the School Climate Surveys to be shared annually with Ministry of Education.

2.5 Coordinate the sharing of School Climate Survey data with public health agencies (e.g., via the Ministry of Health and Long-Term Care and Public Health Ontario) through appropriate data sharing mechanisms.

Recommendation 3. Develop and formalize knowledge exchange practices through the use of centrally coordinated data sharing agreements.

Suggested Lead Ministries: Ministry of Education, Ministry of Health and Long-Term Care
Suggested Supporting Ministry: Ministry of Children, Community and Social Services

Rationale: In 2015, Public Health Ontario's Child and Youth Data Sources Project Report identified over 25 data sources for Ontario. While these sources (e.g., Canadian Community Health Survey, Ontario Student Drug Use and Health Survey, and the Kindergarten Parent Survey, etc.) cover different aspects of child and youth health and well-being the results are not always readily disseminated or made available to school boards, public health units, or other organizations due to perceived privacy and legislation restrictions. The lack of coordinated data sharing practices and knowledge exchange between key stakeholders and decision-makers creates a barrier to the development of evidence-based programs and services to improve the health and well-being of children and youth in Ontario communities.

3.1 Establish a formal requirement mandating that all data collection systems (that meet the inclusion requirements of the registry) used in publicly-funded schools and school boards be registered through the central web-based data registry.

3.2 The Ministry of Education should develop and require a Memorandum of Understanding (MOU) between the Ministry and each data collection organization. These MOUs should support sharing of data between:

- Publicly-funded schools and school boards
- Publicly-funded school boards and the Ministry of Education
- Publicly-funded school boards and local public health units
- The Ministry of Education and Ministry of Health and Long-Term Care (in support of requirements for local public health units).

Recommendation 4. Develop and implement a centralized research ethics review process to support research activities in Ontario school boards.

Suggested Lead Ministry: Ministry of Education

Suggested Supporting Ministries: Ministry of Health and Long-Term Care, Ministry of Children, Community and Social Services

Rationale: The Task Force recognizes the significant barrier that a de-centralized and non-standardized research ethics review model poses to external researchers and public health authorities attempting to collect health data on students in schools across Ontario, as described in the *Children Count Report* (Population Health Assessment LDCP Team, 2017). The Task Force supports a more streamlined approach to the current patchwork of ethical review processes and a consistent model for determining appropriate consent (active versus passive) practices. These streamlined ethical review processes should consider The OCAP principles of Ownership, Control, Access and Possession for research involving Indigenous communities. This approach can be monitored by the proposed registry in Recommendation 1. To this end, the following sub-actions are required.

4.1 Adopt definitions and interpretations of research and surveillance in compliance with the Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans (pre.ethics.gc.ca/pdf/eng/tcps2-2014/TCPS_2_FINAL_Web.pdf) that are acceptable across publicly-funded school boards.

4.2 Raise awareness across Ontario publicly-funded school boards, public health units and other child service agencies about the difference between research and public health monitoring as it applies to data collection activities, such as the School Climate Survey.

4.3 Develop a streamlined approach to the current patchwork of ethical review processes. Streamlined ethics process should be considered for all surveys following criteria set out for the data registry (action 1.2).

4.4 Develop a consistent model for determining appropriate consent (active versus passive) practices that is acceptable across the publicly-funded school system that facilitates data collection across all age groups.

Recommendation 5. Work with the Information and Privacy Commissioner (IPC) of Ontario to develop a guideline for the interpretation of privacy legislation related to student health and well-being data collection in schools.

Suggested Lead Ministries: Ministry of Education, Ministry of Health and Long-Term Care.

Suggested Supporting Ministry: Ministry of Children, Community and Social Services

Rationale: Monitoring activities in schools are important for shaping policies, programs and services to improve student health and well-being, yet monitoring generates legitimate concerns across stakeholders charged with safeguarding the information. Information collected from students can be for public health monitoring purposes or can be for strictly research purposes. In public health monitoring, health and well-being related data are regularly collected and analyzed to monitor the frequency and distribution of health outcomes in the defined population to inform health service planning. It is a subtle, and therefore confusing, nuance. Often the distinction between public health monitoring and research is not well understood and this can have implications for scope of responsibility, methods for data collection and analysis, and most importantly on where and how privacy regulations apply. There is a need to ensure all health and education stakeholders understand this difference and they acknowledge that monitoring activities may be developed to comply with Ontario privacy legislation.

5.1 Integrate specific privacy best practices and legislative requirements in the guideline to assist educators and partners legislated to conduct monitoring activities in schools.

5.2 Establish consistent, clear interpretation of privacy legislation for Ontario publicly-funded school boards and public health units in the guideline.

5.3 Address and clarify issues related to the consent process for collecting health and well-being monitoring data in the guideline.

5.4 Establish knowledge processes between stakeholders, including school boards and public health units to ensure the guideline is understood and implemented.

The findings of the Children Count report and subsequent work of the provincial task force were validated in the recently released 2017 Report of the Ontario Auditor General which recognized children as a public health priority population and that epidemiological data on children (and other populations) are not readily available to public health units for planning and measuring efficient and effective programming. This finding led to a recommendation that the Ontario Ministry of Health and Long-Term Care identify areas in which relevant data are not consistently available to all public health units, such as data on children and youth, and develop and implement a process to gather needed data. (Office of the Auditor General of Ontario, 2017). The report also contained recommendations related to:

- The coordinated, efficient and effective delivery of health promotion initiatives to children and youth through efforts by the Ministry of Health and Long-Term Care and Ministry of Education to form partnerships between school boards and public health units
- Avoiding duplication in program planning and research for effective, evidence based public health interventions by coordinating and sharing research
- Properly measuring public health unit performance in delivering health promotion programs and services by establishing indicators linked to the new Ontario Public Health Standards

The recommendations developed by this task force can help to advance action in these areas and foster inter-ministry collaboration for establishing and monitoring meaningful indicators. These indicators can be used across all three Ministries, local school boards and public health units to guide actions that sustain and promote the health and well-being of Ontario's children and youth.

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GLOSSARY OF TERMS

Active consent - In an active consent procedure, the introductory letter explains the nature of the study and provides a method to document permission. Active consent requires parents or guardians to sign and return a consent form if they consent for their child to participate in an activity.

Assessment - The action or an instance of making a judgment about something. In relation to child and youth health data, assessment is the evaluation of health status of children and youth.

Locally-Driven Collaborative Projects (LDCP) The LDCP program brings public health units (PHUs) together to develop and run research projects on issues of shared interest related to the Ontario Public Health Standards. Working collaboratively on an LDCP helps PHUs build partnerships with each other and with students, academics, and organizations that are doing related work. As public health unit staff develop and lead projects, they strengthen their skills in research and project management, and ensure that the results of these projects are directly relevant to the work of Ontario's PHUs.

Knowledge exchange - In this report, knowledge exchange is defined as "a dynamic and iterative process that includes the synthesis, dissemination, exchange and ethically sound application of knowledge to help educators understand and apply privacy legislation related to student health and well-being monitoring activities in schools". This definition is adapted from Canadian Institutes of Health Research.

Passive Consent - A passive consent procedure typically involves distributing a letter to the children's parents or guardians explaining the nature of the study and providing a method to retract permission. Passive consent procedure assumes that the parent or guardian has consented unless some action is taken.

Registry - Registry of data sources for health and well-being of children and youth in publicly-funded schools in Ontario: an official platform and catalog for registering data collection systems that collect health and well-being data among students in publicly-funded schools in Ontario.

Research - An undertaking intended to extend knowledge through a disciplined inquiry and/or systematic investigation.

Student - Children and youth attending schools in Ontario (grade 1 to 12).

Monitoring/Surveillance - According to World Health Organization (WHO) and United States Centers for Disease Control and Prevention (CDC), surveillance or as this report identifies "monitoring" is the continuous, systematic collection, analysis, interpretation, and dissemination of data needed for the purposes of program planning, implementation, and evaluation. In this report, data collected through surveillance activities are health-related among students in Ontario and the ultimate goal of monitoring/surveillance is to improve health and well-being.

Well-being - According to Ontario's Well-Being Strategy for Education, well-being is a positive sense of self, spirit and belonging that is felt when our cognitive, emotional, social and physical needs are being met. Well-being in early years and school settings is about helping children and students become resilient, so that they can make positive and healthy choices to support learning and achievement both now and in the future.


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