Centre d'excellence en santé mentale des jeunes
Centre of Excellence in Youth Mental Health

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CEYMH Advisory Councils Evaluation

The Youth and Loved Ones Councils were established in July 2023 to help guide new research initiatives at the Centre of Excellence in Youth Mental Health (CEYMH), including the BLOOM Program, which recruits young people aged 9 to 25. CEYMH was also the first organization to create a dedicated Teen Council. These groups quickly became a trusted resource, consulted not only by CEYMH project leads but also by external partners in both research and clinical settings. In addition, we developed a clear and equitable compensation policy for our collaborators with lived experience, positioning CEYMH as a leader in meaningful lived-experience engagement.

The lived experience advisory councils are led by Lived Experience Coordinators who serve as the primary liaison between the teens, youth, loved ones, and collaborators (researchers, clinicians, community organizations). In this role, they advocate for the meaningful inclusion of the voices of people with lived experience that they serve and ensure that they are authentically heard.

To better understand the perspectives of our advisory members and their experience thus far, the idea of evaluating the councils blossomed. To inform this process, the coordinators reviewed the literature on previous evaluations of youth involvement and engagement, along with the evaluation of patient partners in research. From this literature review, an evaluation guide was created to structure the focus group discussion. An evaluation focus group session was run with each council. The guide was composed of a series of questions that were designed to elicit feedback and encourage reflection on their experience thus far. The following sections will summarize common themes and some of the overarching experiences and feedback from the three CEYMH advisory councils.

1. Participation

Members of the councils were asked to reflect on their overall participation and share if they felt their lived experience was valued.

- Teen members reflected on their participation as a meaningful learning experience of meeting with collaborators that broadened their understanding of mental health. One teen reflected that it was fun to be a part of something that can help others in the long run, *"…the cool thing is that since we had several different studies come to us to get our opinion, we definitely may have been able to help a lot of people."*
- Loved ones members reported more on the importance of participation in council meetings, with one member stating, "*…we know that our opinion matters…you know, it's by participating in things like this that we're going to slowly change things."*

- Youth council members echoed the sentiment, with one sharing, "*I feel that our opinions and experiences carry weight and value…the people who come to us for our opinions would say they discover things when we talk to them*."

However, there were some shared concerns that there was **a lack of knowing if their feedback was useful**, with a loved one saying, *"…it would be interesting to see concretely what our answers tell you and where this whole project is leading."* Another teen reflected that they felt like they were learning more than they were consulting. The coordinators reminded them, even the small insight they are sharing can go a long way to help research, as it comes from a perspective of teens, which is valuable.

2. Effectiveness

Council members were asked to reflect on the effectiveness of the council and the importance of including lived experience. They were also given a chance to suggest topics they would like to explore in future meetings. All groups stressed that **having lived experiences in research is essential for creating sensitive and effective mental health approaches**.

- One teen expressed that without lived experience input in research, "*there are ways of approaching it that are really insensitive and can be harmful*."
- Youth members echoed this, sharing that it can help the relevance in the work, with one youth saying, *"it allows doctors, researchers... to be really more in touch with reality, since I get the impression that sometimes there are those who lack* that."
- A loved one member stated that it helps research move faster, *"it takes years and years and years to uncover with traditional research methods that don't integrate the opinion of people who know first-hand the experience*."

The council's member feedback supports what is stated in "Reporting lived experience work" (Davis et al., The Lancet Psychiatry) on how it is especially important to centre lived experience in shaping research, care, and policy to restore trust and rebalance, as psychiatry and research have a history of unbalanced power dynamics and unethical practices. It is especially important to centre lived experience in shaping research, care, and policy to restore trust and rebalance. [i]

3. Learnings from the councils

Members were asked to reflect on their learnings from their time on the council. While learnings varied between members of each council, in all of them, there were members who shared that they had learned something.

- A teen highlighted that they learned *"that having these [mental health] problems is normal; it doesn't mean you're crazy, it can happen to anyone*."
- A loved one, meanwhile, noted learning "*that what really matters is detecting psychosis as early as possible, when people are very young. So I'm really happy about that because, in my case at least, the illness was detected really late*."

Another common takeaway among **youth and teen council members was gaining a better understanding of mental health professionals and how research processes work**. They learned about the steps that go into research and different positions in mental health work.

- One teen stated, *"…peer support worker, right? Yeah. I didn't even know that existed. You know, it opens up new avenues for us*."
- A youth member expressed, *"I didn't know there was so much going on, and also just like learning about so many new resources that are available for people our age…"*

Actually, to support this feedback, in a survey of 243 high-school students in rural Nova Scotia, more than 70 % were aware of at least one mental health resource, but among those who **had not** accessed services, "unsure of what treatment would entail" (mean ≈3.33/5) and fear or uncertainty were ranked among the top individual-level barriers, while community-level were mainly "lack of mental health education" and "lack of knowledge about available resources." [ii]

While exploring the resources on offer, some teens said they could still learn more. One of them stated, *"I know more places, I know more people, but I wouldn't necessarily know how to do it [get help]."* When asked what more they would like to learn about navigating the system, another teen answered, *"…when do you need to get help?"*. Another teen suggested it would be helpful to know how to subtly warn others about possible mental health symptoms by explaining how *"to show small signs without saying, "this is serious" but just say that maybe you're acting this way because of something and that it could get worse."* The coordinators took this feedback into consideration.

4. Feedback for coordinators and collaborators

The councils generally had positive comments about how the coordinators helped to create a safe environment for members to share as much as they wanted and validated their input. A common note for the coordinators was suggested to improve the coordination and scheduling of the meetings, such as having one main message with all the info in one place, keeping reminders minimal to avoid a cluttered inbox, and stating the estimated length of every meeting.

There were some common notes between councils when providing feedback about the collaborators. One was to ensure clarity when presenting themselves and their project.

- One teen stated that if there are few specifics of what is asked of them, *"then I don't feel like I'm meeting their expectations."*
- A youth member commented that *"they could also, like bring a little bit of like they're like mission… or how maybe even like how they got into the profession, just so we can see a bit more humanity, since, like we're sharing ours."*
- Some other suggestions from the council members were to help meetings run smoother by having a visual presentation and by "*providing the slides beforehand.* [So] *I can look at them… it lets me formulate my thoughts better rather than on the spot".* Also, to "*have a piece of paper with the plan* [for the session] *written on it, and maybe underneath that write down any definitions that might be important."*

All the councils mentioned that after providing feedback to researchers in meetings, participants often didn't hear back about the impact of their contributions. They understood that research takes a long time for results to come in, even just getting the funding. One teen expressed, "*…we give them our opinion on a project and then sometimes never see them again, and we don't know if it was useful or not, maybe if they send you something afterwards saying, this, this, this worked, it was useful for our project. Afterwards, thank the group and talk about it before the next meeting or something like that, that might be good too."*

This aligns with data in a UK qualitative study looking at the benefits of involving young people in mental health research with 13 young people (aged 13–24 years) who had experience of being involved in mental health research. The youth emphasized the importance of researchers keeping them informed throughout and after the project, so their input continued to feel valued. After investing significant time and energy, participants appreciated receiving updates on the project's progress and learning about the longer-term results of their work.[iii]

5. Next Steps and Improvement

Council members were given a chance to explore next steps for the council in the future. All councils agreed that increased involvement with the centre and learning surrounding mental health would be beneficial. Teens and youth expressed a **desire for future opportunities like skill-building workshops** (e.g., how to support peers). There was a call to improve the council's diversity and ensure outreach reached underrepresented communities. The youth council recommended advertising in diverse communities and institutions, tailoring outreach to local issues like financial stress and immigration-related mental health challenges and emphasizing the value of lived experience in research. The loved ones shared these recommendations and reflected on the **lack of diversity**. They suggested reaching out to ethnic communities and promoting the council's paid opportunities to attract diverse voices. The teens again reflected on the importance of diversity in the council but also commented on how **they feel comfortable in their group**.

Conclusion

Overall, this process highlighted the value of lived experiences, which offered unique insights that enhanced the authenticity and relevance of the research. It also underscored the importance of expanding future discussions to include additional topics, such as practical challenges faced by youth. Participants emphasized the need for clearer communication, more effective visual materials, and greater outreach efforts to engage diverse communities. Lastly, there was a recurring concern about the lack of clarity regarding what happens after their feedback is shared, pointing to the importance of transparency and follow-up in future engagements.

Guided by these key insights, we are developing several ways to shape the next steps of our LEP initiatives.

- **Keep councils informed** about the progress and outcomes of the projects they contributed to.
- **Create feedback loop documentation** to help clarify expectations & help members manage their mental and emotional energy/commitment.
- **Improve and simplify** how we schedule the meetings.
- Open the Loved Ones Council to include **anyone who is a caregiver** of a loved one with a mental health struggle.
- Diversify our councils by recruiting in **diverse communities and institutions** by moving to a youth and caregiver network model to include more diverse voices
- **Strengthen partnerships** with organizations, clinical teams, and research groups that value the input of lived experience.
- **Ensure meeting topics** coincide with council members' interests
- **Support youth-led initiatives**, such as podcasts or other creative activities that involve them with the CEYMH and amplify their voices.

[i] Davis, S., Pinfold, V., Catchpole, J., Lovelock, C., Senthi, B., & Kenny, A. (2023). *Reporting lived experience work: Working with people with lived experience in mental health research. The Lancet Psychiatry.* https://doi.org/10.1016/S2215-0366(23)00245-8

[ii] Marmura, H., Cozzi, R. R. F., Blackburn, H., & Ortiz-Alvarez, O. (2024). *Adolescents Identify Modifiable Community-Level Barriers to Accessing Mental Health and Addiction Services in a Rural Canadian Town: A Survey Study. Pediatric Reports*, 16(2), 353-367. https://doi.org/10.3390/pediatric16020031

[iii] Watson, R., Burgess, L., Sellars, E., Crooks, J., McGowan, R., Diffey, J., Naughton, G., Carrington, R., Lovelock, C., Temple, R., Creswell, C., & McMellon, C. (2023). *A qualitative study exploring the benefits of involving young people in mental health research. Health Expectations, 26*(4), 1491–1504. https://doi.org/10.1111/hex.13722