# From Crisis to Quality: The Family Edition



Policy Recommendations for the Ontario Provincial
Government

Family Engagement Committee - Children's Mental Health Ontario



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#### Introduction

Young people with mental health concerns in Ontario are in crisis, and that means that their families are in crisis. Families (including parents, caregivers, guardians, siblings and other family members) are struggling to access timely and high-quality care that meets the needs of their child or youth, due to long waitlists. They navigate through a system that is fragmented and uncoordinated in some places, and significantly under capacity in others. The impact of a mental health or addiction (MH&A) issue on the overall health and well-being of a family can be dramatic. Families are often left to fend for themselves while waiting for services, and seldom find or are offered the supports they need as service providers attempt to pull together a safety net of supports without the budget to do so.

In November 2018, Children's Mental Health Ontario (CMHO) and the Family Engagement Committee (FEC) released an online survey for parents and caregivers of children and youth who have received mental health care in Ontario, asking them to reflect on their experience in the child and youth mental health (CYMH) system.<sup>1</sup> Data from the survey were troubling and highlight a number of key challenges and opportunities in the CYMH sector. A similar survey – directed at siblings of children and youth with MH&A concerns – was released in January 2019 and identified similar themes.<sup>2</sup>

Based off the survey data, and the personal experiences of the FEC members and other families in the province, the FEC has developed a set of policy recommendations for the Ontario government. The recommendations focus on improving the family experience in the CYMH system. More specifically, they concentrate on the following areas: 1) Expanding supports for families, and ensuring these supports meet the needs of all families, 2) Increasing resources at or near schools to better support families, 3) Ensuring the system is designed to meet the needs of families through family engagement, and 4) Expanding the availability of effective and high quality care for all children and families, especially those in rural, Northern and remote communities.

#### Recommendations

- 1. Expand the availability of supports for families, and ensure these supports meet their needs.
  - According to the CMHO Parent and Sibling Surveys, in most cases (57%), parents and siblings
    are not offered the supports they need to weather the storms associated with their
    child/youth's or sibling's MH&A issue. However, when supports are made available to family
    members, they are eager to take full advantage of them (94% uptake rate). This
    demonstrates that there is a real opportunity to ensure services are available to support all
    family members as they navigate through the CYMH system.

<sup>&</sup>lt;sup>1</sup> The CMHO Parent Survey, released in November 2018, received a total of 226 responses.

<sup>&</sup>lt;sup>2</sup> The CMHO Sibling Survey, released in January 2019, received a total of 99 responses.

- The types of supports families indicated would be beneficial include: peer support for themselves and their other children, treatment directly in the family home, education on strategies/skills to support the child at home, crisis supports when the situation is too tough to handle alone, having someone to advocate for their child, and respite care so that families can take much-needed breaks. Fundamentally, the system should focus on keeping families together and keepings kids at home while they receive MH&A treatment.
- Ontario's children, youth and families are incredibly diverse and require culturally safe and tailored programming and supports. Therefore, the expanded supports for children and families – like those described above – must be designed to meet the unique needs of all communities, including Indigenous, LGBTQS2+, and racialized peoples.

#### 2. Increase resources located at or near schools to better support families.

- There is a significant opportunity for health care services to be co-located at, or located near, schools to provide expanded supports to families. The CMHO Parent Survey found that 95% of parents are not receiving supports through the education system, yet schools play a significant role in children's lives and are often a first point of contact for families trying to access MH&A supports.
- Future investments in the education sector should build on the work already occurring throughout the province through programs such as <u>School Mental Health ASSIST</u> and should support improved collaboration between the education and community CYMH sectors.

#### 3. Ensure the system is designed to meet the needs of families through family engagement.

- The CYMH system needs to be designed to meet the needs of families. Right now, families
  are being asked to meet the needs of the system. There are significant gaps in care,
  including wait times, accessibility issues, and lack of post-care and other transitional
  supports.
- In order to design a system that meets the needs of families, family engagement and
  involvement in system planning, design and implementation is critical. Family voices, along
  with the voices of children and youth, must be at the table. This will require additional
  funding to ensure structures are in place to allow service providers to engage in meaningful
  dialogue and collaborate with families.

### 4. Expand the availability of care for all children and families, especially in rural, Northern and remote communities.

- Although availability of MH&A services is an issue across the provinces, there are even more
  significant disparities for families in rural, Northern and remote communities. In fact, the
  location and proximity of programs to clients has been identified by parents as a major
  barrier to care, with 42% of caregivers reporting that the location of programs (i.e. program
  located outside of their local community) is a significant gap in the CYMH system.
- Indigenous youth and families living on and off reserve face even more serious barriers to accessing MH&A treatments.
- These gaps must be addressed. And new services must be culturally relevant and appropriate given the unique realities and needs of these communities.

• It is also important to ensure that children, youth and families in rural, Northern and remote communities are not forced to access MH&A treatment online or over the phone. Although these delivery mechanisms may be effective for some, families deserve and expect a choice of treatment options to ensure care is meeting the child and family's needs and preferences.

#### **Economic Costs**

Government investment to address the recommendations above will not only directly improve the well-being of families across Ontario but will also provide significant broader economic benefits across society. Presently, families are being asked to shoulder this crushing and unsustainable burden with far-reaching impacts and costs. According to the CMHO Parent Survey, 73% of families reported that their financial wellbeing was impacted due to their child's mental health issue. On a provincial scale, a 2017 IPSOS survey of parents of children with anxiety issues found that 1 in 4 parents have missed work to care for their child,<sup>3</sup> and a new research by the University of Toronto has quantified the economic cost of this lost work time at over \$420 million per year.<sup>4</sup> This demonstrates the immense cost of mental health and addictions issues in children on the economy and highlights the need for government action.

#### Conclusion

The time for action is now. We have the data in hand to demonstrate that a significant investment in children's mental health is urgently needed. In fact, it's long overdue. Investing in the children's mental health system will save lives and money – both today and for many decades to come. We call on the government to demonstrate real leadership by adequately funding and supporting a coordinated system that is critical for the wellbeing of Ontario children and their families – and to the overall health of our communities.

The recommendations included in this submission support and complement the priorities and strategic investments outlined in <u>CMHO's 2019 Pre-Budget Submission</u> and the <u>Youth Action Committee's 2018 From Crisis to Quality</u> report.

#### **About the Family Engagement Committee**

The Family Engagement Committee is a collection of family voices from across the province supported by CMHO, who, through consultation with families, work to develop recommendations for service providers and government, and outline how the CYMH system can better support families of children with mental health concerns by elevating the voices of parents.

<sup>&</sup>lt;sup>3</sup> Ipsos Public Affairs. *Children and Youth Mental Health Survey,* October 2017.

<sup>&</sup>lt;sup>4</sup> Canadian Centre for Health Economics and Children's Mental Health Ontario. *The Productivity Costs of Parents in Ontario with Children who Experience Issues Related to Anxiety,* November 2018.