

A close-up portrait of an elderly Black woman with short, curly grey hair. She is looking slightly to the left with a thoughtful expression. She is wearing a colorful patterned top and a green square earring.

PANACHE: Principles and Practicalities

Situating the **P**references **A**nd **N**eeds for **A**ging **C**are
among **H**IV-positive **E**lderly people in Ontario
within the UN Principles for Older Persons

Older Adults and HIV in Ontario

A person's well-being in older adulthood is impacted by their chronological age, their life experiences, the conditions in which they live, and the support available to them. How an older adult living with HIV understands and navigates the aging process is therefore impacted by their HIV diagnosis as well as the HIV treatment, care and support they have received over time. For many there comes a point when aging-related healthcare and broader support needs eclipse HIV-related needs, but the experience of living with HIV, and that of being an older person, remain interwoven.

The average age of people living with HIV in Ontario, Canada, 48 years old, has been on the rise since the introduction of combination antiretroviral therapy (cART) 25 years ago.¹ According to the most recent data available (2015), over 60% of people diagnosed with HIV in the province are 45 years old or older. This demographic shift reflects both the improved longevity of people living with HIV long-term and the fact that one in every five new HIV diagnoses is in someone over the age of 50.² Ontario is home to more than 4,000 people living with HIV who are 55 years old or older and this number will continue to grow over the next decade.



"I don't really even consider my HIV status when I think about housing or food or, you know, sex or any... you know, it... 'cause it's just not that predominant in my mind anymore, you know? It's something I have, I take my pills, I do what I'm supposed to do to as best... to my best of my abilities."

¹Ontario HIV Epidemiology and Surveillance Initiative. HIV care cascade in Ontario by sex, age and health region: Linkage to care, in care, on antiretroviral treatment and virally suppressed, 2015. February 2018.

²Ontario HIV Epidemiology and Surveillance Initiative. New HIV diagnoses in Ontario, 2017. Toronto, Ontario, July 30, 2019.

The PANACHE Ontario Project

Preferences **A**nd **N**eeds for **A**ging **C**are among **H**IV-positive **E**lderly people in Ontario (“PANACHE ON”) is a qualitative community-based participatory research (CBPR) study that conducted community consultations with people aging with HIV at nine community-based organizations in Ontario, Canada to ascertain their preferences and needs for aging care.

“I think we need more focus group like these, because this is where you can hear the hurt. You can feel people's energy, this is a place that they can vent and know that they're heard.”



We are using this information in two ways:

1. To make recommendations to policy makers, healthcare leaders, and organizational decision-makers that prompt change that improves the quality of life of older adults living with HIV, whether by increasing access to existing services or informing the development of new programs.
2. To develop a survey that will be used to gather information regarding the comprehensive healthcare and social support needs and preferences of a larger group of older people living with HIV across Canada.

The PANACHE ON project team includes a wide variety of stakeholders. In keeping with the principles of the greater involvement of people living with HIV/AIDS and the meaningful engagement of persons living with HIV/AIDS (GIPA/MEPA), about half of the 32-member research team identify as persons with lived experience of aging with HIV.

Also represented are healthcare providers, staff of HIV organizations, people with CBPR experience, and academics. CBPR principles, including equitable partnerships, capacity-building, and mutual respect for

different forms of knowledge, guide our work together.

The information presented in this report was collected through nine Peer Researcher-led community consultations involving small groups of older people living with HIV from communities across Ontario in the summer and fall of 2019. Key themes emerging from these conversations were identified by a small project analysis team using the DEPICT model for participatory qualitative health promotion research analysis³. The study received approval from the University of Toronto Research Ethics Board.

PANACHE ON Community Consultation Participants

Nine community consultations were held in Hamilton, London, Oshawa, Ottawa, Peterborough, Sudbury and Toronto involving a total of 73 participants. Five of these consultations were open to all older adults living with HIV, regardless of their gender, sexual identity or racial background, while four were designated for specific communities, including:

- Older gay, bisexual and other men who have sex with men living with HIV
- Older women living with HIV
- Older people living with HIV who use, or have a history of using, drugs
- Older adults living with HIV from racialized or ethno-cultural minority communities

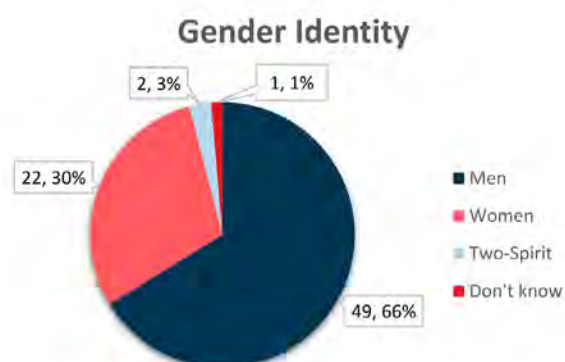
“So we have that, that ageism. Then we have the HIV issue. Then we have LGBTIQ thing... so I mean seriously, you know, you got 5 strikes there already, you know what I mean? By the time you add it all up. So, you know, you're starting from the... what's the word I want? An unvoicable position, so to speak.”

³Flicker, S., & Nixon, S. (2015). The DEPICT model for participatory qualitative health promotion research analysis piloted in Canada, Zambia and South Africa. *Health Promotion International*, 30, 616 - 624.

PANACHE Ontario Participant Dashboard

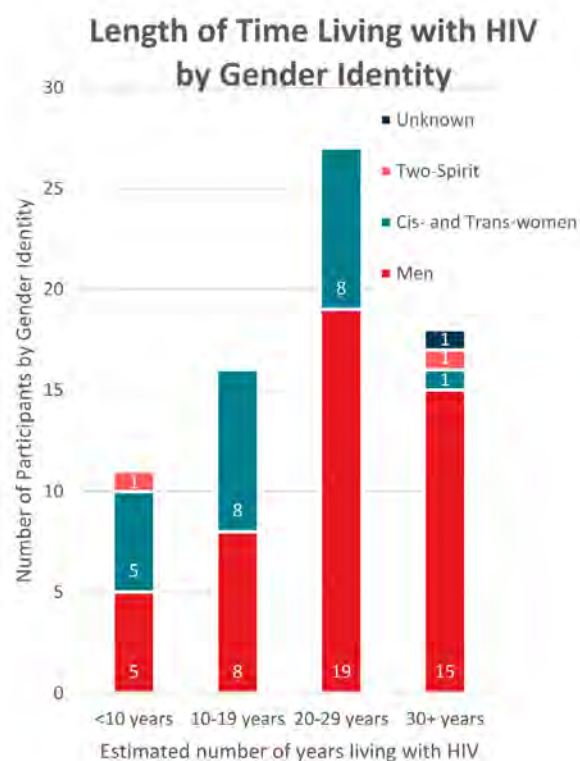
Age and Gender Identity

The average age of participants was 64 years old (range: 55 to 77 years). Two thirds of participants self-identified as men (n=49, 66%), and roughly one third as women (n=22, 30%), including 1 trans-woman. Two people described themselves as Two-Spirit (n=2, 3%) and 1 person did not specify their gender.⁴



Length of Time Living with HIV

The average length of time participants had been living with HIV was 22 years. A majority of people living with HIV since the pre-cART era (prior to 1996) (n=45) identified as gay or bisexual men (n=26, 58%).⁵

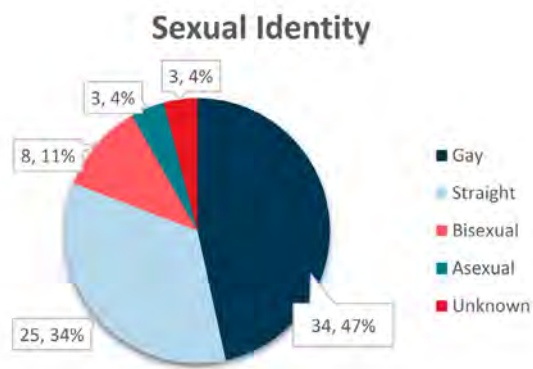


⁴The total number of responses for gender identity is 74. One individual self-identified as both a man and a Two-Spirit person.

⁵In the graph Length of Time Living with HIV by Gender Identity: one person did not provide an accurate answer as to how long they had been living with HIV so only 72 responses have been graphed; also, one person who self-identified their gender identity as both Two-Spirit and Man is captured as Two-Spirit.

Sexual Identity

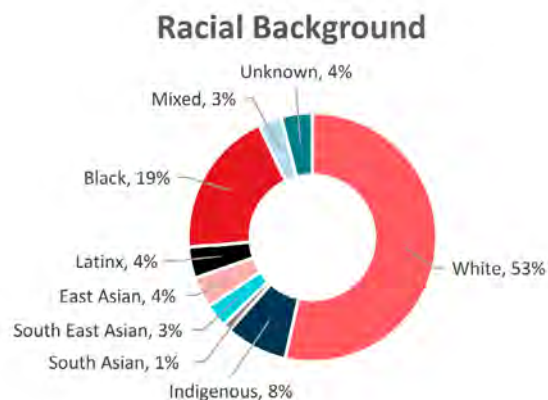
With respect to sexual identity, almost half of participants (n=34, 47%) identified as gay (32/34 were men) and one third of people (n=25, 34%) identified as straight (17/25 were women). Eight (n=8, 11%) participants identified as bisexual (7/8 were men). Three (n=3, 4%) people identified as asexual (1 woman and 2 men) and 3 (4%) people did not specify their sexual identity.



Racial Background

About half of our participants identified their racial background as White (n=39, 53%). Six (n=6, 8%) participants identified as Indigenous, including Inuit (n=1, 1%), First Nations (n=4, 5%), and mixed First Nations/White (n=1, 1%); 1 (1%) person as South Asian; 2 (3%) people as South East Asian; 3 (4%) people as East Asian; 3 (4%) men as Latino; 14 (19%) people as Black; and 2 (3%) people as mixed race. Three (n=3, 4%) people did not identify their racial background.

Men in the study identified predominantly as White (29/49 men, 59%) while women and trans-women were more likely to be Black, Indigenous or People of Colour (12/22 women, 55%).



Housing & Living Arrangements

Most participants (n=51, 70%) in the PANACHE ON study reported renting their housing while a much smaller percentage were homeowners (n=12, 16%). Three (n=3, 4%) people reported living in a housing facility where they have their own room, but share a kitchen and bathroom, and where they receive care and support related to HIV; and 2 (3%) people indicated they lived in a self-contained room in a house. Five people did not respond to this question.

"They keep raising the rent every couple years. Not a lot, but, you know, like, again, my income's fixed and the rent keeps going up and... oh I'm living in a bachelor's for God sakes and I've looked around at other places and there's nothing out there."

Two thirds of study participants reported living alone (n=45, 59%) while others lived with a spouse/partner (n=14, 18%), children (n=8, 11%), parents or extended family (n=3, 4%), and/or unrelated people, including friends or roommates (n=5, 7%). One person did not specify who they lived with.⁶ Participants were similarly likely to live alone, whether they identified as men or women (including trans-women) (59% vs. 68%, respectively).

Employment and Finances

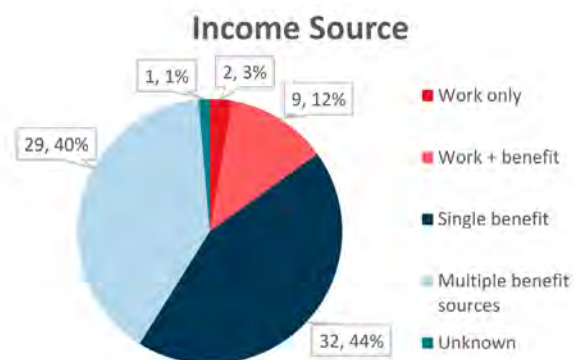
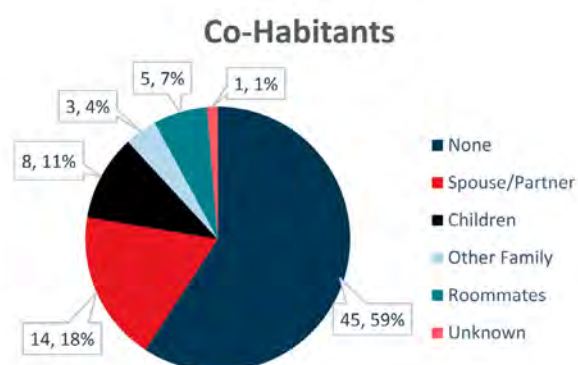
Eleven (n=11, 15%) people reported being employed either full- or part-time. Those working full-time (n=2, 3%) did not report any additional sources of income. Of the 9 (12%) people who worked part-time, 7 (78%) were also receiving income from the Ontario Disability Support Program (ODSP), 1 (11%) from Canada Pension Plan-Disability (CPP-D), and 1 (11%) from a combination of public and private pensions.

Just under half of participants (n=32, 44%) reported a single source of income other than employment, including: 21 accessing ODSP; 1 accessing Ontario Works (OW); 1 receiving CPP-D; 1 receiving Old Age Security (OAS); 6 receiving Canada Pension Plan (CPP) payments; and 2 receiving long-term disability (LTD) from work.

Just over half of people (n=38, 52%) reported accessing multiple sources of income, including different combinations of: work, provincial social assistance (OW, ODSP); federal pension(s) (OAS, Guaranteed Income Supplement, CPP); federal disability (CPP-D); and private disability and/or retirement payments.

"Like I hear some people say that they're worried one day I might die alone. For me, I don't care, like dying is the last process that I worry. What I worry is that if I'm not well, like, if someone can help me."

One person did not report their income source. One in five people (n=13, 18%) reported having a private pension or retirement investment.



⁶Total number of responses exceeds 73 as three respondents indicated they lived with people from more than one category of co-habitant.

"For me the housing experience, I submit my application for Housing Connections in 2003, and up until now, I still have no answer. 16 years and I update my application every year, and every year I come to the office they say you're on the waiting list."



"Even free transportation we can go to the park. We don't need to go the movie or whatever, we can go to the park and have a walk."

"I have been helping someone who's sick who can not make chores, I just helped someone who was very, really, really sick, couldn't do anything, so I gave him a hand. And I hope I will find people who can help as well."

"I went into the food bank last Tuesday, the amount of food I got lasted me, when I stretched it out, till Friday. I've had next to nothing to eat since Saturday, Sunday, I had a bit to eat yesterday, and then I had lunch here today."



Study Findings

There is no easy way to summarize the diverse lived experiences shared with us by our study participants. Each person we engaged followed a different path to older adulthood. All are *resourceful* but some have historically and currently better *access to resources* than others, including support and practical means.

Three Universal Experiences Shared by Older Adults Living with HIV

Older adults living with HIV, especially those diagnosed for many years, share in common a triad of experiences – trauma, stigma, and fear and uncertainty – that intersect to undermine the ‘normal’ aging process. In the context of limited external resources, another shared reality for many people living with HIV, it can be challenging to carry these burdens over the life course and into older adulthood.

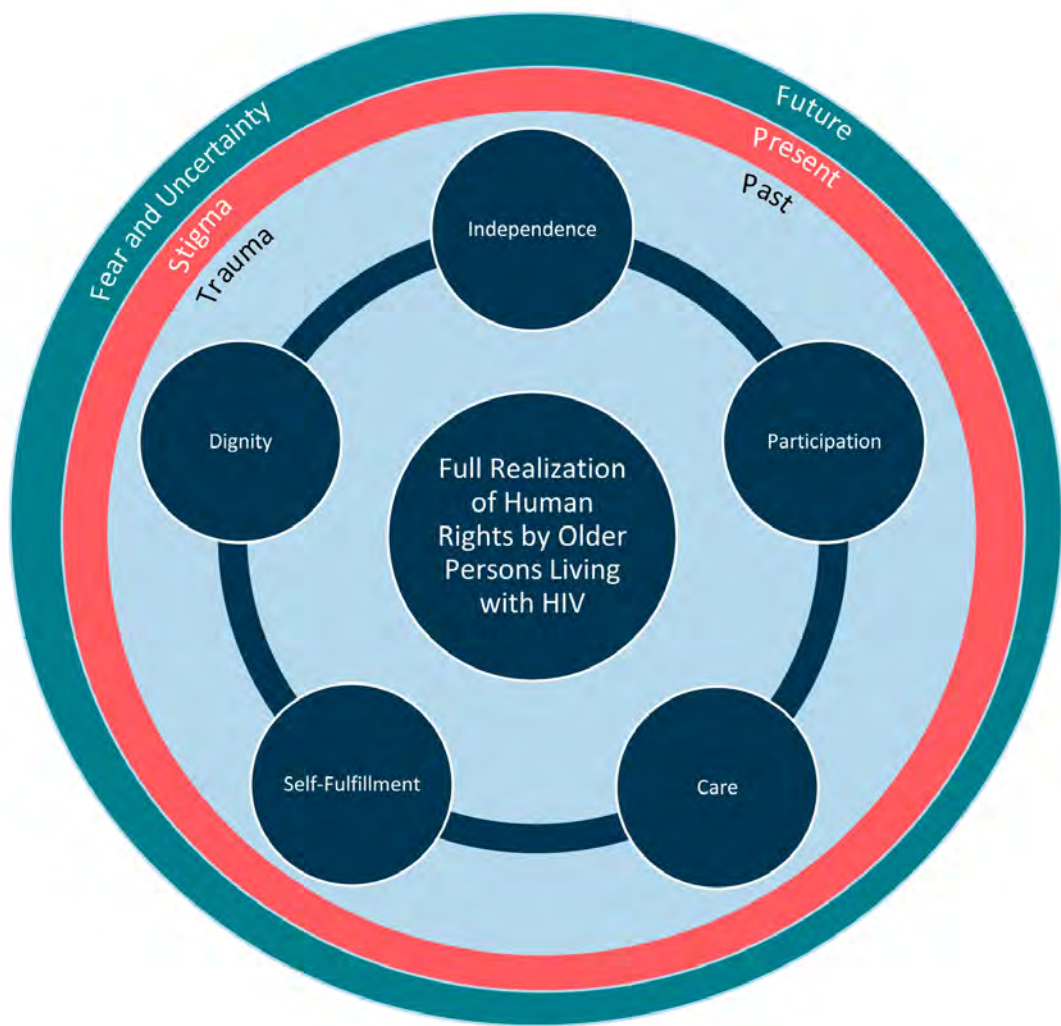


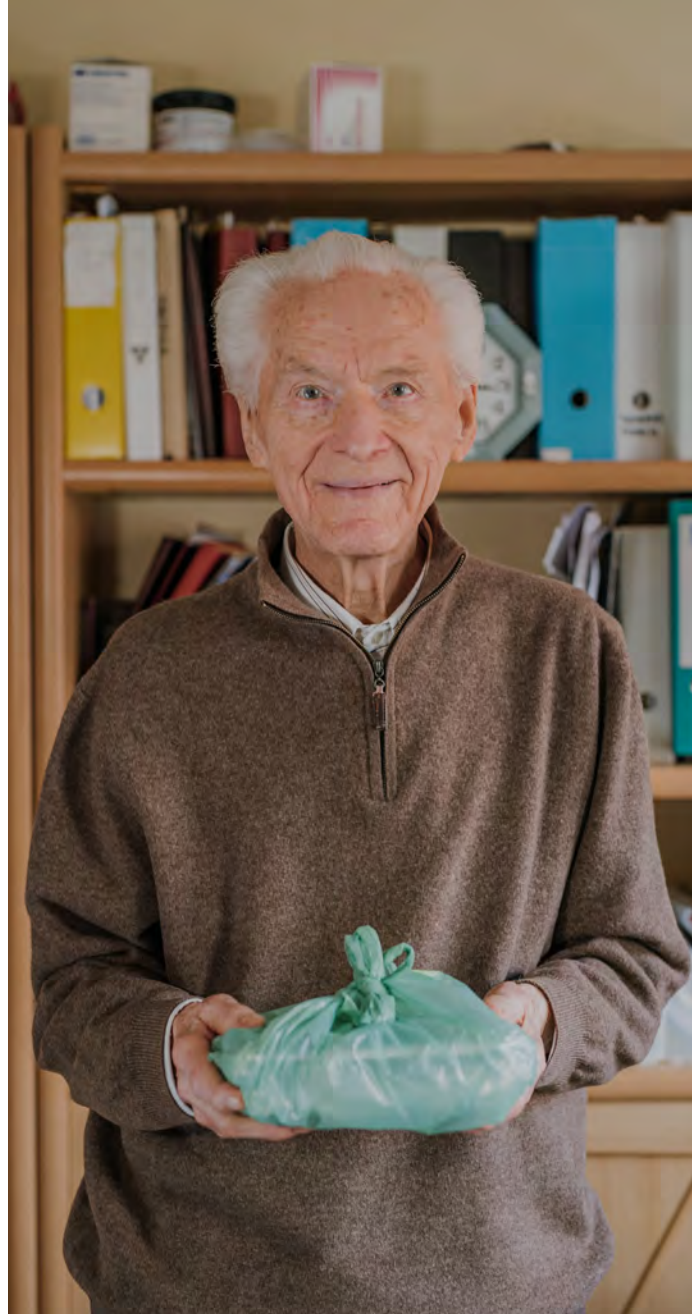
Figure 1: The full realization of human rights by older persons living with HIV, as outlined in the United Nations Principles for Older Persons (navy blue), is affected by three universal experiences – trauma, stigma, and fear and uncertainty.

Trauma

Receiving an HIV diagnosis at a time when there was no treatment available, losing significant others to AIDS, and abandonment by family after disclosing Two-Spirit, lesbian, gay, bisexual, transgender or queer (2SLGBTQ+) identity, substance use or HIV status, are a few of the hurtful and life-altering events that our study participants have experienced. These incidents impact the way older adults living with HIV interact with the world to this day, especially if they haven't been able to access the mental health support needed to address past trauma.

Stigma

HIV stigma persists four decades into the epidemic and undermines the well-being of our study participants. Internalized stigma about being 'dirty' is damaging to their mental health and self worth. Fear of stigma prevents them from disclosing their HIV status and limits their social support. Whether experienced today or anticipated in the future, discrimination based on HIV or intersecting forms of stigma such as homophobia, racism, and classism can prevent access to vital aging care and services by older adults living with HIV.



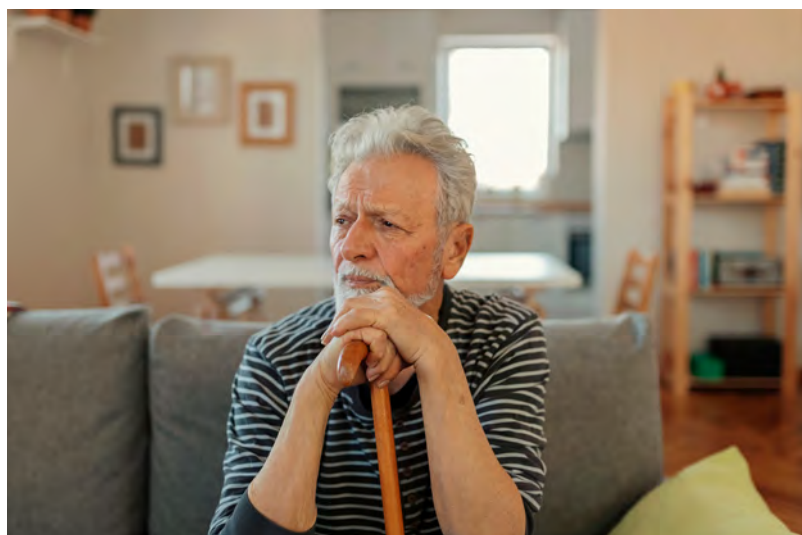
“Tell you one thing, when I got diagnosed with HIV, I had to go home and tell my wife, and I'm telling you that was the scariest thing, and me, I was like this all night long, I couldn't sleep, I thought I was going to die, and I wanted to kill myself. I gave all my tools away and quit my work, everything. It was horrendous.”

Fear and Uncertainty

Fear and uncertainty pervade the day-to-day lives of many of the older adults living with HIV in our study population and impact their feelings about the future. Common sources of illness uncertainty in the present include: not knowing how well they will feel from one day to the next; constantly having to adjust to new limitations when additional illness pops up; and a lack of clarity about whether changes in the body and mind are a normal part of aging or whether they are the result of HIV or exposure to HIV medication over time. Whether they will be able to meet their basic needs for food and shelter is an additional source of uncertainty for many older adults living with HIV who live on a fixed income.

Uncertainty about the future was also raised often by our study participants. Many reported changes in memory and concentration and had questions about whether they should expect further decline and, if so, what the impact would be on their future independence. There were also many unknowns related to future care and support raised by participants. Some people were unaware that formal home and community

care services exist, while some wondered if they could count on their families, including adult children, to help them if they needed it. Many were fearful that their current income, or the amount they guessed they might receive when they reached age 65, would not be enough to meet their basic needs.



Fear about the future also results from *knowing* that one's circumstances will get worse, based on their current health, financial or social realities. One participant spoke of rent increases that have forced them to downsize their unit several times already in order to remain housed. Now that they are living on a fixed income in a bachelor apartment, they know that they will soon be priced out of the rental market altogether and pushed into subsidized housing, if it is even available. Others report being alone, without family and friend support, and knowing they will be reliant on formal systems of care if they need assistance in the future.

"You start to get a little fearful 'cause you're living alone like what the hell's going to happen, you know there's no money to get anybody to come in and do anything..."

"I was 65 in September and I've been on ODSP for the last few years, and I'm fortunate to live in a co-op. But the finances will pretty much stay the same. And it's been a very challenging experience to live on ODSP. So the future, living unendlessly in reduced circumstances of finances, is a very miserable future."



A Rights-Based Framework for Aging with HIV

One of the goals of the PANACHE Ontario project is to make recommendations for policy and practice change that render HIV a “non-issue” in aging. In other words, we’re calling for changes that ensure that older people living with HIV are fully able to realize their human rights just as every older person should be able to do. To this end, our study findings are organized using a rights-based framework: The United Nations Principles for Older Persons.⁸ This framework elaborates on the fundamental human rights outlined in foundational documents (e.g., the

Universal Declaration of Human Rights), to guarantee that universal standards are upheld for all older adults. The principles address five themes: independence, participation, care, self-fulfillment and dignity. Under each theme, we summarize relevant ideas shared by study participants and identify what we think either contributes to, or prevents, the full realization of human rights by older persons living with HIV.



“I wasn't really worried about anything HIV was going to do to me. It was really obvious to me though that I had to be more concerned about things that my fellow human beings might do to me because of my HIV status. But because of my politics, because of my sexual orientation, because of a whole lot of things... I was already targeted by the same people who weaponize HIV against LGBT people.”

⁸ The United Nations Principles for Older Persons (1999) can be found at:

<https://www.un.org/development/desa/ageing/resources/international-year-of-older-persons-1999/principles.html>

Independence

UN Principles for Older Persons #1: Older persons should have access to adequate food, water, shelter, clothing and health care through the provision of income, family and community support and self-help.

Income and Access

Many of our study participants reported that their income does not keep pace with their living expenses and they struggle to access adequate food, shelter and health resources. For those who have been living with HIV long-term, financial resources are especially scarce. Members of this cohort reported not expecting to survive more than a few years with HIV. With no future prospects, many gave up opportunities to earn and save, and dispensed with any existing savings or assets. Understandably, income insufficiency is a significant source of stress for all who experience it.

Many older adults living with HIV who participated in our consultations, especially those who live in big cities, described struggling to cover necessities such as housing and utilities. Several participants reported going without or rationing food, and many rely on community food programs (e.g., food banks and community meals) because their disposable income is so scant that they cannot afford to buy enough groceries to last all month. While the importance of nutrition to aging persons living with chronic illnesses, and the desire to eat healthily both came up, cost was a practical barrier to eating well.



"I had to leave, I was so sick I was incontinent at my desk in 1990. My pension from 14 years of working on The Hill, is \$800 bloody measly dollars a month."



Participants also discussed not being able to afford out-of-pocket medical expenses such as nutritional supplements, certain vaccinations, and over-the-counter medications.

The loss of health benefits when a person turns 65 years old and transitions from a provincial income support program on to one or more federal pension programs came up often. It is worrisome and counterintuitive to participants that coverage for expenses like dental work, hearing aids and eye glasses is discontinued at a point in life when they are most likely to need it.

The PANACHE ON team noted several instances in which participants shared conflicting information about their income and benefit entitlements before and after age 65. These misunderstandings indicate that the array of provincial and federal income support and benefit programs Ontarians have to navigate is overly complex.

*"I need that operation,
I can't have it done 'cause I
can't afford it. I have to get
a new pair of glasses after
it's over with. I don't have
\$500. And I never will.
So what am I going to do?"*

Family and Community Support and Access

The fact that many of our study participants receive some level of emotional support from partners, family, peers, neighbours or a network of close friends is heartening. Practical support from the same network of informal carers was described less often, but there were several good examples nonetheless. A few people described helping out friends who needed it and were hopeful similar support would be available to them in the future. It was common for individuals in our study to have small or loose social networks because HIV stigma and/or homophobia, loss and cultural norms have strained family relationships or led them to develop strictly casual friendships and sexual relationships. Many long-term survivors lost significant others in the early days of HIV and have been unable to rebuild their support systems. Several people said they were entirely without support.

Community-based (HIV) organizations were cited by participants as low-barrier sources of informational, social, and tangible support, including

community meals. In contrast, several people described the subsidized housing system as being riddled with barriers for older adults living with HIV including long wait lists, limited housing options, unsafe and unsanitary living conditions, and disrespectful treatment by housing providers.



"I have been HIV for a very extended period of time, and have lost a lot of my connections, people have died. Period, that is our reality. As an individual, you don't have that sort of formative relationship with new people. So the dynamics in terms of looking for support from them is a bit different, it almost is nonexistent. So you have to rely more on whether they are good agencies that you're connected with, whatever family members are remaining..."

“You put them in margarine containers and throw them in the freezer...You know? So then when you're near the end of the month and your money's runned out, you've got that meal.”

Self Help and Access

Study participants described a variety of strategies they use to cope with financial short-falls and limited access to support, including:

- Not paying bills some months, not using utilities, negotiating with lenders, and accumulating debt
- Accessing food banks and community meal programs and stretching food budgets through batch cooking, avoiding waste, and careful shopping
- Finding no- or low-cost services such as student-run health programs, library internet access
- Returning to work in older adulthood, drawing on retirement income before retirement age



“I don't have a payment for Internet every month. So I have to use the public library for 1 hour maximum, and you have to sign up, sometimes wait for two hours in order... the spot free for you to use.”



***UN Principles for Older Persons #5:
Older persons should be able to live in
environments that are safe and adaptable to
personal preferences and changing capacities.***

Our study participants have to make trade-offs when it comes to their housing. Some people have opted to live rurally or in suburbs in order to spend less on accommodations, but they are further from support and healthcare services, more reliant on infrequent transit services, and potentially more vulnerable to HIV stigma in these smaller communities. Market rent in an urban setting, close to a multitude of services, can be prohibitively expensive and increase reliance on subsidized housing. Some older adults report feeling an increased sense of vulnerability to violence in their city neighbourhoods and poor living standards in their dwellings.

Regardless of their needs or preferences, some older adults are stuck where they live, or anticipate being stranded in future, because they can't afford the costs associated with moving or

there are long wait lists for supportive housing. Study participants had varying preferences for HIV-specific and age-specific housing environments.

***UN Principles for Older Persons #6:
Older persons should be able to reside at home
for as long as possible.***

Multimorbidity, cognitive changes, and financial and social precarity are all common in this study population. Many of our participants have difficulty carrying out the day-to-day tasks necessary to live independently, including cooking, housework, yard work, groceries, and dressing. The question of whether they would have access to the support they need to stay in their own home as they age was raised by participants, however formal home care services were rarely discussed across the consultations. This may indicate that older adults living with HIV are not familiar with the community care and supports available to help them adapt to changes in health or function and remain at home.

Recommendations to Foster Independence:

- * Ensure a living wage
- * Universal pharmacare
- * Better access to affordable housing

"I find when I get up on a ladder I can climb it up, but I... I don't know how to get down. I fall. I end up falling."

Participation

UN Principles for Older Persons #7: Older persons should remain integrated in society, participate actively in the formulation and implementation of policies that directly affect their well-being and share their knowledge and skills with younger generations.

Numerous study participants hold paid or volunteer positions within community-based (HIV) organizations, and participate in events like camps, retreats and community meetings for people living with HIV. These activities support older adults' on-going connection with peers in the HIV community, and *sometimes* facilitate their formal or informal involvement in decision-making about the programs and services provided in these settings. Unfortunately, older adults living with HIV don't always feel heard by the very organizations some of them helped to establish. Instances of tokenism, and dwindling opportunities to gather with the community and provide mentorship to people more newly diagnosed due to changes in organizational or funder priorities, were both described. One person observed that there is no HIV organization in Ontario whose exclusive mandate is to address and advocate for the needs of older people.

Ageism, in combination with ableism, homophobia, classism and HIV stigma, prevents active participation in society by older adults living with HIV. Several research participants feel ignored by organizational and government decision-makers because of their age and the associated perception that older adults are no longer 'active contributors' to society.

Recommendations to Foster Participation:

- * Build coalitions with other communities
- * Enhance mechanisms for participation in decision-making
- * Combat ageism

"They made promises, and I said to myself we're just a number on a file waiting to be closed. And I said there's no need for me to be on the board, if I come on the board and I make a suggestion and they said yes and they never even make the effort to call, especially me of all person make that suggestion."

Care

UN Principles for Older Persons #10: Older persons should benefit from family and community care and protection in accordance with each society's system of cultural values.

As previously described, emotional support from close friends, peers, virtual communities, family (including adult children) and partners is readily available to a fair number of our research participants. Seeking support from others was one of the most commonly reported mental health coping strategies currently used by this sample of older adults living with HIV. Some could also access caregiving and practical supports from their networks. Knowing this social safety net was in place if they needed it was reassurance enough for one person who had a strong resolve to remain independent.

Self sufficiency was a necessity for others who do not have the same level of support in their lives. For this sub-set of people, social network size and quality had often been compromised over the life

course by intersecting forms of stigma, adverse childhood events and multiple losses. Poor mental health, mobility issues and trauma were cited as barriers to maintaining or building new relationships.

"You know, with the electric wheelchair you can spin on a dime. But they keep denying it you know what I mean? And it would really give me a lot of... enjoyment of life or, you know..."

UN Principles for Older Adults #11: Older persons should have access to health care to help them to maintain or regain the optimum level of physical, mental and emotional well-being and to prevent or delay the onset of illness.

Physical Health and Care

There is a high prevalence of self-reported chronic illness, pain and disability among our study participants. They described living with diabetes, lung and heart disease, arthritis, peripheral neuropathy, cancer, infections, osteoporosis, ulcers, and stroke in addition to HIV. While a few people said they remained as active as ever, mobility issues, low energy, falls, pain, and loss of dexterity contributed to varying degrees of difficulty with activities of daily living for most others.

Access to health benefits, healthcare and assistive devices is inconsistent. Individuals spoke of systems-level barriers such as wait times for specialist appointments, inconsistent



interpretation of eligibility criteria for health benefits and difficulty paying out-of-pocket for uninsured medical supplies and health services. Other care-related concerns for participants are: the perceived lack of knowledge among healthcare practitioners regarding the underlying mechanisms of disease among people aging with HIV; having health concerns discounted by medical care providers who perceive those living long-term with HIV as being on “bonus time”; and feeling that help-seeking does not align with their self-image.

"I don't sleep, I'm on sleeping pills, I still don't sleep. I'm the type of person that a lot of people think is strong and I've gotten this all my life "you're so strong....I told you I'm not so strong, does a strong person become a substance user?" I said no. I said that's where my weakness goes, that's where I break and I can't handle things, that's my escape."

Emotional Health and Care

Peer support is valued highly by many study participants. Learning from others' experiences, knowing someone else experiences the same things and feeling heard and understood helps improve mental health. Community-based (HIV) organizations were acknowledged as facilitators of this kind of support. Older adults in our study

described episodes of self-isolation, insomnia, substance use, and demotivation and attributed these experiences to poor mental health and stress linked to poverty, poor health, stigma and loss.

Several individuals spoke positively about the mental health care they had accessed, celebrating supportive providers, taking an active role in their treatment, finding the right medications, and participating in group programming that built mental health coping strategies such as meditation. In contrast, barriers to accessing reliable professional mental health care including cost, wait lists, and loss of a trusted therapist were also raised. Some older adults have also had negative experiences with counselling and therapy which impacts their willingness to engage. In one group, participants expressed feeling uncomfortable talking with much younger counsellors in



their local community-based (HIV) organization about aging-related experiences because they felt embarrassed and/or poorly understood.

Mental Health and Care

Cognitive changes such as difficulty with word-finding, memory, following a conversation, multi-tasking, and concentration, were reported across all groups. These changes have an emotional impact on older adults living with HIV as well as practical implications that threaten health or independence (e.g., missing appointments, taking medications incorrectly, being unable to complete important paperwork). Many are using compensatory strategies to cope with changes but there is little formal care available to assess or treat these symptoms, especially outside Toronto.

"Now I'm forgetting friends name, at what point do I forget my dog's name, or what... at what point, you know, is this a... is this a degenerative thing we're dealing with?"

"I'm starting to see people I'm meeting, getting to know, liking, and all of a sudden they're dying too. So it's mimicking what we went through in our 20s with all these deaths, and it brings back all that old baggage."

UN Principles for Older Persons #12:
Older persons should have access to social and legal services to enhance their autonomy, protection and care.

Community-based (HIV) organizations were acknowledged by our participants as facilitators of social connection among people living with HIV by providing safe, welcoming spaces to connect with peers, however some older adults face barriers to accessing these services. Study participants lamented the inability of local HIV organizations to provide services to those who are housebound, or respond immediately to pressing support needs. Participants also reflected on the impact of changing funder priorities and HIV organization mandates.

UN Principles for Older Persons #13 and #14:
Older persons should be able to utilize appropriate levels of institutional care providing protection, rehabilitation and social and mental stimulation in a humane and secure environment; and should be able to enjoy human rights and fundamental freedoms when residing in any shelter, care or treatment facility, including full respect for their dignity, beliefs, needs and privacy and for the right to make decisions about their care and the quality of their lives.

The older adults living with HIV who took part in our study anticipate doing poorly in long-term care facilities due to understaffing, neglect, stigma or inhospitable conditions in low-budget facilities. Past and present experiences of systemic and interpersonal discrimination predispose many of these individuals to high levels of anxiety. Participants frequently discussed whether people living with HIV could expect to receive safe, high quality care in residential care settings, especially if they were 'out' about their 2SLGBTQ+ identity.

Recommendations to Foster Care:

- * Deliver HIV and aging education to service providers across settings of care
- * Simplify processes for accessing care
- * Ensure equitable access to aging-related benefits and services
- * Provide more support for mental health
- * Supply more resources for aging in place



"So I have to be able to plan for what comes next, and looking at the problem dealing with not one of us, but two of us. And how do we plan for that to happen where both of us knowing that situations in retirement homes may not be ideal for HIV positive people in the first place, and gay couples in the second place."



Self-fulfillment

***UN Principles for Older Persons #15:
Older persons should be able to pursue
opportunities for the full development of their
potential.***

Older adults living with HIV in our study said that staying engaged within their communities, seeking out opportunities to learn, and occupying a significant role in their social network helps provide them with a sense of purpose and fulfillment. While one person said that HIV has no impact on how they live their life, many feel that HIV has limited their potential in some way. People living with HIV long-term described not having had an equal opportunity to pursue their passions, establish close, intimate relationships with others, and make plans for the future.

Physical limitations, social inequities and gaps in formal support service access necessitate that older adults living with HIV use a multitude of strategies to make ends meet and complete

*“You know, it’s my grandkids.
My grandkids keep me going.”*

activities of daily living. The time and energy required to pursue personal goals, or even enjoy simple pleasures, is not always available after this work is done. Several people said cooking for and eating with others is a joy, but sometimes they are too tired to even prepare food.

Work is an additional avenue for community connection and a sense of purpose, both of which were described by our participants as important strategies for mental well-being. Unfortunately, opportunities for older adults living with HIV to engage in the workforce are limited by: policies governing eligible earnings for people receiving social assistance; the professionalization of HIV services and associated undervaluing of lived experience; and the lack of vocational support

for people living with HIV who are re-entering the workforce after a long absence.

Some of our participants indicated that they feel fulfilled by their relationships while others expressed being lonely or longing for greater intimacy or sexual satisfaction. The importance of touch to combat loneliness was mentioned more than once. HIV stigma and problems with sexual function act as barriers, preventing some of the older adults living with HIV in our study from having the sex they want.

"It's not about sex or... it's more the companionship, you need a hug, and stuff like that. You know, as we age, we are being... feeling very lonely."

"If you want to engage someone that... maybe not younger, maybe 5... few years younger than you oh you're too old. Right? Or you're not my type, you know? There's actually a double stigma besides HIV, you're also getting older and then maybe they don't think that you have a very healthy sex drive."



UN Principles for Older Persons #16:
Older persons should have access to the educational, cultural, spiritual and recreational resources of society.

Several of our participants are buoyed by their faith and receive support and a sense of belonging from their faith communities. Others nourish their bodies and minds through exercise, retreats for people living with HIV, preparing and eating culturally-specific comfort foods, or keeping on top of new information about HIV and aging. They have found ways to overcome transportation problems, income insufficiency and stigma to access affirming spaces and tangible resources such as gym memberships, art supplies, specialty ingredients, research summaries and more, though this often means having to invest significant effort.

Our research participants also use an array of internal resources and self-management strategies to improve their physical, mental and social well-being, including:

- self care activities
- harm reduction
- pacing and setting priorities
- radical self acceptance and refusal to internalize stigma
- maintaining a positive attitude
- social pruning

The fact that older adults living with HIV in the study have developed such a comprehensive suite of coping strategies despite having inequitable access to educational, cultural, spiritual and recreational resources is a testament to their resilience.

Recommendations for Self-Fulfillment:

- * Provide opportunities for learning, creativity and social connection
- * Eliminate policy barriers to employment
- * Subsidize transportation

"I don't want to give up my independence. Like since moving in with my brother I've given up my artwork, it's sitting at home not being done, I've given up my writing, I don't have a computer to work on, you know, I'm sitting there... I'm isolated with him for my safety, but I'm not able to do any of the things that make my life worthwhile."



"I have personally had to learn how to say to myself this is not important, and it can wait till tomorrow. I really just need to sit and veg in front of the TV, or I need to go fishing, or... or whatever."



Dignity

UN Principles for Older Persons #17:
Older persons should be able to live in dignity and security and be free of exploitation and physical or mental abuse.

Living in poverty contributes to feelings of worthlessness for our research participants. More specifically, several people described feeling trapped in sub-standard living conditions, and others worried about having to move into second-rate long-term care facilities in the future. Problems with pests, excessive noise, crime and poor maintenance contribute to stress and indignity. Several people described threats to their personal security. Examples were provided of financial exploitation by relatives, crime and violence in subsidized housing, and bullying or discounting by service providers. Participants in one consultation had a lengthy discussion about feeling increasingly vulnerable as they age.

Participants who are experiencing disability in aging also struggle to maintain their dignity. Participants described struggling to carry out day-to-day tasks and feeling embarrassed about it. Many were reticent to ask for help. Not wanting to be perceived as 'old' or feeling like a burden on their social circle are symptoms of internalized ableism and ageism among our participants.

"I don't want to hinder anybody with the burden of having to call me every day just to... are your sugars okay? Hey, is this okay? Like... I just want to get old. I mean, we're going to die. I just want to do it with dignity, I don't want people all hanging around me saying, you know, let me poke... I have a medical team that does that."

UN Principles for Older Persons #18:
Older persons should be treated fairly regardless of age, gender, racial or ethnic background, disability or other status, and be valued independently of their economic contribution.

One of the most significant factors affecting the dignity of our study participants is HIV stigma. Some people, particularly those who identified as gay and bisexual men, maintain their self esteem in the face of HIV stigma by refusing to internalize the notion that they are 'less than' and by cutting ties with those who treat them with disrespect. This can be difficult for older adults living with HIV from some cultural communities who experience intersecting forms of stigma. Several people reported being unable to disclose their status to family or friends and experiencing shame and

disconnection as a result of keeping their HIV status a secret.

Participants in our study have experienced intersecting forms of stigma across the life course which has compromised their ability to access services or resulted in poor treatment within systems of care. Many fear that these injustices will continue or worsen as they age and they will no longer be able to advocate for themselves.

Recommendations to Foster Dignity:

- * Challenge HIV stigma in the general population and in all environments where people living with HIV live, work, and seek care and support
- * Ensure stricter regulation of long-term care and retirement homes

"You know, hiding HIV hurts because I've been away from my home for 14 years now, and when I left, I was HIV. And I never had the courage to tell my sisters or my brothers."

"But I've been looking for an apartment, I call up and on the phone I guess I don't sound Native, so I get there... and they're like 'oh... yeah, we just gave it away to somebody.' I'm like I just called you, like, 5 minutes ago."



In Summary

Regardless of their HIV status, it is common for older adults to have questions about what the future holds for them. What is unique to people living with HIV is that they experience the aging process with three additional burdens: trauma, stigma and fear rooted in multiple sources of uncertainty.

How does trauma affect aging with HIV?

Trauma predisposes people to fear. Our study participants, especially those living with HIV long-term, have experienced significant losses and harmful marginalization over the life course and have every reason to assume that this will continue in their senior years.

How does stigma affect aging with HIV?

Stigma impacts their relationships with potential aging-care providers, whether these are family and friends, or professionals within systems of care. Material deprivation means many of those we spoke to are unsure about whether they'll have the resources they'll need to weather aging-related changes in income, health, and function. They don't have the financial means to pay for care in order to fill gaps in the publicly-funded system.

How do fear and uncertainty affect aging with HIV?

Not being able to exercise control over their aging-related care is an additional source of uncertainty for this group. Aging care, benefits and services are notoriously hard to navigate and misinformation is abundant. Criteria for determining eligibility for programs are not always transparent and access to supports is not always equitable. Though community-based (HIV) organizations are largely experienced by our participants as safe spaces and facilitators of peer support, they are not currently meeting the needs of people aging with HIV.

Our participants fear becoming less able to advocate for themselves as they age which is a frightening prospect for people living with HIV who have always had to fight to get what they need. If they live alone, also a common occurrence for people aging with HIV, they may be more reliant on formal services which leads back to concerns about access and exercising autonomy.

Limitations

The PANACHE Ontario study used community consultations to collect qualitative data. Our findings represent the lived experiences of the 73 people we spoke to and cannot be considered representative of all older adults living with HIV in Ontario. We recruited for our study through the community-based (HIV) organizations that hosted our consultations which means that our findings are most reflective of the experiences of older adults living with HIV who are connected in some way with such an organization. We engaged very few participants diagnosed with HIV within the last 10 years whose experiences are likely to be somewhat different than those who've been living with HIV long-term. Finally, we would have liked to engage more transgender older adults living with HIV.

Recommendations

We conclude our report with a summary of policy and practice recommendations which aim to address care and support gaps and remove barriers to service access by older adults living with HIV in order to *make HIV a non-issue in aging*. Our study shows that older persons with HIV, especially long-term survivors, often have a smaller, more delicate personal safety net than others in their age group. Since many in this population will rely more heavily on formal systems of care and support as they age, it is prudent that policies and practices in all service settings support their best interests. Changing policies and practices that are harmful to people aging with HIV will, by extension, improve the lives of older adults more broadly.

We offer four categories of recommendations. Policies and practices to build on, resume, start and stop. The HIV community should take the lead when it comes to raising awareness among organizational and political decision-makers about responses needed to address the unique issues faced by people aging with HIV. In other circumstances, the HIV community should build coalitions with advocates in other communities (seniors, disability, 2SLGBTQ+, etc.) to amplify their calls to action.



POLICIES AND PRACTICES TO BUILD ON

Meaningful Engagement: Hone mechanisms that enable older adults living with HIV to contribute to the development and/or modification of organizational and government policies and programs that affect their lives.

Addressing Stigma: Do more to combat ageism in society, community-based (HIV) organizations and healthcare settings. Continue to challenge HIV stigma in the general population and in all environments where people living with HIV live, work, and seek care and support. Insist that policies and programs are responsive to the impact of misogyny, transphobia, homophobia, racism, classism, and ableism on older adults living with HIV.

Approaches to Care Delivery: Build interprofessional teams to provide care to older adults living with HIV. Continue to offer virtual healthcare and support services after COVID-19 restrictions end and increase access to these programs by fostering technological literacy and making devices available.

Publicly-Funded Support: Increase funding for programming that addresses the mental health and social needs of older adults living with HIV, including uncertainty and loneliness. Increase access to publicly-funded professional mental health services. Expand the availability of publicly-funded and subsidized services that support independent living in the community (e.g., maintenance, cleaning, food preparation, shopping, etc.)

"I lay there no food in the house, medically sick, and unless I call the ambulance, which I don't have the money to pay, I've got two bills right now... I'm locked down. I've been to the point of near death because I get locked down and can't get help where I am. And I... and because of the mental health issues you just... you just give up and not even going to call anyway. The hell with them."

Safe spaces: Maintain safe, welcoming spaces for older adults with HIV to learn new things, interact with peers, mentor others, be creative and set and achieve goals. Recreational programming should be accessible within and outside of the HIV community.

Expanding Housing Options: Increase the affordable housing stock. Reduce wait lists for subsidized housing. Develop more long-term supportive housing for people living with HIV. Address safety issues and improve the quality of subsidized housing.

Simplifying Navigation: Establish clear, simple processes for accessing aging-related benefits and services. Ensure people aging with HIV are aware of the benefits and in-home and residential care services available to support them *in advance of need*.

POLICIES AND PRACTICES TO RESUME

Holistic Programming: Re-allocate HIV funding toward creative and social programming (e.g., retreats) that fosters a high quality of life for older adults living with HIV instead of focusing solely on physical health outcomes.

Regulation of Long-Term Care: Impose stricter regulations and resume routine comprehensive inspections of long-term care and retirement facilities to ensure they are safe and comfortable places to live and that resident care and dignity are prioritized over profit.

"You know, and so that is one of my greatest concerns, getting to that age where you're so defenceless, like, you have no form of defence, and the people who are supposed to take care will make sure that you're safe, are not concerned."

Providing a Living Wage: Introduce a universal basic income program. Provide a living wage to people who rely on provincial income support programs and/or Old Age Security.

Facilitating Better Access to Medicines:

Establish a universal pharmacare program. Increase the scope of the Ontario Drug Benefit (ODB) program to ensure it covers ALL prescription and over-the-counter medicines and medical supplies required by people age 65+.

Fostering Inclusion: Take a life course approach to HIV education, ensuring that service providers are aware of the history of HIV/AIDS and recognize medical and social ‘turning points’ that may impact the present-day well-being of older adults with HIV. Affirm the right to intimacy and sexual expression for people of all sexual orientations and gender identities living in residential aging care settings.

"I'm in my own house too living alone -- you'd be surprised how much damage gets done to that house just sitting, and... how much you get buried in garbage, and all your belongings and then your belonging start to get ruined and then the house becomes totally unliveable, but I'm living there. Any time I've had people come in to do any work, I've been ripped off for all of the things I could have sold if I'd had the energy, for the money to be able to get out of there."

Education for Carers: Cross-train health and social service providers in geriatric and HIV care.

Promote intergenerational exchange and reduce the likelihood of stigmatizing care by training younger people living with HIV to act as carers to older people living with HIV. Mandate orientation and in-service training for long-term care staff on the needs of people aging with HIV.

Supporting Aging in Place: Increase funding for lower acuity care (e.g., home and community care, supportive housing) to support aging in place and decrease reliance on long-term care facilities.

Valuing Carers: Provide better pay and working conditions for personal care providers.

Ensuring Equity: Address inconsistencies in the availability, eligibility criteria, and assessment processes for publicly-funded services and supports that facilitate independent living, including rehabilitation services, assistive devices, and the mandatory special needs benefit.

Getting People Moving: Subsidize public transportation for people accessing income supports and government pensions to facilitate the use of green space and cultural venues.

Demanding Accountability: Institute a report-card or credentialing process for long-term care homes and other seniors' services to increase transparency about how HIV-friendly and HIV-competent they are.

POLICIES AND PRACTICES TO STOP

Prescription Fees: Eliminate the ODB co-payment for each prescription filled or refilled.

Downloading Care: Stop downloading caregiving onto informal carers (family, friends, neighbours) by increasing the number of contact hours between paid carers and older adults in the community and in long-term care.

Claw-backs: Eliminate policy barriers to employment since work can provide a sense of purpose and opportunities for social connection.

"...once I pay all my utilities and everything I have \$150 a month that's my discretionary income, that includes my food."



"I find that you don't... if you make too much money, then you're starting to lose 50 percent of that off of your cheque. So it doesn't really help to have a job. Really, it's the only way it helps me is that I have the paycheque every two weeks, so I have some cash, you know? Otherwise I'm waiting till the end of the month like everybody else and then they're taking off, like, if I make over \$200, 50 percent now is coming off."

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