Feedback on HQO's Draft Quality Standards for Anxiety Disorders and Obsessive-Compulsive Disorders

Introduction

Children's Mental Health Ontario (CMHO) and its members—child and youth mental health (CYMH) agencies across the province—along with the Ontario Centre of Excellence for Child and Youth Mental Health, appreciate the opportunity to provide feedback on Health Quality Ontario's (HQO) draft quality standards for the care of anxiety disorders and obsessive-compulsive disorders. Provincial quality standards are critical for guiding improvements in practice, and we are very pleased to see HQO's continued commitment to promoting quality in mental health and addictions services.

In both draft standards, HQO notes that "This quality standard focuses on care for adults (age 18 years and older), but it includes content that is relevant for children and adolescents (under age 18 years)." In our communication with HQO, we understand that while there was a desire to include care across the lifespan, there are limitations with respect to available evidence in clinical practice guidelines for children and adolescents. Further, HQO confirmed there would *not* be separate quality standards for young people with respect to anxiety disorders or obsessive-compulsive disorders.

After reviewing the draft standards, we feel they hold great potential for improving quality in the care of adults; but we do not believe these standards are appropriate for guiding health care professionals in supporting children and youth with these mental health issues. Further, by claiming to be relevant to children and youth, there is a risk that the standards will actually mis-inform and mis-guide health care professionals about how to effectively work with young people. This perspective is based in three principles, that will be discussed in this brief document:

1. Standards for children and youth must include robust engagement of families (and other support systems);
2. Standards for children and youth must be developmentally appropriate; and,
3. Standards for children and youth must be based on child- and youth-specific research and guidelines.

Ultimately, we recommend that child- and youth-specific standards be developed. As a first step, it would be helpful to begin by developing an over-arching standard on how to *approach* working with children, youth, and families in delivering developmentally-appropriate, family-centred mental health treatment.

1. Standards for children and youth must include robust engagement of families (and other support systems)

In both draft standards, HQO highlights the importance of family and caregiver involvement for children and youth. In the draft standard for obsessive-compulsive disorders, *Quality Statement 3: Self-Help* notes that "Guided self-help may be considered in conjunction with support and information for family and caregivers*"; Quality Statement 4: Support for Family and Caregivers*, notes that for children and adolescents "it is especially important to consider the needs of family and caregiver". In the draft standard for anxiety disorders, *Quality Statement 4: Self-Help*, notes that "guided self-help may be considered in conjunction with support and information for families and caregivers".

While we appreciate that HQO acknowledges the relevance of families and caregivers in supporting children and youth, the draft standards do not provide meaningful guidance about *how* to be responsive to this consideration. To the extent that these standards are intended to provide direction to health care professionals—for example, primary care providers

who have typically received only limited training specifically in child and youth mental health—it is not clear how these standards might successfully guide their engagement with families and caregivers in a concrete way.

It's important to emphasize that, particularly for children, family and caregiver engagement isn't just beneficial or recommended—it's effectively required, wherever possible. Given the developmental realities of children and youth (discussed more in the next section), families and caregivers play an essential—often irreplaceable—role in supporting children and youth. And this is not just true in relation to supporting a young person in managing their mental health issues, but in their development and progression in life more generally. As such, efforts to provide support through promoting guided self-help and the development and execution of treatment plans must actively engage families and caregivers—as well as the young person's broader circle of support, including schools—in order to be effective. And quality standards that are intended to guide practice on how to support children and youth with mental health issues must provide concrete guidance about what such engagement could or should look like.

These issues, in some ways, become increasingly complicated as the young person ages into adolescence and has greater autonomy from their families. Again, thinking in terms of how these standards might intend to guide work of primary care providers or other health care professionals, we also need to provide guidance on considerations with respect to confidentiality practices. Doing so can ensure that a young people's privacy is respected and at the same time, that they are receiving the necessary support from their families and caregivers in order to progress and remain safe.

Additional points of feedback (not specifically related to the three principles)

- In the "About this Quality Standard" section of each draft standard, the historical context of the lives of Indigenous peoples throughout Canada is acknowledged and the First Nations Mental Wellness Continuum Framework is highlighted. We are pleased to see this. But it is important to make this section more prominent as the needs of Indigenous communities—including Indigenous children and youth—are especially urgent, and the location of this section of text is easy to miss, as it sits outside of the set of quality statements.
- It is also important for the standards to prominently acknowledge the unique needs of specific communities, including 2SLGBTQ+ youth, who face an increased risk of experiencing significant mental health issues.
- Although there are limits to what can be achieved within the context of a quality standard, there may be value in recognizing that children and youth are presently served in a separate sector with different criteria and that transitions and collaboration between health providers and community providers are challenging.
- On page 14 of the draft anxiety standard, it is noted that: "People with an anxiety disorder frequently also have other physical or psychiatric conditions, and these might affect presenting symptoms and the person's response to treatment." It's also important to highlight that physical illness or physical substances can actually mimic or cause anxiety. For example, excess caffeine intake and hyperthyroidism can mimic anxiety, and so should be ruled out prior to diagnosing an individual with an anxiety disorder.
- Guidelines from the UK, including various NICE guidelines, are very useful and there are several respects in which it makes sense to borrow from them. For example, NICE guidelines for promoting the social and emotional well-being for children and young people provide very helpful guidance in terms of system planning and support planning. However, it is also important to ensure we are leveraging existing Canadian guidelines (e.g., CANMAT guidelines for treatment of mood and anxiety disorders) where possible—particularly with respect to psychopharmacology, where the particular medications used and prescribed in Canada sometimes depart from standard practice in the UK.

2. Standards for children and youth must be developmentally appropriate

Efforts to support young people with mental health issues must be approached within the context of their developmental stage. Not only must we engage in this work with a strong understanding of the differences between young people and adults, but even more specifically, with an understanding of the differences between children at various developmental stages—including infancy, latency, adolescence, etc. And then for each individual child or youth, we must also endeavor to understand their particular developmental level or ability.

Because HQO's draft standards are, first and foremost, targeting adults, they do not possess this developmental sensitivity. Treatment for anxiety disorders and obsessive-compulsive disorders in adults is diagnostically driven. But for children and youth, we need to contextualize their challenges—and how to collaboratively address those issues—within their developmental stage. Quite intentionally, work with children is developmental in nature. It recognizes that the child changes over time. What a young person is like now is different in some key respects from how they will be in six months, one year, etc. And as such, diagnosis is often avoided pending an improved understanding of the particular young person over time. Indeed, some behaviours which are normal at one age, may not be at another (e.g., bedwetting, which the DSM doesn't identify as "enuresis" until after age five).

When diagnoses *are* made, it is important that they are arrived at using validated tools that are specifically normed for children and youth. The presenting symptoms for anxiety disorders and obsessive-compulsive are often different for children and youth than they are for adults; the tools used must be sensitive to these differences. Further, tools targeted to adults often rely on a relatively high degree of accuracy in self-reporting, and often children and youth are typically less able to clearly express themselves, as compared to most adults. Using such tools for young people can increase the risk of under- or over-diagnosing for children and youth. Over-diagnosis can result in young people receiving treatment—potentially including psychopharmacological treatment—that may be unnecessary. Under-diagnosis can result in simmering issues going untreated and becoming more severe over time. And in either case, this result will have been produced while providing care in line with the quality standards.

Relatedly, we need to understand the nature of the mental health issues afflicting children and youth in the relation to their stage and circumstances in life. For example, for young people presenting with social anxiety issues, understanding the relationship between their anxiety and their school-life—and knowing the extent to which they are absent from school—is critical to understanding their challenges (e.g., whether or not there is a diagnosable disorder or simply an elevated level of normal anxiety in relation to school) and offering supports at the appropriate level of intensity.

Finally, we need to ensure the treatment interventions we are deploying—both psychopharmacological and psychotherapeutic—are matched to the unique needs of young people, across developmental stages. For example, in both draft standards, cognitive behavioural therapy (CBT) is the only specific psychotherapeutic intervention attached to a quality statement. And undoubtedly, CBT is an incredibly valuable, evidence-based tool. But, like any intervention, it will not work for all clients. For younger children in particular, it requires an emphasis on the behavioural aspect, because CBT in some forms can be highly cognitive—requiring a certain level of self-reflection about thinking patterns and behaviour which is unrealistic for many children. Even with a behavioural emphasis, though, CBT may still not be an appropriate intervention because of the required language and thinking skills. Alternatively, play therapy has been shown to be an effective tool for delivering therapy for younger children. This highlights the need to identify and promote the use of all of the evidence-based tools at our disposal.

3. Standards for children and youth must be based on child- and youth-specific research and guidelines

As HQO notes, quality standards outline for clinicians and patients what quality care looks like. Indeed, quality standards should offer guidance for clinical practice, based on the best *available* evidence (understood as the optimal combination of scientific research, clinical judgment, and patients' values and preferences) for treating a given health issue, within a given population. But, of course, sometimes knowledge gaps exist and what is available changes over time, as evidence bases evolve and emerge. The existence of knowledge gaps should not be used as a reason to not develop quality standards; rather, they should be identified and promoted as areas in need of more and higher-quality research.

Historically, there has been less research into understanding mental health issues in children and youth, and subsequently, less progress in validating tools and treatment interventions tailored to the needs of children and youth. As such, it is unsurprising that there is less evidence to work from in developing quality standards. However, it would also be a missed opportunity to proceed without leveraging the high-quality evidence base specific to children and youth that *does* exist. There are high-quality, research-based best practices for psychopharmacology for children and youth, differentiated across developmental stages; high-quality guidelines for psychotherapeutic interventions for young people; and validated and normed screening and assessment tools for assessing children and youth. We need to use these resources to build standards that are specific to children and youth. If we simply fold children and youth into adult standards, we misdirect from the valuable child- and youth-specific research that exists, in favour of less developmentally-appropriate interventions, and we may inadvertently undermine calls for additional research. Notably, there's precedent for HQO to develop unique standards for young people—as has been done in the case of asthma.

With all of this in mind, we believe it is essential that child- and youth-specific standards be developed. As a first step in developing provincial standards for child and youth mental health, it would be valuable to begin with an over-arching standard on how to *approach* working with children, youth, and families in delivering developmentally-appropriate, family-centred mental health treatment. This could be followed by the development of standards specific to various presenting mental health issues and/or diagnoses.

Conclusion

We greatly appreciate the opportunity to comment on HQO's draft standards and want to emphasize that we applaud HQO's efforts to promote standardization in high-quality mental health and addictions care. HQO's quality standards for anxiety disorders and obsessive-compulsive disorders hold great potential for improving practice in the care of adults.

However, for the reasons articulated in this document, we feel the standards are not appropriate for guiding the care of children and youth. We believe that child- and youth-specific standards should be developed, and we hope to be able to collaboratively pursue this work in the near future.