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Engaging with People with Lived and Living Experience of Mental Illness Effectively: The MHCC's Advisory Councils



The Mental Health Commission of Canada (MHCC) recognizes the importance of ensuring that its programs and policies are informed by the knowledge of people who have lived and living experience (PWLLE) of mental health and substance use concerns. Their involvement brings a diversity of perspectives to our work, enriches our organization, and leads to more effective and higher quality work. In 2008, the MHCC established two advisory councils, the <u>Youth Council and the Hallway Group</u>, to ensure that the voices of lived and living experience are embedded in the MHCC's work.

# An overview of the MHCC's advisory councils

### **Youth Council**

The MHCC established the Youth Council in 2008 to provide a platform for individuals aged 18 to 30 years with personal experiences of mental health challenges or substance use issues. The Youth Council plays a crucial role in shaping the strategic direction and operational activities of MHCC programs, projects, and policies by offering a youth perspective on mental health and recovery. Members actively participate in mental health events and discussions nationwide to ensure that policies and practices are responsive to the needs of young people.

### **Hallway Group**

In 2009, as part of the Opening Minds anti-stigma program, the MHCC created the Hallway Group. Compromised of individuals aged 30 years and older with lived and living experiences, this group provides leadership in several subject areas from the grassroots to the system level, contributing feedback on tackling stigma related to mental health and substance use health in communities. The group's name reflects its mission of bringing essential conversations from hallways to decision-making tables. The Hallway Group advises the MHCC on strategic initiatives, projects, and priority areas, drawing from expertise beyond the traditional mental health field. Additionally, the group identifies key issues for the MHCC to consider, undertakes activities to enhance the lives of those affected by mental illness and/or substance use, and provides insights into contributor perspectives.

Both councils' memberships span a diversity of geographic locations, ethno-racial and cultural backgrounds, sexual and gender identities, and educational and professional backgrounds, ensuring that engagements at the MHCC centre equity, diversity, and inclusion – crucial organizational values.



## Inclusive engagement: Prioritizing diversity and accessibility in the MHCC's advisory councils

The MHCC recognizes that PWLLE may face barriers to engaging with, contributing to, and committing to the work of the councils. To help council members to participate equally, we offer the following supports:

- We provide an honorarium and reimburse relevant expenses to encourage a range of opportunities for involvement that benefit every member. Providing honoraria is a way to recognize expertise and honour significant time commitments.
- We encourage people living with disabilities to join the advisory councils and provide accommodation(s) to our best ability.
- We actively accommodate members' needs as best we can when they travel for in-person meetings or events.

# The IAP2 spectrum: The MHCC's adapted IAP2 spectrum for inclusive engagement

Over the years of working with the Youth Council and Hallway Group, we have heard that members want to be more deeply involved in the work of the MHCC. They have expressed a desire to participate in early project development and to collaborate on and influence our initiatives.

To ensure meaningful engagement of council members, a two-year pilot project was implemented using the International Association for Public Participation (IAP2)'s Spectrum of Public Participation. An adapted version of the IAP2 spectrum was developed in collaboration with advisory council members to reflect how PWLLE are engaged at the MHCC. Throughout the two-year pilot, engagement opportunities were tracked, allowing us to leverage the advice, expertise, and interests of our council members by involving them in the decision-making process. This approach has enhanced council members' trust in the MHCC, increased the MHCC's credibility among council members, improved the quality of the MHCC's decisions, increased transparency, and built stronger relationships.

The IAP2 spectrum outlines various levels of public participation in decision-making processes. It provides a flexible and adaptable framework for engaging contributors at different stages, from informing them about a decision to empowering them to be actively involved in the process. The spectrum values the inclusion of all contributors and ensures their voices are heard and considered.

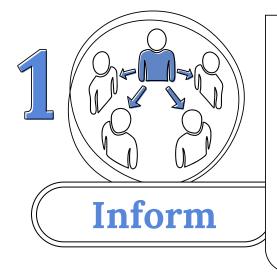
## The MHCC's adapted IAP2 spectrum

The following is an adapted version of the spectrum, divided into two primary categories: goal and commitment. The goal category outlines the objectives at each level of the spectrum from the perspective of PWLLE. The commitment category details the expectations for staff members wishing to engage PWLLE in their projects or initiatives.



## **IAP2 Adapted Spectrum**

#### Increasing impact on the decision



#### Goal

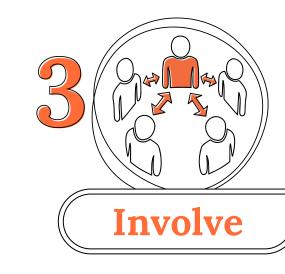
Provide advisory council members with MHCC insights

#### Commitment

To inform and enhance the knowledge base of advisory council members

#### Example

Conference attendance, share information and updates via email, meetings, website, newsletter, etc.



#### Goal

development of the engagement

#### Commitment

#### Example



#### Goal

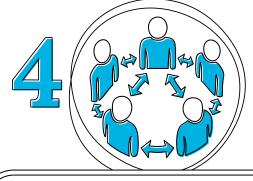
Invite advisory council members for project feedback

#### Commitment

To acknowledge feedback and integrate the voices of people with lived and living experience into decision-making processes

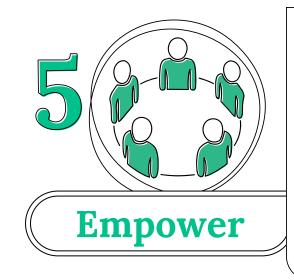
#### Example

Participate in focus groups, feedback on resources, documents, RFPs etc.





- Engage in multiple conversations on an ongoing basis and keep advisory council members informed throughout the
- Incorporate input to shape project outcomes
- Contribute to webinars, panel discussions, project specific advisory committees etc.



#### Goal

Provide full autonomy to advisory council members over the initiative

#### Commitment

Implement decisions with full support and resources

#### Example

Knowledge product development, advisory council led project

#### Goal

Collaborate with advisory council members in shared decision making

#### Commitment

Co-design projects with advisory council members

#### Example

Content creation, conference session planning, strategic planning

# The Value of Engaging with People with Lived and Living Experience

#### **Diverse perspectives**

First-hand experiences offer insight into real-life challenges, needs, and nuances in a given situation.

#### Authenticity

As experts in their own lived and/or living experiences, PWLLE can provide genuine insights based on their experience living with a mental illness and/or substance use concern. This authenticity helps build trust and credibility and improves the quality of knowledge exchange within a community.



#### Empowerment

Engaging PWLLE empowers them by providing a space for them to share their stories and perspectives and contribute to the decision-making process

#### **Reduced stigma**

Sharing personal experiences can help challenge prejudices and stereotypes.

#### **Enhanced collaboration**

Co-creating can lead to innovative solutions and a more inclusive and informed decision-making process.

#### Advocacy and awareness

PWLLE who advocate for change can help raise awareness and positively influence public opinion.

# Key Considerations for Effective Engagement with People with Lived and Living Experience

#### Early-stage engagement

By seeking input from advisory council members early on, you can address concerns and incorporate valuable feedback into the planning stages of your work. Early engagement fosters a sense of partnership in the decision-making process.



#### IAP2 levels of engagement

When seeking input from advisory council members, include the level of engagement that you are requesting. This helps set clear expectations about what is being asked of them. (Refer to the IAP2 spectrum on pages 6 and 7.)

#### Engagement kick-off briefing

Convene a session at the outset of the engagement to present an overview of the project requirements, share pre-read material, define goals, synchronize expectations, and establish a shared comprehension of the deliverable(s) and role for each advisory council member involved. This session serves to offer context and confirm members' availability for scheduled engagements, factoring in diverse time zones. Additionally, it is crucial to communicate the honorarium amount for their participation.





#### Active listening

Create an environment where people feel comfortable sharing their experiences. Acknowledge personal contributions by taking the time to listen attentively, empathetically, and without judgment to their stories and input.

#### Communicate clearly and with plain language

Avoid acronyms and technical language that may be unfamiliar to advisory council members. When presenting topics that have not been brought to the council before, provide context and explanations to enhance understanding. It is also recommended to include a warning when sharing content that may evoke a strong emotional reaction in some individuals.

#### Keep members informed

Once advisory council members have participated in your endeavours, provide them with updates regarding a project advancement or milestone including how and where their input was incorporated. This approach sustains interaction while fostering an ongoing rapport and trust.

#### Language and terminology

Use first-person language and avoid stigmatizing language. The <u>Language Matters</u> resource provides context on how to use language when combating stigma related to mental illness. "Using the IAP2 framework has been a game-changer for me in terms of how I engage with projects and opportunities with the MHCC. Prior to incorporating this framework, I often found myself unsure about what I was signing up for when I volunteered for a project. But now, with the structure and guidance provided by IAP2, I feel much more confident in my ability to engage meaningfully and contribute in a way that aligns with my skills and interests."

– Myriam Lecousy, former co-chair, Youth Council

"I have used the IAP2 framework for over five years and find it an easy way to know how to engage with my work. I really like knowing up front what to expect from my involvement in MHCC projects. The IAP2 framework allows me to decide if I have the time or interest to engage."

– Anita David, co-chair, Hallway Group

## Acknowledgments

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