

HIV in My Day – Interview 21

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Interviewee: Art Zoccole (AZ); Interviewer: Sandy Lambert (SL); also present: Ben Klassen (BK)

Sandy Lambert: Art, so when did you get involved in the gay community?

Art Zoccole: Oh my god. So, I came out rather late when I was twenty-six years old. I was living in denial in my community, and at one point I decided I needed to tell my family. That is where I started from. At first, I was very apprehensive about disclosing that I was gay or Two-Spirited to my family. I grew up in the community of many religious organizations, the Roman Catholic being one of them, of which my grandfather belonged to, and that, I think prevented me from coming out. But when I came out and I started to talk to each one of my brothers and sisters – one at a time, because I come from a large family – the first few responses that I got was, “We knew that. You didn’t have to say it. We knew it all along.” And others were – a brother that I had was very macho, and he said, “We are going to send you to psychiatrist and he is going to make you be corrected,” but after a while he was my greatest supporter in the long run around coming out.

SL: You came out later in life, so how did you entertain yourself in the bars and the gay community?

AZ: Living in a very small remote community and not seeing anybody else that was gay... later on in life, I did find out that there were other gay people that lived in this small town that I grew up with and I was quite shocked actually to not know that when I lived there that they were actually gay. So, I moved to Thunder Bay, Ontario where I enrolled myself in college to take an accounting program, so moving to a smaller city and encountering – it wasn’t something I was looking for in terms of a gay community. It just so happened, one evening, and then I realized, oh, so this is how things are done in a small city for connecting up with other gay men. And it was usually in the darkness of night, cruising around in a car, and I thought this is quite unusual – and anyway that was the circumstance in this small city. When I went to college, I decided that at some point, that in order to follow the path that I chose in terms of being an accountant, at some point, I thought the place to go would be Toronto. So, building up to moving to Toronto, I had heard other stories from other gay people in Toronto that, “Wow, Toronto is just fabulous there. They have many establishments that you could go to,” and one of them that was pointed out to me was the Parkside Tavern.

So, when I arrived, I was really excited about, wow, I finally get to experience a gay bar, gay life. And you know, being far away from my family, I thought I would be anonymous, right? But even at the same time, you know when you are coming out and you are going into a gay bar for the first time, I paced up and down outside that gay bar like a sentinel for hours on end before actually going in. And I happened to arrive at the end of October, and so it was getting close to Halloween, and I heard from people in the gay community that the St. Charles Tavern was the place to see all the people dressed up as women going into a bar, which I had never seen before. And so, I stood across the street from the St. Charles Tavern and I was absolutely horrified

because what I saw and witnessed was people who were dressed up in women's clothing – drag queens as we would come to know them later – were being harassed, names were being thrown at them, and people on the side of the street that I was standing on were hurling obscenities at these individuals as they were going into a gay bar. And I was so shocked. I went around the corner, found a park bench and I sat there I would say for two hours really questioning, “Is this what I really want to get myself into? Look at how...” I came from an Indigenous community and in my life I had experienced racism, and now I was seeing racism toward gay people. And so, as a young Two-Spirit man I was going, “Oh my god, what am I doing?” I was really questioning, “Do I stay? What do I do?” So, I think at that point I decided I need to stay, but then I was very cautious about going into gay bars and would use back alleys, I would never go in through the front door – those kinds of things based on what I had seen and what I had experienced. It was very traumatic in the very beginning.

So, that would have been in the 1970's, and during this period I had lots of friends – Quebec people, people who were from England, and from all over Canada. And there was this one instance where a friend of mine had made his way to New York city many times and he really liked going to New York, and at one point when he came back to Canada, he ended up in the hospital. And we heard that he didn't want anybody to come and see him in the hospital, which was really, really unusual for all of us. This was 1982. He ended up in Toronto General and he passed away, and when we found out later on, he actually had KS. And then that's when we started to hear about this disease that was happening in the community and then that eventually... The word that described it was GRID [gay-related immune deficiency], and so that sort of put us on guard of what was happening out there, but we didn't know what to do. There was no messaging, there was – and you know, in the '70s and '80s was the sort of the gay revolution because of what was happening in New York City around Stonewall in the 1970's, so it was starting to happen in Toronto, the gay liberation.

So, the early days of when AIDS hit the Toronto community, there were some protests that I took part in as well as others, but you know, I just went to support the community because we would pick up a copy of *Xtra!* and there would be two pages of young men who had passed away from AIDS, and this was on a regular basis. So, each month there was a whole new set of pictures in the paper and you would look and see if you knew any of these individuals. And there was such a large number at the time, and you know, you would see people who had KS and the wasting syndrome. And then, in the Indigenous community, it eventually entered our community. And with our friends, that's where we decided to start taking care of people who we had become friends with, and we would do impromptu care teams, so we would take turns of being with an individual on their journey to their spirit world. And so, there was a large number of us to do it. And one of the things I want to say is it was the Two-Spirit guys, the gay men, who came together to help do the caregiving, but the next group to come along to help were the women, and in particular the Two-Spirit women, because they were their friends too, right?

And so that leads into a place where we started to think about, maybe we should start organizing – and I am going to use his name and you can take it out after – his name is Tomson Highway, who is a well-known playwright in the Indigenous community, and he approached me and said, “We should start a Two-Spirit...” – we didn't call it a Two-Spirit organization, that came on later – “...We should start an organization for gay people.” The original idea was, yes, we need

to support the people who were becoming infected with AIDS, but also at the same time they wanted to bring an artistic or a theatre piece to the organization to go out and spread the message to the communities. And so, that was in our first objects of our incorporation. But one step back, the government of Ontario heard what we were doing and approached us and said, “How would you like to have 50,000 dollars to start an organization?” And we had no idea what we were getting ourselves into. We said yes, and we struggled in the very first years in getting the right people, getting on the right path to do the work in HIV, right? And then, years later, we changed our by-laws to take out the theatre pieces because we hired educators to go out in the community eventually.

SL: How did you end up on Vancouver? When did you come to Vancouver?

AZ: Once we started the organization in Toronto, I was in a relationship and I separated from my relationship, and I thought, “Okay, I need to get out of Toronto.” And my sister happened to live here in Vancouver at the time, and I was here and sort of got involved somewhat in the gay community on Davie Street back then. That was 1989 to 1991, so AIDS is still there in about but I didn’t really focus in on HIV and AIDS. So, one of the things I got a job as is the GM of Vancouver Native Housing Society and worked at that during the time that I was here during that period. But I think also, at the same time, when I was involved in housing, then you begin to realize that the people who are living with HIV and AIDS need supportive housing – maybe getting a subsidy, maybe having buildings that are accommodating to people who are living with HIV and AIDS. Because at that point, still there is a lot of fear and discrimination. We had those conversations, but at that point, I don’t think anything became reality until years later.

A good friend of mine, who is Ken Clement, who is the CEO of the Canadian Aboriginal AIDS Network, back then was the ED of Healing Our Spirit. You know, it was a great organization, I really enjoyed... I actually volunteered at Healing Our Spirit a number of times, ‘cause when I got here, I think one of the things that I had to help them do is plan celebrations of life, because we had started to do that back in Toronto. When somebody had passed away, we would do a celebration of life, because back in Toronto, when somebody died, the communities would not let the bodies come back home because people thought that AIDS was coming back home with the body, so we, in the city, had to do something about getting their spirit to the spirit world. And we came from many Indigenous nations – Mohawk, Iroquois, Anishinaabe, Cree, and even out here, there were people from the Haida nation. And so, there was a large number of Indigenous nations, so when we prepared the celebrations of life, there was no one way of doing it. Whoever got up to speak in whatever language was respected; whatever ceremony was conducted was respected as well, and we all came to these urban centres with these gifts and we showed other people.

And with my experience as well – because of the Sixties Scoop, there was a large number of individuals that when they reached eighteen and they were gay, they would be put back out into the streets – they were no longer in care and they would end up at our door. And we would say to them, “Okay, we need to begin to figure out where you are from.” Some of our challenges, too, was around that people, their records were sealed so we were not able to find, sometimes, their home community. But once we found their home community and who they were, we began to

teach them some of the culture and some of the ceremony, and some of the things that they needed to find out who they were, right? It's quite a process.

SL: Did you – were you ever involved with any of the organizations, like the Greater Vancouver Native Cultural Society? Because I know that they were – when this epidemic happened, they were very involved in that.

AZ: Personally, remember when I said there were a number of people who were from this part of the country who lived in Toronto? There was a number of Two-Spirit guys who were from BC [and] they moved back here to Vancouver. So 1989, when I got here, I looked them up again but what I saw turned me off. And the Abbott Hotel I think it is called, and that is where they used to have some of their functions. So, one evening I thought, I will go down and see what they are up to, but what I saw doesn't sit well with me because they were dressed up in traditional outfits and they were in a bar and drinking beer, so the two to me doesn't mesh. And so, I just – I knew who they were and I never attended any of their functions again, because my personal beliefs and how I lived my life, the two collided and in my view the two needed to be separated. You don't do alcohol and ceremony at the same time.

SL: Did you find that the Indigenous world and the non-Indigenous world were separated? Did they ever come together?

AZ: During the epidemic, it was a very challenging position to be in sometimes. Like in Ontario, there would be a larger number of non-Indigenous groups versus the Indigenous groups - and again, my personal view is that – and I don't want to be disrespectful in any way, but it has been years or longer of teaching non-Aboriginal people about who we are as Indigenous people. So, sometimes it is like two row wampum, if you are familiar with that, where you live side by side, coexist, and from time-to-time we shared the information that we would have with each other. That is where I have come all of my life and I have spent my entire life educating non-Aboriginal people about who we are to the point where I did a research project called "Two-Spirit Men Wellness and Longevity," with Dr. David Brennan, and in that study we really got to the core of what and how Indigenous people view the world, the holistic way that we do health. Right from the beginning of the epidemic, we used the medicines that were prepared by the pharmaceutical companies that tried to deal with HIV and AIDS, which in some case,s which I witnessed in the very early days of the epidemic, is individuals taking AZT, four pills every four hours, which was horrible. And I witnessed that to the point now where we have antiretrovirals that some individuals – well, myself, I am on three antiretrovirals right now, but some people can go down to one antiretroviral.

So, at the same time – I think I have to go back to when I was diagnosed with HIV. I was placed into St. Michael's Hospital, and my community in Toronto heard that I was in the hospital, and I almost died when I was diagnosed. And by the time I was hospitalized, my CD4 count was 60 and it further went down to 30. While I was there, the community brought in our Two-Spirit drum which is big and they brought in braids of sweet grass and placed them on top of the drum, and also they had placed cedar around my hospital room. And my sister in her life she had an eagle feather and she was always instructed, "Wherever you sleep, you will have to put that eagle feather above where you sleep on the wall or someplace close by." So, my sister had given me

that eagle feather. So, when I was in the hospital, I had eleven doctors and I can't remember how many nurses or orderlies or people who cleaned my room, but everyone who came into my room asked, "What are these articles?" And I said, "I am Indigenous and those things are going to help me. The care that you are providing is also going to help me, so both of them together are going to make me better." And a week later, I walked out of the hospital, amazingly, after all that care from the Indigenous side and the western side, and that began my journey of taking really good care of myself. And at that point, I was also diagnosed with diabetes, so that is a double struggle of life and that has been thirteen years since diagnosis.

SL: To come back to Vancouver, how did you find the activism or the advocacy? Where did you seek that because back then they had ACT UP and they had protests? Where did you find that or were you involved with that?

AZ: I think when I got back here to Vancouver the second time, again I got involved with Healing Our Spirit, and when I was volunteering, I met a couple of individuals – Alex Archie and Nadine Caplette. So, the three of us started having these conversations and we came up with this idea, and supported by Ken Clement as well, to establish a task force, and it was called the BC Aboriginal HIV/AIDS Task Force. We set out to develop strategy for Aboriginal people in BC, but there is one key player and that is really quite in the background – maybe two of them. And one of them who has now passed away, who was Dr. David Martin, and he worked at the First Nations health branch at Health Canada at Sinclair Centre. He really wanted to see this happen – and along that line in the provincial side was Elena Kanigan – yeah, she was with the Ministry of Health and so with the support of the provincial and Health Canada, we were able to move forward. It was exciting. We tried to move the development of the strategy very quickly and it was a BC strategy, so we needed to get in contact with people from the north, from the island, from the Downtown Eastside.

There was a young lady who was on the task force with us who was living with HIV but had been in the Downtown Eastside and some of our meetings were held at Vancouver Native Health Society. And Lou Desmarais really supported – you know, he gave us free space and to have our meetings. And he had one of the staff members who I had a lot of respect for, she was a front line nurse, Viola Thomas, and you – just amazing. But back to that young lady – I remember one morning that she showed up for the meetings and discussion that we were having about developing this strategy and she got there and she was distressed, absolutely distressed. And the reason for her distress was that she had been an active user in part of her life, and where we were having our meetings, she was having to walk through the Downtown Eastside, and she was just uncontrollable. So, what we did instead of just moving right into our work, we had an elder there and the elder took time to do a ceremony, and we spent about two hours to actually calm her down, to make her feel that she is very supported and she was in a supportive place and safe place – to let those feelings go. It took a couple hours to do all of that. I was so glad that that elder was there – her name was Mary Louis and she was just absolutely amazing during the development of the strategy, because when we were developing the strategy, there was a lot of urgency, there was a lot of anger, there was a lot of emotions in developing this strategy. But this elder, when she saw us going through those different stages, and she had a big eagle feather, and she said, "I want everybody to stop right now." She would get up and she would walk around the circle and she would talk, and we would watch her and observe her, and she would realize that

until we would all settle down, then we were able to continue on and do our work in a good way – just amazing.

SL: How did Red Road come about, because you were part of that as well?

AZ: That was the beginning part, when we developed the strategy. We launched it in Nanaimo, and there was an amazing story about Nanaimo – when we went to different places in BC to have the annual Aboriginal HIV/AIDS conferences, we were greeted by the local Indigenous community. And I can't remember what the name of the nation is, but I remember standing in front of the mirror saying the Aboriginal name of Nanaimo hundreds of times, because I wanted to – you know when you go somewhere, you have to say it in their language, and I practised and practised and I got it right. They did a ceremony for us, for Alex Archie and myself, and we were instructed to go to the centre of the room and just stand there, and they were going to put head dresses on us that were hundreds and hundreds of years old, and these headdresses went straight up and we were not to touch them. They put the headdresses on us and then they put a blanket around us and then what they did is they all gathered around us and they drummed. And it was such a special moment because I remember when I was trying to find out my identity, who I was, I went to many many libraries to look up Indigenous gay people, and there was one particular picture that I remembered from the Sauk-Fox nation, and it is around Pennsylvania or the higher part of North America, where they had a ceremony to honour Two-Spirit people, and it looked exactly like that picture that was happening to us at that time. And that was such a proud moment of being recognized – for being recognized for who we were, and it took HIV and AIDS to do that.

And then to go on from there, once we released the strategy, and I think it was in Nanaimo where we started talking about establishing a provincial group. And so, I remember we said, yes, we are going to do it but I remember the process – “What are we going to name it?” And there were some interesting names that came up but the one that we ended up with was the Red Road HIV/AIDS network, which was supposed to be representative of all the province and all of the issues that were coming from the various parts of BC at the time. And so, when we incorporated, we shared offices with Healing Our Spirit and as you can imagine, when you are running an organization, proposal writing is always at the top of the list, so Health Canada at the time said, “We realize in HIV now we need to do research,” so they said, “This is what we are going to do. We are going to have 500,000 dollars for Indigenous HIV research.” I'm sitting here in Vancouver and I am thinking there are ten Aboriginal HIV groups around the country... 500 thousand, I will apply for 50 thousand. So, very quickly – there was a very short period of time to write the proposal – I wrote a proposal on GIS mapping of HIV services for Aboriginal people in BC, it got funded. And then I realized that I should have gone for the whole 500 thousand – nobody else applied. But anyway...

I think – just to get into research for a little bit, you know, Health Canada had no idea what they were doing. They were not set up to give out HIV or research dollars, so because we are an Indigenous pot of money, we said we wanted Indigenous reviewers, which worked out in the beginning. But years later, I remembered applying for another research project, and in those days you would get your – the reviewers comments back and I remembered looking at some of the comments of the proposals I wrote and I thought, my god, this is an Aboriginal Indigenous

person reviewing our research? They had no clue around culture, around who we are, ceremony and how that all plays into us to do the research. And it was an Indigenous person – I was just shocked. So, that is when things at Health Canada kind of went into a tailspin, and shortly thereafter was the creation of the Canadian Institutes of Health Research, and that I liked in the beginning because when CIHR started funding research projects – I am not an academic – I was an executive director of an organization and I was able to hold the funds, and you get all the funds up front. I was like, yes! But then years later it changed, where you had to go back to an academic source.

SL: Do you think community, the Indigenous community back then, came together compared to today?

AZ: Things have changed in three decades or longer. I remember when we started doing education and prevention work I would go back to Toronto at the native community centre, which is a friendship centre, and there were these all gay guys with a little booth in the corner and they had condoms out. And in those days, we had dental dams and I remember all these Indigenous women coming up to our table because sex and sexuality in the Indigenous community was taboo – it was something that was not easily spoken about in public, right? So, these Indigenous women would come up to us and pick up the dental dams and they would say to us, well how do you use this? So, us gay guys would go like this [pretends to hold up dental dam] and it became humorous, and that broke the ice. But then the next thing we knew, when we looked at our table, all those dental dams were gone. So then, the women were empowering themselves to protect themselves as well, because we didn't know at that point how HIV was being transmitted. Generally, you knew it was sex, but was it oral sex? How was it? So, we had condoms, and I remember when we first brought out the first female condom and the women were like, oh my god, what was this thing. But the gay men were going, I love this thing. It was fun as well – you had to have fun because HIV and AIDS was a topic that scared a lot of people.

But what I really appreciated in the long run around HIV education was mothers would come up to our table. They would have youngsters in puberty – you know, twelve, thirteen, fourteen – and they wanted their children to have condoms and these prevention things. And even in my own family I noticed the right of passage for young men – my nephew, my sister and my brother-in-law sat and spoke probably in the first time in our history that they actually said, “This is what you need to do in order to protect yourself.” So, that was happening now in families. The education message took a long time to get out there, but it got out there. And going back to Toronto, you hear about gay pride and what it has become. So back then, we would distribute condoms and thousands and thousands and thousands and – but after a while it became... I don't know what the worked is. You know when the one company says you can only distribute during pride? That is what it came to and it was the Trojan company, which turned off a lot of people because there were other brands, there was other flavours, there was other sizes. And after a while, we just went, “You want to distribute Trojan. You distribute trojan.” So, there became a battle inside the gay community around that but also at the same time too in gay culture, gay history. In the early days of the pride movement, I remember our organizations being right in the village, right on Church Street, and after the years, years later, then the more the companies would get the main areas and the HIV organizations were off to the side. And so after a while, people discontinued participating setting up a booth at pride because they were at a place where

people couldn't get to them. So, there is quite the history of that whole movement and how it has changed.

SL: Going back to Indigenous people, has it always been that the women are here and the men are here, or in the early days were we closer than we are today?

AZ: I think the way that I like to describe it is the Two-Spirit men were the leaders in the beginning, then Two-Spirit women, then women, but it took the men – the straight men – a long, long time to come and join us. And I think some of it is part – again, I will use Ken Clement as a leader. He was such a strong leader, he actually asked the national leaders, including the national chief and the leader of the Metis nation of Canada to do annual messages, and I think when you start to see that that I... When you start to see more of the men coming in to be supportive – and one of the most here in BC, he has recently passed away, was chief Leonard George. He was – oh my god, unbelievable – such a strong supporter of HIV and AIDS to the point where he actually came to Healing Our Spirit to do volunteer work, and they asked him to open up a conference because we were holding the conferences in his traditional territory. He would accommodate, make time for HIV, and he was always on the AIDS Walks, you know, for years.

SL: You talked about our leaders and our chiefs. Do you think – and it took a long time to step up to the plate. Do you think they are closer to us in helping us with this disease?

AZ: I am going to say – you have to go way back to when I first started working for Indigenous organizations in the '70s. I worked in education, and I remember in Ontario, one of the regional chiefs, I heard him say, "We don't have a gay Indian problem." And I was sitting there and I heard him, and I am sitting there thinking, "My god, I'm gay. Doesn't he know that?" I worked in the office with him, so that kind of discrimination was happening within Indigenous communities and I think because we have lost so much of our traditional knowledge that I don't think he would have said that had he himself had more of his traditional knowledge on how everybody in our community is part of the community. That is the way I was raised, even though people would ask if I was gay, I was still supported for what I was.

I have been in a number of books and one of the things that I cite in my personal history was when I was about fourteen, where I am from, we pick wild rice and there is a ceremony that we do where you give a handful of the rice that you picked to a communal pot, the women in the community prepare the rice, and then we would do a ceremony. At the ceremony, the traditional knowledge keeper who was conducting the ceremony had had a few drinks so it was under the influence of alcohol, and during the ceremony, we are all sitting around the blanket and he looks right directly at me and he said, "How would you like to fuck me up the ass?" And all the women on this side scolded him immediately, and said, "You are not here to do that right now. You are here to perform the ceremony. Please continue." So, at that point, when I am very young – I was about fourteen years old – I knew I was supported by the community, because they spoke up for me immediately. Had we had that in all of our nations across Turtle Island, I don't think that you know that the discrimination ingrained against Two-Spirit people would have existed as much as it did in the beginning. But I think over the years, now it has kind of eased off a bit. You look at the community and climate of the country we live in, where you know there is now same-sex marriage and so many things that it is easier to be a gay Canadian than it was in our history.

SL: Two-Spiritedness, back in – years and years ago, before it was brought out again in 1990 – we were the leaders, we were the warriors. Where did we lose that?

AZ: I think through colonization and through the churches, and I came from a catholic family of which I don't practice that religion – I practice my Indigenous culture. A lot of that is that impact that it had on us, and a number of us from across the country now, there are well known Two-Spirit leaders in this country, and people who have actually written books. And there is a Mi'kmaq women researcher that I have connected up with over the years – I was supported by Dr. Don McCaskill from Trent University when we did the Toronto Aboriginal research project in the city of Toronto. I had come in to say, "I think how we should look at the Aboriginal or Indigenous community in Toronto is through the health aspects," and the people in the community said, "No, we want to know more about the Two-Spirit community." It didn't come from me, it came from the Native community centre, Native trauma, family services, women's groups – "We need to know more about Two-Spirit people. How can we help and provide programming and safety for Two-Spirit people within the city of Toronto?" So, it has come a long way. My experience is from both sides – the HIV side, the Indigenous side and the Two-Spirit side, and all my life, that is what I have advocated for moving those issues forward, speaking about those issues. And sitting at a table time after time after time: "My name is Art. I am Two-Spirit, and this is where I am from, and this is the organization that I represent." It was being consistent as well, 'cause if a lot of us haven't been consistent, it would go back underground so easily.

SL: Was it your mother that gave you your Indigenous name? You always say it.

AZ: No, my – it's strange to explain, but in my culture the word is weimas [sp?] and the equivalent in English is godfather. So, my grandfather actually gave me my name and I just want to quickly tell this story. So, when you are given a name by an individual, when that person dies, in our culture, you have to stay up for 24 hours with that individual, with their spirit, because it is the last time on this earth that you are going to spend with them. I think I was about eight or nine years old, and I was like, "Oh my god, I get to stay up all night!" And amazingly, as a little kid, I knew what I was supposed to do – I was supposed to keep company the spirit of my weimas, my grandfather, which I felt so honoured to do because I was the only one in the whole community that was asked to do that. And all night long, I was treated really – I didn't get tired but when I was hungry or thirsty, people would come to me and give me water, food, whatever I needed – it wasn't constant, it was as I needed. I felt very special. And in the morning, when the sun came up, another ceremony took place and at this point, now we are saying not our goodbyes, but I am realizing that his spirit is going to make its journey to the spirit world. So, they light up tobacco and at that point they would blow the smoke on me because I am a little kid, they don't expect me to do the pipe, or I just touch the pipe and then the adults do it. And it was such an honour.

SL: Just coming back to our health and as professionals that work in health, how do you feel we were treated with doctors and nurses and the whole profession of...

AZ: Some of it – there's two sides of it, right? I remember the very early days in Toronto. It was Riverdale Hospital and one of our friends on his final journey with AIDS was in there, and so the

family had asked if they could do a smudging ceremony, which in most cases would not have been allowed inside a hospital setting. So, they went to the higher ups within the administration and they approved it, but one of the things that happened was that the nurses and doctor who were on staff at the time had never seen this before and had asked, “Is it okay if we observe?” And the family said, “Yes.” And I think it went as far as can we take a picture. [Laughs] It was interesting. I can’t remember what happened with the picture, but it was kind of the first time but they were being accommodating. Living in Toronto, it’s not always easy and there has also been other places where there has been a lot of discrimination and the reason being is for example some of our people have been using substances, alcohol – one of them – so when they show up to the hospital setting, sparks fly. In a lot of cases, the Indigenous person will just leave out of frustration under the influence, but then in other cases it’s – you know, it resulted in a screaming match and then the police being called and so on. But as a result of that I think, in Toronto, there was the establishment of an Aboriginal committee to deal with racism within St. Michael’s Hospital and it went on for many, many years – it was a good thing that came out of it.

SL: So, you are talking about cultural safety that was implemented.

AZ: So, when I worked at Two-Spirited people in Toronto, we had an educator. We realized too that one of the things that needed to happen is that we don’t need to talk to the doctors now, it is the ones that are going to become doctors. So, we had our staff person go into University of Toronto and other places where nursing and doctors and they learned cultural safety – we would send in our staff person to catch them at that point. I did a research project called “What Health Care Providers Can Learn” – another one – and I went back to our community and I said to them, “What are your experiences in the hospital setting?” And what sort of started all of this for me is a friend of mine who is also living with HIV was on his way to a medical appointment one morning and as he is sitting in the waiting room, the receptionist points out to an individual, calls them out by name, and says, “Okay, the doctor is ready to see you.” And the Indigenous person is sitting there and thinking, you know, “I had an appointment. Why is she taking everybody else ahead of me?” So, he walked up to her and he said, “Why are you doing this?” And she said, “Well, all these people have to go to work,” right? In other words, “You don’t have a job,” and he was on his way to work and he was being accommodating to go early enough so that he could go to work, but just based on looks, that was what her reaction was. So, that sparked me to do a research project – how are Indigenous people being treated when they are approaching health care providers. Read all about it. So much.

SL: How are we doing? Are we good? Is there anything else you want to?

AZ: Oh, lots.

SL: Well, continue.

AZ: Ask my own questions, eh? Well, I think one of the things along the way is having people inside the systems. Inside the systems can mean Health Canada, it can mean St. Paul’s hospital, I can talk about community based organizations. And it is having individuals like that who are supportive, who go to bat for you, and who want to make things change – and in the early days of HIV and AIDS, I know the people that they hired at Health Canada were all from community,

so when they got there, they made a lot of changes, they made it happen. So, that community-based groups were actually getting the funding, and then after a while what I noticed is that there was a shift from hiring community-based folks to hiring – nothing to say against people who come from academia... There is a nurse I remember in Ottawa who was hired to Health Canada. You know, when we talk about HIV it isn't easy and I was sitting there explaining what is happening in the Indigenous community and how they are being treated and all the things that were happening and she cried and I handed her the Kleenex and I said, "Keep going. I am just going to keep on talking, and you don't have the time to wait for this individual to come up to speed," but she has been there for a number of years now and has grown a thick skin like the rest of us in the community and is able now to be an advocate for... because when you go in there, it is so overwhelming, there are so many demands. Where do you go?

And just another fact is the – in Canada, the Minister of Health convenes at their whim or convenience a panel or a counsel of people from the community, so in the early days I was asked to be part of the National Aboriginal Council on HIV and AIDS, and I thought, "Oh my god, they are finally going to get it right? So, they would go quarterly and the meetings would be held in Ottawa and we would bring up all kinds of issues. The one that comes to mind is a colleague of mine from Ontario at the time – she has now since passed away – Laverne Monette, was on the council with me and what we were seeing in the Indigenous communities was the breastfeeding of Aboriginal women who were HIV positive and the formula that they needed to have access to. So, we brought that forward to the council and the role of the council was that we were to bring the issues forward, and inside Health Canada, they were supposed to do something about it. Well, they never did anything about it. I think it was about two years later and we had brought lots of issues – when I bring the issues forward, I always often think, "Okay, we brought this issue forward. What did you guys do?" And they would come back to us and say, "Well, we haven't done anything." I went, "That's it. You are wasting my time. I am out of here," so I resigned.

There was – and I think to myself in the epidemic, when you want to get your message out there and it's not being listened to, and you are wasting your time, why bother? Move on to something that is productive, that is going to help people, eventually to help people deal with HIV/AIDS issues. It was just so frustrating at some points dealing with that, but you know, I think Canada – we have been able to... Again, I go back to Laverne Monette, and I was living in Toronto around 2004. There was an announcement that the World AIDS Conference was going to be in Toronto, so there was a meeting of the Ontario AIDS Network from time to time that we attended and Laverne got up and made a statement. She said, "When we have the World AIDS Conference in 2006, we are going to have an Indigenous meeting as well at the same time." I looked at her – we don't even have any partners at this point. There was the two of us and we were able to secure funding and we embarked on inviting people from Indigenous communities from other countries – so, Australia, the Maori from New Zealand. We found an individual, a trans Indigenous woman from Mexico and – who else? The United States, but the United States has always been – Indigenous groups have not been productive... But anyways, we – in 2006, we had that and the Indigenous satellite and there was a number of people there from all over the world and so that embarked on our international work. And to this day now, there's an international Indigenous HIV/AIDS organization that became incorporated.

SL: IIWGHA [International Indigenous Working Group on HIV & AIDS]?

AZ: No, IIWGHA, is the project. They have now incorporated an international working group – not a working group, it is an international HIV/AIDS organization. So, to come that far in that period of time, which has been very good and excellent, because when they went to South Africa, the question was are there Indigenous people in Africa? And of course, there is – there's Indigenous people throughout the world, including Finland, Norway, and Sweden – the Suomi people, right? Of which, the upcoming conference in Amsterdam, they will act as hosts for us, so it is interesting to connect up with all of these Indigenous groups from all over the world. The challenging part is, I think, the language and the language is the Spanish piece which I struggled with when we did the 2006 gathering. So, it was challenging but some of the issues faced by Indigenous groups in other countries are sometimes similar and other times unique to their country, so it has been very, very interesting, and something that has taken a while to get going.

I think to the point here in BC, where there has always been a lot of work that has been done here in BC, and some things that have been created here that are very specific to BC. And I think of the subsidy program, which I don't think happens anywhere else, and the other one is probably the allocation of HIV units in social housing – that it's not a well-known fact, but if you are living with HIV and you have a good advocate, those things can become possibilities for HIV individuals, Indigenous individuals, and those two programs are unique to BC. I think that is a lot of hard work of the people within BC itself. There's a document that the Canadian Aboriginal AIDS Network has – I don't know if you have a copy of it. So, during one of the Canadian Aboriginal AIDS Networks annual general meetings and skills building and I think it was the one that was held here – it's that hotel down there, yeah – and they had a specific day for BC Aboriginal HIV/AIDS individuals, and a document was produced out of that.

SL: Yes, I led that.

AZ: In that document is a brief history, I think, within there of BC. There's all these pieces of the history of the movement, right? But you know, a lot of it's not documented as well I think because, in the HIV/AIDS world, we're really close – we are really tight – but when you need to look beyond that... So, for example, and I don't know what the equivalent here in BC would be, but in Toronto, there is the Canadian Gay and Lesbian Archives, and in there they are beginning to catalogue a lot of the history of the gay and lesbian movement in Canada. Recently, they have reached out to Indigenous folks which is very different from years past – they never used to do that, right, and I don't know the equivalent here.

SL: We do have people who are archiving our history here in Vancouver. There are a couple people.

AZ: I think sometimes because the gay movement and the HIV/AIDS movement happened at the same time, and a lot of our organizations fought for those things at the same time, the injustices that were happening to gay people as a result of HIV and how policies changed, how the government has changed... So, just to go right back to the very beginning, when we started to incorporate in Toronto, the government at the time, the provincial government was unwilling to grant us incorporation status because we are a gay organization. It took two years, and that was

only one battle. The next battle was the charitable status – that took another two years. It was unbelievable. We started in 1989, and we were finally incorporated in 1995, six years later. It took all that time for governments to change their minds around who they were going to let be non-profit organizations. That is how – you know, these kinds of battles were not known by people in the community, by people who were on boards, the directors, and those kinds of things that you had to be up on.

And then, at the same time too, policies by funding bodies becomes an obstacle. An example would be the city of Toronto, or any other municipal government. So, they have a non-discrimination policy, right, so they want you to sign that thing before you get funded but when you are signing these non-discrimination policies, there was nothing in there around sex and sexual orientation. We were like, “Hello?” So, we had to go back to the government and say “Hello? Don’t you think your dumb discrimination policy should include us, the ones you are funding?” And that is just an example of municipal governments, and it happened with provincial governments and federal as well, so there were all these battles and policies that needed to be changed along the way. And in the Indigenous community, we need to change, and some points come up with our own policies, I remember, and it all started in our organization of Two-Spirit trans women being disrespectful to Indigenous Aboriginal straight women, so we saw this in our community. And we are going, “This is not right.” So, what we decided to do is to create a policy and we said, “There isn’t going to be any more discrimination within our own community.” And so, we came up with this policy and we thought, “Wow, it is such a great idea for our organization, but what about places where our community members are accessing services?” So, we tried it out in the Indigenous communities’ organizations within the city of Toronto.

One of the things, when we introduced it to them and they went, “Wow, this makes sense to us,” and they adopted it. They made a plaque – it was on the stairwell. “Wow, look at this. No more discrimination. I feel really safe in here.” A couple of years went by and staff had changed and so what I saw one day at the centre was discrimination against Two-Spirit people, and I thought, the guy who was doing the discrimination is standing right beside the plaque. Oh my god. So, you know, what we realized too is that you put in policies, but what you needed to do was redo them over again – not do them over, but say to community groups, “I think you need to train your staff again. Not us – you.” It has been quite the interesting road to be on around seeing all of these changes happening, and to be I think to a point now where you feel somewhat comfortable in accessing... And one of the things that I did in my life was that being an advocate for all the people that I provided services too, but I undertook it personally. I had a physician in Toronto, and he was non-Aboriginal and every time there was a document produced by the Indigenous community, when I went to my doctor’s appointment and I would bring him a copy. And I would put it on his desk and I would say, “Here is a copy for you to read at bedtime to educate yourself.” So, I undertook that to, you know – I wasn’t forcing it on him, maybe he tossed it in the garbage for all I know but it was a way to educate him in a very informal – here you go, you have it. So, it is up to all of us, individually, everybody, to speak up and to advocate for people who are living with HIV and AIDS.

Ben Klassen: Going back to the late ‘70s and moving into the ‘80s, how was the gay community in terms of being inclusive around Indigenous Two-Spirit folks?

AZ: Part of my history, personal history is that in Toronto there was a bar called That Bar – very famous place, you’d have loved it. And going there, you would tend to see other Indigenous people, and so you would go over and introduce yourself, and you soon became friends with them. And after a while, there was a special place in the bar, and we called it Indian corner – we would all be there, having a good time, but at the same time too alcoholism back then was more prominent, I would say. So, there was this whole racism piece around the “drunken Indian,” so there would be those remarks being made inside a bar, not to the point of physical fights, but there might have been occasionally if somebody got really agitated that there would be physical fights, but there was still some discrimination. But on the flip side of that, our Caucasian guys who have this Indian-cowboy fascination. There is always a good side and a bad side to things. So, you never knew, right?

One of the things I want to say about the early days of the epidemic which I saw and I witnessed in Toronto was after it became the HIV diagnosis, you would see somebody standing at the bar and they would have a conversation with another individual and the person would be right up front and they would say, “I just want to let you know that I have HIV.” What I saw was that the person that was being told would not say another word, would turn around and walk away. And oh my god – to me at that point, it was just so frustrating and hurtful, and you wanted to support that individual, but at the same time, what could you do? And this is the kind of discrimination that was happening so openly and in public, too. People who were living with HIV – and now we’re social media - Grindr, all these sites, undetectable, and it goes into describing your situation so it is up to... It is very different now and that is how technology has changed the interactions between gay men, Two-Spirit men, those kinds of finer details, but it has been quite... And when you went to a bar in the ‘80s, people had the wasting syndrome and they would still go to the bars and you would see these individuals in the bars, and some of them were having a good time up to the very, very, very end and that was their right – they could be there. Or if one of our friends was there and they happened to be out and all of a sudden not feel well, it would be up to us to take that individual, and make sure they got home and placed into bed, and then leave. Because in those days, you were very helpless, you know. You could be supportive, you could be there, you could bring them whatever they needed, but you know that there was nothing that the medication, all that stuff – it was such a time that you just needed to be there for the individual to help them out the best that you could.

BK: Do you have a sense of whether those HIV organization that were forming in Toronto and Vancouver – not explicitly Indigenous – were those organizations inclusive or whether there were issues?

AZ: There was very few places for people to go. And so, I know one particular place in Toronto called Casey House, where a number of our friends ended up, was very supportive, very understanding and we didn’t seem to have any confrontations, any issues – they were quite helpful. But on the other hand, some of the other agencies, people didn’t feel comfortable going there, because their Indigenous background, they would have been labelled, they would have been... so they didn’t even go. And when they did go, they would be frustrated and then they would discontinue, and that happens in Indigenous organizations too. So, when people really needed help and support – and sometimes it was financially. One of the things that – the annual

AIDS Walk as an example. In Toronto, the annual AIDS Walks, the funds were divided up to eleven agencies. We were one of them, so when I got back to Toronto in 2003, I am just going to say that our funds that we received was about – I would say about \$15,000 on the walk, and that enabled us to have an Aboriginal people living with HIV fund. And so, our board at the time said what we will do to help alleviate some of the financial burden, of people living with HIV and AIDS is if they come in with their phone bill, we will pay twenty-five dollars, and if they come in with their hydro, we will pay twenty-five dollars, and if they have cable, we will pay twenty-five dollars. So that \$15,000 with the clients we had, we would be able to spend the money all in one year. As the years progress and the AIDS Walk starts to diminish in participation and funds being distributed, the same things happened and our agency was getting less and less and less – I think to the final year it may be about \$5,000. So, then at one point, the AIDS Walk realized that this was not benefitting all of the eleven groups, so they decided to channel all of the funds to the main agency at that time. I had to, at that point, say to our community the fund no longer exists, which then the financial burden goes back to the individual client, because you know the amount of funds for people on disability is not a great deal. But when we had that little bit of fund to help them, they would be able to provide, maybe pet food, food for themselves and other small things that they may have needed, right? Toiletries as an example. That money went a long way but there is a history too of how that even impacted community groups. So, it has been quite the position when you're a leader to say, these things no longer exist, so you can just see what reaction you get from the community, right? So, lots of stories. Lots of stories. Enough?

SL: If you have anything to add.

AZ: What time is it? Just kidding.

SL: Or we can save it for another occasion.

AZ: If I think of anything... I said quite a bit.

SL: You did. I told you you would.