

## Tracking Children's Mental Health in the 21<sup>st</sup> Century: Lessons from the 2014 OCHS

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In July 2018, the only fiscal commitment retained by the newly elected conservative government in Ontario from the previous liberal government was to mental health and addictions.<sup>1</sup> This commitment acknowledges Ontario's concerns about challenges to mental health in the population—concerns raised by the Auditor General of Ontario (2008)<sup>2</sup> and Provincial Advocate for Children and Youth (2012)<sup>3</sup> drawing attention to deficiencies associated with children's mental health services. At the heart of these deficiencies was the lack of information on: 1) the prevalence of child mental health problems in Ontario, and 2) the characteristics and outcomes of children receiving mental health services. In combination, the 1983 and 2014 Ontario Child Health Studies (OCHS) address this lack of information by identifying: (1) changes in the prevalence and determinants of child and youth mental disorder over the past 30 years, and 2) continuing challenges with access and targeting of child mental health services.<sup>4-10</sup>

The overall goal of health policies and programs in Canada to improve population health should be guided by two basic principles: accountability<sup>11</sup> (being answerable for meeting defined objectives) and equity (reduction of poor health among disadvantaged groups).<sup>12</sup> Ontario can stay true to these principles and constructively address the weaknesses that continue to undermine the effective provision of child mental health services in two ways (1) by developing an information system that measures children's mental health in the general population every 5 years; and (2) by incorporating identical measurement into intake and follow-up assessments of all children accessing provincially-funded community-based mental health agencies. These measures could be used in tandem to monitor the success of our provincial response to child mental health needs and identify specific changes needed, ensuring that services are responsive to the configuration of needs in the general population. This would be achieved by testing for parallel changes in the epidemiology of childhood mental disorders among children in the general population, and those accessing services at child mental health agencies.

This commentary: 1) summarizes findings from the 2014 OCHS to argue that core measures of child mental health be collected in the general population at regular intervals; 2) points out the limited information recorded on the mental health of children accessing community-based mental health agencies to argue that core measures be administered on all children at baseline and follow-up; 3) explains the value of collecting identical information in the general population and community-based child mental health agencies; 4) describes the content, requirements (practical and scientific) and operational features for the core measures; 5) demonstrates how the core measures can be used to improve decision making aligned with the basic health principles underlying policies and programs; and 6) concludes with a brief summary. While Ontario is home to the 1983 and 2014 OCHS, we believe that this commentary has broad relevance to other provinces and territories in Canada.

### **2014 OCHS—Changes in Child Mental Health**

Change between 1983 and 2014 is a powerful, recurring theme of the OCHS papers.<sup>8,9</sup> The proportion of males aged 4 to 11 years with attention-deficit/hyperactivity disorder has jumped dramatically. In adolescence, there has been a steep increase in anxiety and depression among males and females, but there was also a substantial decrease in the prevalence of conduct disorder among males. The prevalence of disorder among children in immigrant versus non-immigrant families dropped by almost 50% from 1983,<sup>9</sup> and there is strong evidence that children in poor households are at elevated risk for disorder when this occurs in combination with contextual factors like neighbourhood antisocial behaviour.<sup>13</sup> There appears to be a

geographic shift in the prevalence of disorder from large urban areas to small-medium urban and rural areas<sup>8,9</sup>. Finally, concerns persist about access to mental health agencies among children identified with disorder: although the proportion of children with mental disorder having service contacts increased from 1983 to 2014, those without contacts remained the majority.<sup>5,8</sup> The dramatic changes in child mental health documented by the 2014 OCHS indicate that core information on child mental health in the general population is needed at much briefer intervals than 30 years.

### **Limited Information Recorded on Child Mental Health**

In Ontario, children with mental health challenges access community-based mental health agencies by way of referral (general practitioners, centralized intake) or direct requests for help. Within these agencies, psychiatrists, psychologists and social workers collect information on child mental health relevant to their practice. However, there is no provision across agencies to collect the same measures of child mental health that could be used system-wide to examine the characteristics of those accessing services or the benefits accrued by doing so. The administrative information most relevant to understanding child mental health in Ontario is limited to diagnoses recorded by physicians at each visit and related billing codes for services provided. This information limits the identification of children with mental health challenges to the minority accessing walk-in clinics, urgent care, emergency rooms, hospitals and physician practices. In addition, failure to implement standard assessment methods results in varying degrees of reliability and validity for the information collected. Although health-information abstracted from administrative records has important, specific uses for health services research,<sup>14</sup> it is not a viable option for assessing or ensuring public accountability.

### **Alignment of Core Child Mental Health Measures**

In the study of children's mental health, there is a deep divide between the evidence and inferences on health system performance obtained in general population studies, such as the 2014 OCHS, and administrative data cumulated by service providers on patients. Differences in approaches to defining child mental health, methods of assessment and sampling of respondents make it impossible to assess the policies, programs and services developed by governments to address children's mental health needs in either the general population or in those accessing community-based mental health agencies. By collecting a core set of child mental health measures in the general population and the subset of children accessing community-based child mental health agencies, these two approaches could be aligned. Such an alignment would provide the information needed to understand the scope of children's mental health needs in the general population and the adequacy of provincial responses to these needs.

### **Content, Prerequisites and Organization of a Child Mental Health Information System**

We believe that the core measures of child mental health should include three indicators: emotional and behavioural problems measured as both dimensional and categorical phenomena; perceived need for professional help with emotional or behavioural problems; and functioning represented as academic achievement and social competence. Although a variety of ways exist to conceptualize child mental disorder,<sup>15,16</sup> there is a general consensus among child psychiatrists, psychologists and service providers that assessments of child mental health need revolve around problems of emotion and behaviour.<sup>17,18</sup> The underlying continua of these problem behaviours (number, intensity, frequency) provide direct insight on the severity of mental disorder. In

contrast, perceived need may be linked more closely to help seeking and the potential to benefit from services provided<sup>19</sup>. It speaks to child, youth and parent subjective recognition of mental health problems. Indicators of functioning focus on elements of human capability essential for engaged, productive and fulfilled lives. However, if compromised by mental disorder, they must be addressed in our service response.

The core indicators of the information system should: a) be operationalized in a single instrument that demonstrates reliable and valid measurement; b) be inexpensive and practical to implement in general population surveys and as part of intake and follow-up assessments done by service agencies; c) pose minimal burden to respondents and service practitioners; and represent the perspectives of youth and families on important mental health outcomes. We believe that a questionnaire, self-completed by parents of children aged 4 to 17 and youth aged 12 to 17 years in less than 7 or 8 minutes—a time threshold at which survey completion rates start to drop-off<sup>20</sup>—can meet these requirements. This type of instrument is inexpensive to implement, poses little time burden to respondents, can be completed in almost any setting, adapted to various modes of administration (e.g., in person via tablet/computer, internet), computerized to eliminate data entry costs, implemented in mental health agencies with little involvement of service practitioners and incorporated into general population surveys at modest additional cost. We see this instrument being implemented in the general population at 5-year cycles—a time interval suitable for identifying constancy or change in mental health need—and sampling children with enough precision in census boundaries associated with service catchment areas to provide reliable estimates of population need. This cycle could either capitalize on existing data collection opportunities provided by Statistics Canada (Canadian Health Survey of Children and Youth,<sup>21</sup> Canadian Community Health Survey<sup>22</sup>); or identify simple, unique data collection mechanisms through the internet or school-based anonymous assessments. We see this instrument being implemented in service agencies at intake and at 3 or 6-month follow-up, depending on service length. To implement these assessments consistently in service agencies would require investments in change management methods to overcome resistance among agencies opposed to modifying their data collection processes and adequate longer-term funding to support data analysis to address system evaluation questions.

In work associated with the 2014 OCHS, we have shown that self-completed questionnaires can meet all of the requirements discussed above and that brief problem checklists, developed to measure child mental disorders as dimensional phenomena, can be converted to binary measures of mental disorder (categories) that achieve levels of reliability and validity comparable to standardized diagnostic interviews implemented by lay interviewers in general population studies.<sup>23,24</sup> An example questionnaire that includes measures of mental health disorder symptoms and perceived need for help appears in the appendix.

### **Improved Decision Making**

How might this information system be used to better align policy decisions with the underlying health principles adopted by government? In general, this system would provide the evidence needed to evaluate the extent to which these principles are operating in practice. For example, at the population level, the system would track changes over time in child mental health, its geographic distribution and socioeconomic determinants. On its own, population level information would provide core data for evaluating the effects on child mental health of major government policy and program initiatives associated with prevention and treatment (improved health outcomes) and inform government about changes in socioeconomic gradients for child

mental health (health equity). Coupled with identical assessments obtained by service providers, the system would quantify the responsiveness of community-based child mental health agencies to population shifts in child mental health need (accountability). At the individual level, routine intake and follow-up assessments would provide evidence to assess change among children accessing community-based mental health services (improved health outcomes).

Aggregating population level information on children's mental health needs to service catchment areas would provide independent catchment area estimates of child mental health need. Bringing together these area estimates of child mental health need with identical information collected by child mental health service agencies could be used to assess the principle of accountability by evaluating service access among children in the general population with mental health needs. This would provide estimates of coverage (the percentage of the children in catchment areas receiving services); and service targeting (the percentage of children receiving services meeting criteria for need). Bringing together catchment area estimates of child mental health need with service expenditure and resource allocations could be used to assess the extent to which geographic expenditures and human resource allocation match general population needs (equity).

## **Summary**

There are high levels of child mental health need in the general population, temporal shifts in the configurations of mental disorders experienced by children and youth, and important information gaps about who receives community-based mental health services from agencies in Ontario and what services are obtained. An information system that uses an identical instrument to measure child mental health in the general population and in children receiving mental health services would provide government policy makers with the evidence to assess the extent to which the principles of accountability and equity apply to the provision of child mental health services. Although many different factors influence policy development, evidence can only contribute to the process if the appropriate information is available

Ontario has provided needed leadership in the past—the Ontario Ministry of Community and Social Services commissioned the 1983 OCHS. Along with the Canadian Institutes for Health Research, three Ontario ministries (Health, Education, Child and Youth Services) contributed funds to the 2014 OCHS. The Ontario Ministry of Children and Youth Services introduced the idea of core measures<sup>25</sup> by requesting children's mental health centres to implement the Brief Child and Family Phone Interview and Child and Adolescent Functional Assessment Scale between 1999 and 2015. The information system proposed here constitutes little time burden on service practitioners and no impediment to the collection of clinical information most relevant to their practice and objectives. There would certainly be start-up challenges to overcome associated with informed consent, the protection of privacy, the institution of consistent methods for collecting, processing and transmitting data for system-wide evaluation and for individual agencies to track outcomes if practitioners and administrators wished to do so<sup>26</sup>. These challenges are well worth addressing in view of the potential benefits to planning associated with the proposed information system. Surely it is time be strategic in our planning for children's mental health, linking what we do (process) to what we achieve (outcomes) with the goal of better addressing children's mental health needs.

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# PARENT/CAREGIVER QUESTIONNAIRE

## (OF YOUTH AGE 4 TO 17)

### *Instructions*

Below are some questions about how your child is doing. Please put an 'X' in the box next to your response. Leave the question blank if you prefer not to answer it.

The statements below describe some of the feelings and behaviours of children/youth. For each statement, please select the response that best describes this child/youth now or within the past 6 months.

	Never or not true	Sometimes or somewhat true	Often or very true		Never or not true	Sometimes or somewhat true	Often or very true
Angry and resentful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Finds it hard to stop worrying	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Anxious or on edge	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Gets back at people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Argues a lot with adults	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Gets in many fights	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Can't concentrate, can't pay attention for long	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Has been physically cruel to others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Can't stay seated when required to do so	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Has trouble enjoying self	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cruelty, bullying or meanness to others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Impulsive or acts without thinking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Destroys things belonging to their family or other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Loses temper	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Distractable, has trouble sticking to any activity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Nervous, high-strung or tense	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Easily annoyed by others	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Runs away from home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fails to finish things they start	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Talks about killing self	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Feels worthless or inferior	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Too fearful or anxious	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fidgets	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>				

**In the past 6 months do you think this child/youth needed professional help for emotional or behavioural problems?**

No       Yes

The items are scored as follow: Never or not true=0, Sometimes or somewhat true=1, Often or very true=2.

**Internalizing, Externalizing and Attention domains scores:** Scale scores can be generated by summing together the following sets of items.

**Total scale score:** All 23 items can be summed to together to generate a total score.

Internalizing (7 items)

Finds it hard to stop worrying  
Anxious or on edge  
Has trouble enjoying self  
Nervous, high-strung or tense  
Talks about killing self  
Feels worthless or inferior  
Too fearful or anxious

Externalizing (10 items)

Angry and resentful  
Gets back at people  
Argues a lot with adults  
Gets in many fights  
Has been physically cruel to others  
Cruelty, bullying or meanness to others  
Destroys things belonging to their family or other children  
Loses temper  
Easily annoyed by others  
Runs away from home

Attention problems (6 items)

Can't concentrate, can't pay attention for long  
Can't stay seated when required to do so  
Impulsive or acts without thinking  
Distractible, has trouble sticking to any activity  
Fails to finish things they start  
Fidgets