



THE SCHOOL
OF PUBLIC POLICY

Communique
Volume 16:14
April 2023

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EXECUTIVE SUMMARY

Mental health concerns among children and youth in Alberta are increasing while poor mental health remains as one of the largest threats to childhood in Alberta. In Canada, mental illness impacts 1 in 4 youth. Demands for mental health services have steadily increased over the past 10 years. To address the child and youth mental health crisis, strategic coordinating and monitoring of child and youth mental health service outcomes are important. This information can inform planning, funding allocation and evaluation.

Mental health services were already in crisis when the COVID-19 pandemic hit. The pandemic has only exacerbated the issue, particularly among youth. Delivering supports and services that meet the needs of youth is critical. A better understanding of the efficiency and effectiveness of mental health services is required. Patient-oriented outcome measures are important for gathering information that can incorporate the patient's own perspectives of their outcomes during treatment. Such measures can inform equitable distribution of funds and efficiency of systems planning.

Despite patient-oriented research being a national priority, Canada does not have a policy directing how to conduct patient-oriented research; thus, provinces are creating their own. Alberta lacks a unified approach, resulting in various tools and measures being used, which, has led to issues tracking patient outcomes, identifying trends and referring patients to services. Strategic guidance and policy regarding how to measure and track outcome measures are needed to gather consistent data and provide better services. A lack of consistent data from patient's perspectives impacts ability to make evidence informed, value-based decisions when allocating funds.

Policy related to youth mental health in Alberta is present in many ministries; however, no overarching cross-ministry strategy exists. This communiqué presents three findings from key informants who are knowledgeable about Alberta's youth mental health services and patient-oriented outcome measures.

1. **Measure what matters:** A lack of provincial consistency for measuring child and youth mental health outcomes was identified. A provincial strategy to improve measurement and monitoring of youth mental health is required. This needs to be a multi-ministry strategy that specifically considers children and youth. Key actions include the measurement of patient-reported outcomes more uniformly and addressing cross-ministry fragmentation in the child and youth mental health sector. Inconsistent or a lack of data being collected across Alberta has created inefficiencies, including the inability to identify trends and compare outcomes across jurisdictions.
2. **Bridge the equity gap:** Equity gaps in the mental health sector exist for marginalized children and youth, which have grown during the COVID-19 pandemic. Barriers to access services are greater for marginalized children and youth and many have fallen through the cracks throughout the pandemic. It is critical to ensure children and youth have access to resources that meet their needs and that mental health services are monitoring their outcomes during their treatment. Guidelines on how to measure and monitor patient-oriented outcomes are recommended.
3. **The need for a cross-ministry youth mental health strategy.** The absence of a youth inclusive mental health strategy impacts the implementation of patient-oriented outcome measures for children and youth in Alberta. Without co-ordinated action to improve service delivery and monitoring, there is increased risk of long-term adverse impacts on child and youth mental health. Equity deserving groups must be part of the design and implementation of the provincial strategy to allocate resources appropriately.

One in four children in Canada are impacted by mental illness. It is critical for the Alberta government to measure what matters and provide strategic guidance to improve equity and efficiency of youth mental health services delivery.

RECOMMENDATIONS AND CONCLUSION

Policies that are responsive to children and youth and designed through engagements with subject-matter experts and marginalized children, youth and families are necessary.

Three recommendations are provided to address the gaps in mental health research and support:

1. Develop or refresh a provincial cross-ministry strategy for improving youth mental health;
2. Design provincial guidelines on measuring and monitoring patient-oriented outcomes;
3. Engage equity-deserving groups in the design and implementation of the provincial strategy and guidelines.

INTRODUCTION

POLICY ISSUE

In Canada, mental illness impacts an estimated one in four children and youth (Barbic et al. 2019; Mental Health Commission of Canada 2013), and approximately 80 per cent of mental health disorders first occur before the age of 26 (Power et al. 2020). Triggered by life events, prolonged stress or trauma, the consequences of mental illness can be severe and debilitating (Canada 2015). The Raising Canada Report (2022) ranked poor mental health as the second-largest threat to childhood and demands for mental health services have steadily increased over the past 10 years (Children First Canada 2021b). During the COVID-19 pandemic, studies have found that spikes in children's and youth's overall mental health have exacerbated the mental health crisis (Hamid et al. 2022; Vaillancourt et al. 2021). Emerging research shows that symptoms of anxiety, depression and eating disorders among children and youth have been clinically elevated throughout the pandemic, leading to a pediatric emergency labelled #CodePink by Children First Canada (Racine et al. 2021; Children First Canada 2021a; Hamoda et al. 2021). In addition to elevated mental health concerns, researchers have found that not only have mental health services been insufficient to meet service demands, but they also estimate that increasing demands due to the pandemic will soon become insurmountable (Hamoda et al. 2021). With increasing calls for greater funding for child and youth mental health, the need to better understand the value of mental health investments has never been more pressing.

Patient-oriented outcome measures is one method used to obtain patients' perspectives on their outcomes or changes to their mental health status during their treatment (CIHI 2019; Jensen-Doss et al. 2020; Roe, Mazor and Gelkopf 2021). Despite patient-oriented research being a national priority, Canada lacks cohesive policy to guide how it is conducted across the country (Barbic et al. 2019; Roe, Mazor and Gelkopf 2021). To fill this gap, provinces and territories have designed a patchwork of strategies to capture patient-oriented outcomes (Roe, Mazor and Gelkopf 2021); however, Alberta still lacks provincial policy outlining requirements or guiding how patient-oriented outcomes are measured (Amarbayan et al. 2021; APERSU 2020). This communiqué describes perspectives on Alberta's youth mental health policy.

ALBERTA'S VALUING MENTAL HEALTH STRATEGY

In Alberta, tracking outcomes across systems and improving information sharing using data measures is a strategy listed in the *Moving Forward Progress Report on Valuing Mental Health: Next Steps* (herein *Valuing Mental Health*) report (Government of Alberta 2019). The report indicated that children, youth and families are a priority population. *Valuing Mental Health*, however, did not provide a clear explanation on what this means — specifically, whether the strategy to track outcomes across systems meant that children's and youth's mental health outcomes would be tracked or how this would be achieved¹.

¹ After this communiqué was complete, the Government of Alberta published *Toward an Alberta model of wellness: recommendations from the Alberta Mental Health and Addictions Advisory Council*. Recommendations include designing policy that enables outcomes tracking, using standardized measurement tools, and ensuring appropriateness of services for youth which generally aligns with the strategies in *Valuing Mental Health*. Similar to *Valuing Mental Health*, the recommendations in *Toward an Alberta model of wellness* are high-level and the publication does not specify how or when this will be done, or whether tracking outcomes will be applied to child and youth mental health.

VALUE-BASED HEALTH CARE USING PATIENT-ORIENTED OUTCOME MEASURES

Selecting patient-oriented outcome measures that track outcomes which are important to patients is one method to achieve value-based care (health outcomes relative to the cost of delivering a service) (Baggaley 2020; Amarbayan et al. 2021). By this definition, a quality improvement has occurred when patients determine that outcomes which matter to them have improved, costs decreased or both occurred simultaneously (Baggaley 2020). Patient-oriented outcome measures are self-assessed surveys that allow patients to provide feedback on their treatment outcomes and to measure changes in health status (Morris et al. 2020; Kingsley and Patel 2017). These measures can be gathered before, during or after treatment and allow practitioners to identify whether a patient's mental health status or outcomes are improving or deteriorating (Lewis et al. 2019; Mellor-Clark et al. 2016; Kingsley and Patel 2017). By working with children and youth to determine which patient-oriented outcome measures are measuring the outcomes that are important to them, practitioners can begin to collect value-based data. At a systemic level, policy-makers can assess the cost-effectiveness of services by gathering and analyzing cumulative data sets derived from the patients' perspectives to deliver value-based health care (Amarbayan et al. 2021; Kingsley and Patel 2017). This can inform how effective a treatment has been from the patient's perspective and whether changes are necessary to improve the trajectory of a patient's outcome (Lewis et al. 2019; Mellor-Clark et al. 2016; Morris et al. 2020; Kingsley and Patel 2017).

PURPOSE

The purpose of this communiqué is to describe key informant perspectives on Alberta's youth mental health policy and strategies used to track child and youth mental health patient-oriented outcomes.

METHODS

Key informants in Alberta were asked about their knowledge pertaining to patient-oriented outcome measures used with children and youth accessing mental health treatment. Key informants were defined as individuals from various organizations and health services who have subject-matter expertise on patient-oriented outcome measures, make critical choices within their organizations related to child and youth mental health or outcome monitoring or make policy-related recommendations that impact the way child and youth mental health is delivered². Approval for the research study was granted by the University of Calgary's conjoint research ethics board (REB21-0146).

² Additional details on this study can be found in "Policy Perspectives on Patient-Oriented Outcomes for Children and Youth with Mental Health Concerns" (Koftinoff 2021), a capstone report by Jillian Koftinoff.

KEY FINDINGS

From June to July 2021, the primary researcher conducted 10 qualitative semi-structured interviews with 12 Albertan key informants (nine women and three men at different stages of their careers) working across government, academia and non-profits, to understand their perspectives on patient-oriented outcome measures used with children and youth, Alberta's child and youth mental health landscape and impacts from the COVID-19 pandemic. The interviews provide insight into the challenges for the collection of patient-oriented outcome measures in a child and youth mental health context. Key themes include:

- 1) A lack of provincial consistency for measuring child and youth mental health outcomes;
- 2) Equity gaps in the mental health sector for marginalized children and youth; and
- 3) The need for a cross-ministry youth mental health strategy.

A NEED FOR CONSISTENCY IN MEASURING CHILD AND YOUTH MENTAL HEALTH OUTCOMES IN ALBERTA

With no overarching patient-oriented outcome policies, there was an identified need for greater continuity in the way that Alberta organizations measure their patients' outcomes during mental health treatment. The absence of guidance in the implementation of child and youth patient-oriented outcomes has led to various outcome measures being used. This is contributing to many inefficiencies, including fragmented data collection, barriers for tracking and comparing outcomes and a lack of value-based care. Key informants perceived the government to have an important role in providing guidance and optimizing processes:

[Government] could lend itself to perhaps a bit more streamlined ways of working that can tell and capture a collective impact a bit better, rather than all of these different ad hoc tools and reporting methods.

—Sam³, describing the need for continuity in implementing patient-oriented outcome measures

By moving away from various ad hoc tools in favour of a unified approach, key informants believe there is potential to advance efficiency improvements across multiple services. They said that the lack of continuity has led to challenges, such as the tracking of patient outcomes (short- and long-term), the identification of geographical trends and referring patients to different services. It also poses challenges for patients who seek to transfer to another city and must engage with a different branch of an organization or Alberta Health Services (AHS) zone.

There was broad support for the province-wide implementation of patient-oriented outcome measures for child and youth mental health with explanations ranging from benefits to the patient, provider, or funders.

[The] Government could actually say, look at the impact we're having on Albertans, the investment we've made in mental health is making a difference.

— Josephine on the government mandating the use of patient-oriented outcomes

³ The names of all key informants have been replaced with pseudonyms to protect their anonymity.

Critical to successful province-wide implementation is guidance around how to measure and track patient-oriented outcomes. Key informants pointed to a lack of consensus on which outcome measures to use, with as many as 20 different outcome measures reportedly being used when discussing with our informants. While child and youth mental health organizations and frontline workers have developed their own internal policies and strategies for guiding the use of patient-oriented outcome measures, these are often not in alignment with other organizations. Key informants highlighted that the province could play an important role in unifying organizational approaches:

The actual change that needs to happen is at the system level, not at the frontline worker level, the frontline worker level has the readiness to do this work and are intuitively probably working around the system to do this work.

– *Charlie, describing the need for systems to become involved in implementing patient-oriented outcome measures*

Key informants with provincial insight into the implementation of patient-oriented outcomes explained that although implementation has begun in several places, it is not done everywhere and the current approaches for applying these measures vary significantly, from different types of measures used to variations in the frequency of administration. Variation in how patient-oriented outcome measures are implemented and a lack of alignment across services are two of the key factors that illustrate the need for more consistency.

Previous literature on patient-oriented outcome measures emphasize the lack of value-based approaches in Alberta (Amarbayan et al. 2021). This means that services and organizations are missing a crucial opportunity to become more responsive to the perspectives of children and youth. The lack of consistent child and youth patient outcomes data and the inability to compare outcomes also pose challenges when trying to assess programs and when conducting cross-jurisdiction analysis (Roe, Mazor and Gelkopf 2021). Consequently, policy-makers and government are often tasked with making financial decisions regarding programs without rigorous data, which presents a risk that programs leading to the best outcomes, as ranked by children and youth, may be defunded (Janse et al. 2014). Besides the lack of integration, studies show lower completion rates of patient-oriented outcome measures by children and youth who are Black, Asian, older, girls and from under-resourced communities, which illustrates a need to better understand and address the needs of these demographics so that decisions to fund particular services are not biased (Morris et al. 2020).

EQUITY GAPS IN THE YOUTH MENTAL HEALTH SECTOR

While youth mental health is of broad concern, key informants emphasized that the challenges are more severe for marginalized children and youth; the COVID-19 pandemic has exacerbated many existing gaps. This is supported by reports highlighting that children and youth with limited access to services or multiple mental health issues have fallen through the cracks during the COVID-19 pandemic (Cardenas, Bustos and Chakraborty 2020; Children First Canada 2021b). This gap in mental health service delivery and

measurement of outcomes is of particular concern for low-income families, children or youth with disabilities, families in rural or under-resourced communities, 2SLGBTQQIA+, First Nations, Métis, Inuit, Black, Asian, other ethnic minorities, immigrants and refugees.

Key informants shared examples illustrating how children or youth tried to access different services or relocated within Alberta, and were required to start anew with their mental health treatments, which was perceived to limit progress and benefits of therapy. The following quote illustrates the variation in mental health services across jurisdictions:

What you're getting in Edmonton [from mental health services] is very different than what you're getting in Calgary, Camrose, with all those [mental health] organizations. So, if you're a family moving, you can't assume that that support group will exist in the same fashion, depending on the individual needs and desires and focus of the community.

— Fabricio, describing differences in services across the province

These gaps have impacts on the provincial government, organizations and individuals' understanding of the impact of mental health services, resulting in inefficiencies for children, youth, and their families:

So, sometimes they might have to be admitted to acute care setting, and then go to a community clinic and then maybe go to a different clinic and so I don't think that information is potentially being transferred through all those kind of areas that they have been being seen for their mental health and so it's hard to evaluate the progress.

— Cara describing the need for consistency in different service settings

Due to significant changes to the provision of child and youth mental health services during the COVID-19 pandemic, it was believed that the province was missing an opportunity to collect valuable data on child and youth outcomes during the pandemic.

THE NEED FOR A CO-ORDINATED CROSS-MINISTRY YOUTH MENTAL HEALTH STRATEGY

The role of multiple ministries in the provision of youth mental health services in Alberta was commonly highlighted, and the need for a co-ordinating strategy emphasized.

I would say the leading pieces that came out of [the post-pandemic working group in Alberta Health Services] was there needs to be still far greater connection between community-based service and Alberta health. And because families, kids, they're getting caught up in a very complex system that we're asking them to system navigate and it's pretty difficult. The goal I think across the system and in the sector is that any door needs to be the right door and that people need to be able to get the help that they need at the right time.

— Jose, describing the importance of cross-ministry co-ordination

During the interviews, *The Alberta Provincial Valuing Mental Health Strategy* was the most recent strategy. While it does include children, it does not have particular focus on child and youth mental health despite unique service delivery considerations. Recommendations

in the *Valuing Mental Health* (2019) strategy highlight the importance of data, tracking patient-oriented outcomes (and the co-ordination of this tracking as described above). However, this is not standard practice for all child and youth mental health services.

Even though the *Valuing Mental Health* (2019) strategy never became fully entrenched, key informants still believe there is value for the province to become actively involved in facilitating continuity through implementing patient-oriented measures. This aligns with a U.S. study conducted by Jensen-Doss et al. (2016), which found that clinicians perceived monitoring patient feedback favourably, but they are not used consistently in therapeutic settings, and Roe et al. (2021), who found that without policy, integrating patient-oriented outcome measures into mental health care is fragmented and inconsistent.

Funding agreements are one method that can be used to motivate organizations to use patient-oriented outcomes (Jensen-Doss et al. 2016). This approach has previously been applied in the U.K. and U.S. (Daleiden et al. 2006; Edbrooke-Childs et al. 2015; Mellor-Clark et al. 2016; Morris et al. 2020). Hawaii's Department of Health, Child and Adolescent Mental Health Division (CAMHD), has also mandated and funded state-wide mental health services and outcome measures resulting in improved quality of care for children and youth (Daleiden et al. 2006; Lyon et al. 2015; Scott and Lewis 2015). Similarly, the National Health Services has policy that supports gathering patient-oriented outcomes data on child and youth mental health through a centralized system (Morris et al. 2020). A state-wide CAMHD training institute was opened to facilitate the distribution of relevant information and to act as a training hub for educational purposes (Daleiden et al. 2006). Evidence shows that training at the onset, and ongoing communication and progress monitoring at specific intervals can lead to long-term implementation of evidence-based practices such as patient-oriented outcome measures (Dorsey et al. 2016; Lewis et al. 2019; Lyon et al. 2015). These are significant considerations for Alberta because as previously noted, the current lack of tangible assistance for advancing the strategy of tracking patient-oriented outcomes has contributed to variation in the ways that organizations apply them, leading to inefficiencies and gaps in services available.

RECOMMENDATIONS AND CONCLUSION

Without co-ordinated action to improve measurement of patient-oriented outcome measures in Alberta, there is increased risk of long-term adverse impacts on child and youth mental health (United Nations 2020; Hertzman and Williams 2009). The interviews and literature highlighted the importance of a guiding strategy to facilitate common patient-oriented outcome measure collection across Alberta along with a long-term plan to allocate appropriate resources (Amarbayan et al. 2021). The following three recommendations are intended to address the current gaps evidenced by the literature and key informant interviews.

1) Develop or refresh a provincial policy strategy for improving youth mental health.

Given the impacts of COVID-19 on youth mental health and service delivery changes that have evolved during the pandemic, we recommend developing or refreshing a multi-ministry strategy (led by a multi-ministry working group) through consultation with key stakeholders (such as Alberta mental health organizations serving children and youth,

and service users). This strategy needs to include considerations for children and youth specifically, vulnerable populations and implications for diverse approaches to service provision, both virtual and in person. Along with the strategy, a sustainable plan for implementation and resources to support it are required.

2) Design provincial guidelines on measuring and monitoring patient-oriented outcomes

to assess outcome improvements for children and youth and assess the impact of mental health services for them. Mandating provincially funded mental health services to integrate patient-oriented outcome measures (including patient reported outcomes directly from children and youth) will be a valuable first step in advancing value-based care in Alberta. Integrating children and youth (prioritizing those who have been underserved) will be key as value-based care requires that the outcome measures track factors that are important to the patient. Evaluation of the collected patient-oriented outcome data and regular service improvements as new information emerges are also critical.

3) Engage equity-deserving groups in the design and implementation of the provincial strategy and guidelines.

Targeted efforts must be made to connect directly with equity-deserving groups (including low-income families, children or youth with disabilities, families in rural or under-resourced communities, 2SLGBTQQA+, First Nations, Métis, Inuit, Black, Asian, other ethnic minorities, immigrants and refugees) for their participation in the design and review of the provincial strategy and guidelines on outcome monitoring. These children and youth are significantly underrepresented and underserved by mental health policy, research and programs. A multi-pronged approach, including a general call to the public for participation through social media, multicultural brokers, ethnocultural liaisons and organizations that serve diverse demographics will help to reduce bias and barriers for participation. This must be done in an intersectional way, recognizing that children and youth are experts in their own care — meaning it is important not to tokenize only one child or youth by asking them to be representative of all other children and youth who share similar social locations. Rather, multiple opportunities to engage should be presented throughout the process with incentives such as honorariums to compensate for their subject expertise. The participation of these demographics in research and in the policy design will help to ensure that resources are appropriately allocated to meet their mental health needs.

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ISSN

ISSN 2560-8312
The School of Public Policy Publications (Print)
ISSN 2560-8320
The School of Public Policy Publications (Online)

DATE OF ISSUE

April 2023

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