



Positively Speaking

A podcast from Casey House

Season 1, episode 4 - HIV and Housing

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[theme music]

Liz Creal [0:05]
[music continues
in background]

Welcome to *Positively Speaking*, a podcast that explores the experiences of people living with HIV, the virus that causes AIDS. I'm your host, Liz Creal. *Positively Speaking* is being produced by Casey House, Canada's first and only standalone hospital for people with HIV/AIDS. The topic for this episode is HIV and housing. Specifically, how HIV impacts a person's access to housing and how housing or the lack of it can affect the way a person manages their HIV.

Access to affordable housing in Toronto as challenging as it is in many parts of Canada. The waitlist for rent geared to income housing can be years for a single person. Living with HIV adds another set of barriers and challenges as many people rely on supportive housing for stable health.

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According to the City of Toronto, the average market rent for a one bedroom apartment is \$1270 and \$1100 for a bachelor, but the average monthly income for a single person living on the Ontario Disability Support Program is just \$1100. Xica is an HIV positive trans woman of colour originally from Honduras. now living in Toronto, she struggled to find an affordable and safe place to live.

Xica [1:15]

Being a trans person and in a settler in this country, I have found myself kind of going from place to place trying to hold on to a job, trying to hold on to an apartment, trying to hold on to friends. But, the housing has been an issue for me for the last, since I got here because it's really not affordable for somebody who is, who has a hard time finding work or living with HIV.

Ben [1:46]

Many people living with HIV find themselves homeless due to multiple factors, the lack of supply of affordable housing, insufficient income, loss of employment income due to poor health, and in certain cases, their HIV status. In Toronto, the waiting list for rent geared to income housing is 7 to 10 years, even longer for a single person. As mentioned already, market rent is unaffordable for people who live on the Ontario Disability Support Program.

[atmospheric
background
music]

Ben is a 41 year old gay man who was diagnosed with HIV at a young age. He remembers what it's like to be homeless and having to stay in shelters.

Ben [2:24] I was homeless first. And then I did my application and waited exactly 11 years and got accepted for a co-op in downtown Toronto.

I became homeless because I got sick with HIV and AIDS because I had HIV and tuberculosis. So I got sick and I was hospitalized for seven weeks. So, while I was sick, I ended up losing my job. And, I couldn't go back to school for sign language. And, I wasn't able to pay rent at that time, so I ended up staying in the shelter system for the first time. I was 26 years old, which was unfortunate because a lot of the youth shelters was 25 and under.

[atmospheric music fades out]

I managed to sneak into a youth shelter for a while north of the city but decided to move back to Toronto to access services, and that's where I found myself homeless and just kind of bouncing from shelter to shelter. And, that's where I found two organizations Fred Victor center and Fife House Foundation, who helped me apply for the housing connections waitlist for the first time, and it was a very confusing, not having an address and applying for housing. They asked for an address. And, I used, I used one of the housing agencies address as my own to receive mail.

Liz [3:55] As Ben explained there are numerous barriers to applying for rent geared to income. You have to be organized, have a bank account, government issued ID and a birth certificate. For people who are homeless, another barrier is not having a fixed address, of requirement from housing connections, the centralized housing registry. And, even if you have an address, you have to have physical energy to get out there and look for housing. For those lucky enough to live in rent geared to income housing, it's still a struggle to get by financially. Just ask Kevin. He's a long term survivor who had stable housing until he split up with his partner.

Kevin [4:31] So, financially it's been even with rent geared to income, I still have to have an outside income that I have to report to ODSP every month and after, I believe it's a couple \$100 they start taking 50% of your paycheque. So I can work only so many hours before it's not worth my while to keep working, which I I've asked about you know, why don't they change the system? At least let us get to poverty level before they start taking off 50%.

Liz [5:06] And sometimes the only affordable housing options available can do more harm than good.

Ben [5:10] First, I went into a rooming house, I think that lasted a month, because it was so chaotic. I had no idea what I was moving into. It was the middle of winter, and I just wanted a place of my own where I can shut the door and lock it. It ended up being very detrimental to my health, so I didn't stay very long. I actually would rather be in a shelter situation than a place where I felt completely unsafe.

- Liz** [5:43] Managing money while dealing with physical and mental health issues, as well as substance use can be next to impossible without support. Derek left home as a young teenager and was homeless for years. He finally found stable housing after he was given the opportunity to live in supportive housing for people with HIV. He describes his experience of substance use discrimination and losing control of his money.
- [atmospheric background music]
- Derek** [6:05] But then, addiction sets in, HIV set in, denial sets in, you know. Back then, you were afraid to mention it at work, that you are HIV positive. At one point in my life, I had assigned PG and T, public guardian and trustee, in which you your cheque goes into them and they give you your money, and then you get your \$50 and you go into transitional and give it to Fife House. So, in other words, you weren't allowed to control your own money. And, if you get extra money, you'd end up getting a grocery card with extra money. And I had that for about 15 years. And, it taught me a lot at first there was a lot of anger, hatred towards my money. I should be able to spend when on what I want. But, there's no if ands or buts about it because this was appointed by a psychiatrist.
- Liz** [6:55] Fife House is the only housing provider in North America that provides transitional supportive and permanent housing specifically for people who are living with HIV. Derek describes how through their support, he was able to thrive and keep his apartment.
- [atmospheric music fades out]
- Derek** [7:09] I needed what Fife House later on provided: case management; a little somebody to talk to; to understand and to help me, to guide me and teach me how to keep an apartment. By keeping the apartment, I mean, knowing who to invite, keeping it clean.
- Liz** [7:27] Supportive housing for many people living with HIV is a necessity. It's key for people who need assistance, accessing and navigating supports and services.
- Xica** [7:36] Having proper housing is everything, because if you don't have proper housing, by that I mean affordable, and according to your needs, somewhere that you that you can have some support is everything. Because if you don't have that, you won't be able to excel on anything else, because you'll be just trying to survive.
- [atmospheric background music]
- Liz** [8:02] Access and affordability aren't the only housing issues faced by people living with HIV. As we talked about in the last episode, they also face the pervasive burden of stigma. The stigma of HIV itself, the stigma of being poor, and the stigma that goes with mental health and substance use. Just a note about stigma and discrimination – they're not the same thing. Stigma is a negative stereotype. Discrimination is unfair treatment due to a person's identity; it's the behavior that results from this negative stereotype. Under the Ontario Human Rights Code, every person has a right to equal treatment with respect to among other things, their disability and sexual orientation. Matthew is a young

gay man originally from Ottawa who's come face to face with this stigma.

Matthew [8:47] Becoming homeless and seeing a lot of judgment towards people that are homeless, a lot of judgment toward people who have mental health and addiction issues. And, because back then when I became homeless I never thought or... being on the opposite end of the spectrum, looking at someone who's homeless, sometimes you have compassion. Other times you judge them because of their mental health or different things. But, when you actually live in the moment of being that person, it's quite challenging, and it's quite sad to see how people think and process things. It's almost as if, at one point, like a similar experience that I had was being treated as a second class person. Literally like I walk into a bus terminal and was told to get out because they thought I was homeless.

Liz [9:42]
[atmospheric music fades out] People living with HIV and looking for housing carry an extra burden. If a landlord finds out their status, they could lose their housing. Xica and Matthew describe the struggles and blatant discrimination they've experienced in this regard.

Xica [9:55] The social stigma with people of different races, age, background. It's, it's very pronounced. We've done some work, there's been you know, we're now trans people are in the Human Rights Act and the laws on HIV have slightly changed due to the U=U campaign. But, the stigma in people is still out there, it's really it's really heavy. So, being able to like not have a home or not affordable housing, when you have all these barriers are it's, it can be, it can be very detrimental.

Matthew [10:41] It was probably going to drop down for the first time to about, I think was about minus 10 outside. And, it was December, beginning of December. I spent the night on the bench at the 519. I had my ex-fiancé walk by and put \$5 in front of me because he didn't trust me enough to be on his couch, which was the most harshest thing I've ever had to encounter. This was my ex-fiancé. So, it was hard because here I was struggling with my addiction, not knowing what to do. And at this point I was missing doctor's appointment, I was really struggling.

Liz [11:25] Due to the lack of affordable housing, many people are forced to live with roommates, some by choice, some not. Some people pool their resources and share a market apartment with friends. Some live in rooming houses, shelters, some couch surf, and some share accommodations. But, living with others when it's not by choice, but by a necessity can be stressful. This was definitely the case for Xica, she's lived in transitional housing, a program that helps people transition from homelessness to permanent housing.

Xica [11:57] It was a struggle, I'm not gonna lie. It was a struggle to be in a transitional housing program, living with 12 other people from different

backgrounds, and different values. But, it definitely gave me the lesson that I had been waiting for all my life.

Being able to actually see how everyone is vulnerable, because the stories are from people that are worse, very successful at some point. And, it's not really the HIV or the sick that got them, that got us, there. It was stigma. And it was it was all that this is traumatic stigma that really goes after people's souls, you know, to just really push them down and keep them down there.

Liz [12:55]
[atmospheric
background
music]

It's well known that the level of violence, safety and social cohesiveness in a neighborhood can influence health and well being. It can increase stress, and can limit movement and social interaction, which prevents people from engaging in healthy practices like walking, cycling, or even accessing essential health services.

Many people who are living with HIV also need to deal with concerns about poor housing conditions. In Toronto, there's a huge backlog of needed repairs for many buildings. This is an additional stress that Kevin is well aware of.

Kevin [13:27]
[atmospheric
music fades out]

It was a mess when I first moved in. They did the balconies, which was about six to eight months of just jackhammering every morning and noon and night, it felt like. It was very stressful, extremely stressful. I made it through, but I was screaming at a lot of people at that time. Then they did the garage, which was another year of banging and hammering that went. I've dealt with cockroaches, bedbugs. It's just been a mess. It finally quieted down about two years ago. So I've been in there about 10 years, so I've had two years of almost calm depending on who your neighbors are as well.

Liz [14:13]

Bedbugs are another huge issue. According to the Toronto bedbug registry, Toronto was ranked the city with the highest bedbug infestation in 2017. A 2013 *National Post* article likens health care's reaction to this epidemic to the early days of AIDS, when patients with this disease were often treated as pariahs. Casey House clients have reported that some agencies refuse to provide services in their homes until their bedbug infestation is cleared up. This adds another layer of stigma. But, there's another cost associated with bedbugs, one that Ben experienced firsthand.

Ben [14:47]

And, another thing I learned about downtown is there's a lot of issues with bedbugs, which is something I've never had in my entire life until now. And, cockroaches is another thing I've never had to, you know, deal with before. But cockroaches are easy to contain. It's these bedbugs, that I've never had to throw out my furniture before, after just kind of re-establishing my life after graduating and coming downtown and being all excited and furnishing an apartment and being, you know, super happy and I'm so close to my services. And now I'm at the point where I'm throwing out my bed and my couch is halfway thrown out.

- Liz [15:30]** Replacing furniture is expensive, and finding housing without pests can be challenging. Housing is one of the most urgent unmet needs facing people living with HIV in Canada. While the disease crosses the full socio economic spectrum, the majority of people with HIV live on a fixed income. The day-to-day reality of someone trying to maintain their physical and mental health, struggling with substance use and try to maintain their housing can be really challenging. Accessing needed supportive services can be another burden
- Matthew [15:58]** in the housing situation, especially for someone living with HIV. The services in terms of like getting personal care workers are only provided to people who are really sick or really really struggling. I've had date and but you can't predict that because the problem with HIV or living with HIV, mental health, and addiction is some days are better than others.
- Liz [16:23]** According to the Canadian AIDS Treatment Information Exchange, people who have a stable place to live and the support they need feel better physically and mentally, and they're more likely to follow their treatment plan. That's why getting a housing subsidy can be a game changer, and an opportunity for people to make a fresh start to rebuild their lives.
- Ben [16:40]** With the subsidy I stayed there for 10 years and I loved it. I stayed there and I went back to work and I went back to school and I got a personal support worker certificate.
- Liz [16:59]** [atmospheric background music] For people living with HIV, having healthy social connections is essential to one sense of well being. So is living in a community where you feel safe and accepted. To Kevin it's made all the difference.
- Kevin [17:11]** This feels like home. The moment I came and landed at the Roman Baths years ago, that felt like home. And it always has been downtown Toronto, where the boys are out, you know, where I can watch two gay men hold hands down the street and not have to hear screaming and yelling, and you know, fistfights happen because of it. So, I hope that Church and Wellesley survives, because that seems to be being pushed, you know, the community I remember, that I needed to come into as a gay boy coming from a small town into the city, I needed that community. I'm not sure if it's as needed now. But it definitely felt like home.
- Liz [17:54]** But, there's some potential risks to living in a tight knit community.
- Ben [17:57]** There's definitely pros and cons about living downtown, I love the convenience. I have access, I mean, walking distance between all of my circle of care and health care providers, and all of my supports are all within walking distance. I really like that. And then I guess some of the cons would be like, I see a lot of my friends who were I was street
[atmospheric music fades out]

involved with, using a lot of drugs, in particular crystal meth, and, you know, asking to stay with me or you know, just it, it disheartens me to see my friends, you know, kind of deteriorating and not able to find their own stable type of housing that I have.

Liz [18:56]
[atmospheric
background
music]

Finding stable, appropriate housing is an absolute must. Xica puts this clearly and succinctly.

Xica [19:02]

Looking back and thinking about what would have happened if I wouldn't have found the proper housing for me at that particular time. I think I'd be dead. I'd be, I'd definitely be dead.

Liz [19:22]
[atmospheric
music fades out]

Access to clean, safe, affordable housing can be challenging, but there were important and positive messages our guests conveyed about not selling yourself short, and accepting unsafe, poor living conditions.

Kevin [19:33]
[uplifting music]

Yeah, I think again, it's home isn't just that little pad you live in. It's the extended community outside of that. I think, for me, at least that makes a home, not just my little one bedroom apartment.

Ben [19:47]

I wouldn't recommend that people settle for a place to stay temporarily. I wouldn't recommend people move into a place thinking oh well, I'll only be here for a couple months because that tends to like, if it starts off by being a bad situation, it will probably remain a bad situation if not get worse. I wouldn't settle for anything less than what you're willing to conditions you're willing to live in.

Matthew [20:18]

If you're someone who's living with HIV and you're struggling to get housing, or you've given up the little bit of hope that you think that you can get housing or you can change, or that there's nothing out there, don't. Like there, there eventually there is help, there are good people out there.

Derek [20:40]

Well I'm 53 years old right now, and I've learned the importance of family, the importance of friends, and making your house a home, standing up each other in solidarity, and being proactive, sharing your life with others. But, also being respectful to yourself as an individual. And, it's really hard. I learned this through CSAT, Community Sensible AIDS Treatment. Sometimes you just gotta say no.

Xica [21:08]
[music fades out]

I have been able to do some capacity, social justice, capacity building, training, and I have been able to do work for the community as a peer leader, activist, trans activist, HIV advocate. And, I've also been able to go back to my artistic roots. And, it's like things are going well. I'm still struggling a lot with my health in certain ways. But, being having supportive housing has really allowed me to be able to take the load off and be able to feel, you know, supported, so I am a very, very lucky girl. You know, where you need to be told that you are if you are special, you do matter, that you count. And, that's what happened to

me. And when I started feeling that positive feedback, I started thinking, yeah, you know what I am something of value.

Liz [22:16]
[theme music]

We've heard from our guests about the many barriers to finding affordable and safe housing compounded by the stigma of being HIV positive. We've heard about the often deplorable conditions people are forced to live in. But, we've also heard about the importance of living in a community that one identifies with, and about people overcoming barriers and finally finding a place they can call home.

If you're someone living with or affected by HIV, there are many wonderful organizations and groups in the community who can provide supports and services, please visit [HIV 411.ca](http://HIV411.ca).

We'd like to thank our guests Xica, Derek, Ben, Kevin and Matthew for sharing their stories.

This episode was produced by the RTA School of Media at Ryerson University. It was written and produced by Andre Ceranto, Amanda Crawford and me, Liz Creal. The music was composed and performed by Nick Nussbaum. Remember to subscribe to *Positively Speaking* on your favorite podcast platform. If you have any comments or questions about this episode, we'd love to hear from you. You can email us at podcast@caseyhouse.ca. You can also visit our website at Caseyhouse.com. For a transcript of this episode, a glossary of terms and occasional bonus material.

Our next episode will be about HIV and isolation. Here's a short clip to give you a taste of what's to come.

Allan [23:38]

It's it's hard, especially in the summer to go outside and like see what I'm missing. And then it feels like it kind of hurts because I realized that there's good weather out there and that there's another life I could be having. Instead of you know isolated playing video games and watching movies and whatnot.

Liz [23:59]

Thanks for listening.