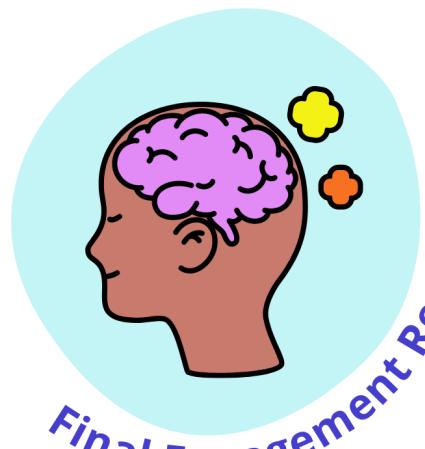


# MEASURING, UNDERSTANDING, AND IMPROVING QUALITY OF LIFE IN A YOUNG ADULT SUBSTANCE USE PROGRAM: IMPLEMENTING AND EVALUATING YOUTH ENGAGEMENT PRINCIPLES AND PRACTICES

PROJECT: February to July 2022

FINAL ENGAGEMENT REPORT:  
August 31, 2022



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## Introduction of Report

In February 2022, the Young Adult Substance Use Program (YA-SUP) received a grant through Frayme's 'Great Big Stories' (GBS) initiative to conduct a study focused on measuring, understanding, and improving the quality of life of young adults enrolled in the Young Adult Substance Use Program (YA-SUP).

Within the scope of this study was the goal of increasing the program's capacity for engagement with youth and families with lived experience of addiction. This was to ensure that the direction and outcomes of the study were informed and guided by youth and families' needs, interests, experiences, and perspectives.

The funding from the grant allowed the project staff to conduct interviews and focus groups with youth and families, consult youth for feedback on project materials and data results, and formally hire two youth with lived experience as part-time research assistants.

As the study comes to an end, the project team would like to provide an overview of the engagement conducted in preparation for and throughout the study. This report was written by the young adult research assistants (RAs), with support from a youth with lived experience of mental health and substance use (MHSU), and will discuss the following:

1. The engagement principles and practices implemented into the YA-SUP
2. The barriers faced in implementing engagement into the YA-SUP
3. Reflections on the impacts of engagement on our study
4. Future recommendations for engagement in the YA-SUP and other programs

## Introduction of Authors

**Mackenzie Mawson** (she/her) has experience working with community partners from the age of 22 until 25, applying her lived experience as a mental health service user to inform organizational decisions. She openly identifies as a transgender woman and uses this experience to advocate for trans/gender diverse individuals within healthcare. She works as an Registered Nurse and hopes to continue working within mental health, particularly with those belonging to marginalised identities.

**Madeleine Luvisa** has an educational background in recreation therapy and social work. Madeleine has a passion for holistic approaches to wellness and community-oriented care. Madeleine has worked in a variety of engagement contexts and has experience with program planning and delivery, evaluation, system improvement, and enhancing organizational engagement capacities.

**Kalia Douglas-Micallef** (she/her) aspires to research addiction genetics. She is particularly interested in this realm of work largely due to lived experience, and for its nuance and complexity. She hopes to give back to those working tirelessly in the field by spreading awareness and engaging with the efforts of healthcare professionals to reach the common goal of changing lives.

## Defining Engagement

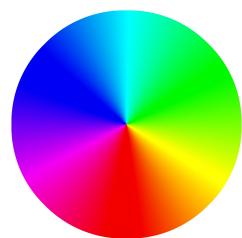
It is difficult to place a single definition on engagement, as it is multidimensional and complex. From our understanding, which has largely been shaped by our own experiences, **engagement is inviting people with lived experience into the work**. It is intentionally creating space in a traditionally clinical or exclusionary setting for people to come in and **not just participate, but contribute** to the work being done and the decisions being made. Engagement is a key process in the planning and delivery of services in all sectors, as well as in the development and implementation of research projects. Though it is less common in research settings, engagement has numerous benefits for researchers, stakeholders, and research project results – this will be discussed later in this report. **How can communities be effectively served or supported if researchers and service providers do not ask what is most important to them?**

**Youth Engagement**  
isn't just about  
**participation** but  
**contribution.**

There are many ways to engage people, and there are many factors that impact engagement practices – including resources, settings, communities, projects, methods, timelines, and more. Engagement is often understood as existing on a linear continuum from “bad” to “good”, with a narrow definition of “gold standard” engagement.



We understand engagement as existing on a gradient rather than a spectrum (like a colour wheel you use to pick your text colour). When practitioners and organizations try to place themselves on a line, it rarely allows for **nuance, complexity, and multidimensionality** in assessing engagement practices. The idea of a gradient allows multiple factors to be considered at the same time, and for the value of each factor to be specific to the person or the project. The gradient holds space for a more holistic evaluation or reflection of the quality of engagement practices.



When thinking about engagement, consider:

1. *What does the community or project need? How is this being determined?*
2. *In what capacity are youth or stakeholders interested and/or able to engage?*
3. *Based on the above, what are you doing well and what could you do better?*

It is important for practitioners and organizations to acknowledge their capacity for engagement in the here and now, while also striving to work toward more meaningful and collaborative engagement with people and communities. This is an ongoing process – high quality engagement takes a lot of time and effort. No one is able to engage perfectly, but a **commitment to doing your best and trying to do better is most important**.

# Engagement Values and Practices

## How was engagement incorporated into the YA-SUP and the Quality of Life study?

From the beginning of the YA-SUP, the research and clinical teams have strived to integrate the perspectives of mental health and substance use service users into the development and evaluation of the program. This was done through three main approaches:

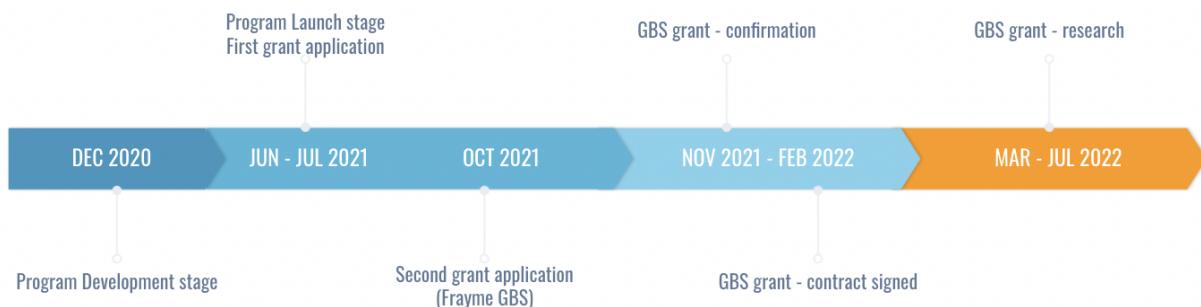
1. Drawing on existing research and reports that summarize the perspectives of young people with lived experience.
2. Consulting with researchers and clinical experts who work closely with young people with substance use concerns.
3. Conducting several consultations with local young adults with lived experience who have navigated the mental health system.

The catalyst of the youth consultations came from numerous sources and consultations with researchers outlining the importance of integrating perspectives from the population of interest. Ultimately, you cannot effectively care for or study a specific group of people without speaking to them first. The articles recommended the following values when enacting engagement: **flexibility, mentorship, authentic decision making, reciprocal learning and mutual respect** (e.g., Hawke et al., 2019). These values were implemented throughout our working relationship as youth consultants and research assistants (RAs) with the YA-SUP.

**“What I have lived through, experienced, and survived is knowledge.**

Youth engagement has also been at the core of the Quality of Life study. Two of the RAs working on this study were also involved as youth consultants for program development from December 2020 to January 2022. Jillian, the Quality of Life study research lead, facilitated the youth feedback during the development of the YA-SUP. These program consultations occurred before writing the two grant proposals and beginning the Quality of Life study. Therefore, there was a pre-established relationship between the us and Jillian prior to the Quality of Life study. The timeline of this partnership is depicted in Figure 1.

**Figure 1. Timeline for engagement in the YA-SUP**



The development of youth consultations and subsequent progression to RAs was successful due to the enactment of the previously mentioned values. We felt **respected**, which resulted from the immediate application of our voices and feedback. Jillian valued our input and did her best to integrate our ideas whenever possible.

The **positive and consistent communication** between team members was also notable. This was accomplished by consistent check-ins. During these times, Jillian was patient and able to work around conflicting schedules, while prioritising the voices of those with lived expertise. Any contribution felt as though it would be met with honest, respectful dialogue. The effective communication also involved a level of transparency when feedback could not be implemented due to organisational barriers or research constraints. Jillian would discuss limitations and work with us to mitigate these barriers or look for alternatives.

The **flexibility** amongst team members was aided by virtual correspondence. We were able to move around team meetings when schedules changed to times that worked for all of us. There were also instances where two out of three of us would meet and then speak with the missing member afterward.

There are noticeable gaps between some of the tasks, which resulted from Jillian insisting engagement was to be **compensated** – this represents a tension between values of ongoing engagement and values of financial compensation. Each consultation ended with honoraria and many of the project tasks for the study were not started until the hiring process by St. Joseph's Healthcare Hamilton (SJHH) was completed.

#### *Values and principles at the heart of engagement during YA-SUP engagement:*

- Stakeholders compensated for their time and expertise (*engagement was done when there was a budget to compensate adequately*)
- Clear, transparent, timely communication of expectations and outcomes
- Accessible, flexible, and adaptable engagement practices (*especially in the context of a pandemic*)
- Stakeholders have a right to be involved in their care
- Self-reflection and accountability
- Valuing experiential knowledge, reciprocal learning and mentorship, and diverse perspectives
- Mutual respect

#### *Methods of engagement used:*

- Reviewing existing reports and research that have summarized the voices and perspectives of young people with lived and living expertise
- Virtual Consultations (synchronous and asynchronous)
- Virtual partnership roles (research staff, resource development leads)
- Quantitative surveys (in-person and online)
- Online qualitative surveys
- Virtual Interviews
- Virtual Focus Groups

Presenting at the Frayme conference was our first task as RAs. Jillian had developed the foundation of the presentation (given delays in hiring and valuing compensation), but wanted it led by us. We worked as a team to provide feedback and edit the presentation. The goal of the presentation was to provide an overview of the YA-SUP and the plan for the GBS funding. The presentation was successful (with 80+ engaged attendees), in part due to the positive pre-established working relationship - namely, flexibility and communication between team members - allowing quick revisions of the presentation once hired. Our involvement in the conference is another depiction of how valued we felt, while also highlighting Jillian's goal to include us in as many phases of the project as possible.

There were two other young adults actively involved in the design and interpretation of the study. Kalia, who also has lived experience in the MHSU system, provided feedback on research materials. Along with the two RAs, she discussed language that could be altered in the interview and focus group guides to ensure they were accessible, youth-friendly, and non-stigmatizing. Kierryn, a young adult who participated in an interview also provided written and verbal feedback on thematic results, supported the interpretation of the findings, and led the creation of resources based on the key messages of the study. All young adults involved in the study process were compensated for their time and expertise.

*"As a youth consultant, the compensation provided was a bonus, however, I found that I was eager to contribute regardless, and was my primary reason for reaching out for involvement. I went into this without knowing what the result would be like. The co-authorship along with the set of values displayed spoke for itself in regards to mutual respect and the value in what I have to offer. Everyone has to start somewhere and I know I will have the opportunity to build research skills once I begin my career as a student. This experience was synonymous with starting over in life and taking initiative. I chose to attend my first meeting in rehab where I was dedicated to change my life within those walls. This experience has really been a stepping stone to where I want to go in life, so the financial aspect, to me, is incomparable to what this experience has truly given me based on the attitudes and approaches of those I've had the privilege to work with. Starting over in recovery isn't possible for everyone depending on their age, commitments, social location, and general outlook. Throughout my recovery, I've had to climb the ladder slowly, and I'm okay with that because it's what changed my life. I'm grateful to be involved and to watch myself grow within this role." - Kalia*

Our interest in applying for the GBS grant was driven by the desire to strengthen current YA-SUP care and evaluation. The research team understood the importance of working with youth beyond consultations. As part of the research project itself, interviews and focus groups were conducted with young adults in the YA-SUP and parents who had attended the Loved Ones Education groups to ensure that the voices of individuals with lived expertise are at the centre of our research methods and results. This study focused on ensuring the way we measured program outcomes was meaningful to young people and their supporters. **The grant allowed for the study to be co-designed, co-facilitated, and co-interpreted with young adults with lived expertise** including the young adult RAs (Madeleine and Mackenzie) and additional youth consultants (Kalia and Kierryn).

## Barriers to Engagement

We experienced a number of barriers throughout our study relating to the facilitation and quality of our engagement practices. Some of the most notable barriers we faced had to do with funding, timelines, organizational contexts, and the needs or capacities of the individuals being engaged. While the funding we received through the GBS grant allowed us to be engaged more deeply and consistently as RAs throughout the study, our budget only allotted 4 hours of work per week for each of us (this increased to 7-10 hours per week the final 2 months of the funding). This means that we were unable to participate in certain aspects of the study or to contribute as fully to certain tasks as we would have liked to. Additionally, engagement with other consultants was difficult to do as we were often unsure of how much flexibility we had in the budget to do so. While those of us who were engaged certainly provided valuable guidance and insights, we were limited in numbers and unable to capture the diversity of perspectives and experiences to be represented in the project or the program overall.

We also faced barriers relating to unanticipated delays in our timelines. Most notably, our study was anticipated to begin in January 2022, however due to delays in the hospital's contracting and hiring processes, our formal start date was in late February. While we were initially willing to begin working before then, Jillian placed the highest priority on ensuring we were compensated for our time. This demonstrates conflicting values in facilitating engagement: equitable compensation and true co-design could not be simultaneously carried out as values in this situation, and a decision had to be made as to which value we would adhere to first. We collectively decided to prioritize compensation, which meant that we were unable to guide or take part in certain tasks (e.g. developing our presentation for the Frayme conference, designing research materials, etc.).

### *Engagement barriers:*

- *Funding/budget*
- *Organizational buy-in*
- *Geographical*
- *Recruitment*
- *Timing*
- *Lack of knowledge/skills/resources*
- *Societal contexts*
- *Stakeholder attitudes/capacities*

(Hawke et al., 2019)

One of the most significant barriers we faced, especially in the later stages of the study, was related to the needs and capacities of the individuals being engaged. Our progress was often impacted by situations occurring in the personal lives of those being engaged. For example, both of us (the young adult RAs) started new jobs mid-way through the study. As another example, the submission of this paper was pushed to a later date than originally anticipated as a result of an emergency in one of the RA's families. Certain roles or responsibilities were shifted throughout the study in response to our needs and interests as

team members. While Jillian did an excellent job of being responsive to such changes, it nevertheless complicated some of our work and impacted our timelines, outcomes, and individual capacity/bandwidth.

In addition to the aforementioned, virtual engagement can result in its own specific set of barriers. For example, on a number of occasions some of us found ourselves with little to no access to technology or reliable WiFi, which made us unable to participate in certain tasks or opportunities. Since engagement in MHSU settings often involves the sharing of one's personal story or experiences to guide the work being done, we sometimes struggled to find a safe and private space to participate in meetings while other people were home. Another very common barrier related to virtual engagement is the difficulty participants may face in staying attentive, focused, and engaged with a screen. This is something we often struggled with – since all of our work was completed virtually, we found ourselves dealing with 'screen fatigue' during synchronous and asynchronous tasks alike. As was the case with other barriers we faced, this impacted our productivity and progress in the study over time.

# The Impacts Of Engagement

Incorporating stakeholder perspectives and ideas has tremendous impacts on clinical programs and research projects. Co-design can lead to more relevant research questions, alignment with stakeholders' priorities and increased outreach success (Armstrong & Manion, 2013). During the development of the YA-SUP, the research team reached out to a local youth council to gather feedback on the direction of their program – this is where we were recruited and how we became connected to the YA-SUP. These consultations drove many of the earlier changes. Originally, the program was going to have 'emerging adults' in the title, but we spoke of its clinical, unrelated feeling. 'Young adult' was determined to be a better alternative. We also suggested using the term 'loved ones' instead of 'families' due to its more inclusive nature. We wanted the program to acknowledge that young adults have various definitions of 'loved ones', and to avoid restricting this group to legal/biological family.

There was acknowledgment of when specific topics or terminology would be triggering for the population of interest. **Working with people who have lived experience relating to the population receiving care, applies a lens of context that would not be available otherwise.** An example of this is when we were reviewing the informed consent forms and realized that some of what is talked about in the interviews or focus groups could stir up emotions for the participants. Though the consent form included a section on possible emotional or psychological harm and provided encouragement to talk to a clinician or support alongside a crisis number, we felt this was insufficient. Thus, we proposed developing comprehensive resource lists that could be emailed to the participants across studies.

- Impacts on service users/community members:***
- Improve wellbeing and suicidal ideation
  - Gain experience/skills
  - Professional development
  - Feel a sense of empowerment
  - Develop advocacy skills
  - Feel seen, heard, supported
  - Networking/collaboration opportunities

- Impacts on service providers/researchers:***
- More relevant research questions
  - Alignment with stakeholder needs/priorities
  - Increased recruitment/outreach success
  - Bridging the knowledge-to-action gap
  - Gain new and diverse perspectives
  - Creative and innovative approaches
  - Sustainable outcomes/results

(Allemand et al., 2021; Armstrong & Manion, 2013; Canas, Lahance & Phipps, 2018; Hawke et al., 2019)

During the Frayme grant, we (the RAs) developed and facilitated a presentation to Peter Boris Centre for Addictions Research (PBCAR) staff. The goal was to build engagement capacity within the Centre by explaining reasons for including engagement in research and/or program planning and how to do so successfully. We used our lived experience engaging with community organizations as well as research evidence. At the

beginning of the presentation, Centre staff were asked two questions rated on a scale of 1 (low understanding/comfort) to 5 (high understanding/comfort):

- 1) What is your level of understanding of engagement?
- 2) What is your level of comfort with engagement?

For the first question, only one person answered with a rating greater than four (see Figure 2); a rating of two was the most popular. For the second question, the majority of participants answered with a rating of three (see Figure 3). Afterward, when the goals and processes of engagement were explained, participants were asked what words came to mind when thinking of meaningful engagement (see Figure 4). The answers reflect critical understanding gained during the presentation, as the most common words were '**communication**' and '**collaborative**'. At the end of the presentation, the feedback was very positive – participants expressed feeling better equipped to start thinking about and implementing engagement into their work. This is a great example of the power of brief capacity building in generating awareness, inspiration, and commitment to future positive engagement.

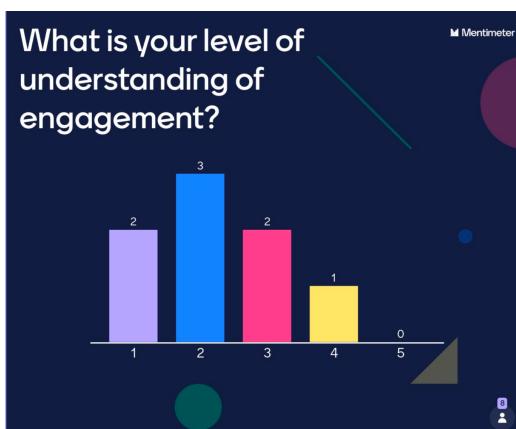


Figure 2

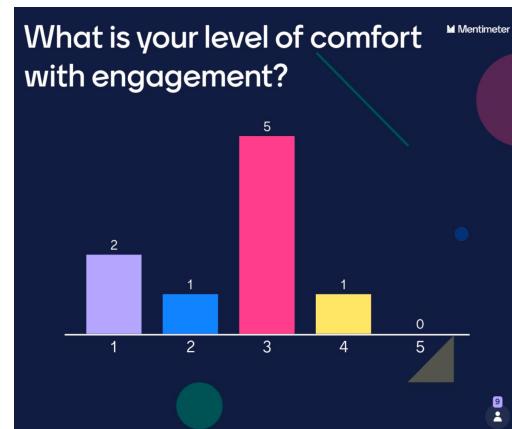


Figure 3



Figure 4

Engagement has impacted us on a personal level as well. This experience has provided us with the opportunity to be hired by a local hospital; understand its work culture; connect with program/project leads; present to a series of audiences in smaller and larger settings; understand research language, methods, and procedures; and code research data. This newly acquired knowledge and experience will allow us to feel more equipped in future opportunities. We have been able to build our skill repertoire, which has resulted in increased confidence in research settings and beyond.

The progression from youth consultants to research assistants benefitted the outcomes of both the program and the study. Every time we provided feedback as youth consultants (prior to the Quality of Life study), we slowly built rapport with Jillian and became familiar with the expectations of the YA-SUP. The fact that Jillian advocated for us to be involved as staff as opposed to remaining consultants, instilled our trust in her. When the GBS grant was confirmed and the contracts were signed, we were able to accomplish tasks more quickly and effectively because we had already reached a mutual level of trust and respect. If we had not had the opportunity to collaborate as youth consultants prior to the Quality of Life study, it likely would have taken much longer to accomplish initial project tasks. Our pre-existing relationship allowed for a crescendo of involvement, ultimately leading to strengthened team dynamics. This process was also an opportunity to see if it was something we would be interested in and capable of before officially being hired.

*"As someone with lived experience and minimal research experience, engagement has proven impactful on a personal and professional level. A strong sense of community and future employment opportunities can arise from engagement such as these. Engagement helps to shift the one dimensional narrative about research and invites numerous perspectives. This demonstrates valuable contribution across various disciplines, social location and demographics. It helps to expand the network and divert from the general standard of 'one size fits all.' In my personal experience, I feel more willing and trusting of those in the field in ways I otherwise would not have been had I not had such a positive experience with engagement. This was my first research experience, and I found that it really set the tone for how I've envisioned a career moving forward. It also instilled a sense of self worth in the sense that my contribution to research matters from a position of empowerment rather than a feeling of powerlessness. The mentorship provided throughout this experience by the research team and by Jillian in particular proved integral to my evolving quality of life." - Kalia*

The grant provided notable opportunities for reciprocal learning and self-reflection between the youth and the research lead.

*"As both a nurse and researcher, my foundational goal has always been to improve the lives of youth. When I practiced as a mental health nurse, I could see and hear the impact I was having on individual youth on a daily basis. As a researcher, I have the potential to lead research that may eventually contribute to widespread practice and policy changes to improve the lives of many youth. However, it often takes a while to see the positive impacts of research and not every research study leads to a result that merits a policy or practice change. Also, as I transitioned from full-time nursing practice to full-time research (and from in-person to virtual), it became increasingly difficult to know whether I am doing work that matters. Through this grant, I saw the power of youth engagement in research to not only ensure research questions and outcomes are impactful and meaningful, but also to create meaning during the research process itself. The set-up, conduct, and interpretation of our Frayme Quality of Life Study had a level of depth, nuance, and care that would not have been possible without youth engagement through the entirety of the study. Through youth engagement, not only does your research outcome matter (which may have delayed benefits), but your research process matters and can have an immediate positive impact on the lives of youth involved. I am deeply grateful for the opportunity to have been able to work with and learn from all the young people involved in this project - the RAs (Madeleine and Mackenzie), the youth consultants (Kalia and Kierryn), and the young adults and supporters who took time to share their stories during interviews and focus groups." - Jillian*

# Future Recommendations

## Co-Design Approach

There are multiple ‘levels’ of, or approaches to, engagement (see Figure 5). When possible, organizations and researchers should seek to implement a co-design approach. Co-design, or co-development, allows for a more meaningful and authentic relationship between practitioners or researchers and those being engaged. Stakeholders typically participate in decision-making and help guide the structure and delivery of programs or projects. It is important to note that co-design may not always be possible or optimal to use as an approach to engagement. When determining the most suitable approach, practitioners/researchers and stakeholders may want to reflect on the values of and barriers to engagement mentioned in previous sections of this report. While co-design is certainly a strong approach, meaningful engagement can be facilitated at other levels as well – it depends entirely on the needs and interests of the population(s) being engaged, the organizational contexts, and more. The only level to avoid is the ‘red level’. Such engagement could result in harmful experiences for those being engaged and negative outcomes for the program/project, and reduce the quality and/or possibility of future engagement opportunities.

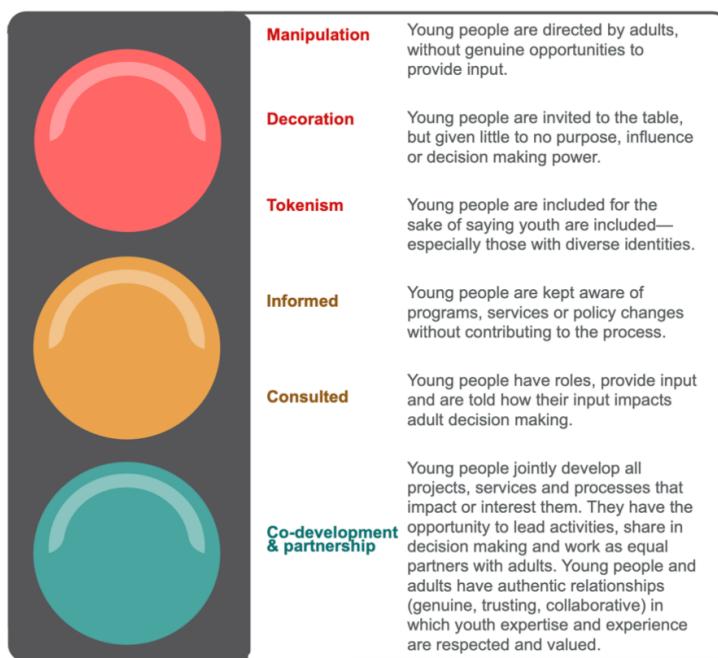


Figure 5 (Danesco et al., 2020)

Most of our work as youth consultants and as RAs fall under the consultation level of engagement. For example, we largely shared feedback and ideas, but were unable to lead project tasks without approval from program managers. Our engagement was certainly still impactful, for us as well as for staff and service users at the YA-SUP. However, for us to achieve true co-development and co-leadership, certain changes would need to be made to the organization’s principles and practices. Such a change might include having teams of service users who participate in decisions about the direction of research studies and help to shape the foundations of the program’s work.

## **Addressing Barriers**

Below is a table listing barriers to engagement that organizations, practitioners, and researchers may face. We have included potential resolutions that could be used to prevent or address such barriers. This is certainly not an exhaustive list of barriers or resolutions – we invite you to reflect on and work through barriers that are specific to your organization, program/project, and population(s) of interest.

**“ Engagement is about disrupting power imbalances. ”**

Barrier	Potential resolutions
Lack of funding or budget	<ul style="list-style-type: none"> <li>• Apply for grants to fund co-development (and include youth when designing and writing these grants)</li> <li>• Fundraising</li> <li>• Review literature that has already collected the perspectives of your populations of interest (e.g. government reports or guidelines, patient preference research, Delphi studies, qualitative studies)</li> </ul>
Lack of organizational or staff buy-in	<ul style="list-style-type: none"> <li>• Advocate to staff and leadership</li> <li>• Raise awareness of the value and impacts of engagement</li> <li>• Openly discuss potential barriers to engagement and how to feasibly address them</li> <li>• Training and mentorship opportunities for practitioners and researchers to learn about engagement and how to do it meaningfully / effectively</li> </ul>
Geographical or regional	<ul style="list-style-type: none"> <li>• Provide virtual or asynchronous engagement opportunities</li> <li>• Provide bus tickets or taxi vouchers to participants who use such transportation</li> <li>• Go to places / spaces that are convenient for your populations of interest to get to</li> </ul>
Participant recruitment and commitment	<ul style="list-style-type: none"> <li>• Partner with organizations who can help connect you to your populations of interest</li> <li>• Virtual and in-person recruitment</li> <li>• Compensate participants equitably for their time</li> <li>• Create an engagement policy / terms of reference</li> </ul>
Timing	<ul style="list-style-type: none"> <li>• Flexible and adaptable practices</li> <li>• Schedule engagement opportunities with a population's needs in mind (e.g. after school, outside of work hours, avoid religious holidays)</li> <li>• Offer recurring meetings or “schedule-as-you-go”</li> </ul>

Lack of knowledge, skills, and resources	<ul style="list-style-type: none"> <li>• Attend / provide ongoing opportunities for capacity building (attending conferences on engagement, reading co-developed literature, etc.)</li> <li>• Establish a network of practitioners and researchers who can help build capacity</li> <li>• Establish engagement evaluation processes</li> </ul>
Participant attitudes, needs, and capacities	<ul style="list-style-type: none"> <li>• Build genuine relationships with the individuals / communities being engaged</li> <li>• Consistent communication</li> <li>• Provide opportunities to reschedule</li> <li>• Offering diverse engagement methods (group meetings, individual sessions, written, etc.)</li> </ul>
Virtual settings	<ul style="list-style-type: none"> <li>• Using headphones for privacy</li> <li>• Scheduling meetings when other people are less likely to be in the home</li> <li>• Team building or fun activities during meetings</li> </ul>

(Canas, Lahance & Phipps, 2018; Hawke et al., 2019)

### Values and Principles

The Knowledge Institute on Child and Youth Mental Health and Addictions co-developed quality standards for youth engagement and family engagement that discuss factors that stakeholders identified as crucial in facilitating meaningful and effective engagement. It is important to note that these standards are not meant to be used as a 'to-do list' for engagement, but rather as guiding values and principles. The quality standard for youth engagement identifies nine quality statements: accessibility, authentic relationships, co-development, commitment, communication, diversity and inclusion, ongoing learning, research and evaluation and safer spaces (see Figure 6; Danesco et al., 2020). The quality standard for family engagement identifies eight quality statements: commitment, communication, diversity and inclusion, empowerment, ongoing learning, partnership, research and evaluation and co-development (see Figure 7; Danesco et al., 2020). Notice that there are similarities between the quality standards, however an organization's approach to engagement should be tailored to the population (i.e. youth or families) they are working alongside.

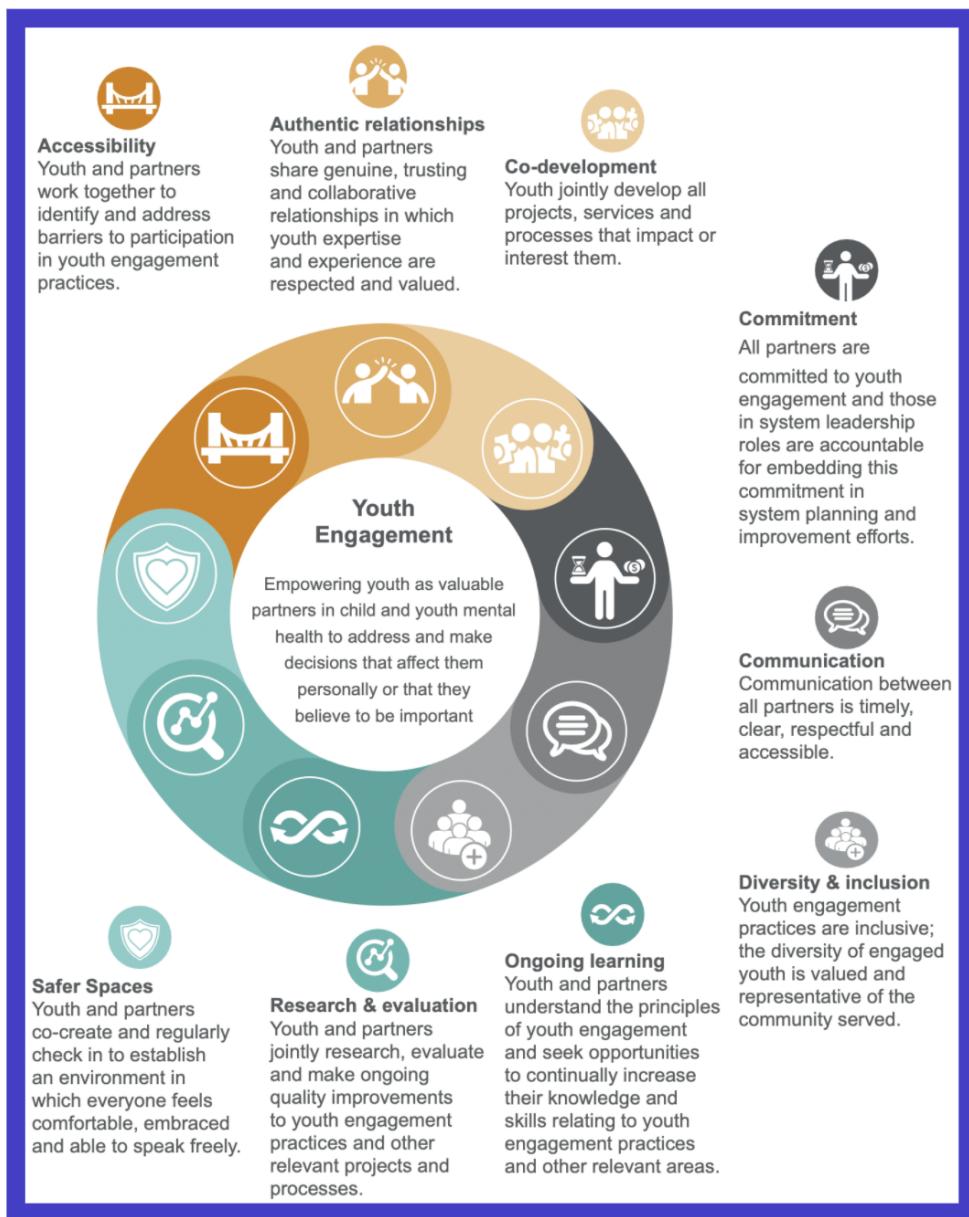


Figure 6 (Figure from Danesco et al, 2020)

Accessibility and adaptability are necessary values when engaging with populations such as young adults with substance use concerns. Practitioners and researchers must acknowledge the nuance of lived experience when facilitating engagement. Participants' wellness journeys may be ongoing and may affect their needs, interests, and capacity to engage at any point. Structuring engagement to be flexible and fluid – for example, by offering to use virtual platforms and asynchronous correspondence – can enhance the accessibility of engagement. Creating a safe(r) space can also provide an environment that assists with communication when various issues arise. This can be done through the language that is used and developing trust and rapport throughout the working relationship. Participants should feel comfortable approaching team leads when barriers arise. One way to do this is if the program or project leads avoid rigid timelines to make space for these personal or system barriers that may arise.

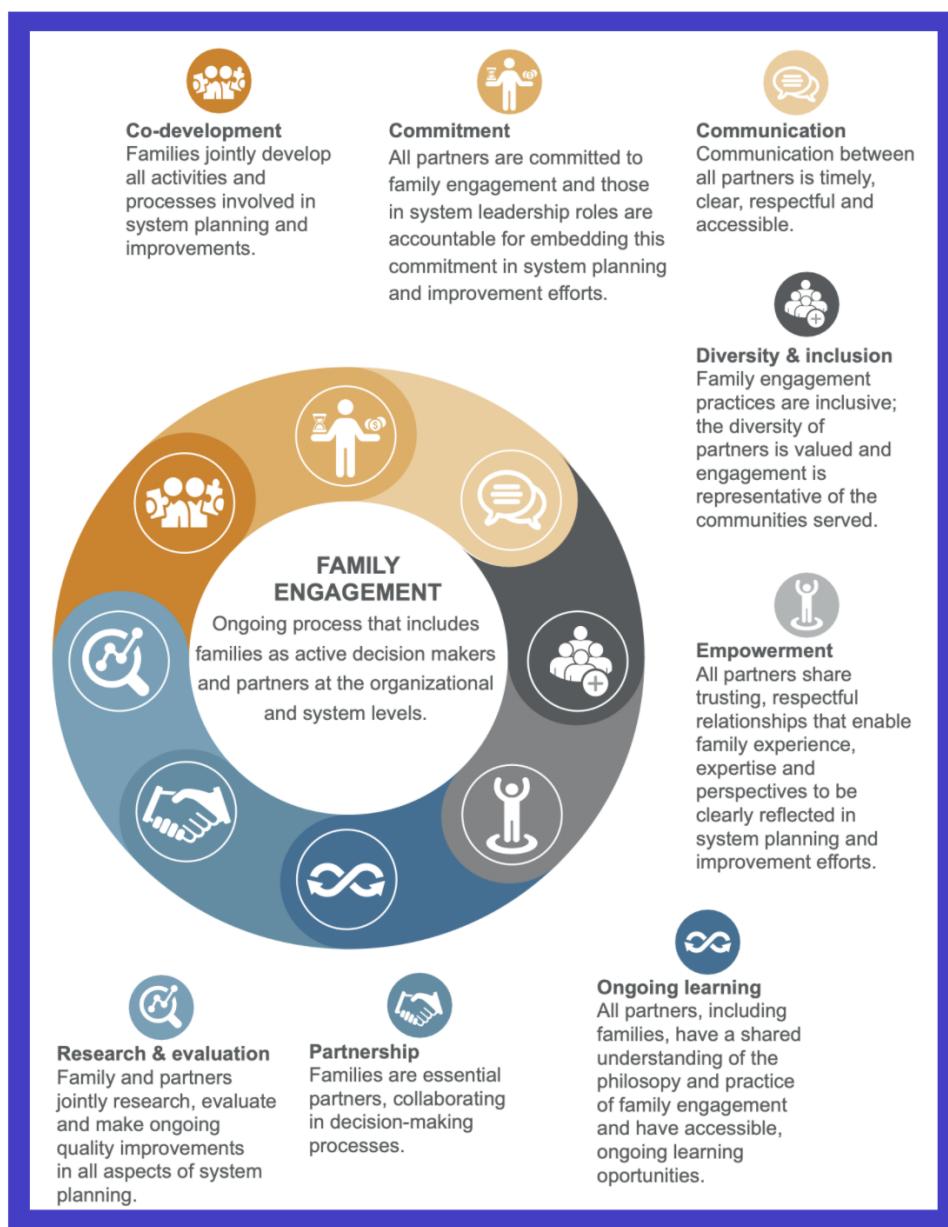


Figure 7 (Figure from Danesco et al, 2020)

Effective communication between all those involved in engagement can be supported by the values of transparency and flexibility. In our project, these values helped to increase our productivity and the completion of tasks despite a series of unexpected barriers we faced. We were able to reschedule team meetings whenever necessary, as we used a virtual platform (Zoom). We corresponded through email to ensure new meetings, schedules, and roles were arranged as needed. When we were presented with organizational barriers such as delays in contracting, Jillian was transparent about what was and was not possible. Our original timeline for this grant was adapted to meet each of our needs and capacities. It is important to understand that this could be a possibility when beginning engagement but if the team is able to work around conflict, tasks will still be completed.

***Values and Principles for Successful Engagement:***

- Stakeholders are compensated for their time/expertise
- Clear, timely communication and expectations
- Accessible and adaptable engagement practices
- Stakeholders have a right to be involved in their care
- Self-reflection and accountability
- Valuing experiential knowledge, reciprocal learning, and diverse perspectives

(Allemand et al., 2021; Canas, Lahance & Phipps, 2018)

### **Evaluating Engagement**

Evaluating your engagement practices is integral to facilitating meaningful and effective engagement. It is important to evaluate not only the outcomes of engagement for your program or project, but the process and experience of engagement for participants as well. Involving participants into the development of your evaluation tools or processes can help to ensure that the information you gather and what you do with it remains relevant and useful to your program/project and your population(s) of interest.

Below are a few examples of questions that practitioners and researchers may want to use when reflecting on their engagement practices at a personal and organizational level (Allemand et al., 2021; Canas, Lahance & Phipps, 2018; Hawke et al., 2019):

- How do your engagement practices reflect or relate to your personal and/or organizational mission and values?
- What opportunities or benefits are you providing those with whom you engage?
- When, where and how are you inviting stakeholders to participate in your engagement opportunities? Who are you missing or leaving behind?
- How do you support stakeholders before, during, and after engagement?
- How are social contexts such as the COVID-19 pandemic impacting your engagement practices, experiences, and outcomes?
- How does power show up in this situation or relationship? How does power affect what you are doing and who is involved? How can you disrupt the dynamics of power that are at play?

As we discussed above, there are many different ways to do engagement. When evaluating your engagement practices, a helpful goal might be to acknowledge your personal or organizational capacity for engagement in the here and now, while working toward building more meaningful and collaborative relationships and practices with those with whom you engage.

## Conclusion

Since its launch in February 2021, the YA-SUP has provided services to many youth and families in the Hamilton community. From the early development stage of the program, staff have sought to incorporate youth and family perspectives and experiences into the structure, delivery, and evaluation of the program. This project significantly improved their capacity to do so.

On behalf of youth, families, and staff at the YA-SUP, we extend our sincere appreciation to Frayme and the Great Big Stories initiative for making this research project possible. We are grateful for the opportunity to have learned with and from one another, and we look forward to continuing to do so to improve substance use treatment for youth and loved ones in our community.

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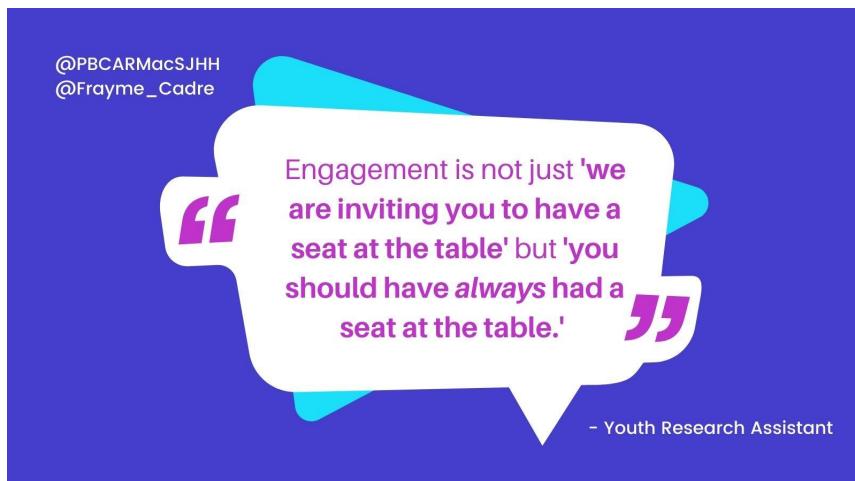
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## Resources and Opportunities

Below is a list of various resources that may be helpful for practitioners and organizations to begin to increase their capacity for engagement, to implement engagement into their work, or to enhance their current engagement practices.

- Frayme Groundbreakers is a national network of youth, caregivers, and advocates with lived experience of mental health and addiction concerns who can be recruited for engagement initiatives that support system/service improvement across Canada.
  - <https://frayme.ca/groundbreakers>
- The Knowledge Institute on Child and Youth Mental Health and Addictions developed quality standards for youth and family engagement, which describe the principles that contribute to high-quality engagement with youth and families in Ontario.
  - Youth Engagement quality standards:  
<https://www.cymha.ca/Modules/ResourceHub/?id=64172b4d-af0d-432a-8d66-880ba2292486>
  - Family Engagement quality standards:  
<https://www.cymha.ca/Modules/ResourceHub/?id=98d4c18b-e062-4ebb-b16d-1a9cc1c0ae80>
- The New Mentality (a program of Children's Mental Health Ontario) provides several resource documents, including the meaning and value of youth engagement in the mental health sector as well as youth engagement facilitation techniques.
  - <https://www.thenewmentality.ca/resources-for-members/>
- The Canadian Centre on Substance Use and Addiction published a paper that provides a series of guidelines for how to engage folks with lived experience of substance use and/or their loved ones in a meaningful and sustainable way.
  - <https://www.ccsa.ca/guidelines-partnering-people-lived-and-living-experience-substance-use-and-their-families-and>
- MINDyourMIND has a 'research' page on their website, which has a number of articles, documents, and research papers discussing various aspects of youth engagement, such as the value of youth voice in service or resource development.
  - <https://mindyourmind.ca/about/research>
- The Homeless Hub website provides this resource about building more meaningful, effective, and sustaining partnerships between youth and adults within the child and youth mental health system.
  - <https://www.homelesshub.ca/resource/ready-set-engage-building-effective-youth-adult-partnerships-stronger-child-and-youth-mental>
- The Government of Canada's website features a page on The Canadian Institutes of Health Research where they explore the engagement framework for the Strategy for Patient-Oriented Research (SPOR).
  - <https://cihr-irsc.gc.ca/e/48413.html>
- The Centre for Addiction and Mental Health (CAMH) created this guidebook that outlines the importance of youth engagement in research contexts and how to facilitate engagement in research projects across disciplines.
  - <https://foundrybc.ca/wp-content/uploads/2020/06/E.12-INNOVATE-Research-Youth-Engagement-Guidebook.pdf>

## Social Media Posts





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