

'Nothing has changed': The roots of Saskatchewan's HIV crisis

Melissa St. Denis radiates a quiet strength.

St. Denis is a peer mentor at the Persons Living With AIDS Network of Saskatchewan. She was diagnosed with human immunodeficiency virus (HIV) 13 years ago, the result of a boyfriend who lied about his health.

At first, she was angry.

"I found out on my birthday, and then I got high," St. Denis said. "For a year straight, every day I got high."

"But you know," she said. "I just got tired of it. I just realized it wasn't going to help me and that I needed better."

St. Denis got sober. Today, she dedicates her life and time to helping women whose shoes she was in.

"I just find myself to be a mama bear," St. Denis said. "If I see it, I say it. I don't mean to be blunt, but I have to be straightforward and honest. Especially when it's girls I've known my whole life, and they're still out there and they're still addicted and they're still struggling. They're HIV positive. It's hard to watch that. It really is."

St. Denis is just one story of HIV diagnosis in Saskatchewan.

Last year, there was a new HIV case in the province every 28 hours — totalling 168 people, or a rate of 14.1 per 100,000 people. That's more than twice the national average. In the province's 83 First Nations communities, the rate is four times the national average.

To understand how we got here, you have to go back — to the trauma of colonization, to stigma, and to the history of a crisis many say we should have seen coming.

Deep roots

Saskatchewan's problem isn't just bigger than the rest of Canada's: it's also unique.

In the rest of the country, a 2017 study indicated men who have sex with men are the most vulnerable population.

Saskatchewan is the only province where injection drug use — not sex — is the primary risk factor in HIV transmission. Seventy-one per cent of people diagnosed with HIV in 2018 injected drugs, according to a provincial report.

"People really perceive that to be an issue that affects gay men, or men who have sex with men," said Saskatoon Sexual Health education and outreach coordinator Natalya Mason.

"In some provinces that may be the case. But in Saskatchewan, the primary group of new infection is people who inject drugs. The secondary group following that is heterosexual sex."

The cost, material and personal, is enormous. The Ministry of Health estimates the average cost-per-life bill for each case is \$1.3 million, including \$250,000 in health care bills. It's part of why the ministry spent \$667,000 last year on harm reduction initiatives like needle exchanges and condom distribution.

Saskatchewan distributes more needles per capita than any Canadian province — roughly seven per person. That's on top of \$43 million poured into HIV prevention and treatment since 2010.

AIDS Saskatoon executive director Jason Mercredi says the amalgamation of health authorities has helped spread best practices provincewide. Last year, the number of new cases decreased by five per cent.

His organization is preparing to open the province's first sanctioned safe consumption site, which he believes will reduce the number of HIV cases by as much as 15 a year by giving people a safe, sanitary place to use drugs. It will be the only safe consumption site between Thunder Bay and Lethbridge.

"We need to keep innovating," Mercredi said. "We can't just rest on our laurels."

On reserves, regional medical health officer Dr. Ibrahim Khan of Indigenous Services Canada reports fewer new cases and improved connection to services compared to 2017. Ninety-six per cent of diagnosed cases are linked to care within one month.

"These are things that we couldn't imagine ten years ago," Khan said.

To understand HIV, Dr. Carrie Bourassa says you have to understand colonization.

The scientific director of the national Institute of Indigenous Peoples' Health says safe consumption sites are needed to turn the tide, but she believes the roots of the crisis are the effects of displacement, the residential school system and discrimination.

“It’s pretty well known that this is rooted in intergenerational trauma, and not just historic impacts of colonization,” Bourassa said.

In 2018, 76 per cent of new HIV patients in Saskatchewan self-identified as Indigenous.

Bourassa conducted interviews with 148 HIV and hepatitis C-positive Indigenous women as part of work with the group All Nations Hope. She found many were unable to connect with care and faced racism in the health system.

St. Denis knows it well. She says she once had to intervene after a nurse at a hospital commented that another Indigenous woman “shouldn’t even be here,” and that the hospital didn’t have room for her.

“It’s always ‘If you’re native, you must be addicted. If you’re native, you must be HIV positive,’ ” St. Denis said.

When a new patient is diagnosed with HIV, they have to make regular connections with doctors to suppress the virus before it develops into acquired immunodeficiency syndrome (AIDS).

But Dr. Ibrahim Khan says many of Indigenous clients are so scarred by racism they encountered in the health system that they are wary of reaching out for support.

“The majority of these people who are being diagnosed have serious mental health issues stemming from the long impact of colonization and the post-colonization effects, which still exist,” Khan said.

“It is 100 per cent rooted in colonization.”

As of this year, Khan notes 38 First Nations communities now have self-run harm reduction sites with a focus on culturally safe care.

“This is an indicator you would not see anywhere in Canada,” Khan said. “It’s only Saskatchewan, in our communities, where we’ve been able to achieve that.”

Bourassa wants health care to move toward a model of cultural safety and self-determination where Indigenous communities can shape their health care systems.

“I feel that’s what reconciliation is about — it’s figuring out how to live together so we can all prosper,” Bourassa said. “But we can’t just forget what happened. And we can’t discount it. There is a context there. It’s not about blaming or shaming or anything else.”

Stigma

Even as health agencies get better at fighting the sickness, they’re still struggling to overcome the stigma around people living with HIV or AIDS.

Before Cheryl Barton's brother was diagnosed, she says her house would always be full of friends. But Barton, now the executive director at the Persons Living With AIDS Network of Saskatchewan, says they suddenly stopped coming after it was revealed her sibling had HIV.

"People didn't understand," Barton said. "And we didn't have the time to educate them. We were looking after someone who was very sick."

When Khan began working in Saskatchewan 16 years ago, he says people would literally be "expelled" from their communities when they were diagnosed with HIV.

"People ended up in the ER with full-blown AIDS," Khan said.

"Those times are gone, but there is a great deal of stigma associated with HIV, especially for Indigenous people, particularly drug users or women."

Mercredi said the fear is driven by a lack of education. Many people don't know HIV can be treated to prevent further transmission, for example.

"We hear people that aren't allowed to have dinner with their families," Mercredi said. "We hear from people who are told they have to leave their community. "People can live with the virus, but they can't live with the stigma and the discrimination."

Mercredi said even if people may not consider themselves to be at risk, getting tested helps break down stigma around the virus.

Last year 85,617 HIV tests were performed in the province, a new record, driven partially by improved access to testing at point of care sites.

"I can't tell you how many times I've had people in our offices crying because they didn't think they were in an at-risk category," he said.

"You'd have to live in a box."

The UN has set goals that 90 per cent of people with HIV will be diagnosed, treated and have the virus suppressed. Saskatchewan has met its target for treatment but, as of 2016, 30 per cent of people living with HIV in the province did not even know they had it.

"Eliminating that stigma of HIV is going to be such a huge piece of achieving those goals of eliminating HIV as a public health concern," Mason said.

St. Denis says not much has changed about having HIV in 2019 versus 2006. The stigma is still there. The biggest difference is the one that she's made — both as a peer mentor supporting her friends in need, and the path she has chosen.

"As long as I feel that I've made it right with people and brought some good into this world, I'm good," she said.

