

PICTURING PARTICIPATION



EXPLORING ENGAGEMENT
IN HIV SERVICE PROVISION,
PROGRAMMING AND CARE



“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.



REFLECTING ON JOURNEY

What's your story? How did you arrive here? Many participants depicted journeys, growth, and transitions in their photographs and narratives. In some cases, they were evoking literal migrations across continents, or across cities travelling to organizations. In others, they were referencing metaphorical roads towards healing, acceptance or personal growth. Participants also reflected on organizational change. For some, personal transformation was connected to, and intersected with, organizational change.

Although journey was important at all sites, what this looked like at each organization was very different. At Empower, participants captured images of plants and flowers in many stages (seeding, growing, blooming and decaying) to symbolize growth. They recounted how systemic barriers inhibited them from reaching their full potential, and spoke evocatively to the importance of inclusive spaces where they could bring their whole selves to the table. At PWA, participants photographed paths, and reflected on how PWA has helped them along in reaching their goals and dreams. At Casey House, participants referenced the construction of the new facility as a metaphor for re-building hope around health, and their desire to 'give back.' Transitioning from an AIDS hospice to a small community-based hospital, Casey House is now a place where people try to get well, be comfortable, or stabilize their health.

“ I chose, you know, to take a different path when I was diagnosed with HIV. . . . I am not going to let HIV [stop] me from fulfilling my dreams. . . . You can see it's here and it's up to us. You know, which way do we wanna walk? ”

– PWA VOLUNTEER

“ It's living, it's not dying. You walk through the door – it's open space again. It's a new beginning over there. ”

– CASEY HOUSE CLIENT

“ I found my voice . . . I feel that's growth, finding your voice or reclaiming your voice. . . . I think that the more you give yourself permission to shine, the more you give others permission to do that as well. ”

– EMPOWER PARTICIPANT



Open Road, Open Dialogue
- Andra



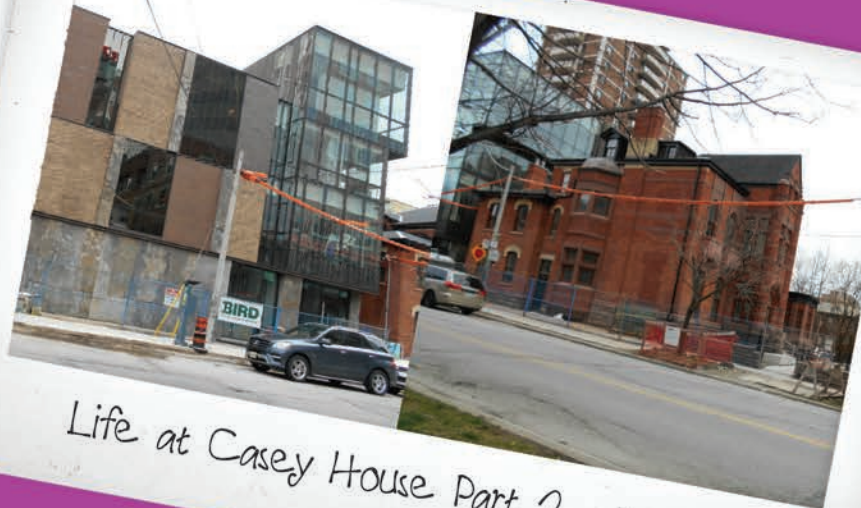
Isolation - Alberto



My Journey Starts Here
- Graham



Journey Back - Khalil



Life at Casey House Part 2 - Rosy

QUESTIONS TO CONSIDER:

- 1) In our project, peoples' motivations for engaging in programs or decision-making was often connected to personal or organizational journey. How might leveraging the metaphor of journey help your organization engage community members in decisions about organizations, in peer-led programs, or their care?
- 2) Many participants spoke about their organization's journey to intentionally become more inclusive to broader communities living with, and affected by, HIV. What's your organizational story? How do you share it? Do communities have the resources and power within your agency to intentionally shape it? How do the personal journeys of community members you serve influence the services and programs you provide?



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

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



Journey

The Emptiness

- Josh



I chose this photo mainly in relation to me because I went to this school growing up in the big city. It reminded me of the isolation and stigma centered around HIV/AIDS. The loneliness of the court represents the real people who will be there for you through the long process.

Emerging

- 2 Bite Brownie



This photo captures the growth that comes with finding your own voice in Empower or other supportive youth program. Emerging more authentically in someone we're always meant to be.

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.

Growth

- Lydia



Seeds drop into an empty pot.
Left and forgotten. Dry and cold.
Panicking while being transported.
Temperatures changing and severe.
Mist of water, warm light, and the cold
window pane.

Wait...

Sprout. Quickly growing, when left in peace.
Given food and light.
Respectfully left on its own.
And given time to settle.

Opening Doors

- Chris



Participation in Empower provided me with skills to become more involved in the community. This interactive drawing was created when I had the opportunity to take part in the planning of a conference on sex, substances and safety. The sticky notes attached by conference attendees reflect the bouquet of flowers in my Orchids photo visually and symbolically. This was the first time I enjoyed drawing in a long time because I knew it served a direct purpose and allowed me to feel more engaged with the community.

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.



Life at Casey House (Part 2)

- Rosy

This represents the new beginnings that are going to come along with the new Casey House. It also represents a more personal connection to a lot of the clients here as we used to hang out over there before construction began.



Untitled

- Brenda



That's the door...when I come through I know there's friendly faces there. And that's the heart, and the new building.

The door is never locked, you're never locked out. There's usually someone smiling. When you walk past the desk, they have all the information you need, you don't need to go searching for something. The desk is there ready for you to sign in. It's all so simple.

People have to walk through the door... so when you walk through the door, then you can walk back out the door, to the front, then there's a nice porch. I like the peacefulness of looking out there.

It's living, its not dying, you walking through the door. It's open space again and there's a new beginning over there.

Gatekeeper

- DKO



Peer engagement.

As a gatekeeper, you lead the way, and show people how to open the door.

The skills and values learned during capacity building at the Positive Leadership Development Institute (PLDI); the Ethno-racial Treatment Support Network (ETSN); and Turning to One Another (TTOA) show us how to be an effective leader while giving back to the community.

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

- Marc

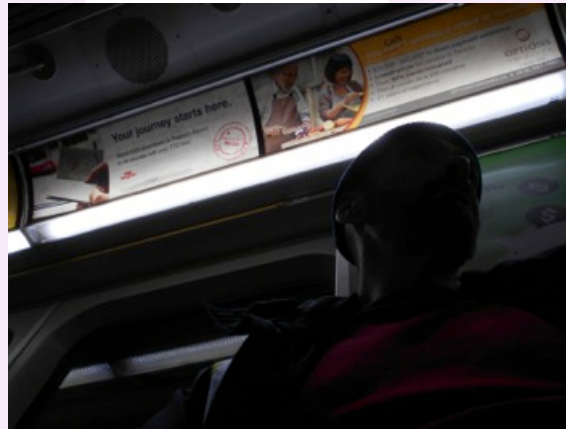


The photo represents our collective losses and grief we have shared, by both the client and the staff at ASOs. We honour those losses by remembering them. We all mourn these passings.

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

My Journey Starts Here

-Graham



Untitled

- Robert



This place was all boarded up and they were trying to come up with a slogan for Casey House, and you notice on the banner here they have a heart, so when they tore all the boardings off this house, low and behold, there was the heart. I wouldn't say coming in it is a welcoming thing, but leaving it is a welcoming thing because you don't notice it coming in sick, people come in on a stretcher and stuff like that. ... This is where I want to be when I pass away. It's loving, the heart says it all.

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....

Open Road, Open Dialogue

- Andra



Client engagement is a journey that we navigate without the help of a roadmap. The empty and diverging highways in this photo remind me that there are many routes to engaging clients in their care, but that promoting open and honest lines of communication - like this open road - is always a good place to start.

Untitled

- Amanda



This photo means many things to me, letting some light in, opening up, being able to view something from a different perspective, everything I try to do when I am engaging our clients.

Untitled

- Joanne



If we don't ride in the right lane we will veer off track quickly and not be a reflection of those we serve

Untitled

- Joanne



Our organization should be a reflection of the people it serves, this is at the foundation or roots of our philosophy. Engagement can be challenging and as we work together, it may be 'muddy' but the joy comes working through those muddy times and light at the end causing the reflection.

The Commitment

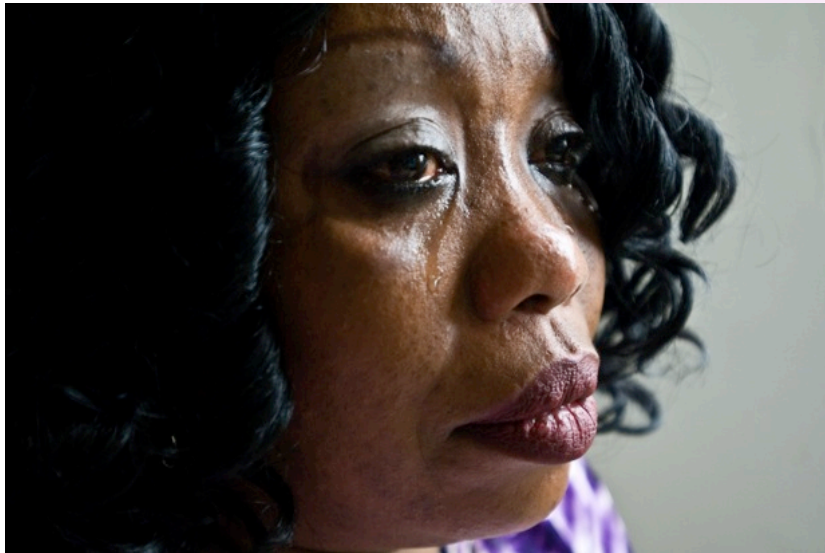
- Shona



For most of us, half the battle is getting there. We all have good intentions for our health but making the commitment to 'show up' for our minds and bodies sometimes proves to be the hardest part of treatment.

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.

Weapons of Destiny

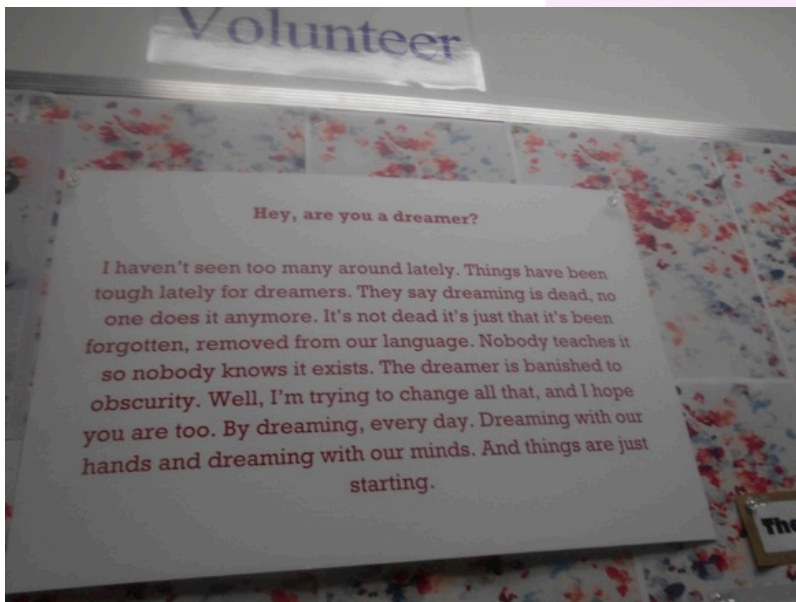
- Chantal



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.

Community Engagement

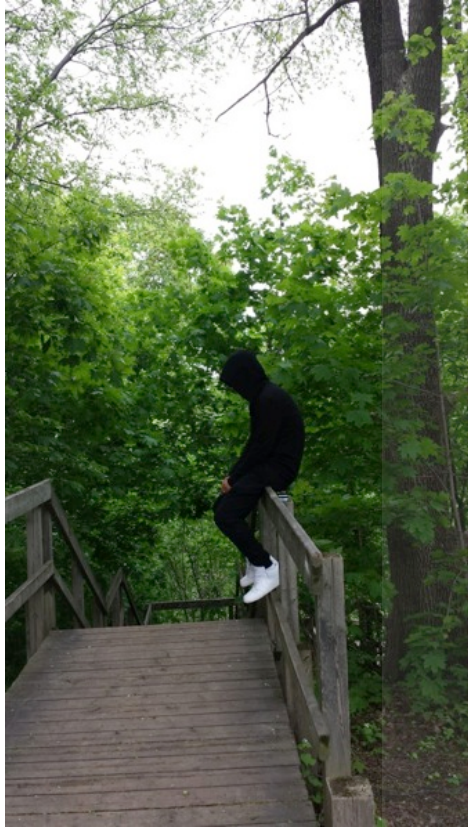
- Dakarayi



A picture paints a thousands words. In this picture, it shows volunteer engagement at PWA. The dots around the picture are the people who come to access services at PWA, who come with different needs. Some come for appointments, some come to get food for nourishment, some come for harm reduction, and some for therapeutic care and some are newly diagnosed clients. The new clients when the walk on the hallway, they see the dreamers quote, which motivates them to believe in themselves. It is moment to say dry bones live again, build confidence, self-esteem and overcome stigma. A quote on the picture is a self-realization of the beginning of new life with a purpose to make impact, find meaning, and live up to their full potential as human beings as well as achieving happiness and a fulfilled life.

Isolation

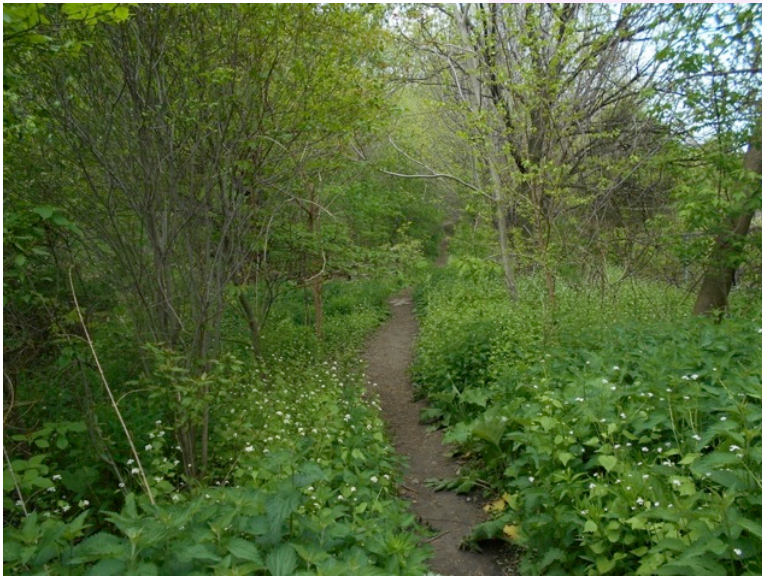
- Alberto



Sitting down for too long can prevent you from missing out in life. Don't dwell on the past, focus on the present to make a better future for yourself.

The Path

- Alberto



Life is like a path, you
decide which way to go.

Journey Back

- Khalil



My involvement with PWA has taken me from isolation to a welcoming space of acceptance, services, hope, friendship and a new lease on life. Ready to take on the World Again.

A Dark Day?

- Raul



In a dark day of life I seek for help, and found many possibilities that show me many ways, and above all, I could walk freely in a path because life continues even if it's a dark day.

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.

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.

“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.

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.

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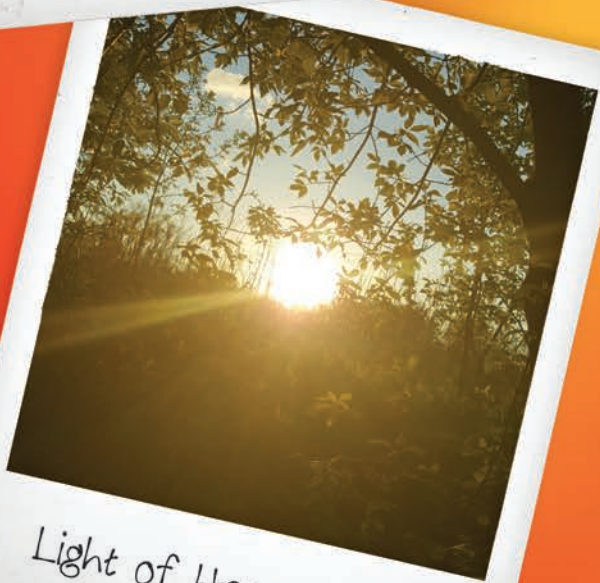
Sarah Switzer; Sarah Flicker; Soo Chan Caruosone; Alex McClelland; Tatiana Ferguson; Neil Herelle; Derek Yee; Shelby Kennedy; Bahlelisiwe Luhlanga; Kamilah Apong; Amber Corrdick; Charlene Grant Stuart; Anne Marie DiCenso; Karen de Prinse; Adrian Guta; Suzanne Paddock; Carol Strike. (2017). *Picturing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

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Bridging the Gap - Buttercup



Light of Hope - Nick

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