



Realize ANNUAL REPORT 2019 - 2020 Putting Quality of Life at the Centre of the New Normal

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!

https://youtu.be/73rLqrAz5vE

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 chronic and potentially episodic conditions, with a primary focus on healthy aging, optimal 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.



Realize participated for the 2^{nd} time in the Toronto Scotiabank Waterfront 5K in October 2019 – raising support for our work and getting some exercise too. The weather that day was perfect, and the company was great. *Photo:* **Realize**

In the last months covered by this Annual Report, the COVID-19 pandemic and the global response affected us deeply, as well as the communities we serve. **Realize** is dedicated to bringing people and communities together to envision a way forward and to find a way to put quality of life at the centre of the new normal for people living with HIV and other episodic disabilities.

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 <u>www.realizecanada.org</u>.
- Make a donation
 (https:/www.realizecanada.org/en/take-action/donate/)
 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.

"The work and advocacy of **Realize** has transformed the care provided for people living with HIV beyond Canada, impacting on the development and implementation of HIV rehabilitation services in the UK."

Our Reach

Realize has individual and organizational members across Canada, and strong partnerships internationally. Our Board members include a strong mix of health care and other professionals, as well as activists from the HIV and disability communities. We convene or play a vital role in many key agency coalitions that focus on issues of critical concern to people living with HIV and other episodic disabilities. In addition, we have 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.



The **Realize** Team works hard, but we know how to have fun too!! Photo: **Realize**

Realize

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Our Thanks

The impact of **Realize**'s work transcends the size of our organization because of the expertise and dedication of our volunteer Board of Directors, as well as our staff, members, partners and donors – individuals, corporations, and public institutions. **Thank you**.

We particularly thank the Public Health Agency of Canada, Employment and Social Development Canada, the Government of Ontario, Gilead Canada, the Ontario HIV Treatment Network and ViiV Healthcare Canada for their generous support.

Realize continues to attract first rate, post-secondary education practicum students. During this reporting period, Elizabeth Racz, Afia Amoako and Samuel Morrison completed their practicum placements with the **Realize** team.

Realize extends a heartfelt thank you to Stéphanie Claivaz-Loranger for her expertise and dedicated leadership as a member and then Co-Chair of our Board of Directors. Stéphanie first became a member of Realize's Episodic Disability Network (EDN) in 2008 and has also served on Realize's Research, Education and Practice Advisory Committee. She is currently one of Realize's Co-Chairs, and also chairs the governance committee. Stéphanie's Board term comes to an end in September, but we welcome her continued guidance as an active member.

We also extend heartfelt appreciation to Chris Sulway, whose time on the Board will also come to an end this September. Chris has been involved as a volunteer with *Realize* for over 15 years, has chaired the Board's former Research, Education and Practice Advisory Committee and served as Co-Chair on the Strategic Planning Committee. We wish Chris well as his professional star continues to rise and look forward to him also remaining an active member of *Realize*.

Message from the Co-Chairs

Realize emerged from an evolving global health crisis 21 years ago. Drug treatment breakthroughs were beginning to change the survival outlook for people living with HIV in Canada and elsewhere but important questions of quality of life remained unanswered. In 1998 a concerned group of people living with HIV, AIDS service organization representatives, government program and policy makers, teachers, researchers, rehabilitation and other health care providers gathered in Quebec City to brainstorm rehabilitation as one potential answer, and **Realize** (then the Canadian Working Group on HIV and Rehabilitation) was born.

For over two decades, Realize has served as a catalyst for change – bringing people together and creating the space for forward thinking and action to help mitigate the complex health, social and economic challenges people living with HIV and other episodic disabilities experience. Our work in HIV and aging, access to rehabilitation and meaningful social inclusion continues to break new ground in answering those critical quality of life questions. We invite you to read more about this work in the following pages but first, here are a few highlights from our year (April 2019 – March 2020).

Realize has always focussed on building community capacity and has been driven by our community members and partners. In 2019 we were honoured to present the Elisse Zack Award for Excellence in HIV and Rehabilitation to member Michael Bailey for his exemplary work as a community organizer and educator in Ontario and Quebec.

Until recently, people in Canada with episodic disabilities (long-term conditions that are characterized by periods of good health interrupted by periods of illness or disability) were left out of government programs and thinking. Finally, after years of advocacy and consultation with government representatives and policy makers, **Realize** and our partners from across the disability sector were excited to see the Accessible Canada Act (ACA) receive Royal Assent in June 2019. The ACA is the first piece of federal legislation to include 'episodic disabilities' within its definition of 'disability'.



Stéphanie Claivaz-Loranger

https://youtu.be/CdtiiqrNL7o



https://youtu.be/xxEj04i4ll4

As the secretariat of the National Coordinating Committee on HIV and Aging, *Realize* has been the leader in Canada for community-based research on what it means to age with HIV. In November, we released, *To the Beat of Our Own Drum*, examining what it means to age well with HIV in the African, Caribbean and Black communities in Canada – the first resource of its kind.

The HIV community has had a long and troubled history with the insurance industry even though some health and life insurers now provide coverage for people living with HIV. In September **Realize** hosted Canada's first National Dialogue between the HIV Sector (Community Based HIV Organizations) and the Insurance Sector.

As Co-Chairs, we and the Board of Directors have focussed our energies on ensuring **Realize** has a strong governance model and a sure organizational footing and direction. In September we approved a new strategic plan, *Roadmap to Impact*, to guide the organization through 2022.

The end of the fiscal year was overshadowed by the spread of the COVID-19 pandemic. Here in Canada, the strains on our health and income systems and the broad social restrictions necessitated by the spread of the virus have hit hard amongst our members and the communities we serve. At the same time we have all had to curtail or change our ways of working. It's been a challenging time but as we imagine what the new normal will be – what does quality of life mean? – there are many signs that *Realize's* role in bringing people and communities together to envision a way forward is needed now more than ever.

Stéphanie Claivaz-Loranger and Paul Curwin Co-Chairs, Board of Directors

Realize Programs

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.





Realize's Elizabeth Racz and Tammy C. Yates with Lori Sigurdson, Member of the Legislative Assembly of Alberta for Edmonton-Riverview, after discussing priority issues for people living with HIV and/or other episodic conditions. *Photo:* **Realize**

As part of our ongoing efforts to support community members living and aging with HIV, **Realize** launched the PANACHE (Preferences and Needs for Aging Care among HIV Elders in Ontario) study, funded by the Ontario HIV Treatment Network (OHTN). Nine focus groups were held across Ontario from July to October 2019, including Ottawa, Peterborough, Oshawa, London, Hamilton, Sudbury, and Toronto. The data collected will be used to inform the development of a national survey tool.

In collaboration with Dr.
Christopher Klinger of the
Quality of End of Life Care
Coalition of Canada (QELCCC),

Realize co-authored a scoping review on research gaps for end of life and palliative care that has been submitted for publication. A two page infographic has been developed describing the results of the review, which will be used as an advocacy tool and informational document in upcoming QELCCC programming, meetings and conferences.

Realize conducted capacity building workshops on HIV and Aging for community organizations including Moyo Health and Community Services, the AIDS Committee of Toronto, the Toronto HIV/AIDS Network, Casey House, BlackCAP, as well as at Central and Central West Opening Doors. Recognizing the needs of our community are changing during the COVID-19 pandemic, the Uncertainty in HIV and Aging training and capacity building workshops have been redesigned for a web-based, town hall format, facilitated in English and French. The workshops are timely given the heightened uncertainty being experienced by our community and others during COVID-19.

The Sheridan College Gerontology program implemented **Realize**'s HIV and Aging blended curriculum for winter 2020 courses offered at the college. Two community volunteers spoke to fourth terms students at the Oakville and Brampton campuses. Fanshawe College continues to be engaged in using the curriculum for their nursing students.

A total of 20 registrants from three provinces were scheduled to attend a two-day capacity building workshop on Uncertainty in HIV and Aging on March 18-19, 2020 in Montreal. The workshop was postponed due to COVID-19 as was further Uncertainty training for HIV Edmonton staff and plans for similar engagement with AIDS Vancouver and Vancouver Island.

Realize continues to engage with policy makers across Canada seeking improvements in programs and policies that affect people aging with HIV. In person meetings with policy makers in Edmonton, Alberta as well as with leadership from Alberta Health Services were held in February 2020. There was support from all policy makers for the blended HIV and aging curriculum, as well as for the need to include HIV and aging training for long term care employees. In Newfoundland we met with provincial policy makers and engaged with the team at the AIDS Committee of Newfound and Labrador (ACNL) who were equally supportive, and provided insight into work already underway in long term care homes to support intersectional and multidisciplinary training. Virtual meetings and calls with policy makers from Quebec and British Columbia further indicated support for our work on a national level.

"Thanks to **Realize**, I have a better handle on how to age well with HIV."

https://youtu.be/jzagS5zMGqc

Optimal Access to Rehabilitation

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.



Optimal access to rehabilitation for people living with HIV and other

episodic disabilities continues to be a strategic focus of **Realize'**s work. While the early months of 2020 shifted global priorities to responding to the emerging threat of COVID-19, the impetus and goals behind our work on access to rehabilitation remain current and valid. This past year has focused on physical activity for people living with HIV, and reaching out to policy makers to encourage positive change related to chronic health and physical activity programming. This occurred along with the research partnerships, and educational initiatives that occur throughout the year.

We've had to change the way we work, change the way we live, and change what we do on a daily basis. However, the recommendations for physical activity have remained the same: 150 minutes of moderate physical activity per week. Although this is harder to achieve now, it's much more important than before. With physical distancing being our new normal, we need the benefits that physical activity can provide.

"For me, partnering with **Realize** is essential to Canada's HIV response as we enter the fourth decade of the epidemic."

Physical activity promotion for people living with HIV has been happening through community-based HIV organizations, making connections with fitness centres and via information sharing on social media. We have shared the Guide to Promoting Rehabilitation and Wellness for People Living with HIV with community-based HIV organizations (CBHOs) across the country as well as policy briefs discussing physical activity for people living with HIV (and specifically women living with HIV) with both CBHOs and fitness centres.

Realize met with policy makers from coast to coast to share the message that HIV needs to be considered within chronic health condition programming and physical activity programming at the provincial level. Starting with the basic acknowledgement that HIV is a chronic health condition – something that **Realize** has promoted for years – we are working to ensure that people living with HIV have access to supports and services that will lead them towards optimal health and wellbeing.



Realize's Puja Ahluwalia with Hal Johnson and Joanne McLeod from Body Break at the June 2019 Research to Action Conference, titled 'Keeping Fit' at Western University's Canadian Centre for Activity & Aging. Hal and Joanne presented on staying active throughout your lifespan including being active as you move into older adulthood. We definitely endorse that!!! Photo: **Realize**

□ https://youtu.be/InF0FlS2aZ8

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, **Realize** engaged with frontline staff of Community Based HIV
Organizations and AIDS Service Organizations across the country to
increase their resiliency and strengthen mental health at work. We built strong connections with these organizations that are a vital part of our national network.

Positive Outlook 2.0 – *Realize*'s training on HIV and mental health for front line workers in community based HIV organizations – took us to eight new cities for full-day workshops: Saskatoon, La Ronge, Meadow Lake, and Prince Albert in Saskatchewan; Winnipeg, The Pas/Opaskawayk Cree Nation in Manitoba; St. John's, Newfoundland; and Dartmouth, Nova Scotia. We also lead two sessions in Toronto in partnership with Casey House, and the Ontario AIDS Network. This year, Positive Outlook focused on the wellbeing of frontline workers and ways that they can address burnout, better support each other through grief, and build resiliency through self-care.



A fun selfie after a successful workshop! **Realize**'s Melissa Egan with participants at our *Positive Outlook* mental health workshop held in collaboration with Healing Our Nations in Nova Scotia. *Photo:* **Realize**

We supported the Institute for Work and Health to engage with a diverse group of people living with episodic disabilities to host a feedback session on the Strategy on Disability and Work. Our community shared their stories and experiences to better inform the Strategy and to ensure that it includes the particular issues facing people living with episodic disabilities at work.

2019 brought the Workplaces REVAMPED (Workplaces Recognizing the Value of eMPloyees with Episodic Disabilities) project to life and with it the formation of our Employers' Network on Episodic Disabilities. This is a group of 12 individuals with an interest in creating awareness around episodic disabilities and work. We will be consulting with them throughout the project along with our Advisory Committee. This is a strong group of advocates with lived experience of episodic disabilities who will support the creation of our Speakers' Bureau and the development of an awareness-raising workshop.

To continue strengthening our policy and advocacy work, the National Episodic Disabilities Forum met four times in 2019 and added six new members. We are now a pan-Canadian group of 60 members many of whom have lived experience of episodic disabilities, who work at agencies, educational institutions or in government. As a group, we collaborate to increase awareness of episodic disabilities through our work and our lives.

The end of 2019 and International Day of Persons with Disabilities brought **Realize** to the Disability and Work Conference where we led a session on Unconscious Bias to a large audience. **Realize** Executive Director, Tammy Yates was one of the featured speakers.

"Realize's work on episodic illness afforded me, my clients, community organizations and employers a way to view how life could resume..."

https://youtu.be/NYjQZxyB50g

Elisse Zack Award for Excellence in HIV and Rehabilitation 2019 Recipient - Michael Bailey

Realize is pleased to announce that the 2019 recipient of the Elisse Zack Award for Excellence in HIV and Rehabilitation is Michael Bailey.



Michael Bailey

Michael received his HIV diagnosis in 1987. He joined the CATIE team 15 years ago, serving in various education roles including as director of program delivery. This year, he is excited to return to the position of regional health education coordinator for Ouebec.

Prior to joining CATIE, Michael worked at the Toronto People With AIDS Foundation, where he developed programs and fundraisers for people living with HIV. Michael's connections in Quebec run deep, having lived in Montreal for more than 20 years, where he studied English and French literature, translation and community service. Michael is passionate about HIV and hepatitis C knowledge exchange, and is proud to work alongside the many volunteers and frontline workers who make a difference in the lives of the people they serve.

"Michael is always there for others, whether to lend a hand, a listening ear or a shoulder to cry on. He is always the first to offer help and to shoulder others' responsibilities. "No" is not a word in his lexicon. Michael is always humble, always compassionate, always thinking of others and always ready to lend a hand."

Excerpt from the Nomination Statement

https://youtu.be/mwBfuYU9w8g

