



Realize

ANNUAL REPORT 2020 - 2021

Reset | Reimagine | Rebuild

realize

FOSTERING
POSITIVE CHANGE
FOR PEOPLE LIVING
WITH HIV AND OTHER
EPISODIC DISABILITIES

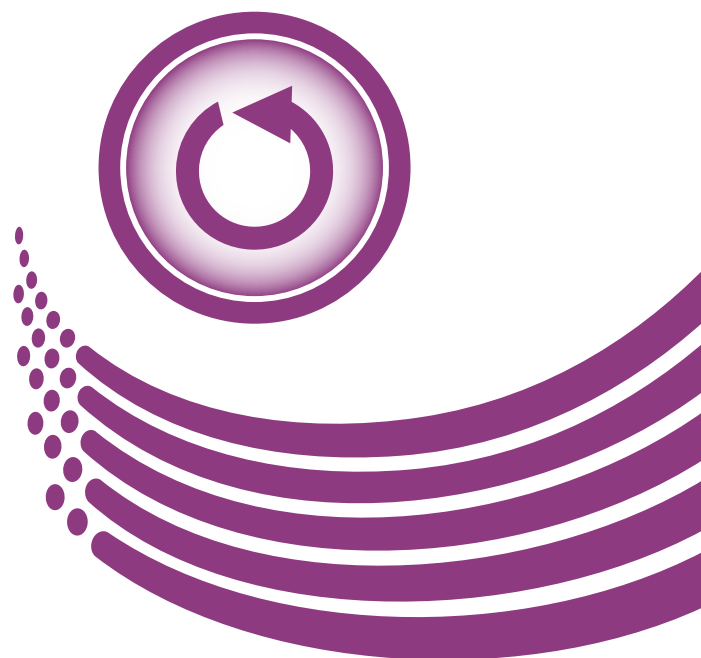
Land Acknowledgement

Realize acknowledges this land on which we work. For thousands of years, Turtle Island has been the territory of many First Nations, Inuit, and Métis Peoples.

Today, this place we call Canada, is still the home to many Indigenous peoples and we are grateful to have the opportunity to live and work on this land.

We also acknowledge the many other peoples who have contributed to this place we now call home. We want to acknowledge the many traditions and cultural backgrounds that are represented.

You, your families, and your ancestors, all have roles to play in making this space an inclusive and welcoming one and for that, all of us at **Realize** say, Thank You!



About Realize

Realize is the leading national, charitable, organization working to improve the health and well-being of people living with HIV and other episodic disabilities, across their lifespans, through integrated research, education, policy, and practice (www.realizecanada.org).

Realize promotes innovation and excellence in rehabilitation in the context of HIV and other episodic disabilities with a primary focus on healthy aging, equitable access to rehabilitation and meaningful social inclusion. **Realize** is multi-sectoral and multi-disciplinary in its membership and activities. Members come from across Canada, as well as internationally, and include people living with HIV and other chronic conditions, members of community-based HIV and disability organizations, national associations of health professionals, government agencies, private businesses, universities, and the employment sector.

The year covered by this Annual Report was shaped by the COVID-19 pandemic. The pandemic, and the global effort to contain and overcome it, affected the communities we serve deeply and required us to reimagine our work. **Realize** is dedicated to bringing people and communities together to focus on quality of life for people living with HIV and other episodic disabilities – work that became even more important amidst the uncertainty and disruption of COVID-19.

We can only make this happen with your help!

- Become a **Realize** advocate and share our work with the people you know.
- Become a **Realize** member – see our website at www.realizecanada.org.
- [Make a donation](#) – you can make a one-time gift or become a monthly donor, an easy and affordable way to give that helps **Realize** plan more effectively.



Our Reach

Realize has individual and organizational members across Canada, and strong partnerships internationally. Our Board membership is diverse and includes health care and other professionals, as well as activists from the HIV and disability communities. We convene or play a vital role in many coalitions that focus on issues of critical concern to people living with HIV and other episodic disabilities – including our role as the Secretariat of the National Coordinating Committee on HIV and Aging, as the convening organization for the Episodic Disabilities Forum and as the founding organization of the National Community Advisory Group on optimal health and wellbeing in the HIV community.

Realize has a national constituency of over 3,400 people we reach annually through our courses, forums, and think tanks who apply their learnings working within a wide range of community-based organizations, professional associations, care centres, clinics, and research groups.

Realize

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Established 1998, Incorporated 2002,
Charitable Registration number 85699 5535 RR0001

Our Thanks

The impact of **Realize**'s work transcends the size of our organization because of the expertise and dedication of our Board of Directors, staff, members, volunteers, partners, and donors. Thank you.

We particularly thank the Public Health Agency of Canada, Employment and Social Development Canada, Gilead Canada, Canadian Institutes for Health Research, National Research Council Canada, and the Ontario HIV Treatment Network for their generous support.

Realize continues to attract first rate, post-secondary education practicum students. In Fiscal Year 2020-2021, Asma Muhammad, Ayesha Khan, Jacob Mathew, and Nicole Truman were invaluable members of the **Realize** team.



Message from the Co-Chairs

In April 2020, as the 12 months covered in this Annual Report began, we had just begun to adapt to life during the COVID-19 pandemic. It affected the way all of us live, work, learn, interact, and come together as communities and more broadly in society to get things done. It was life-altering for everyone, but many of the pressing challenges of living in COVID times were all too familiar to people in the HIV and disability communities. Older adults were at great risk and yet our systems of support across Canada were inadequate. People's livelihoods were threatened and opportunities to make a living disappeared. Social isolation and marginalization increased with physical and mental health consequences.

Realize's work continued to focus on all of these issues critical to people living with HIV and other episodic disabilities across the country. We were determined to find ways to keep moving forward. It was important to reset, reimagine and rebuild.

In adapting during COVID-19, it was crucial to the **Realize** team that we not just "make do", but that our new ways of working create real opportunities for meaningful community engagement and momentum for change.

Our Annual Forum this past year (reimagined and moved from fall 2020 to winter 2021) was a collaborative initiative with the CAN LhIVE WELL research team. Titled *Living Your Best Life* (LYBL), it was split into two phases to better reflect and amplify the voices of people with different experiences of living with HIV, with the goal of defining optimal health and wellbeing. In the first phase, five small-group community consultations were held in both English and French, facilitated by community members engaged specifically for the project. Their findings were then presented during the



Gayle Restall



Paul Curwin

second phase at the larger Forum that was held virtually over four days. The response was terrific with participants joining from all corners of the country. **There is strong agreement that living well with HIV requires much more than medical management, and growing momentum to make optimal health and well-being a priority in Canada's HIV response.**

The failure of elder care supports across Canada to protect our aging population has been one of the wake-up calls of the COVID-19 pandemic. For people living and aging with HIV there was added uncertainty. Over the year of this Report, **Realize** and a team of dedicated community-based researchers advanced a ground-breaking study called PANACHE (*Preferences and Needs for Aging Care among HIV-positive Elderly people*) to make sense of the experiences of older adults living with HIV and brainstorm solutions to the challenges they face. We are immensely proud of the way we approached this work, its outcomes, and its potential to influence policy discussions and better practices.

Livelihood and employment concerns were top of mind for many people during the disruption of the COVID-19 pandemic. **For people living with**

episodic disabilities, finding, and keeping work is a familiar worry that the pandemic amplified. People living with disabilities were among the communities left most vulnerable by loss of employment. Ironically, in a rare, positive, COVID-related outcome, the need to shift ways of working (for instance, many people across the country suddenly working from home), prompted a much wider discussion about workplace accommodation.

In March 2021, Realize convened the first ever, virtual National Summit on Episodic Disabilities and Employment. The response to the three-day event was extraordinary. With presentations from people with lived experience, researchers, business and union leaders, top government officials, and human resource experts, the Summit prompted lively discussion and new collaborations towards the creation of a National Action Plan on Episodic Disabilities and Employment. **Realize** has also experienced increased interest in our training sessions and online courses on episodic disabilities in the workplace and workplace accommodation as employers begin to think about what the future of work will be like in their organizations.

In the process of **Realize's** ongoing dialogues across the HIV and disability sectors, many important concerns were raised. Since June 2020, to help keep communities moving forward on these concerns during the disruption of the pandemic, **Realize** has been hosting a series of virtual town halls under the banner *Real Talk with Realize*. Topics have covered: race and disability in Canada, racial justice in the HIV movement, challenging ageism in the HIV community, working towards barrier-free recruitment, income security and COVID-19, advance care planning, and many other key topics. We're grateful to the inspired presenters and partners who have collaborated with us in these town halls. The response has been energizing.

These are just a few examples of the wide-ranging work **Realize** has accomplished and the issues we have helped build momentum on during 2020-21. As the co-chairs of the Board, we have been inspired by the expertise, energy, and creativity of the **Realize** team and that of our valued members, partners, volunteers, and funders. As a Board we have also been diligent that we 'walk the talk' when it comes to Inclusion, Diversity, Equity and Accessibility Leading to belonging (IDEAL). We have formed an IDEAL sub-committee to inform both our internal policies and procedures, but most importantly, our approach to program conceptualization, implementation, monitoring and evaluation. In this, and all our work, we are driven by our goal to foster positive change for all people living with HIV and other episodic disabilities in Canada.

Gayle Restall and Paul Curwin,
Co-Chairs,
Board of Directors



Realize Programs

Realize and COVID-19

COVID-19 dominated the twelve months covered by this Annual Report (April 2020 to March 2021), and forced everyone (the public, government, our partners, funders, members, volunteers and staff) to reimagine ways of doing things. We raced to adapt and find new ways of working, connecting, and supporting each other, while coping with social isolation. **The pandemic exposed inequities and outright neglect in our social systems and how those systems (and policies) have failed older adults and others in long-term care, people living with disabilities, racialized communities, lower income families and those with precarious employment.** There are so many lessons to be learned, some of which the HIV and disability communities know well and have been working to address, and others where we all need to do better.

In our convening and knowledge-building role, **Realize** was well-placed to carry out our work in the virtual world, but we acknowledge that this was more difficult for our partners that deliver frontline services. **The needs and social support landscape for people living with HIV and with episodic disabilities changed during COVID-19 and is likely to look different moving forward.** Though everyone is eager to get to a post-COVID world, the pandemic's impacts on mental health and the effects of long-COVID, for instance, are likely to be with us for years to come. Long-COVID is increasingly being recognized as an episodic disability with the potential for long-term, personal life impacts for those affected. **Realize's** study of these potential impacts on employment and workplace accommodations – [Pandemic Pandora's Box](#) – is available on our website.

In the program reports that follow, you can read how **Realize** reset our ongoing work on healthy aging, equitable access to rehabilitation, optimal health and wellbeing, and meaningful social inclusion during the year. **Amongst the challenges of work during COVID-19, however, new opportunities also opened-up.** Focusing our engagement with people in the HIV and disability communities in the virtual world broadened our ability to engage people across the country and in more remote communities. The need to rethink ways of working forced by the pandemic, across employment sectors, has lessened some of the stigma that existed about workplace accommodations, with the potential to benefit many people living and working with HIV and other episodic disabilities. We see this in the increased numbers of employers and human resource professionals interested in our courses and training on workplace accommodation. In the policy realm, there appears to be new energy to understand how people's intersecting identities and other social determinants of health affect personal and community well-being – key components of our understanding of optimal health.

At **Realize**, we're determined to take the lessons learned in 2020-21 and help figure out how we build back better than before in the HIV and episodic disability communities.



Healthy Aging

Realize promotes healthy aging with episodic disabilities including HIV and other chronic conditions by leading coordinated efforts in bridging new and strengthening existing partnerships, across clinical, research, community, and policy domains in chronic disease, aging and rehabilitation.

During the uncertainty of the COVID-19 pandemic, Realize's commitment to issues of HIV, aging and older adulthood never wavered despite the need to approach our relationship-building and collaborative activities in virtual ways. We continued to lead a national conversation on the impact of ageism on older adults living with and vulnerable to HIV through our Real Talk with **Realize** event, *My Age Does Not Define Me*.

The knowledge co-creation phase of the OHTN-funded Preferences and Needs for Aging Care among HIV-positive Elderly people in Ontario (PANACHE Ontario) study culminated in an engaging, inclusive analysis process. Members of the large community-based research team, including people aging with HIV, clinicians, and community-based researchers, met in cyberspace over a dozen times to make sense of the living experiences of over 70 older adults living with HIV and brainstorm solutions to the challenges they face. We are immensely proud of the way we approached this work – in meaningful collaboration with community - and its outcomes. **PANACHE Ontario represents a steppingstone**



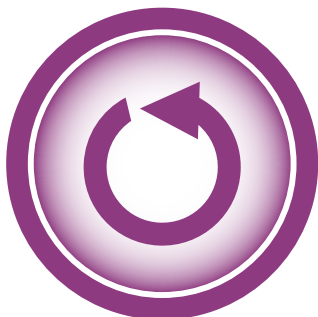
*Illustrations by Caroline Ellis/Brilliance Mastery

toward a national survey on the care needs and preferences of older people living with HIV. It also has the potential to influence policy and practice change for the better at the provincial level.

[You can read the PANACHE report on the **Realize** website.](#)

Our Think Tank, an annual cornerstone in **Realize's** calendar of interactive events, was reimagined as six focused, small-group consultations co-hosted by the magnificent Jade Elektra/DJ Relentless. We exchanged ideas with diverse older adults living with HIV, community-based researchers, program evaluators and implementation scientists, HIV clinician-researchers and gerontologists from across Canada, zeroing in on priority areas for ongoing research in HIV, aging and older adulthood and identifying facilitators and barriers to making this research happen. **These conversations will inform the release of a Pan-Canadian Research Agenda on HIV, Aging and Older Adulthood, a road map for advocates, researchers and funders on the findings needed to inform evidence-based care and public policy for the growing number of people living with HIV in Canada who are approaching their senior years.**

We led and collaborated on educational initiatives for post-secondary students and front-line service providers in community-based HIV organizations, building on their knowledge, skills, and capacity to deliver high-quality care and support to older adults living with HIV. Particularly salient during the turbulence of the COVID-19 pandemic was our workshop *Tolerating Uncertainty: Supporting People Growing Older with HIV*.



None of this would have been possible without the wisdom of a significant number of people who shared their lived experiences of aging with HIV, eloquently and unreservedly.

Community Voice

Brenda Gagnier is a woman in her 70s living with HIV in Ontario. She played an active role in Realize's PANACHE Ontario study and in Living Your Best Life, our Annual Forum.



"My name is Brenda Gagnier and I have been living and aging with HIV for 31 years. I became a Peer Research Associate or PRA in 2012 with the OHTN (Ontario HIV Treatment Network), and in 2013, I joined the CHIWOS (Canadian HIV Women's Sexual & Reproductive Health Cohort Study) PRA team. This fall I will be participating in a virtual training and clinician mentoring series promoting the Women-Centred HIV Care toolkit – an outcome of the CHIWOS study.

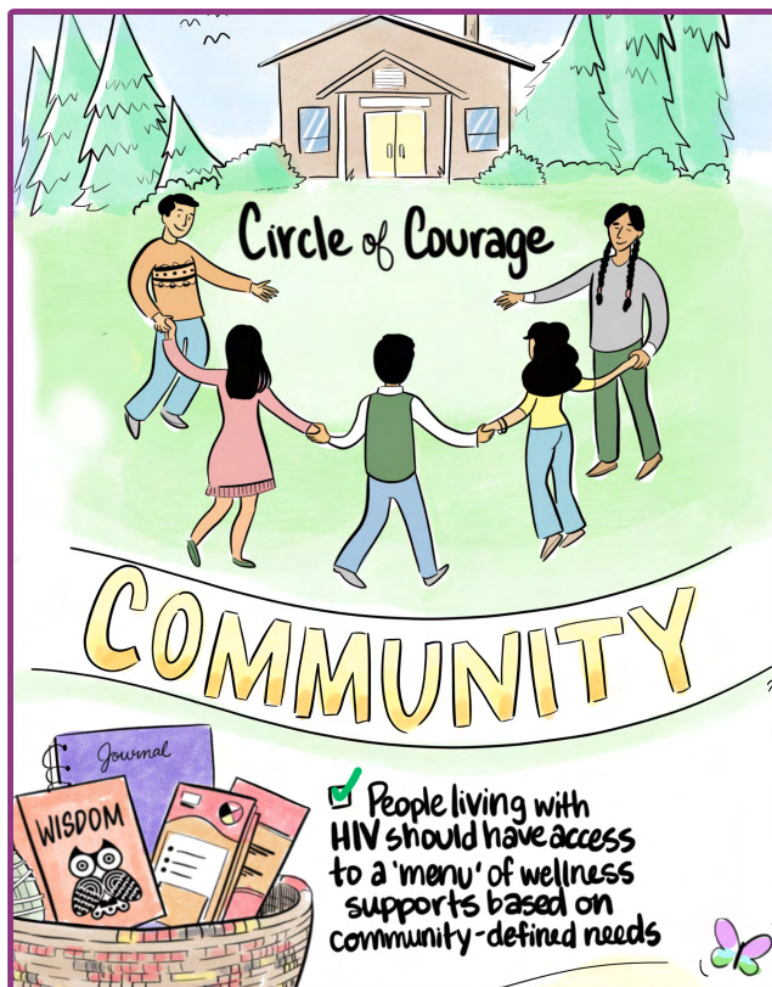
Earlier this year, I participated in the Living Your Best Life (LYBL) meetings. I enjoyed LYBL very much. It was a chance to connect with other people living with HIV (PLWH), friends and colleagues during the isolating days of the pandemic. The meetings provided insight into how PLWH from diverse communities are living well with HIV.

I am soon to be 73 years of age and was thrilled to be a PRA with PANACHE. The findings obtained from the focus groups we facilitated provided the information for the first national study on PLWH over the age of 50. I am very excited about my involvement in this study's development and rollout. Recently, I received the opportunity to be on the planning committee of the Canadian HIV Trials Network (CTN) and **Realize** - HIV and Aging Symposium. I am looking forward to the latest research around HIV and Aging. This symposium ensures that we are not forgotten and that there is hope for those who are living a longer life with HIV.

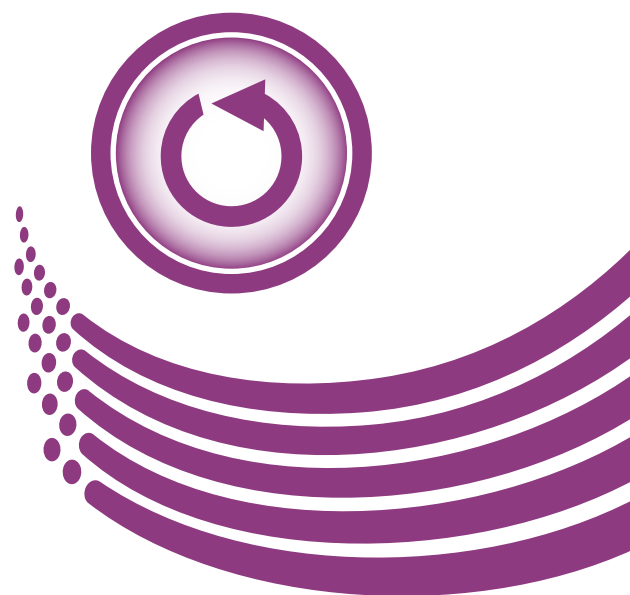
As for my hopes, I would like gender specific research to be conducted so that women living with HIV can have the same life expectancy as men. I also would like policy changes that would promote a better quality of life for all persons living with HIV.

Living a longer life with HIV should be looked upon as an accomplishment to be proud of."

[Watch the video of Brenda's full interview on **Realize's** YouTube Channel.](#)



*Illustrations by Caroline Ellis/Brilliance Mastery



Equitable Access to Rehabilitation, Optimal Health and Wellbeing

***Realize** plays a significant leadership role in promoting positive changes in policy and practice to enhance timely and appropriate access to rehabilitation for people living with HIV and other episodic disabilities by advancing education with clinical, research, community and policy stakeholders on evidence-informed rehabilitation interventions and models of service delivery to prevent or mitigate disability.*

As a community, this year has shown us that **the idea of “optimal health and wellbeing” should be even more of a focus when developing programs, policy, and research that impacts people living with HIV**. Our Annual Forum this year – Living Your Best Life (LYBL) – was a major step in that direction. What started as an introductory conversation with the CAN LhIVE WELL research team, led by Principal Investigator Dr. Jason Brophy (Children’s Hospital of Eastern Ontario) and Principal Knowledge User Muluba Habanyama, in January 2020, about an in-person event in the fall, led to a 4-part virtual event in February 2021 in the middle of a pandemic!

Since we had to keep physical distance, we coordinated to develop new ways to meaningfully engage with the community. We decided that although we might be able to reach a broader audience with a virtual event, the meaningful engagement with people living with HIV would occur in smaller community consultations led by peers. Six community consultants were hired, participated in training, co-facilitated five community consultations for different populations of people living with HIV (in English and French), participated in thematic analysis of the consultations, and presented the findings of the consultations at the LYBL events.



The ideas and approaches shared by participants in these community consultations and through the engagement strategies used at the LYBL events, exemplified that **living well, beyond medical management, is important to people living with HIV**.

This growing understanding also motivated increased collaboration on initiatives related to quality of life for people living with HIV through the National Community Advisory Group on Optimal Health and Wellbeing. The momentum within this group of community members and HIV organizational representatives (convened by **Realize**) is exciting.

As we move into our second year, the Group is looking to grow its mandate and membership.

We are looking forward to the next year as we continue to involve ourselves in initiatives focused on Optimal Health and Wellbeing for people living with HIV.

Community Voice

Amira (not her real name) is a young, black, Muslim woman living in Ontario. She is HIV positive. Amira played a key role in the community consultations that lead up to Living Your Best Life – **Realize**'s Annual Forum in 2020-2021.



"I was born with HIV. I've lived with it my whole life and don't know what life is like not being HIV positive. I contracted the virus from my mother (perinatal transmission), and it surprisingly, actually made our relationship super close.

The reason why I asked to disguise my identity is not because I'm afraid of people knowing I'm HIV positive, but mostly for my mother's sake. I know that if our community ever found out that I am positive, my family will be excommunicated. The sad part is most people will just stop talking to my Mother.

I got involved in the sector and with **Realize** because I am passionate about the work they do. I feel like this is my community, and who better to help understand our needs than ourselves. I got involved in a project called Living Your Best Life. It was amazing. It was a partnership between **Realize** and the Can LhIVE Well research team.

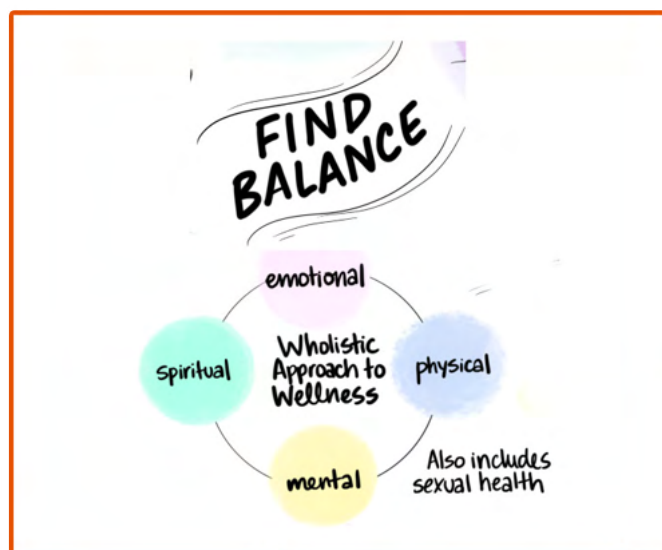
I was so passionate about working on that project because they were looking at wellness, or wellbeing, and what it means to different populations of people living with HIV. This was interesting to me because most of the time when people think about people living with HIV, we're seen as our disease.

It's like they think 'you're living, so you're good!' Now, the conversation has switched from how can I live with HIV to how can I live well with HIV. I thought that was awesome. This is what I needed. The project opened my eyes to a lot of things and gave me different opportunities. The project was not just about researching people like me. We were a part of it, and we were talking about our lived experiences. It was beautiful.

One of our biggest problems isn't actually the disease itself. It's the stigma. Many of us live in lower income areas. A lot of us are on government assistance and are struggling with poverty. Having stigma in places like the workplace, healthcare system, schools, and with government – it follows us around a lot. It's funny because other people with other diseases get to just be a person with that disease, and everyone's okay with it. They move on. But with HIV it's like this extra layer of never being allowed to really talk about what's going on with you.

I would love for more studies and more organizations in general to ask the question of how we can better help people living with HIV in their everyday lives – how can we lower stigma? With that, maybe a lot more people will get tested. A lot of people will have these conversations and a lot of people who are HIV positive can live a better life because there's less mental stress. You can just be a normal person in your community."

[Watch the video of Amira's full interview on **Realize's** YouTube Channel.](#)



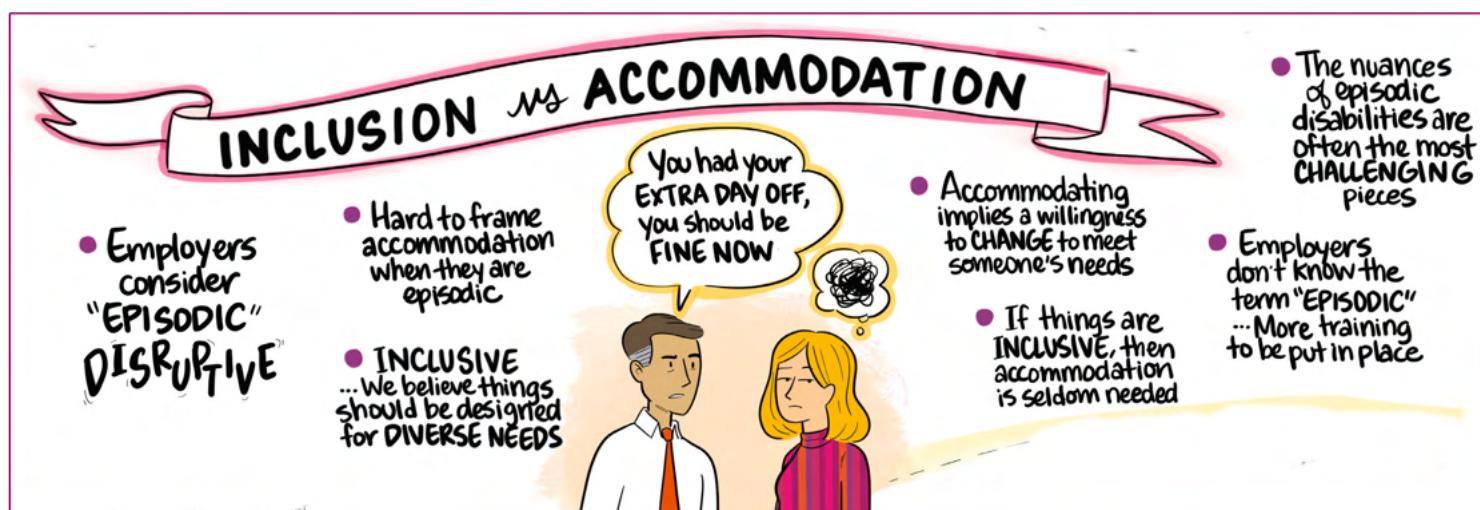
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Meaningful Social Inclusion

Realize is a national voice in championing and promoting the social inclusion of people living with HIV and other episodic disabilities by leading a network of employers, insurers, rehabilitation providers, representatives from community organizations, and government stakeholders for advancing social inclusion and financial security for people aging with chronic illness.

This year has been so different for everyone! The realities of working during a global pandemic have been both challenging and an opportunity for learning. **Realize** adjusted some of our methods of engaging with people around the country and discovered some new and exciting ways to connect.

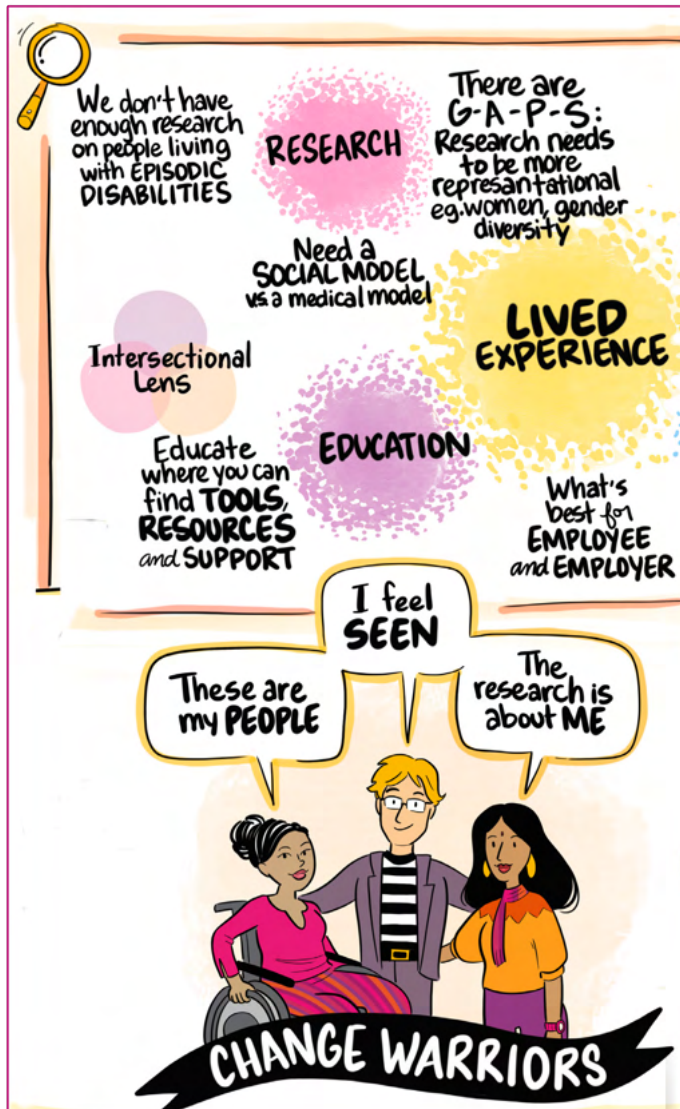
To continue our work focused on the employment sector we have released an important policy brief entitled, "Should I Tell Them: Working Towards Barrier-Free Recruitment in the Canadian Labour Market." This document highlights some of the challenges that people with episodic disabilities are facing as they look for work. We focused on the path from application to hiring to highlight the stigma many individuals are facing regarding job applications, interviews, and the decision to disclose their disability at work. The brief can be found on our [website](#).



*Illustrations by Caroline Ellis/Brilliance Mastery

We have also released results from our recent survey of Human Resources (HR) professionals. This was disseminated across Canada and gives us new insight into what HR representatives know about episodic disabilities. We determined that this group has some familiarity with episodic disabilities and that they are very interested in online courses to build on their existing knowledge. Find our survey report in the Resources section [here](#).

To provide employers with accommodation best practices related to COVID-19, we conducted semi-structured interviews with employers in Ontario and New Brunswick (i.e., CEOs/Executive Directors/Managers/Supervisors) about their



*Illustrations by Caroline Ellis/Brilliance Mastery



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experiences with workplace accommodation and how this has changed in the context of the pandemic. We were interested in how the COVID-19 pandemic has impacted accommodations in the workplace. Our [Pandemic Brief: COVID-19, Episodic Disabilities and Workplace Accommodations](#) provides evidence-based findings and recommendations that employers can implement in their organizations to better support employees.

In March 2021, we hosted the first ever virtual National Summit on Episodic Disabilities and Employment. This event was attended by over 150 people and included 25 speakers over 3 days. Highlights include sessions on Artificial Intelligence and Disability, profiles of successful community programs for people with episodic disabilities and a welcome address from Deputy Minister Yazmine Laroche. We are looking forward to next year where we'll be launching the National Action Plan on Episodic Disabilities and Employment. To view videos of the conference, please visit our [YouTube channel](#).

Community Voice

Heather McCain (pronouns: they/them) is the Executive Director of Creating Accessible Neighbourhoods (CAN), a non-profit based in British Columbia they founded in 2005. They co-organized our Real Talk with **Realize** virtual town hall: *Queer and Trans Conversations about Disability Leadership*.



"I am a disabled person who has encountered, and continues to encounter, ableism, discrimination, and prejudice. I created my own organization, Creating Accessible Neighbourhoods (CAN), in 2005 to fight a transit issue with inaccessibility and gatekeeping, which is someone denying access to an accessibility feature.

After solving my own issue, word spread, and disabled people came to me with similar situations that needed to be addressed.

As I did this work, I became seen as a leader in the community. Being a leader has not always felt comfortable for me. I was just doing what needed to be done because disabled people were being purposely,

individually, organizationally, and systemically, marginalized and excluded.

I have multiple other intersecting identities: I am neurodivergent, trans, non-binary, asexual, aromantic, queer, and live in poverty. I see zero representation of people like me in leadership positions.

The conversation that happened with Real Talk with **Realize**: *Queer and Trans Conversations About Disability Leadership* was so important as it started a dialogue about disabled and queer leaders, the barriers we face, why so many choose not to divulge their identities in work or leadership positions, and what we can do moving forward to support one another and create environments where people can bring their full selves to their work. It was also personally satisfying to speak with Carmel Tanaka, Founder and Executive Director of JQT (Jewish Queers Trans) and Saltina Shaker, Drag Performer and Disability Activist to hear about their experiences.

I admire what they do and how they have become leaders in their communities. I appreciate that they are both open, publicly, about their disability and queerness, as I am, so that others can see representation.

Following the event, I heard from so many who watched the conversation who said they had never seen three disabled and queer leaders together at any event.

It truly speaks to the importance of events like **Realize's** conversation. People need to see it to believe in it, both that it exists and that they, too, can be leaders.

[Watch Heather's full interview on the **Realize** YouTube Channel.](#)

You can also watch a [video of Real Talk With **Realize**: Queer and Trans Conversations About Disability Leadership](#).

Elisse Zack Award for Excellence in HIV and Rehabilitation

2020 Recipient

Realize is pleased to congratulate Colleen Price, the 2020 recipient of the Elisse Zack Award for Excellence in HIV and Rehabilitation.

Colleen Price lives and works in Ottawa, Canada. She is trained in psychology, sociology and as a social service worker. A survivor of trauma, addictions, Hepatitis C and HIV, Colleen is a committed, experienced advocate for testing, access to treatment, care and support for people living with HIV and HIV co-infection. Colleen has played a leadership role in the community in many ways including as a Board Member of Voices of Positive Women, Chair of the Canadian Treatment Action Council's Peer HIV and Hepatitis C Working Group (2006-2013), and with the Interagency Coalition on AIDS and Development Board. Colleen served a public appointment for 10 years as a member of the Ontario Advisory Committee on HIV/AIDS (OACHA) and 8 years on the Ontario HIV Treatment Network Cohort Study Governance Committee. For the last two years, she has been working on issues of chronic pain and HIV, joining the Global Pain and HIV Taskforce in January 2020.



[Watch Colleen's acceptance video, with testimonials from her peers.](#)

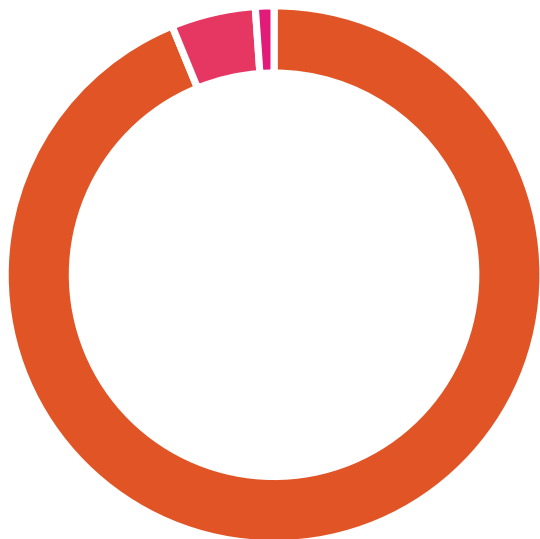
In the words of her peers who nominated her, "As a woman living with HIV and longstanding advocate for rehabilitation in HIV, Colleen tirelessly works to advance the field of HIV and rehabilitation for people living with HIV. As a colleague, activist, and friend, Colleen brings optimism, wisdom, and calm to all those who interact with her."

[Read Colleen's full bio and her thoughts on receiving the Elisse Zack Award on the **Realize** website.](#)



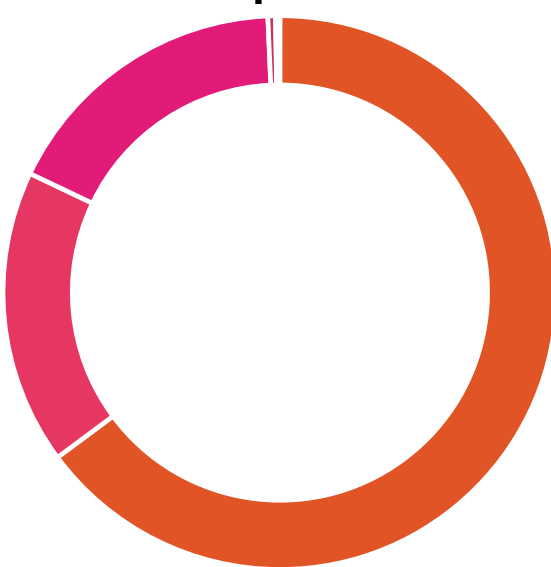
Revenues and Expenses

Revenues



- Grants 93.8%
- Memberships, course and registration fees 5.1%
- Donations 1.1%

Expenses



- Program and Contract Staff 64.9%
- Occupancy Costs 17.2%
- Financial Administration, printing and materials 17.2%
- Evaluation 0.4%
- Travel 0.3%

