

PICTURING PARTICIPATION



EXPLORING ENGAGEMENT IN HIV SERVICE PROVISION, PROGRAMMING AND CARE



EMPOWER



“I love seeing the candle *not* lit, but there’s times when I like to see the candle lit, because I know that person isn’t suffering anymore” – CASEY HOUSE CLIENT

This report is dedicated to all those we have lost in this project, in our families, and in our communities.

PROJECT DESCRIPTION

PICTURING PARTICIPATION is a community-based participatory research project that uses photography and other creative mediums to reflect on the meanings of engagement in the HIV sector. We are a team of community members, researchers, and service providers that partnered with three local organizations to do this work.

The principles *Nothing About Us, Without Us* and the *Greater Involvement of People Living with HIV/AIDS* stress the importance of meaningful inclusion of those living with, and most impacted by, HIV in all aspects of the HIV response. We wanted to document how these principles were being understood and operationalized in diverse community settings: a youth-led HIV prevention and harm reduction program, an AIDS service organization, and a community-based HIV hospital.

Over a period of 10 months, we held 20 interactive workshops (and 17 interviews) with 36 clients, participants, peer workers, volunteers (with lived experience) and staff members at three organizations. We gave everyone a camera and asked them to take pictures that answered the question: *what does engagement mean to you?*

Together, we visually represented, discussed, and analyzed how we understood engagement, and what it looks like in practice at three different sites. Engagement was broadly defined – from participating in programs; to influencing decision-making (within an organization, a program, or in one’s care); to co-leading programs or services.

We organized our key findings into seven themes identified here:



REFLECTING
ON JOURNEY



HONOURING
RELATIONSHIPS



ACCESSIBILITY
AND SUPPORT



ADVOCACY,
PEER LEADERSHIP
& SOCIAL JUSTICE



DIVERSITY AND
DIFFERENCE



GRIEF, LOSS
AND REMEMBRANCE



NON-PARTICIPATION

This report has been designed to help communities think more deeply about how to support and foster diverse forms of engagement for HIV programs and community-based organizations. We share representative photographs and quotes to help illustrate themes and inspire conversation.

Names in report were chosen by participants; many are pseudonyms.

SITES



Casey House is Canada's first and only stand-alone hospital for people living with HIV/AIDS. Casey House opened its doors to clients in 1988 in a house on Huntley street. In the Spring of 2017, Casey House moved into a modern new facility and expanded its services. Casey House continues to provide a continuum of care to those living with HIV. It offers 14-sub acute care beds, a day health program, and community outreach for people living with HIV.

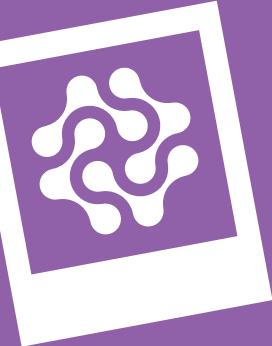
EMPOWER



Empower – a program at Parkdale Queen West Community Health Centre (PQWCHC), is a youth-led HIV prevention, sexual health and harm reduction program that uses the arts to train diverse youth to develop and deliver educational workshops in their own communities. As a partnership between PQWCHC and Gendering Adolescent AIDS Prevention (New College, University of Toronto) Empower was in operation from 2010-2016, and complemented other agency programs such as harm reduction supply distribution, HCV programming for people who use drugs, and street and party outreach.



Toronto People With AIDS Foundation (PWA) is the largest direct support service provider for people living with HIV/AIDS in Canada serving men, transmen, transwomen and women living with HIV/AIDS in Toronto. Its mission is to engage people living with HIV/AIDS in enhancing their health and well-being through practical and therapeutic support services and broader social change, and to inspire them to live into their dreams and discoveries. Founded by people living with HIV, PWA has a long-standing history of engaging people living with HIV/AIDS in all facets of the organization, including its volunteer program which includes over 100 volunteers who give their time and expertise each week.



WORKING TOGETHER: DIVERSITY AND DIFFERENCE

Honouring the differences that make up our communities is vitally important. In the sites we worked with (an ASO, a community-based HIV hospital, and a youth-led HIV prevention program), participants came from many different communities, and held intersecting identities associated with their gender, race, indigeneity, sexuality, ability, immigration experience, class, drug use experience, and health status. Participants spoke about what it meant to listen and learn from people who were not like them; to work across difference without erasing it; and to work in solidarity with each other and their communities.

“ There is a perception that PWA is a white gay men’s organization and I really, really bristle at that because I’ve been in this movement for really long time. . . . It pisses me off because there were women of color in this organization when it was being founded. There were straight men . . . there were lesbians. . . . You know to disappear all these people from our movement. . . . ”

— PWA VOLUNTEER

“ Like now we are going to have the Pride. . . . I am not gay, I am not a man, but I get involved. . . . So me being out there as a coloured woman, an African . . . And [I want] to remove that notion that . . . these activities are only for the Black people... Say like during the Black History month, only the Black people are there -- No, we don’t do that.”

— PWA PEER WORKER AND VOLUNTEER

“ So when I think of some of the feedback we get from our clients there’s that young substance user . . . And there is the older 50 years old, HIV ‘seen all my friends dying’ and they struggle to figure out how to share this space. But there’s actually an opportunity to figure out how to share this space and leverage one another’s kind of wisdom that they bring to the table.”

— CASEY HOUSE STAFF MEMBER

“ Is it ambitious to imagine youth programming that is all-encompassing of everything that we are? I think so, because I think by virtue of being all the different ways we come into programming, I think we’re already fragmented in many ways. I don’t think that programming can necessarily solve that but, maybe can alleviate it.”

— EMPOWER MENTOR



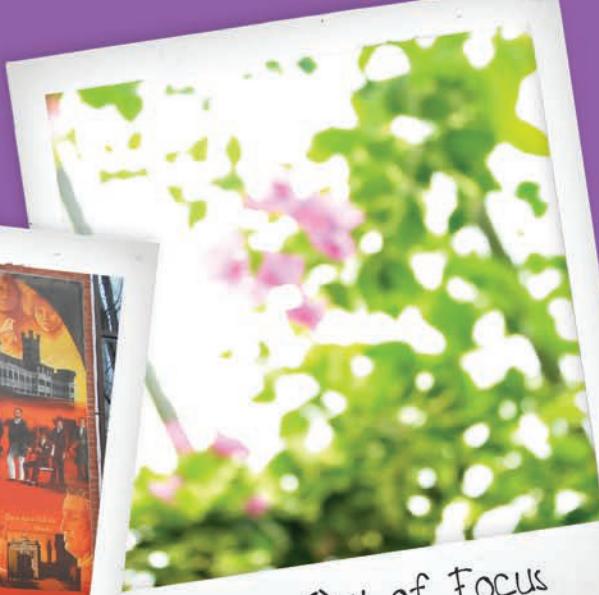
Unity - "Bill Nye"



Stolen Land
We Now Stand - Rainbow



Chair Mountain - Karen



Diaspora Out of Focus
- Tumaini



Rainbow Purse
- Two Bite Brownie

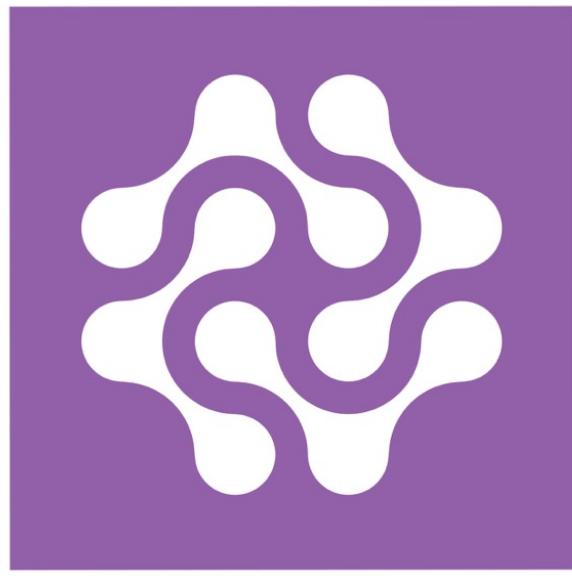
QUESTIONS TO CONSIDER:

- 1) How is diversity reflected within your organizational structures? How are the communities you serve reflected in decision-making roles in your organization?
- 2) How do organizations create spaces where we can work across differences without erasing them? What programmatic spaces or activities have you intentionally created within your organization for allyship and solidarity?
- 3) To be culturally-relevant and responsive to community needs, HIV and Harm Reduction programs are often designed for specific communities. As our participants taught us, this can unintentionally serve to fragment people's identities. How does your organization continue to build community-tailored programs and services while also recognizing people's many intersecting identities?



For more photos and narratives (by theme), please visit:

<https://pictureparticipation.wixsite.com/gallery>



Diversity and Difference

Diaspora Out of Focus

- Tumaini



Being a diaspora babe living on this land, by these waters, by way of economic/cultural imperialism, is a constant piecing together and refocusing. This photo is the fragmentation that is inevitable from being both other and away wherever I am, plus the space that surrounds it. Youth led HIV, sexual health and harm reduction programming is one creative use of fragmentation. The space between our perspective pieces coming together to create an ever refocusing whole moves away from the stagnant, monolith, one-size-fits-all model of programming.

Stolen Land We now Stand - Rainbow



I'm a transgender woman who stands next to my community of brothers and sisters. It is important to be mindful of our stolen land we walk on every morning, and how our children, brothers and sisters fight everyday for accessible food medical services, income and food to feed our loved ones. Healing from our nature - water and trees. When we lose a part of a nature or land, we lose our loved ones impacted from HIV/AIDS. How can we work as a community of mixed races, genders, orientations, and religions to decrease barriers towards our stolen land and protect our loved ones? There is no "i" in "team", but there is us in community. We are all born different and struggle through multiple barriers with the stolen land we live on. Let's always be mindful, stand high and remember who is impacted by what was once here but now stolen from us.

Rainbow Purse - 2 Bite Brownie



This photo really captures what Empower/Positive Youth Engagement is all about: inclusivity, colorful, fun, creative LGBTQ wildness!

Unity

-“Bill Nye the Science Guy”



Every tree that you can think of is in that the sculpture itself holds every tree that you can think of that is Indigenous to Canada anyways.

... Every tree is different. ... Well that's what it looks like when we all come together.

Sometimes it's a source of division, because you're taking in so much, but at the same time, to use your different angle, and a different view of maybe what angle you should be looking at things.

Chair Mountain

- Karen



Chair Mountain - an art exhibit at a downtown Toronto church speaks to engagement as it shows diversity and difference of materials and designs all interconnected. You can walk through and amongst the exhibit highlighting your capacity to be thoroughly engaged (inside) or view from the outside. True engagement is represented as remove any of the pieces and the whole is compromised.

Life At Casey House (Part 1)

- Rosy

This photo represents people coming from all different walks of life and finding a way to work together. The dogs in the first photo are playing and getting to know each other. In the second photo, they are standing together united.



Weapons of Destiny

- Chantal



As PWA family TREE I am strong. I stopped crying and started a new life moving forward.

I have become an activist, an advocate for others - people living with HIV/AIDS without discrimination of age, education, gender, sex orientation and religion. Raising my voice in defense of the social justice of peoples living with HIV/AIDs and those who are vulnerable.

This is my idea now.

Safe Place

- Dakarayi



The layout or set up of the waiting area is the first impression visitors see as they enter Toronto People With AIDS Foundation (PWA) and it reflects the values and personality of PWA. In the waiting area, guests help themselves with coffee, water, books and condoms. PWA offer a relaxed atmosphere for guests with appropriate music. Guests can engage in conversations and build friendships with others. It is also a space for guests can have their moments and reflect on their past, while others may express their emotions. Volunteers are there to ensure guests feel comfortable and welcome while they are waiting. PWA accommodates people from different backgrounds and provide space for children to play. The colors of the furniture in the waiting area is designed for individuals with health issues looking for a safe space where no one is judged. The blue colors of the furniture exhibits inner security and confidence for guests and promotes both physical and mental relaxation. The blue color ensures trust and responsibility, royalty and honesty, which is a true reflection of what PWA represent.

I am a Volunteer

- Yvette



As a volunteer I learn and use valuable new skills and, most importantly, use those skills to do things that matter. At PWA , I am part of the team that provides consistent services with lasting impact through interpersonal relationship with peers and volunteers through MIPA principle. Like most of the volunteers and staff. I speak more than one common and popular languages .I am proud to be part of PWA an agency that accommodates diversity in many ways including language use. I am always ready and looking forward to the day I volunteer at the Therapeutic Clinic. Through GIPA principle its an honor to display my name as the Volunteer on duty to serve even as I wear the badge as well.

“By dreaming every day, dreaming with our hands, dreaming with our minds . . . Things are just starting.”

– PWA VOLUNTEER

We believe that the HIV and Harm Reduction movement cannot exist without the insight, passion, and care of people living with and affected by these issues at the forefront. Whether your organization involves young people affected by HIV in larger prevention efforts, or people who use drugs in specific support services at AIDS Service Organizations, engaging community members must be done in ways that are **meaningful, sustainable** and **feasible**. We must not only dream it, but we must also do it.



RECOMMENDATIONS

1. Engagement has many different definitions. Organizational contexts and people's roles within them will shape how people understand engagement. Work with community members to define what engagement means at your organization, or within your program.
2. Consider the role of personal and organizational journey when designing peer-led programs, and spaces for individuals to consult on organizational change.
3. Honour relationships to self, to others, to your organization, and to the land. These relationships will form the backbone of your work together.
4. Ask community members what accessibility supports they need in order to be able to meaningfully consult on decisions and programs in your organization. In addition to tangible supports (transportation fare, connections to services, food, etc.), this may include support mechanisms to create inclusive programs across gender, race, sexuality, age, class, Indigeneity, drug use experience, and health status.
5. We arrive at organizations with different identities and experiences. These experiences are often linked to the privileges and oppressions we encounter in the world. Consider what it means to work across these differences in your work together.
6. Sometimes, participation can feel tokenistic. Create transparent and accountable dialogue and procedures around how peoples' input, decisions, and labour are being taken up and respected in your organization or program.
7. Reflect on the designation ‘peer.’ What does this mean within your organization? Consider who this label includes and excludes.
8. Create spaces for dialogue about the impact of loss and grief on community members and staff in your agency.
9. Consider whose voices are not at the table. Reflect on why this might be and where necessary, take action to address it.
10. Respect the importance of lived experience – in program and policy design; in peer-led initiatives and services; and in decisions affecting personal care. This may mean challenging deeply engrained organizational values.
11. Take careful note when people are not participating. This may provide valuable insight about how you consult people on important decisions, design inclusive peer-led programs or service delivery, and attend structurally to burn out.
12. Opening up decision-making processes to communities most affected by issues may change organizational plans, priorities or outcomes. Trust in this process – your organization or program will benefit in the long-run.



Bridging the Gap - Buttercup

ACKNOWLEDGEMENTS

Our workshops took place in Toronto (from the Mohawk word Tkaronto). This land is the territory of the Huron-Wendat and Petun First Nations, the Seneca, and most recently, the Mississaugas of the Credit River. Today, this meeting place is still home to many Indigenous people from across Turtle Island, and we are grateful to have an opportunity to build relationships on, and with this land – including with many individuals in our project.

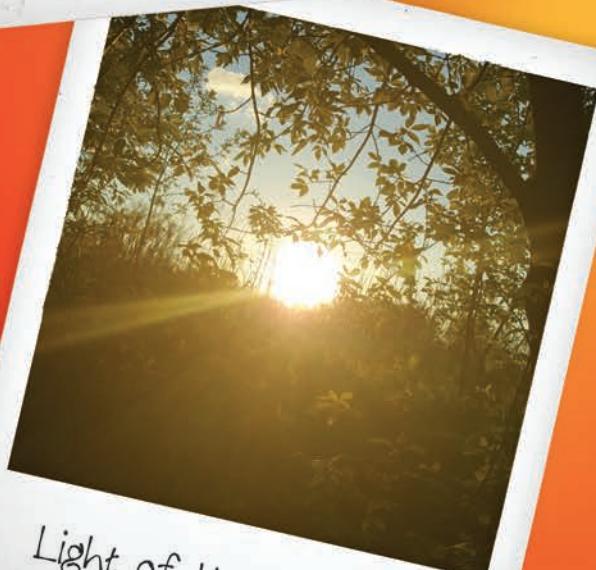
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Light of Hope - Nick

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