



Ontario Centre of Excellence
for Child and Youth
Mental Health

Bringing People and Knowledge Together to Strengthen Care.

Summary of family consultations for child and youth mental health planning

August 2016



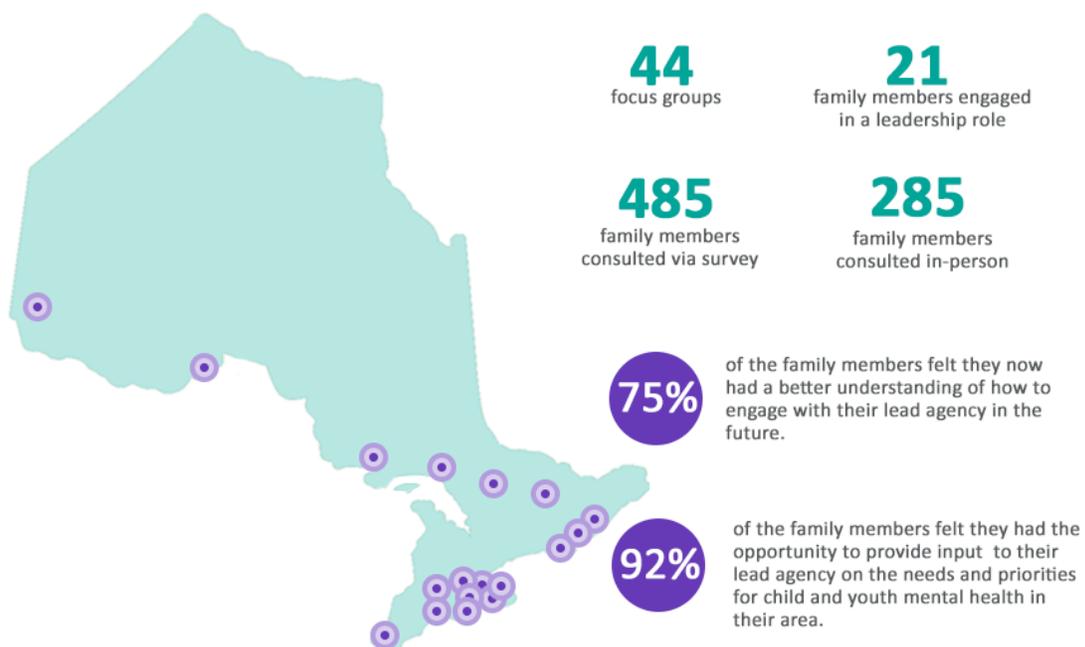
Background and context

The Ontario Ministry of Children and Youth Services' (MCYS) action plan, *Moving on Mental Health*, aims to ensure that children, youth and families have access to mental health services in their communities, where and when they need them most. As part of this plan, MCYS has identified 33 geographic service areas across the province. Each service area has a lead agency that is responsible for developing a Community Mental Health Plan (CMHP) and a Core Services Delivery Plan (CSDP). As part of the planning requirements, each lead agency must engage youth and families in the development process – putting children, youth and families at the centre of meaningful change in Ontario's mental health system.

To help lead agency develop CMHP and CSDP plans, the Centre of Excellence for Child and Youth Mental Health collaborated with Parents for Children's Mental Health (PCMH) to conduct consultations with families in service areas across the province. Our goal was to gather information from families while helping service areas develop and cultivate relationships that allow for sustained and meaningful family engagement. PCMH worked with Synergy Research and Evaluation Consulting to develop tailored consultation methods and tools, and then worked alongside agency staff and local families to plan and conduct service-area-specific consultations.

Eighteen lead agencies requested consultation support, which ranged from planning advice to conducting multiple consultations for diverse communities. We provided each lead agency with a report summarizing the feedback from families in their service area. This document summarizes high-level themes from conversations with families across Ontario.

Process overview





What families said about finding and accessing services in Ontario

What are family experiences like?

- **Lack of knowledge among those outside of mental health** – Multiple sectors (e.g. schools, family doctors, hospital staff, child welfare services and police) have a role in linking families to services. However, many providers outside of mental health are often unfamiliar with mental health or mental health services, which influences how much they are able to help families know where to go.
- **Confusing** – The process of finding help is confusing. They feel as though they are on their own to figure out which services are available, how to access them and the type of help they can receive.
- **Having to search for resources** – Help is often found by asking around (friends, online, etc.) and by seeking out resources on their own through trial and error.

What gets in the way of accessing help?

- **Wait lists** - Families are often unable to access help when it's needed and may endure a the seemingly unending process of slow referrals and multiple intakes (e.g. wait for intake, wait for service, service ends, wind up on another waiting list, etc.). Many are told it could be years before they receive services. They also have to wait for one service at a time. Families feel it often seems they needed to be in crisis in order to get help, or they need to spend money on private treatment.
- **Not knowing what services are available** – Many families across Ontario don't know where to start when they need help. Some key contacts (e.g. doctors and teachers) are unaware of existing mental health services. Many mental health agencies are unaware of other agencies or services available in other sectors (e.g. developmental services).
- **Lack of fit with service** – There are instances where children or youth don't meet service criteria due to age limitations, boundary issues, or the severity of the child's diagnosis (i.e. too severe or not severe enough). When



needs don't align with available services, families end up feeling as though they are being sent down the wrong path.

- **Limited access to specialized services** – There is an inability to access the specialized services families need for their children in their own community (e.g. psychiatrist, psychologist, residential service, specialized assessment, service for dual diagnosis/complex needs, inpatient care, respite care, and in many areas, crisis services). Many are forced to pay out-of-pocket and/or travel long distances to get these services, causing financial burden. This is often the case for families seeking services in French.
- **Logistical barriers** – Locations that are hard to get to as well as a lack of reliable transportation and limited service hours are often cited by families as challenges that prevent access to services. When service hours conflict with work schedules, families often have to take time off of work, and several families have one of the caregivers quit their job to help manage appointments.
- **Lack of engagement in treatment** – Families feel excluded from conversations about their child's mental health care. This causes a fear that service providers may not have the complete story. Families understand issues with confidentiality and legal consent, but want to be able to share their perspective and be involved in treatment planning.
- **Stigma** – Many family members feel reluctant to ask for help out of fear of being judged, misunderstood, blamed or labelled by others. This fear is often due to negative past experiences with the mental health system.
- **Lack of culturally-responsive services** –Service providers should be more culturally sensitive and should take steps to understand the family's culture and consider it as an important factor in how they support the family. This is particularly pronounced in consultations with First Nations, Inuit and Métis families.
- **Transitions between service providers** – Families want to build trust with the service providers they work with, but often get used to a worker only to have them leave without warning or explanation.
- **Multiple points of contact** –It is frustrating to work with several different service providers at a time. Families are asked to repeat their story multiple times and receive conflicting messages from each person they interact with. There is a lack of communication and coordination when dealing with multiple agencies or staff from within the same agency.
- **Transition from child/youth to adult services** –Families of youth between the ages of 14 and 18 years find it stressful to lose services in the child/youth system and move to the adult system without direction or assistance. It makes them start back at the beginning.
- **Services ending before the family is ready** – It is difficult for families when they know that despite their continued need, an agency discontinues a service. Often, they are left with no alternatives, and do not receive the needed information on next steps.
- **Isolation** – Families often feel isolated before and after services. Support and knowledge that they are not on their own is an important factor when receiving mental health services.

Family priorities to improve community mental health services

Families provided a variety of recommendations to improve mental health services:



- **Invest in peer support and navigator programs** – Families need help to find information, ask the right questions and navigate the system. More opportunities to support one another and learn from families who have navigated the mental health system are needed.
- **Provide flexible access** – Access can be improved by providing flexible/extended hours (with crisis services available 24/7), a variety of modalities to access appointments (e.g. Skype/videoconferencing), alternate service locations (e.g. mobile services, in-home supports), and childcare during appointments.
- **Offer more in-school supports** – Schools play an important role in mental health care. More collaboration between schools and local mental health agencies, and more mental health supports available in the schools, is needed.
- **Strengthen mental health awareness** – Those who interact regularly with families (including daycare providers, teachers, education assistants, doctors, hospital staff, emergency responders, etc.) need a stronger understanding of child and youth mental health and more knowledge about local services.
- **Engage the whole family in services** – Services need to be *family*-centred. Families want services to support the child/youth and families in a holistic way, viewing the entire family as the client. Family members want to be engaged in service planning to help determine the most appropriate plan of care for the child/youth and family as a whole. Families need support to ensure they have the information and knowledge to complement the treatment plan in the home setting. Providers need to listen to and respect family concerns.
- **Ensure continuity of care** – The coordination of service is important, whether multiple agencies are working together or several staff from a single agency are collaborating to provide care. A single point of contact with open communication between supports is preferred to ensure consistency, prevent conflicting information from surfacing, and to prevent families from needing to repeat their story. Warm transfers are preferred if a change in service providers is required. There is potential benefit to streamlined and integrated electronic records to facilitate information-sharing between all staff involved in service delivery.
- **Offer support while on wait lists** – Direction and support is needed while on wait lists *before* the point of a crisis, as many families find their situation worsens during this period of instability. This could be an opportunity to invest in peer support programming.
- **Invest in personalized care** – Customized services are important to each family's unique needs. Access to services in the family's preferred language is required, as well as culturally-sensitive services and supports. Service location is an important aspect of child/youth and family needs so flexibility on service location (e.g. home, school, office) is needed.

Strengthening family engagement

Families value sharing with other families, experiencing a sense of community and reducing the isolation they often feel in their journey. Families recommend the following ways service areas could enhance their engagement efforts:

- Engage families in all levels of system and organizational planning.
- Conduct ongoing consultations with families (including key informant interviews at the end of service, town hall meetings with both families and service providers present, anonymous surveys, etc.).



- Engage families in an advisory capacity (e.g. boards, committees) to help shape local mental health services.
- Use technology (social media, emails, webinars, etc.), existing channels (e.g. parent groups, school newsletters), and word-of-mouth to communicate with families.
- Engage families in efforts to raise community mental health awareness and reduce stigma.
- Engage families in the provision of peer support.
- Remove barriers where possible (e.g. offer childcare, support transportation, meet at a variety of times in a central location).
- Recognize family members for their time and contributions (e.g. offer an honorarium for participation in focus groups or key informant interviews).
- Provide families with ongoing communication, updates, and reports on progress and planning. Share back with families how their feedback has been useful or influential in making change.

What next?

Families want to be involved in community planning but don't always know how to engage with their lead agency in that capacity. Sometimes they don't know that consultations are happening, aren't given enough notice to prepare, or can't attend if childcare isn't provided. When they can attend they find the sessions are personally beneficial and they appreciate having a voice in improving services. Those involved in our consultations felt heard, and as a result, felt less alone. A comment of one participant reflected the sentiment of many: "It was very validating to hear other people's stories and know I'm not alone."

Participants are grateful that agencies want to improve services and are open to hearing about challenges and opportunities and they appreciate having an independent consultant conduct the consultations. While the sessions were well received, respondents would have liked the opportunity to be more widely available including to more diverse participants. Many said that the pre-session advertising needed to be enhanced and that the sessions could have been longer. Some people said they would have liked a follow-up to be offered, in the form of more sessions or the opportunity to connect with the group later on.

Lead agencies submit their Community Mental Health and Core Services Delivery Plans annually and will continue to engage families to inform their planning and work. The Centre's consultation support service was offered to lead agencies in their first year in the role, and many have now established positive relationships with families and have developed formal consultation mechanisms. The Centre will continue to be available to support lead agencies with family consultations in collaboration with PCMH, that are tailored to local needs. For further information, please contact us at centre@cheo.on.ca.



About the Centre: *The Ontario Centre of Excellence for Child and Youth Mental Health (the Centre) is a provincial organization that works with child and youth mental health agencies to strengthen services and build an effective and accessible system of care.*