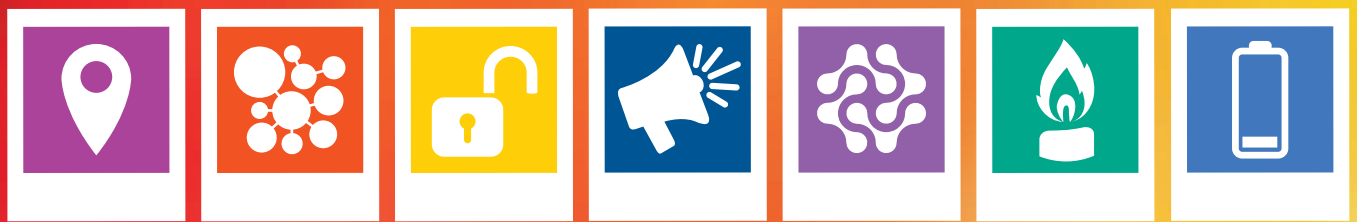


PICTURING PARTICIPATION



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 – 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.



GRIEF, LOSS AND REMEMBRANCE

Loss and grief were dominant themes throughout the research. Many participants spoke about: experiences of losing loved ones; facing personal mortality; and loss on a societal scale through the AIDS or overdose epidemics. Participants also shared their feelings of grief, sadness and frustration as a result of dealing with ongoing systemic oppression, or programming spaces that didn't allow them to show up with all facets of their identity. Loss, however, was not always considered negative. Many participants spoke to the importance of hope and new beginnings in the face of loss.

“ I rushed all the burials, I rushed them and I thought I can escape by making my own film for them. I was in my own denial, not grieving. . . . I don't think I have grieved yet still for my cousin since she passed away. . . . It's the lifestyle of growing up in the hood. . . . What do I do? Like how do I control the situation? . . . [This] could have been prevented by more cash, accessibility to drive to these communities to talk more suicide prevention, all of that. ”

– **EMPOWER PARTICIPANT**

“ Knowing how. . . the epidemic has consciously changed somebody, how strong the impact may be on them, you know? . . . He said that, 'I see the rooms where my friends died'. He said, 'you know instead, I look across the street and I see life, I see hope and I see forward movement... memories and feelings associated with these walls'. ”

– **CASEY HOUSE STAFF MEMBER**

“ Darkness is where you can regenerate first. And the first stage of grief, you have to go through to get to the second stage when you are marginalized or when you're first infected . . . It's OK to isolate a little bit. ”

– **PWA VOLUNTEER**



Untitled - Robert



Untitled - Marc



Untitled - Mama Ou



Untitled - Sunshine



#Hlope - Michael

QUESTIONS TO CONSIDER:

- 1) How has the HIV or overdose epidemic affected individuals (peer workers, participants/clients, staff, etc.) in your organization over time?
- 2) As our participants reminded us, loss sometimes creates rooms for (re-) generative possibilities. What strategies does your organization have for supporting community members and staff during times of loss?
- 3) Loss takes many forms. How might your organization consider larger systems of oppression (racism, transphobia, stigma against drug users, etc.) when thinking about loss?



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

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



Grief, Loss
and Remembrance

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.

Seeds of our Labor

- Buttercup



As an advocate that is committed to raising awareness to issues that impact marginalized youth; my understanding of engagement would be incomplete if I didn't think about the people who are actively working towards social change. I thought about some of the personal challenges. Like a rose that is so beautiful and vibrant in the beginning. As time progresses, without proper care and without being grounded, it wilts. The wilting resonates with my feelings of being burnt out; feelings of distress and agony that often comes along with doing this community work and challenging social norms. Ideally we need sustainable supports so folks do not become burnt out and can continue to work progressively in HIV prevention, sexual health and harm reduction programs.

Untitled

- Marc



The photo represents our collective losses and grief we have shared, by both the client and the staff at ASOs.

We honour those losses by remembering them. We all mourn these passings.

The future of engagement involves learning and listening, whether quiet talks at the beach up to grand town hall meetings.

Untitled

- Robert



I love seeing the candle not lit but there's times when I like to see the candle lit because I know the person isn't suffering anymore. So, there's been some sad moments at that chair for me, you know and it's the first thing I do, is always go to the book when I come in. I engage the book, I guess. For me, that's Casey House right there.

.... People used to come here to die, and people are leaving out the front door now....

Untitled

- Ma Ma Oo



Too much emotion is go in there, in the eye. How when you smile me I show you for your inside. ...The sick people feeling like that. Inside, too much, too much... hard is go in there. Go in to face.

This mean is I always coming here for the learning session...Talking, games, something like that. ... You need the same people holding, hug you, right? The same one. We were here. We were coming in program. Casey House program, we coming not another people...share together, happy together... Open people, you no fight like this.

Untitled

- Marc



I feel this photo has a duality, strength and fragility. Our worlds were turned upside down. Client engagement helps us through the adjustments we need to make.

Untitled

- Sunshine

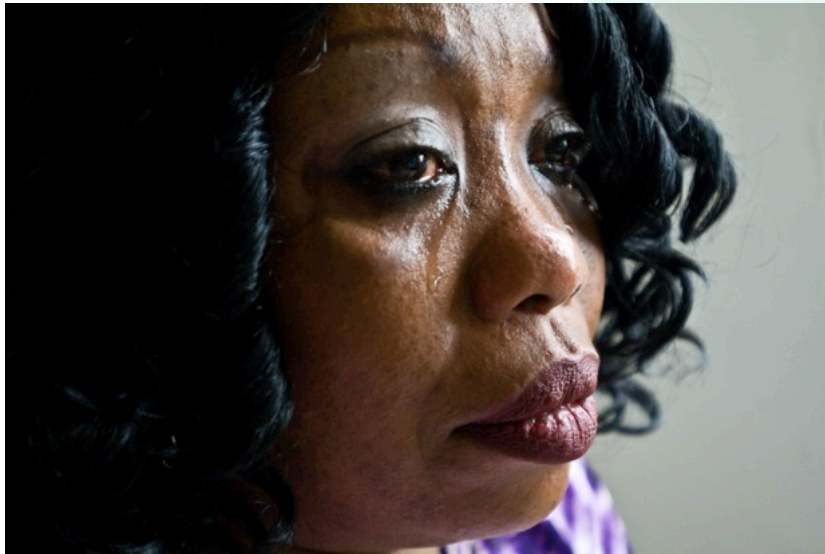


I like the fact that they light the candle in memory of the person who passed, and I think it's really important to remember them and always have them in your hearts and the lady who founded Casey House is there too ... and she's an important person.

So, I think that area is very important. ... If you don't get to say bye to the person, at least you get to write how you feel, and give condolences to the family and how you felt about them. And the candle is lit in memory of them. It's something, it's something you did. It's important to you to always remember them.

Million Tears of Life

- Chantal



Millions Tears of life because of stigma & discrimination I faced during genocide 1994 in Rwanda as victim of rape and survivor of HIV.

I was walking like a dead body, but after I found PWA as a 'family for everybody' I came to ask their HAND in emotional, mental, physical, and spiritual support. From that time, I became a normal human being and started to help other women and girls who are HIV positive to get out of isolation, stigma, and discrimination and make a better life.

This photo was initially taken as part of a project that aimed to fight violence against women.

Keep the Fire Burning

- Dwight



I chose this picture because it made me think of what I went through when I found out I was HIV positive. To me it represents the fire we all have inside, burning strong to help us get along in life. Sometimes we lose ourselves in issues around our health and we tend not to look after ourselves.

This made me think of the fire inside me that kept me going through all the years that I fought tooth and nail to keep myself healthy and alive.

If it wasn't for my stubbornness and will to keep going....I would for sure not be here today.

Seeing the Colours of Life through the Darkness - Dwight



I chose this photo because I felt that a lot of us with HIV or AIDS at some point in their life tend to live in the darkness. I spent many years travelling the road least taken....ending up in some very dark places, doing some very dark things.

When editing this photo I saw the beautiful colours that surround us every day of our lives. Also, when looking out from the darkness, seeing all the colours and things in life going on around us, it helped me come out of my shell and seek out the help that I needed to get where I am today.

Feelings of helplessness, aloneness, and hopeless at times kept me in my dark places. Once I started looking out from the darkness and seeing what was available to me to help me get better and getting involved in my community, I was able to come out of the darkness and see all the beautiful things right in front of me....I then wanted to come out of the darkness and get better.

“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.

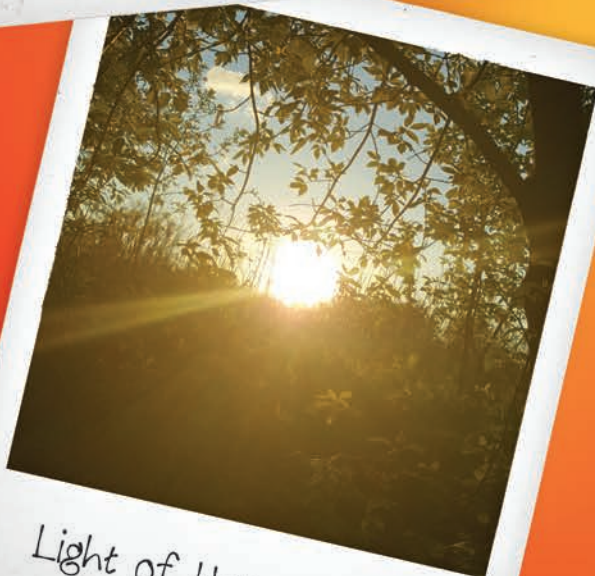


RECOMMENDATIONS

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



Light of Hope - Nick

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.

A warm thank you to all the participants who: contributed to our project, and helped us learn and grow; and to all the co-investigators, and research assistants who supported the project. A special thank you to community report working group members, and staff at the three sites who provided such a warm welcome.

Please cite this document:

Sarah Switzer; Sarah Flicker; Soo Chan Caruosone; Alex McClelland; Tatiana Ferguson; Neil Herelle; Derek Yee; Shelby Kennedy; Bahlelisiwe Luhlanga; Kamilah Apong; Amber Corrick; Charlene Grant Stuart; Anne Marie DiCenso; Karen de Prinse; Adrian Guta; Suzanne Paddock; Carol Strike. (2017). *Picturing Participation: Exploring Engagement in HIV Service Provision, Programming and Care*. [Community Report]. Toronto.

Graphic Design: Ryan White, R.G.D., Mixtape Branding

Funding support generously provided by CANFAR; REACH 2.0; and York University.

© All rights reserved. Picturing Participation (2017). Material cannot be adapted without explicit written consent from lead author.

