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## **“Youth as accessories”: Stakeholder perspectives on youth participation in mental health policymaking [Part II]**

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### **Keywords**

Children and youth, participation, policymaking, mental health, consultation, lived experience

### **Abstract (250 words max)**

**Purpose** To elicit stakeholder perspectives on the findings from our scoping review on youth participation in mental health policymaking, we conducted a global consultation with young people and adults directly involved in mental health policymaking.

**Method** Forty-four stakeholders from 16 countries, including 15 young people, 8 policymakers and 21 facilitators of youth participation, participated in individual interviews and/or focus groups. They were asked about how the review findings contrasted with their own experiences in mental health policymaking. The transcribed data were thematically analyzed.

**Results** All participants viewed lived experience as valuable in identifying policy gaps. Youth pointed out that children and youth with disabilities, diverse sexual orientations, and/or gender identities were often excluded, and spoke about feelings of being an “accessory”, illustrating a lack of power-sharing in a tokenized policymaking process.

Adult participants' accounts highlighted the challenges inherent in policymaking such as the need for political knowledge and institutional time constraints. A range of cultural, socio-economic, and political barriers to youth participation, that were often context-specific, were identified.

**Conclusions** The diverse perspectives of stakeholders extended the review results.

Based on our findings, we recommend that adults and institutions: 1) recognize lived experience as expertise in shaping mental health policies; 2) include diverse groups; 3) reduce tokenistic relationships through the creation of safer spaces, adult feedback, co-production, and social accountability; and 4) adopt an intersectional approach to address cultural, socio-economic, and political barriers to participation. Methodologically, our work demonstrates why stakeholder consultations are an essential component of scoping reviews.

## **Background**

Youth participation in making decisions that affect their life has been recognized as a human right since the adoption of the *United Nations Convention on the Rights of the Child* (UNCRC) in 1989 (UNGA, 1989). Despite the advancement of child and youth participation in the past 30 years, challenges persist, ranging from concerns about tokenism and the lack of impact on decision-making to the lack of sustainability of participation (McMellon & Tisdall, 2020). A lack of diversity when children and young people participate is an ongoing familiar challenge in the implementation of youth-involved policy, practice, and research (Head, 2011; McMellon & Tisdall, 2020; Naim,

Sligo, & Freeman, 2006; Perry-Hazan, 2016). Indeed, policymaking is one of the most challenging areas in which children's participation rights are implemented (Perry-Hazan, 2016).

The global movement for youth mental health is gaining momentum. Worldwide, one in seven adolescents is estimated to experience mental health problems (UNICEF, 2019). About 50% of these problems start by the age of 14 and 75% start by the age of 24 (Fusar-Poli, 2019). Depressive disorders are the third cause of adolescent disability-adjusted life years (DALYs) lost globally, while anxiety disorders are the fifth cause of DALYs lost among adolescent girls (World Health Organization, 2017). The COVID-19 pandemic and ongoing social, economic, and cultural changes can further negatively impact youth mental health (Clark et al., 2020; Mei et al., 2020; Uhlhaas, McGorry, & Wood, 2021). Since youth is a life period when most people complete education, seek employment, and form relationships, mental disorders in young people can have a significant impact on health, social, and economic outcomes that extend into adulthood (Patel, Flisher, Hetrick, & McGorry, 2007). Policy intervention is a key component of mental health promotion and early intervention, including initiatives to address the social and structural determinants of youth mental health (Jenkins et al., 2019). However, limited evidence to guide meaningful youth engagement may result in mental health policymaking processes being tokenistic or exacerbating inequities by excluding those who face structural vulnerabilities or those who would benefit from support in accessing participation opportunities (Jenkins et al., 2020; Jenkins et al., 2019).

We conducted a scoping review to identify available information on child and youth participation in mental health policymaking using Arksey & O'Malley's (2005) methodological framework. The World Health Organization (WHO) defines adolescents as people between 10 and 19 years of age, and characterizes mental disorders as a clinically significant disturbance in an individual's cognition, emotional regulation, or behaviours (World Health Organization, 2014, 2022). In our study, children under the age of 18 years according to the UNCRC (UNGA, 1989) and youth between 15 and 24 years of age according to the United Nations definitions of youth (UNDESA, n/d) were considered. Mental health policymaking was comprehensively defined from well-being promotion to mental illness prevention. One of the major findings from the review was the reduced geographic scope of the existing literature on child and youth participation in mental health policymaking (Part I). While consultations are an optional last stage in Arksey & O'Malley's framework, such consultations provide opportunities for stakeholders: to contribute insights beyond those in the literature (Arksey & O'Malley, 2005); to exchange knowledge; to help develop dissemination strategies, and even translate the preliminary findings of the scoping review into practice, policy, and future research (Levac, Colquhoun, & O'Brien, 2010).

Considering such additional value, we conducted a global consultation with young people and adults involved in mental health policymaking to capture stakeholders' perspectives from a wider range of high-, middle- and low-income countries. As the second part of our two-part series, the current paper presents

stakeholders' experiences and perspectives of youth participation in mental health policymaking.

## **Methods**

Focus groups have proven effective in uncovering a wide range of views and opinions with both adults and young people as they acknowledge participants as experts (Barbour, 2005; Peterson-Sweeney, 2005). We developed a focus group guide to explore how the review findings fit with stakeholders' perspectives and experiences in youth mental health policymaking. The questions were focused on the topics about: 1) socio-demographic characteristics of young participants; 2) extent and nature of participation of young people; and 3) influencing factors and effects of participation. Considering limited availabilities and the difficulties of working across time zones, one-on-one online interviews were conducted with individuals who so requested or were unable to join a focus group.

### **Sample and recruitment**

For our youth group, we included those between the ages of 14 and 25 which overlaps with the age range considered "youth" in many contexts (UN, 2013). We did not invite those younger than 14 years as it would require obtaining parental consent according to the law in the province of Quebec and they might find it difficult to participate in groups with older young people. Other inclusion criteria were experience in mental health policymaking involving young people, communication skills in English, internet/phone access, and provision of valid consent.. Focus groups and

individual interviews were conducted with three stakeholder groups: young people aged 14-25 years (n=15); policymakers (n=8); and adult facilitators of young people's participation (n=21). Policymakers and adult facilitators were included based on our review findings, which showed that youth participation in policymaking is a relational process where the roles of children and youth and their level of participation are closely linked with roles of adults. Also, adult facilitators of young people's involvement (e.g., NGO staff) often play a crucial role in generating dialogue between policymakers and young people (Le Borgne, 2017). The interviews were conducted separately within these groups to create comfortable spaces for the sharing of perspectives and experiences.

Participants were recruited through the researchers' personal and professional networks, which included a range of Canadian and international youth mental health-serving organizations and decision-makers. Snowball effect then followed. The principles of geographic diversity and representation from all three stakeholder groups were applied during the recruitment process. Young people and adults with direct experience in policy processes in the field of mental health participated as experts in their own right and not on the basis of lived mental health experience. As participants brought a range of experiences and perspectives to the discussions, interaction among them generated new knowledge (Green & Thorogood, 2018). To maximize diversity of perspectives and open sharing, only one or two people from any given organization participated in the consultation. Youth and adult facilitators participated mainly through focus groups whereas policymakers were mostly reached through individual interviews due to their limited availability.

## **Procedures**

Given the global nature of the consultation and public health guidelines during the COVID-19 pandemic, semi-structured individual interviews and focus groups were conducted online (Zoom Pro) or by telephone in June-July 2021. Once a potential participant indicated their interest in participating, written consent was obtained, followed by logistical arrangements for the Zoom/phone meeting and distribution of a summary of preliminary review findings. During the interviews, consent was confirmed orally, and participants were invited to provide feedback on the findings and any aspects pertaining to the participation of young people in mental health policymaking that may be missing from the literature. Interviews involved a moderator and an assistant moderator, who took notes, monitored the chat, and provided technical support (Krueger, 2002). Each focus group (with two to five participants) lasted approximately 1-1.5 hours, ensuring that every participant had enough time to contribute. Individual interviews lasted approximately one hour.

## **Data analysis**

All interviews were audio-recorded, transcribed verbatim, and anonymized. Notes taken during and after the focus groups and participants' demographic information (age group, country of residence, and job (adults only)) were also included in the analysis (Barbour, 2014). ■ coded all transcripts inductively and deductively using a code list that ■ and ■ created based on the research questions in terms of: (a) the socio-demographic characteristics of the children and youth participating in mental health policymaking; (b) geographical and substantive contexts of



participation;(c) the extent and nature of child and youth participation; and (d) facilitators of, barriers to, and effects (expected or documented, individual or collective) of the participation of child and youth in mental health policymaking [Part I] (Fereday & Muir-Cochrane, 2006). These codes were later collated to search for emerging themes and sub-themes, that were then contrasted within and across stakeholder groups. The emerging themes were examined with senior researchers on the team who reflexively shared their perspectives based on their extensive experiences with children and youth. To further ensure trustworthiness and rigor, attention was paid to other factors which may influence results such as setting and social interactions (Green & Hart, 1999; Halkier, 2010) and to comments from the focus group and individual interviews which challenged emergent explanations of the data. Analysis was conducted using NVivo11.

## **Ethics**

This global consultation received approval from the ethics board of the [REDACTED]. Written and verbal consent was provided by all participants. For youth under the age of 18 years, informed consent was also obtained in writing from their parents/guardians. Attention was paid to facilitating interviews in a nonjudgmental way and creating a sharing space for participants (Sharts-Hopko, 2001). Participants were offered a voucher for \$20CAD or equivalent in local currency to compensate for their time. To preserve confidentiality, transcriptions were anonymized before coding and no identifying information is provided in publications.

## Results

A diverse sample in terms of age, geographic location, and policy initiatives was obtained and included 44 stakeholders in 16 countries, consisting of 16 youth from Australia (n = 1), Canada (n = 6), Indonesia (n = 1), Nigeria (n = 1), Philippines (n = 1), Turkey (n = 1), UK (n = 3), USA (n = 2); 20 adult facilitators from Australia (n = 1), Canada (n = 10), India (n = 1), Kenya (n = 1), Lebanon (n = 2), Malawi (n = 2), Thailand (n = 1), USA (n = 1), Zimbabwe (n = 1); and seven policymakers from Australia (n = 1), Canada (n = 3), Malaysia (n = 1), Uganda (n = 1), and UK (n = 2). The most represented countries were Australia, Canada, United Kingdom, and United States of America. Four focus group sessions with youth participants, five sessions with adult facilitators, three individual interviews with adult facilitators, and eight interviews with policymakers were conducted. Consultation participants found the review results largely consistent with their own experiences and provided additional perspectives and insights, which are elaborated upon in this paper (see Table 1 for an overall summary).

### **Multiple dimensions of lived experience in participation**

#### **Youth**

While the literature review found a lack of clear definition of lived experience in the retained publications [Part I], youth do not necessarily see mental ill-health based on a disease model. Participants noted that viewing lived experience only from clinical perspectives may exclude the participation of “youth or young adults [who] might not have access to services and might not know or have not been diagnosed yet or haven’t like been able to just access like therapy or anything” (youth). Furthermore, a youth

participant stated that seeing a policy change led by individuals with lived experience can lead “more students [to] feel comfortable sharing their diagnosis or their lived experience.”

### **Adult facilitators**

Adult stakeholders saw lived experience beyond clinical diagnosis and emphasized the importance of clarifying what ‘lived experience’ meant in the context of youth engagement as it is at the core of mental health policy and funding.. With regard to policymaking, one adult facilitator explained the importance of:

making sure that... the framing is really intersectional and talking about the like how poverty interplays with making mental health services better; how racism, homophobia, transphobia all those things are like part of this, because when I talk to youth...that's how they understand mental health. [It] is at the intersections of all the things that harm people's well-being (adult facilitator)

Such a wider view of lived experience is reflected in the practice of one mental health organization that required youth to either have lived experience of mental illness personally or as a family member to participate in youth advisory groups (adult facilitator).

Furthermore, adult facilitators saw lived experience as “a legitimate source of knowledge” that contributes not only to policymaking but also to disrupting stigma-related barriers to participation.

I think people with lived experience are the best educators for mental health.

They understand it, and I believe that the more people with lived experience that we empower, (...) the more you empower people to speak up. And more people speak up the much more quicker you can destigmatize mental health, but a lot of times people don't speak up because of the stigma that comes around with it.

(adult facilitator)

Nevertheless, adult facilitators pointed out that some types of lived experience are acceptable, but others are not, thus preventing young people from “hav[ing] an equal seat at the table” (adult facilitator). For instance, one adult facilitator presented an example of opioid use among youth not being counted as a valuable knowledge source, but instead becoming a barrier to participation.

People are always wanting to, you know, get the perspectives of young people, but if people are actively using opioids, then they tend to discount them and they don't include them and things so it's like, you know, you've got to be clean to come in, you've got to do this, you've got to do that, so it's just that barrier.

(adult facilitator)

Moreover, some adult facilitators raised ethical questions around the unknown long-term impact of disclosure and self-identifying as ‘participants with lived

experience'. One adult facilitator shared their struggle in ensuring that disclosure was safe since youth participants "do not necessarily realize the impact of disclose" while their names were made public on a website, and anyone could see that they were people with lived experience.

## **Policymakers**

From policymakers' perspectives, lived experience was described as "transformative" and "a positive disruption" (policymaker).

However, as mentioned by some adult facilitators, policymakers were aware that adults' lack of understanding of and accommodation for youth participants' mental health challenges can hamper youth participation. They also warned about adults "easily taking over a power role" regardless of the young person's desire and motivation (policymaker)

One policymaker also expressed their concern about the unknown impact of self-identifying as a "person with lived experience" on youth participants' lives.

...it really bothered me and started me thinking, what are we doing to kids that we're bringing them in and we're using their illness identity. And they're in a

very vulnerable part of their human development, the adolescence is very much about identity to it, and if we're reinforcing their identity as someone who was sick...I started to wonder what's the long term follow up on kids who have been involved in these engagements. Have we helped them? Have we harmed them? What do we know about the impact of their being engaged in this?

(policymaker)

With this concern based on the “models of engagement that focus on a group with a particular identity,” they proposed mixed groups including both young people with and without lived experience, since “participants can learn from each other and enrich the consultation” (policymaker).

## **Diversity and Inclusion in the Policymaking Process**

### **Youth**

With regard to the lack of diversity of youth participants identified in the literature review [Part I], youth who took part in the consultation questioned the extent to which adults considered the diversity of children and youth, and how adults' objectives influenced the types of participants invited to join policymaking processes. One youth participant thought young people are seen “as a homogenous group when actually [they] have just as much like diversity and like difference between individual young people as like any other group”. Another youth participant who had experiences

of chronic pain and mental illness found it problematic when adults uncritically and broadly sought youth with disabilities for their concern for inclusiveness and representativeness of diversity; “I don’t know the experience [of] a blind or deaf person, [but] they kind of make you feel like you represent your community [of people with disabilities], which I can’t do that because I don’t have experience like being blind or deaf” (youth). The existing mental health system that categorizes people in a certain way was seen as a barrier to participating in policymaking, particularly for youth with diverse sexual orientations and gender identities. One youth stated:

I think both [mental health services and mental health policy making] kind of systems [are] rooted in like white supremacy and colonialism. You’re going to get a lot of researchers and policymakers that are trying to put people into boxes and, of course, that’s not safe for a person who is gender diverse for sure (youth)

In addition, adults’ “bias” in looking for a specific group of young people may lead to miss “what other subgroups there are within young people that could need specific attention” (youth) and “others are kind of barred from participating” (youth).

### **Adult facilitators**

Some adult participants described policymaking as “quite a privileged space because it’s people who can take the time, who can clear the rest of their agenda and who don’t have other commitments [and] who are able to travel” (adult facilitator). At the same time, another adult facilitator shared the challenge in finding a “balance of

trying to get breadth” between “those that are not normally engaged and those who haven’t built their resume and don’t have all the experience and training skills” versus those “got the capabilities to do the work” as they have previous worked in policy and advocacy.

To address the challenge of lack of diversity, one adult facilitator believed that if adults intentionally “create safe space for diversity of experiences and diversity of cultural background, the group dynamics “can lead to...more strength and more group unity and those differences can really help become strengths for a group”. Furthermore, they continued, “if it’s not done intentionally or...if you don’t have a good facilitator of the group to manage that [dynamics], the opposite can be true where people can be left feeling more unsafe or more vulnerable”. Another adult facilitator who was also a peer supporter highlighted the role of peer support to create a safe space: it is very difficult for many young participants who did “not have a good relationship with adults” in the mental health system a long time ago to tell adults “the truth about how they are feeling and trust them--that they are not going to misuse that information or hurt them.”

### **Policymakers**

As stressed by many youth and adult facilitators, policymakers were aware of lack of diversity among young participants, noting that child and youth with disabilities in particular were often not included in policymaking processes.

There isn’t much attention given to that group of children, which can be a very large group of children, for example, that children with disabilities are



disproportionately vulnerable to bullying cyberbullying, social exclusion, poverty, and marginalization...being brought up in single parent households and so on, all of which can contribute to stress and anxiety and so on, so I would make a plea really for visibility of that group of children and their needs and listening to what they have to say about (policymaker)

### **Youth's Frustration: Lack of Safety and Power Sharing**

#### **Youth**

Many young people expressed their frustration with the lack of power sharing by adults, which the literature review too identified as a barrier to youth participation in mental health policymaking (Part I). Youth lamented not being taken seriously and not being heard by adults who seemed to consider that “[youth] don’t have the power to change” policy (adult facilitator), or who were not inspired by youth perspectives or did not value youth engagement in supporting policy change.

Consultation participants were aware that children and youth are often invited as informants as opposed to having a more active role in co-designing the policy from the beginning. Youth thus felt like an “accessory” in a tokenized policy making process.

In this context, some youth participants tried to transform this frustration into a “source of [more] pressure on the policymakers” by “[letting] those emotions fuel [them] to build a community of allies”. This resilient attitude among youth participants

was not found when the policymaking process became “a cycle of trauma” (youth). In contrast with the expected effect of participation on young people such as increased sense of empowerment and self-efficacy, and better mental health (Part I), one youth participant stated: “you are gonna be traumatized” as “when you do policy making, that’s going to suck the soul out of you” (youth).

It’s just so clear to me that they would expect better mental health this if I’m going into policymaking, I’m not expecting to feel better, I’m expecting to feel frustrated. I’m frustrated because people aren’t listening to me but also like frustrated because I’m having to like re-tell my story. And like not getting like compensated or anything for it hey I just I don’t see. I don’t see policymaking as being good for my well-being at all. Like yeah, I understand the positive feelings afterwards, with like a sense of achievement like oh I’ve helped out with this, but I feel like with the policymaking that I’ve done, it’s just overwhelming frustration, because they just don’t listen to or like the thing that you brought up it’s just completely forgotten or like tossed to the side (youth)

Moreover, an Indigenous youth participant’s experience highlights the need for trauma-sensitive spaces for marginalized youth and fair compensation to assist with the effects of possible retraumatization.

In regard to policy, I don't want, I don't want white people to make, be making policies that affects me as an indigenous person. And, and also like more fair compensation for us saying our stories because, like I know the compensation that like say youth receive are very low, and then say if they're going through cycles of trauma after saying their stories and due to reliving it, they will they'll have to engage in the system again and get therapy and like that's like what expensive so it's like they're still living in that cycle already, so I would just find it again like more access, equity, more compensation, and more like more inclusive spaces (youth).

**Adult facilitators** Adult facilitators were aware that youth were often seen as “[not having] the power to change” policy (adult facilitator). On the one hand, some of them located youth's frustration within the nature of policymaking processes: youth participants were seen “being involved in something bigger than themselves” (adult facilitator) and partly explained by youth's “lack of political knowledge or understanding about how policymaking works or how they can be engaged” (adult facilitator). Furthermore, it “can be really difficult to create a culture where youth participation is prioritized” in organizations and structures, built on hierarchies and embedded practices (adult facilitator).

## **Policymakers**

Policymakers acknowledged the feelings of frustration shared by youth participants. Indeed, in the words of one policymaker who participated in the consultation: “many young people clearly have a negative experience about maybe feeling disempowered by the process or not feeling properly respected in the process, or that they couldn’t have any influence or didn’t believe that was going to have any impact as a consequence” (policymaker). On the one hand, some policymakers saw youth expectations as “ambitious” (policymaker) in the “government context [where] things can move quite slowly” (policymaker). The perceived distinction of attitudes towards the policymaking process between adults and youth was expressed by a policymaker:

One of the issues which comes up a lot, I think, for me is that professionals and experts in the field, you know, have a lot of knowledge and understanding of the issues [and] therefore assume that they know what are the right questions to ask, what are the issues that are critical concern, but when you do open up that space to children, young people, you often do get very, very different take on what actually you know, what are the really important issues or how would you frame that, in a way that actually makes sense to young people or speaks to their own experience. (policymaker)

Similarly, another policymaker indicated that adults “that are working in policymaking world often look at it from the advisory piece, but then not the

engagement piece [while] those two things are equally important” (policymaker). To address these adult attitudes, one policymaker who believed in the power of disruptive experiences to produce change suggested that adults confront the living and lived experience of children and young people and “get surprised by what they hear and the level of insight that children and young people bring” (policymaker).

### **Cultural, socio-economic, and political barriers to youth participation in a global context**

#### **youth**

Socio-cultural norms shape the space for youth participation. For instance, a youth participant in Morocco and an adult facilitator in Thailand described how cultures valuing hierarchy hinder safe spaces due to the “unspoken rule that young people kind of out of respect can’t really speak freely or contradict kind of in a, in a public way the elders so that makes many youths very hesitant to speak up about things that they disagree with” (youth).

Socio-economic environments characterized by unemployment and poverty were also seen as limiting youth participation in some contexts, while negatively affecting youth mental health. As a youth participant in Nigeria explained, even though many people in poverty suffer mental health problems, very few get involved in mental health policymaking because they “are not bothering their mental health” and feel like

“it’s a waste of time because of the situation” where economic hardship and daily financial worry are more pressing needs to be met.

While many youth participants shared unique cultural, socio-economic, and political barriers that they faced, one youth participant described that, in the Philippines, even though talking about mental illness is generally considered a taboo, creating a safe space had boosted youth participation. In that space, participants were given a choice about disclosing identifiable information and their decisions were fully respected.

### **Adult facilitators**

The shared diverse experiences highlighted the role of culture, such as cultural beliefs and gender norms, in shaping the experience of mental health policymaking. An adult facilitator from Malawi shared that some people, particularly in rural areas, not only do not want to talk about mental health but also “do not even know about mental health issues” (adult facilitator). Also, adult facilitators in Lebanon described the difficulty in obtaining consent from parents who are often concerned about the safety of young girls, as the parents were not sure about what girls do and who they talk to when they participate in policymaking. On the other hand, they explained that it is difficult for boys and male-identified youth to find time for participation when they had to work to fulfill their responsibility to support their family.

In LMICs where mental health is often not a major public health agenda (Alloh, Regmi, Onche, van Teijlingen, & Trenoweth, 2018), the political context emerged as being a barrier for youth participation. Both legal prohibitions and lack of infrastructure and financial resources to develop and implement mental health policies can interfere with youth participation. Thus, for example, in Lebanon, regulations and structures that criminalize suicide and substance abuse “don’t allow [adult facilitators] to advocate or to discuss these topics as freely as [they] would have wished” (adult facilitator). In parallel, when the government is seen as having weak capacity and “people really don't have any trust in their decision makers”, motivation for participation in policymaking becomes low. Similarly, one adult facilitator in Thailand felt reluctant to encourage youth involvement in policymaking whilst working with a local government that people generally distrust. Despite this distrust, they navigated the political space to advance at a global level.

Working with [government agencies] is to have that stamp of approval that I can showcase to other countries as well, that is, you know it's supported by this this governmental body, which means that it is trustable right in a way even though the people in the country might not trust it. And that’s why I still have to work with them in a way. (adult facilitator)

The complex political context where different political agendas and interests are present shapes the way children and youth participate in policymaking. For instance,

adult facilitators working in Lebanon encountered some children not being able to attend meetings affiliated with certain political parties because their parents were in a different political party. On the other hand, they also recalled Palestinian children being vocal and delivering very political messages against racism that reflected their awareness of how the political scene is affecting the well-being of their families and communities.

### **Policymakers**

As shared by an adult facilitator from Malawi, a policymaker from Zimbabwe highlighted the influence of cultural beliefs on youth participation in mental health policymaking, as people believe that “mental illnesses are... a result of witchcraft or maybe because someone [has] bad luck” (policymaker). In addition, gender norms play a role in shaping the different degree of participation between male and female youth. In the case of Zimbabwe where postpartum depression among young girls is a common social issue, young girls were seen as more open to participate “because they are [more] familiar with mental health problems than males” (policymaker). Even though the dire economic condition characterized by high unemployment was seen as affecting mental health of male youth, they may feel embarrassed “to be seen participating [as they are] deemed maybe weak” because “boys are taught to be stronger than girls” (policymaker). Even where people are very interested, in Uganda, a policymaker described that consultations were done “on the phone, because there’s no way [they’re] going to be able to get people to come together. People can’t afford transport. They are all in villages all over the country” (policymaker).



## Discussion

### **Lived Experience: Recognized the Value yet Unknown Consequences of Disclosure**

What counts as lived experience often remains ambiguous. Nonetheless, many participants' wide perspective of lived experience beyond clinical diagnosis captures the richness of young people's lives and is compatible with shifting the dominant conception of mental illness away from a disease model (Byrne & Wykes, 2020; Hanson, 2014). Our stakeholder consultation reveals that, if lived experience is narrowly defined as clinical diagnoses, a wide range of youth's perspectives based on their subjective experiences and emotional states will remain unheard. Living and lived experience are especially relevant to policies that shape and can be shaped by the everyday reality of mental illness of people who "live through" change and continuity (McIntosh & Wright, 2019). On the other hand, the monolithic use of the umbrella term of "lived experience" without clarifying what is considered as lived experience carries a "risk [of] erasing fundamental differences among [participants] that matter" (Voronka, 2016, p. 197). Even within the spectrum of mental health problems, certain lived experiences, such as schizophrenia, borderline personality disorder, and substance use, may be less valued or less represented or judged more, excluding certain youth populations.

Children and youth with lived experience can contribute to bridging mental health policymakers/service providers and those accessing services, ultimately improving mental health services for better mental health outcomes (Byrne & Wykes, 2020; Hanson, 2014). Generativity, referred to the contribution made towards others,

communities and society by sharing personal stories of mental illness or distress, is found to support recovery of people living with mental health challenges (Jordan, Davidson, & Bellamy, 2022). Sharing lived experience can help rediscover one's sense of social identity as a worthwhile member of one's community, thus fostering self-empowerment and recovery (Davidson, 2020; Honey et al., 2020). Furthermore, for policymakers, listening to lived experience can be a political strategy of recognition that "give[s] voice and make[s] the invisible visible" (Hanson, 2014; McIntosh & Wright, 2019, p. 463). For instance, inspiring stories of individuals with lived experience can be included in anti-stigma efforts as the stories embody strength and courage despite adversity (Shahwan et al., 2022). Yet, when the shared stories are incorporated into the formal accounting of the policymaking process, there is no guarantee that the messages of people with lived experience are always reflected (Hanson, 2014).

When fluctuation in mental and emotional states challenges their participation, "[adults] blame the young people who are involved" without addressing "cultural or structural barriers" (adult facilitator). Likewise, youth's desire to continue participating may be undermined by adults lacking understanding and not accommodating their needs. Therefore, it is important that policymaking processes are designed in a manner that addresses youth's mental health challenges with patience, flexibility, reassurance, and respect for the right of youth to determine whether they have the capacity to participate (Jones et al., 2021; Viksveen et al., 2021).

Multi-faceted experiences of living with mental illness should be understood within the intersectionalities of individual and collective suffering such as those represented by homelessness, structural discrimination, racism, and poverty (Jones et al., 2021). An intersectionality lens can reveal how the power structures and systems of discrimination shape diverse and complex health inequalities by situating individual lived experience in broader social contexts and experiences such as marginalization, unemployment, and homelessness (Byrne & Wykes, 2020; Holman et al., 2021; Jenkins et al., 2019; McIntosh & Wright, 2019). In fact, many youth participants were aware of the structural determinants of mental health problems such as poverty and discrimination. Paying attention to how social structure and processes produce shared experiences is therefore crucial. Furthermore, mixing participants with and without lived experience can offer participants and policymakers the opportunity to learn from differing everyday realities.

While generativity of lived and living experiences of mental illness in recovery is receiving attention (Jordan et al., 2022; Jordan et al., 2021), a few adults raised concerns over the unknown long-term impact of disclosure and self-identifying as a participant with lived experience. By narrating their unique life experiences, youth participants simultaneously present and construct their identity in the space of policymaking where adults hear their stories and react (Hanson, 2014; Thorne, 2004). On the one hand, youth's disclosures can have emancipatory power, help youth assert and project their identity, reduce mental illness stigma, and garner social support (Chaudoir & Fisher, 2010; Houghton, 2015; Voronka, 2016). On the other hand, when

disclosure results in rejection from communities, it can negatively affect the well-being of youth participants (Chaudoir & Fisher, 2010). Little is known about how youth participants make sense of self and identity in continuous participation processes. Adults therefore need to recognize and inform youth participants of the potential impact of disclosing their identities and experiences in the policymaking process, and also agree to respect youth participants' informed decisions on safe options for public messaging (Houghton, 2015). In addition, institutions should make sure that collective participatory ethics that centers agency, power, and impact of child and youth participants are in place; and that while children and youth have choice and control in the information that they share, adults including policymakers adhere to agreed-upon standards (Houghton, 2015).

### **Inclusion and Diversity: Critical Examination of Representation**

As youth participants perceived adults to be intentionally seeking certain perspectives from young people, there is a need to critically examine how questions and agendas are framed and who is invited in mental health policymaking. Furthermore, adult participants suggested that more work needs to be done to recognize how power dynamics shapes the space of youth participation. Entering a participatory space can be intimidating, especially for people subject to discrimination and exclusion from mainstream society; children and youth with disabilities, diverse sexual orientations, and gender identities, Indigenous background, or low socio-economic status (SES) were seen as often being excluded (Cornwall & Coelho, 2007). Stigma associated with mental illness also intersects with culture, leading to further marginalization of minority

groups of youth based on socio-cultural factors (Molloy et al., 2020). In addition, professional and institutional stigma, which may be conveyed consciously or unconsciously, communicates shame and low expectations to youth participants (Heflinger & Hinshaw, 2010). Modes of communication within a participatory exercise can themselves operate as forms of power and mark the “otherness” of some people and devalue their ideas (Cornwall & Coelho, 2007). While group dynamics can be a barrier to participation [Part I], “adult allies play a key role in ensuring that...the composition of the teams and the communication that takes place [are] always done in a respectful and insightful manner” (policymaker). Without adults creating such safe spaces, some children and youth may be over-represented in the scant consultation that does happen, whereas others are never reached (Tisdall, 2015).

One must also guard against discounting young people’s participation because of criticisms that they are either not statistically representative or democratically representative (Tisdall, 2021). Rather, diversity ought to be seen as a means of mitigating inequities that, by virtue of being different across contexts, require different context-specific solutions. At the same time, uncritical emphasis on representation of diversity and the simple inclusion of certain groups may only account for particular differences and falsely assume homogeneity of certain individuals rather than advocating on behalf of diverse groups of children and youth (O’Toole & Gale, 2008). Individual experiences should be seen as social or larger contextual experiences of children and youth that need representation, rather than trying to find a representative for each type of experience for the purpose of diversity. At the time of recruitment, on

what basis and for what purpose do children and youth participate needs to be clarified since youth who are consulted because they come from specific backgrounds may feel “tokenized” and feel pressured to represent adequately their entire group, an impossible and undesirable goal.

Moreover, what was hardly discussed during consultations were “other inequalities, particularly in terms of the ‘excluded middle’ of young people who were neither the privileged elite nor from disadvantaged groups, but rather the ‘ordinary’ young people who were not encouraged to be involved” (Nairn et al., 2006; Perry-Hazan, 2016; Tisdall, 2015; 2021, p. 229). An often-cited criticism of the lack of diversity of youth participants is largely related to elitism and socio-economic advantages (Augsberger, Collins, Gecker, & Dougher, 2018; Wyness, 2009). In addition to ongoing initiatives, further effort is necessary to create opportunities for the “excluded middle” by addressing inequalities of time, commitment, and interest (Nairn et al., 2006; Tisdall, 2021).

## **Trauma-Sensitive Spaces, and Social Accountability to Address Youth’s**

### **Frustration**

Youth participants’ frustration reflects the contrast between adults’ and youth’s views about the effect of participation. One major source of frustration for youth was the lack of equal power sharing, leading to their tokenized involvement in decision-making. Adults’ tokenistic responses may galvanize some youth participants into further advocacy for change, sometimes with support from adult facilitators (Lundy, 2018).

Youth participants' feelings of not being taken seriously suggest that some adults may have sub-conscious biases against valuing children's opinions (Perry-Hazan, 2016). When consultation participants were informed of the range of youth roles in policymaking found in our review [Part I], they opined that children and youth are in practice often invited as informants, and that their participation remains surface-level. To address this common challenge, consultation participants emphasized genuine co-production as having the most potential as it gives young people a space for decision-making (Tisdall, 2017). Positioning children and youth as experts who produce knowledge gives them legitimacy and credibility to influence decision-makers (Tisdall, 2021).

Adults need to pay attention to youth participants' emotions of frustration and exhaustion by considering what is communicated beyond the words (Tindall, Ferris, Townsend, Boschert, & Moylan, 2021). Particularly in the mental health context, there is a need for safe spaces that consider past experiences of not individual as well as historical and/or system-induced trauma that are present for young people using the mental health system and inherent power imbalances (Tindall et al., 2021). As this statement reflects, a trauma-informed approach should be applied to create safe space through institutional efforts based on principles such as cultural safety, trustworthiness, transparency, peer support, promotion of choice, and intersectionality (Bowen & Murshid, 2016). Institutional efforts should include staff training on the use of non-stigmatizing language and support for fostering a culture of learning (Lee, Kourgiantakis, Lyons, & Prescott-Cornejo, 2021). Particularly, it is critical to be aware

that policies themselves can be a source of trauma that perpetuates the cycle of disempowerment, while shared power in decision-making can enhance empowerment (Bowen & Murshid, 2016). Through the lens of cultural humility, adults should practice ongoing self-reflection and self-critique in interactions with youth participants, particularly discovering one's own patterns of unintentional and intentional racism (Yeager & Bauer-Wu, 2013).

Youth's frustration with "not seeing outcomes" can jeopardize the sustainability of engagement. Some adults ascribed this frustration partly to youth's lack of knowledge of the policymaking process which also relies on complex networks between government and a range of policy actors (Gadda, Harris, Tisdall, & Millership, 2019). It can however be argued that institutional time constraints are often problematic for policy development (Tisdall, 2015). Time itself is a power dynamic: building trust and maintaining true engagement can take time, whereas the pursuit of policy objectives is often interrupted or paused by budgetary and other constraints (Tindall et al., 2021). Also, while the duration of youth engagement often falls between one and three years [Part I], child and youth participants did not see tangible change partly due to certain policy-making changes occurring very slowly (McMellon & Tisdall, 2020). Young people are brought to the table and provide their ideas to influence policies; however, they are often consulted far too late or too peripherally within a process of policy review or creation, limiting their influence on decision-making (Tisdall, 2017, 2021). Furthermore, children and youth do not know if they actually contributed to decision-making because they rarely receive feedback (Tisdall, 2017, 2021). The consequence,



described as “participation fatigue,” results in children and youth becoming disillusioned with participation (Tisdall, 2021).

Building the mechanism of social accountability into the youth policymaking process is key to addressing youth’s frustration and disillusionment with participation. Defined as “an approach that relies on civic engagement, where rights holders, including children and young people, participate directly or indirectly in exacting accountability,” social accountability seeks to create a mechanism to address power (Davis, de la Harpe Bergh, & Lundy, 2014, p. 7; Tisdall, 2017). Children and youth can be effectively involved in oversight processes where powerholders are held accountable and expected to be responsive to promised actions and programs (Mecwan, Sheth, & Khanna, 2021; Nguyen, 2014; Tisdall, 2017). To realize youth-inclusive or youth-led social accountability, capacity building is necessary to understand the rights and entitlements of children and youth as well as the services offered by government programs, develop monitoring tools and communicate and liaise with service providers (Mecwan et al., 2021). Policy designing can be enhanced through a right-based approach in youth-led or youth-inclusive social accountability as young people who are aware of their rights may ask for systemic changes rather than tangible ones (Momentum Country and Global Leadership, 2021). In addition, social accountability involving youth can help data collection at the stage of monitoring and evaluation to gather more relevant information that can help improve programs and services being evaluated to be more youth-oriented reflecting youth perspectives (OECD, 2017).

Adults' feedback that is "sufficiently full, appropriately child-friendly, fast and followed-up" is particularly crucial as it opens a space for further interaction and the continuation of dialogue, aiming to reduce tokenistic participation (Lundy, 2018, p. 352). It is not only children and young people who need to adapt to the timing and mechanisms for policymaking; adults also need to be willing to change their attitudes, institutions, and systems of working.

### **Global Mental Health Perspectives: How Do Youth "Live" Participation?**

Our findings highlight the value of learning from diverse socio-cultural and political contexts where norms and values are embedded. Cultural beliefs surrounding mental health, gender-related values, and social norms about hierarchy were identified as barriers to youth participation in LMICs.

Attention to the intersecting contextual factors that shape specific spaces of participation can broaden our understanding of child and youth participation in policymaking. For instance, some adult facilitators in Zimbabwe and Lebanon explained the limited participation of boys and male-identified youth as being not only due to gender norms and stigma that made them reluctant to talk about their feelings but also to their traditional responsibilities to work and support their families. While the participation of male-identified youth in policymaking was thus limited, their participation in their societies could also be seen in terms of their sense of belonging and responsibility to their family and communities (Twum-Danso & Okyere, 2020). Western dominant discourses that frame "voice" exclusively in terms of children and youth's ability to express their views and participate in decision-making may mask the

fact that children and youth live participation within their cultural and socio-economic contexts. In response, there is a growing call for a “more holistic, inclusive [understandings and practices of child participation] aligned with the meanings that children themselves attach to their everyday lives as well as to the key personal and social relationships that they value” (Faedi Duramy, 2015; Faedi Duramy & Gal, 2020; Twum-Danso & Okyere, 2020, p. 2).

It is also important to pay attention to the structural determinants of youth participation in mental health policymaking. Consultation participants appreciated the link between youth mental health problems and poverty and unemployment. Despite this, youth participation in mental health policymaking remains low in LMICs not only because governments accord low priority to mental health but also because youth themselves “do not see it as important enough to be a part of the process” (youth). Facing acute challenges and daily struggle, such as hunger, disease, violence, and homelessness, can make it hard for youth to envision the future and engage in policymaking (Faedi Duramy & Gal, 2020). Furthermore, even if youth participants may provide profound perspectives of structural issues, including poverty, inequality, and discrimination, that affect their mental health, the feelings of shame may have a risk of further stigmatizing the participants (Bessell, Siagian, & Bexley, 2020; Camfield, 2010). The rights to basic needs such as food, education, health, and safety need to be fulfilled so that the right of children and youth to participate in decision-making can be fully recognized (Faedi Duramy, 2015; Faedi Duramy & Gal, 2020). An intersectionality lens is useful in addressing structural barriers to participation, as it

helps identify the root causes of inequalities and explains the differential effects of policy on people based on their various identities (Jenkins et al., 2019).

Even though the political context of some LMICs may not be supportive and safe for children and youth to participate in policymaking, creative approaches may help enhance their participation (Faedi Duramy & Gal, 2020). Using children and youth's preferred means of communication, such as music, play, and video, has proven effective in promoting the sharing of experiences (Faedi Duramy & Gal, 2020; McMellon & Tisdall, 2020). Such creative ways of communication using the arts can not only uncover the realities of life from youth perspectives but also increase awareness and shape consciousness by tapping into people's feelings (Garcia, Minkler, Cardenas, Grills, & Porter, 2014; McDonald, Catalani, & Minkler, 2012). For instance, in youth-led community change projects through the arts in Egypt and Iraq, despite the initial challenges (i.e., difficulties understanding art without talent based on their notion of the desired artistic skills, and male participants' preconception that arts are for girls), art-based approaches fostered social responsibility among youth participants. This was accomplished through reflecting on challenges in their daily life, while gaining awareness of their potential positionality to make a difference in their community by receiving respect from community and family (Lee, Currie, Saied, & Wright, 2020). As seen in this case, arts-based engagement could facilitate the contribution of youth to policymaking.

### **Limitations**

Despite successfully recruiting stakeholders from 16 countries, participation was constrained by the requirements of being able to speak English and having access to either the internet or a phone. Given that context shapes youth experiences and participation, future research should include young people from many more diverse contexts (geographic, socioeconomic, etc.). In addition, even though participants with diverse gender identities were sampled, they were not asked about their self-identified gender, which precludes our ability to describe our sample in terms of their gender. Another limitation of our study is the small number of participants in some of our focus groups. Lastly, consultations were conducted as a supplementary stage of the scoping review process, and thus the format of asking broad questions to validate the review findings may have resulted in limited access to in-depth accounts of participants.

### **Implications**

We recommend that the following actions be taken by adults working with children and youth, and policymakers.

- Recognize living and lived experience as expertise in shaping mental health policies: Lived experience should be understood beyond clinical diagnosis. Stories shared by children and youth living with mental health challenges, their families and friends can contribute to developing mental health policies reflecting their everyday life.
- Make efforts to include diverse groups (e.g., children and youth with disabilities, low SES, diverse sexual orientation and gender identity, “ordinary” young people, etc.): While a concern with inclusion and representation is kept in mind, it is

important to clarify the rationale and the purpose behind the eligibility criteria if certain groups are invited and question who might be missing at the table.

- Reduce tokenistic child-adult relationships through safer spaces, adult feedback (e.g., regarding outcomes from policy consultation), co-production, and social accountability: Policymakers should consider building a youth-involved accountability mechanism, where youth participants are not only informed but also involved in monitoring how the promised action is taken. It is recommended that adult facilitators help youth participants build skills and relevant knowledge, such as policymaking processes, political literacy, and democratic values (OECD, 2017).
- Apply an intersectional approach to address a range of cultural, socio-economic, and political barriers to youth participation: Barriers to participation are embedded in specific cultural context and socio-economic structures that shape youth's mental health. Considering the situatedness of participation opportunities in their everyday life, an approach to participation needs to be responsive to local conditions and circumstances.

### **Directions for Future Research**

The current review posits future research questions to be explored.

- How do child and youth participants feel about their roles, participation, and disclosure over time? Despite the expected positive effects of participation, long-term consequences of identity disclosure are still unknown. Given that participation in mental health policymaking is an identity-making process, longitudinal studies

that explore how youth shape their identity during their participation and what are the mid-term and long-term effects on their development would be warranted.

- How are certain groups of children and youth sought to provide their testimony and lived experiences? While lack of diversity is recognized as a common challenge in youth participation, adults often decide whose perspectives should be heard. Researchers need to scrutinize what kind of lived experiences are sought in policymaking processes and underlying adults' assumptions behind seeking certain groups of children and youth.
- Understandings and operationalizations of representation and representativeness in mental health policymaking need to be critically examined. Uncritical emphasis on diversity and inclusion may result in seeking a sample that is representative of certain categories of children and youth regardless of their intersectional experiences. Further research needs to explore how shared experiences during mental health policymaking are represented as whose agenda.

### **Conclusions**

Youth participation in mental health policymaking is slowly gaining ground in varied global contexts. This scoping review maps the current state of evidence on the nature and determinants of child and youth policy engagement [Part I]. Even though consultation is optional in Arksey & O'Malley's (2005) framework, we gained rich and complementary insights from participants that went beyond the literature, and helped identify knowledge gaps and areas for future research and action. We therefore strongly recommend consultation as an essential component of scoping review methodology.

Finally, the consultation demonstrates, as does the literature review, that it is the adult side of policy making that needs to change to be inclusive of children and youth as stakeholders. Therefore, institutional commitment and support for adults in practicing participatory ethics and creating safe spaces are paramount.

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*Table 1 Overview of the literature review (Part I) and the consultation (Part*

*II) results*

<b>Review foci</b>	<b>Literature review</b>	<b>Stakeholder consultation</b>
<b>Socio-demographic characteristics of child and youth participants</b>	<ul style="list-style-type: none"> <li>– Representation of children and youth with diverse backgrounds is limited</li> <li>– Socio-demographic information often remains “unspecified”</li> <li>– Almost all studies are from high-income countries</li> </ul>	<ul style="list-style-type: none"> <li>– Children and youth with disabilities, diverse sexual orientations and/or gender identities, low SES, and “ordinary” young people are often excluded</li> <li>– Lived experience was seen as beyond clinical diagnoses</li> </ul>
<b>Extent and nature of child and youth participation</b>	<ul style="list-style-type: none"> <li>– Children and youth often act as informants to shape the content of policies and frameworks</li> <li>– No children or youth participated in the stage of policy implementation</li> </ul>	<ul style="list-style-type: none"> <li>– Youth felt like an “accessory” in a tokenized policy making process</li> <li>– Institutional time constraints in policymaking processes and organizational culture also limit youth influence on decision-making</li> </ul>
<b>Facilitators of and barriers to participation</b>	<ul style="list-style-type: none"> <li>– Facilitators and barriers are multifaceted and interconnected</li> </ul>	<ul style="list-style-type: none"> <li>– Lack of power sharing is identified as a major barrier</li> <li>– Youth think adults’ objectives influence the types of young people who are invited to participate</li> <li>– Cultural, socio-economic, and political barriers exist in a global context</li> <li>– Lived experience can be a facilitator but trauma-sensitive safe spaces are necessary</li> </ul>
<b>Expected and perceived/actual effect of participation</b>	<ul style="list-style-type: none"> <li>– There is a gap between expected and perceived/actual effects of participation</li> <li>– The effects of participation at multiple levels (young people, adults, organizations, communities) are unknown</li> </ul>	<ul style="list-style-type: none"> <li>– Long-term impact of disclosure and self-identifying as participants with lived experience is unknown</li> <li>– Youth participants expected participation to be “frustrating”</li> </ul>