

AAHP
AIDS Activist History Project

Interview Transcript 2016.005

Interviewee:	Dionne A. Falconer
Interviewers:	Alexis Shotwell & Gary Kinsman
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Persons present: Dionne A. Falconer – DF
Alexis Shotwell – AS
Gary Kinsman – GK

[START OF TRANSCRIPT]

AS: We're in Toronto, it's April 1st 2016 and we're talking with Dionne Falconer.

GK: So, we ask some general questions at the beginning that we ask everyone. Where we start is to ask, do you have any memories of when you would have first heard about AIDS and what you heard?

DF: Actually, I do because it was in high school and I remember being in high school and sort of hearing about this disease that was affecting Africans. And I actually even remember writing a paper, like a school paper, about AZT [zidovudine], because that's what had come out. High school for me was in the '80s. When did I graduate from high school? '80-something. So, it would have probably been more towards the early '80s, because I think I graduated from high school in '88 or '86, around there... I can't even remember, but it would have been around that time. And I actually remember doing a paper on AZT specifically.

GK: Wow, that's pretty neat.

AS: Were you in high school in Toronto?

DF: Yes, high school in Toronto up in North York. Up at Wilson, so it was Madonna. That was the name of the high school, an all girls' Catholic high school.

AS: It seems kind of amazing that you would have done a paper on that in an all girl Catholic high school.

DF: It's the strangest thing. But I remember hearing about it and I can't even remember the specifics. It probably was more about like, in the news. It wasn't because I had belonged to a club. I think it was just more of a news story. And just perhaps from my own history and connection with Black people and Black people's struggles, hearing about this thing and becoming interested in it. And I think I also had heard... You know, because at the time I think it was GRID (Gay-Related Immune Deficiency)?

AS: Right.

DF: So, talking also about gay men. Although, I think they would have probably said “the gays.” [laughter] I don't know if I would have said gay men. They probably would have said “the gays” or “the homosexuals” back then. But, I also remember hearing about GRID and remembering *Essence* magazine. At times that would have articles. Those were some of the way back early memories.

AS: There is this period where I experienced talk about AIDS as heavily racialized. So, really like, “Where did this come from? Where in Africa did this come from?” Was that part of the narrative that you remember?

DF: I remember some of the pieces – and this may have been high school or probably more as I entered university – it was more around AIDS being from Africa, AIDS affecting Haitians. There was also the “triple H” – homosexuals, Haitians, and hemophiliacs. So, I remember bits and pieces about that, but I don't remember, “Oh, where did I first hear about it?” ... You know, they were talking about it affecting Black people, that there was an interest. I can't tell how initially, but there was that paper on AZT. How did I talk about AZT? Like, a treatment issue too. I don't know.

GK: So, you already mentioned the connections between AIDS and Africa. Do you have any memories of how you might have felt about that or responded to the social construction of “African AIDS”?

DF: I think I was pretty pissed about it, because I think already Black people were marginalized and then it just felt racist to me. Like, in terms of blaming Black people for HIV, because that's actually what would happen at that time, was that AIDS came from Africa and Black people were at fault. It's from sleeping with Black people why others are being infected. That was part of the conversation and what was out there. From my early HIV work, because of that kind of messaging people also then didn't want to hear. So, you're coming in – myself, my colleagues – wanting to talk about HIV and how it's affecting us, you know, we need to take action, we need to do something, and then people don't want to talk about that, it's “Already they're blaming us for this.” You know, “Why are you coming in to talk about that?” So, having that kind of negative response and that kind of pushing back. And so, for me, I do remember being really angry and pissed off and upset about that. The fact that once again Black people were being blamed.

AS: And then the affect of actually making it more dangerous and difficult for people ...

DF: Yes, Black people are not open to being educated about it, talking about it ... I remember sometimes in those early days too, it was like we were coming in more representing white people's perspectives on us. As opposed to thinking about, “No. This is something that *we* need to do, and this is something that *we* need to respond to, and *we* need to do it for ourselves.” And so here we are coming in to do that work.

GK: You mentioned *Essence* magazine. Are there other publications that had information that was important to you, or in response to at that point in time that you would have been reading?

DF: Not that I can remember. I think probably *Essence* might have been... It was one of the first things that came to mind. Also, I think in high school I was reading *Right On*, which was more like a teen magazine about celebrities, and Black celebrities too, particularly. But, I don't think so. If any magazine or anything comes to mind that's the one that comes to mind, because I don't think many others would have also have talked about it. I mean I suppose there probably was *Time* magazine articles, but I don't think I was paying attention to that.

GK: Alright. So, you were involved in other things during this period of time...

DF: In high school?

GK: ...high school, early university.

DF: Not so much in high school. In high school I was involved in things related to my school specifically, but not around HIV. In university, then I became much more politically involved and aware. I remember I joined the Black Women's Collective [BWC]. And so we were a group of feminists. Also, doing work around social change and addressing issues around gender, sexual orientation, around socioeconomic status, so that's when my time in the Black Women's Collective was a time of politicization. If I think about it now I was politicized in high school. Perhaps not as much as I thought I was, but clearly it was there. But, I think that that kind of deepening my understanding happened in university, and specifically was connected to the Black Women's Collective.

AS: Do you want to say a little more about what the Black Women's Collective was and how you got involved with it, who was involved with it, what it felt like?

DF: It was probably around 1988. For some reason the number 88 is resonating for me. I think it was '88 because that was the year that Angela Davis had come to Toronto and that the Collective had brought her to Toronto to speak at Convocation Hall. And I remember volunteering for that. I can't remember if I joined the Collective before that or after. And I had first heard about the Black Women's Collective, actually, from Angela Robertson, a friend of mine. And both Angela and I... We had these different groups. Angela was up at York and I was at U of T (University of Toronto). Angela was part of a group called Black Women at York, and then I had started a group at the U of T called Black Women at U of T. And then we got connected... Yes, I remember Angela telling me about the BWC, the Black Women's Collective, and I remember going to a meeting. I can't even remember what the membership process was, but going through that and becoming a member of the Collective.

AS: Was it an open collective? Could anyone join?

DF: No, it was actually a small group of women. And so there were specific membership criteria at the time. I'm trying to remember how many of us were there... I'm just remembering myself, Angela, Dionne, Faith, Carol...

AS: That would have been Dionne Brand, Faith Nolan ...

DF: ...Carol Allain, Carol Camper, Leleti Tamu, Linda Carty, Grace Channer ... There were other women before that, but when I joined these were the women that were involved. I think there were a few other women who had been a part of the Collective before and had left, I think, right before I joined. So, probably by the time I joined there were maybe around ten of us – nine, ten of us in total. And so, you know, one of the important things about the Black Women's Collective was also we had a newspaper – the *Our Lives* newspaper. Again, talking about social justice issues and talking about race, talking about gender, talking about sexual orientation, talking about socioeconomic status, talking about colonization, exploitation, global struggle... So, a very political group.

GK: So, did your participation in that help to focus what you might bring with you when you got more involved in AIDS organizing?

DF: Well, actually, part of the link, too, with the BWC was that probably was close to that time Black CAP was getting off the ground – the Black Coalition for AIDS Prevention. I mean, I wasn't there when Black CAP first started. I think you'd want to talk to people like Douglas Stewart and Camille Orridge... Tony Caines, Erica Mercer... Some of those folks were there at the very, very beginning. And so the way that Black CAP was set up was like a coalition, so it had representation from different groups, and one of the groups was the BWC. Like, wanting also to have representation from the Black Women's Collective, and so I became the Black Women's Collective representative to Black CAP. So, that was actually my first connection. And so it was more of a coalition. This was even pre-board. These were the early days, so there's no formalized structure and all of that in terms of establishing the organization. That was how I first connected and at the time, too, there was also another group in Toronto doing work around HIV and the Black community called COMBAT [Community Organizations Mutually Battling AIDS Together]. Jackie... I can't remember Jackie's last name.

GK: I remember Jackie.

DF: Yes, but Jackie Wilson I want to say.

GK: I think that's right.

DF: Yes, Jackie Wilson. So, COMBAT was around. I had got in touch with Black CAP through BWC and then a position became available to do support work at Black CAP and I was successful in getting that position, and that sort of started my involvement there.

GK: Maybe if we just step back for a moment before we move forward into Black CAP. You told us about COMBAT, but did you ever hear stories about other people organizing in Black communities in Toronto or around AIDS and HIV prior to either Black CAP or COMBAT being around?

DF: No.

GK: Okay.

DF: That would have been it. I don't recall any other.

AS: So pretty late in terms of it would be affecting people...

DF: The time frame? Yes. I mean, I think, because part of it – and Douglas Stewart will be able to speak to this more – people who were living with HIV often would go through ACT, the AIDS Committee of Toronto, and he was a counsellor there, so he would have been a key person who would have been working with Black people who were both infected or affected at that time.

GK: So, maybe you could tell us a little bit more about how you get involved with Black CAP after it's formed, but what was going on when you were getting involved? What was the reason for Black CAP becoming its own autonomous organization? There must have been some rationale for why there was a need for an AIDS/HIV group dealing specifically with the needs of Black communities in Toronto.

DF: I think Douglas and people like Camille will be able to speak directly to the conversations that would have been taking place as to, you know, "Why set this up?" But, I think that the need was there because, one, there was an increase in the number of Black people coming forward, and the need to also address our particular needs. Also, there were issues around doing education because, at the time, Douglas was doing support, but education was also needed. People needed to know how to prevent HIV in addition to having a family member with HIV and supporting people living with HIV. The need for that more holistic service, and that wasn't there. I think, at the time, ACT (AIDS Committee of Toronto) ... Douglas being the only person and he was a primary support, and the need for more.

GK: Can you remember if any people have experiences that they might have described as racism with some of the more mainstream white-dominated AIDS groups at that time?

DF: Nothing comes to mind specifically. I mean I'm sure, right? I think that in terms of just when I started to become much more involved people would talk about their discomfort ... I mean there was AIDSphobia and the stigma around living with HIV, but also people didn't want to go in a place where they didn't see themselves reflected. And that's also the reason for a place like Black CAP. Just like the reason for why ASAAP (Alliance for South Asian AIDS Prevention) started – or any of the other groups was that, again, people want to see themselves reflected and feel like, "Oh, this is a much more welcoming environment." ... Or, the way that they were treated when they went in, like, i.e. you're coming in for services and no one's paying attention to you. It's like you're invisible. And so, I think that those kinds of situations happened for people and thus also meant that, "You know what? I don't want to go back." Suddenly, you're also trying to deal with HIV, you're hearing a lot of things ... Because, remember, these are early days, so treatment is not what we see today. People are dealing with all kinds of illnesses and sometimes not fully understanding what exactly is going on in their bodies, struggling with it, not wanting to go to the doctor's, not connected to an HIV doctor, so for all of those kinds of reasons.

GK: Right, for sure. So, you end up getting hired.

DF: Yes.

GK: Can you tell us a little bit about how did that happen? Like, there must have then been funding for Black CAP by that point.

DF: By that point Black CAP had started to get some funding. When I started in support, Douglas was already the Coordinator, so the entity of Black CAP had started. I remember it was after I started in support that I also remember working with Camille, who was the Chair of the Board, to do the incorporation of the organization. This would have been late '80s, early '90s. I remember that happening after I had started on staff, if I'm not mistaken. I remember working with Camille on that, the incorporation of Black CAP. So, funds had started to flow. Back then it would have been, because Black CAP was not an incorporated entity, funding was going through Harambee, which was a social service agency for the Black community. And so, at the time, Harambee was located down by Village by the Grange, near Dundas and McCaul. So, their office was there, and Black CAP was in this back room area. Like, all of us kind of huddled off [laughter]. Now that I think about it it's like, oh my god! There was a lot of us! I remember Douglas... I think there was three or four of us in that little office space, a little room and a little thing off to the side. But, there was some funds because Black CAP had been successful at getting funds from the city of Toronto and from the province, from the AIDS Bureau.

AS: And so your role was support? What did that mean?

DF: I was doing support and outreach, so I was supporting people who were living with HIV as well as family members and counseling people who – I mean they still exist – were the “worried well.” You know, “I did this and I'm freaked out, I'm scared. Do I have HIV? What do I need to do?” that kind of thing. I don't even know if they use that language anymore. I realize that might be an old term, but yeah, there was the worried well. So, doing that support work as well as, part of my job at the time was outreach. Black CAP had started to do a big outreach at Caribana, which no longer exists technically. It's now Scotiabank Caribbean Carnival. But, that was also a time when there were lots of Black people congregated into one space, and so we would do an outreach. Like, a condom distribution outreach. We would wear t-shirts, the slogan on it was, “Ask me about rubber wear.” And then that would invite people in and we would hand out condoms and engage them in conversations about HIV and HIV prevention. So, part of my role was to help organize that. And this was back in the day when Caribana was still on University Ave., so this was obviously a long time ago.

AS: That's a lot for one role.

DF: One position? You know, that's how it was. I mean in community organizations you don't have the same kinds of resources, so therefore you have one person who's taking one and doing multiple things. Just like before I got hired, or other people got hired, Douglas as the coordinator was doing multiple things and juggling multiple balls at any given point.

AS: So, what was that like, that role?

DF: Well, for me, it was really good because, one, I was still quite young – I’m still young right now. [laughter] But, also at the time...

AS: How old were you? Nineteen?

DF: Early twenties.

AS: Yes.

DF: Yes, I was in my early twenties. And so I had a full time job. It was exciting, but also challenging, because we’re dealing with an issue where people don’t really want to hear about it. They’re thinking that you’re in fact, more betraying them than actually helping sometimes. Because I remember back in those early days, us going out to community events and people throwing our table over like, they don’t want you here, you shouldn’t be here. And I think some of that was also homophobia, right? So, I think there was stigma around HIV, but that there was also homophobia. Like, in terms of people seeing that, because there was a time where people would say that HIV is a gay disease, and that was also a message that was often promoted and talked about, especially in the African American community. But that feeds into or drifted here as well. So, you were dealing with HIV stigma, but also dealing with homophobia within the Black community.

AS: Yes.

DF: For me, part of that was also exciting because, for me, providing that education... it was about Black people and so therefore it was something that was important to me, and even with the resistance I’m still going to keep pushing. But, it was also around LGBT rights. So, also, “You know what? I’m not going to move from here. You can be as homophobic as you want, I’m standing right here and we’re going to talk.” So, I think that there were a number of different components. Also, gender... So, you have all of the issues interspersed, intermingled and addressing them, because that’s one of the things that HIV does is that it does bring all the issues together and you can’t always tease them out or pull them apart. You’ve got to address them all at once.

GK: Right, for sure.

AS: Yes. Were there things that you remember that worked or that allowed people to listen or to be open to changing practices or changing how they were thinking and feeling?

DF: I think the outreach. So, talking to people one on one. I think that that was definitely effective. I mean I think it was effective to also have a space where Black people living with HIV could come to and to know that they would be welcome, that they can talk about their issues, and that there would be different kinds of connections, including cultural connections. So, whether people were from the Caribbean or from the continent and being able to have that recognized and valued. So, I think the one-on-one pieces were really good. And I do remember sometimes having somebody

who was living with HIV talking about their experience. Back in the early days that was a challenge. I remember... there were a couple of guys who would talk openly about living with HIV and so they would be speakers. And then there would be a couple of women, but in more discrete kinds of spaces, so they wouldn't be as public about their HIV status because I even remember... I don't remember years, so forget that [laughter] but when Hassle Free Clinic had worked on a video around women and HIV, and it was just really difficult to find a Black woman who was willing to speak, publically, on a video, talking about living with HIV, so I remember that. You know, I even remember there was a poster – yes, it was Voices of Positive Women had done a poster – showing a diversity of women, but again it was a real challenge to have any of the women actually to be in that poster. I remember a colleague and I being in the poster as Black women because, at the time, there wasn't anyone who wanted to speak, not publically.

AS: There's an HIV-positive women's film that came out in the Maritimes and the way that they did it was they just filmed people's hands because no one wanted to have their faces on camera.

GK: So, does your position stay the same or does it begin to evolve within Black CAP as it becomes it's own separate organization and it gets incorporated?

DF: So, from when I started Douglas stayed as the coordinator and then it became the Executive Director [ED] role for a few years. And then I became the ED. You know, again, after he left they had an open competition and I was successful in getting the position. So, I became the ED and I was the ED for a few years before leaving. So yes, I moved into another position while at Black CAP.

AS: When did you start being ED?

DF: Okay, so...

GK: That raises questions around years. We're not supposed to ask.

AS: Oh yes. Sorry. [laughter]

DF: That one I can more remember because I know I was around twenty-five, so that would have been what? '96, maybe.

AS: Or maybe I should ask what was happening in Black CAP at that time when you took over?

DF: I think that at that time, it was a part of building and growing because I remember... Where were we? I think at that time we were on Parliament Street, so by this time Black CAP had moved out of the little Harambee space and then we were just over at Parliament and Wellesley – 597 Parliament. We were there for a few years. And so it was a time of growth because I remember when we first moved into that space having what was a boardroom and over time it became an office because it was occupied by staff. I can't remember who was the first person, but doing some

work specifically around MSM [men who have sex with men] and gay men. And I remember there were different projects as well. So yes, a time when the staff grew a little bit because I remember there was probably three or four people in what started out as a boardroom. And then there was an education coordinator, there was support, there was a reception, there was the ED office. And back in that time, too, that was when Magic Johnson disclosed his status and there was a flurry of activity for a minute with people around going, “Oh, if Magic... What does that mean?” There was a greater interest for a little bit in HIV, specifically in Black communities.

GK: So, you were ED for a number of years?

DF: Yes, I think for about three or four years, because after that I went to a community health centre.

GK: Yes, so maybe before we get into what happens after Black CAP, we could move back into some of the things you started to talk about. You started to talk about some of the HIV-positive Black men and HIV-positive Black women that you met through this work. Are there any stories or experiences that stand out for you in terms of remembering problems they might have encountered in terms of accessing services or getting treatment or other support issues?

DF: Yes. One of the stories I remember is about a Black woman, actually. She was living with HIV and, in fact, by that point she had actually developed full blown AIDS and was in Casey House and, you know, she had a daughter and the challenge of, “What’s going to happen to my child afterwards?” and having to deal with and figure that out. At the time, also, many people didn’t know that she was HIV-positive and so it’s like, “Well, who’s going to take care of my daughter?” There were particular people, and I just remember that that was a really challenging situation because she hadn’t disclosed to many people, so there were very few people who knew, some out of her own fears. And real fears, you know, the kind of stigma, the kind of ostracization from community. Also, fears for her daughter, and just trying to figure that out and having to deal with, you know, there were legal issues as well, while at the same time she’s dying. Trying to do that and go through her own process around her body failing her and knowing that her life is coming to an end, yet still trying to figure out this other piece about her child that will be left behind. So I remember her.

And I remember another woman who, again, at times would be very out there and talk about living with HIV, but more in very discrete circles. And, again, just about the kind of stigma and discrimination and sometimes people just not having support. And so the place that they would get support is Black CAP. And that this is a place where they can open up, they can share, they can talk about things that once they leave this space there’s no one else to talk about it with. It was interesting because, even talking about the stigma and discrimination, I remember when one of the things about the space that we had at 597 was that it also allowed people a certain kind of anonymity. You know, people didn’t necessarily want to go into a space – and it still happens today – where they don’t want to be going into an agency that’s known as an HIV organization. And I remember back then, yes, when I was doing support, that there was a back door for my office so that people could actually leave and enter if necessary, if they didn’t want to come through the

front door because they didn't want anyone actually seeing them going into an AIDS organization. I remember even, at the time, our space physically being able to accommodate that because that was such an important thing for people back then. They didn't necessarily want to interact with the rest of the space. They just wanted to come in, get my support, do what I needed to do, and then leave.

AS: How would people find out about Black CAP?

DF: I think a number of ways. I mean we used to advertise in Black community newspapers. There was, gosh...

AS: The Internet did not exist, so... It was just starting.

DF: No, that's right. No, no! There was paper! [laughter] I remember there was actually a directory called *the Black Pages*. And so we would do an ad in *the Black Pages*. There was *Share [Newspaper]* and *Contrast [Newspaper]* back then, so it would be advertising in those ways. Also, through outreach, you know, going to community events, being in the community, and people hear. I think this still happens now too, is where you're out and you do an educational session, and people are paying attention and there might be that one person who's kind of listening in a different way. And then they might come up after and say, "How do I get in touch? No, don't give me a card. Just tell me." So, you have all of these ways. Caribana, for sure, because we were doing it over time and people also came to expect it. Like, they'd be looking out for Black CAP at Caribana, so I think that was also another means of getting the word out there about the existence of Black CAP.

AS: Was there a pretty good – if you remember – people coming from different parts of the city?

DF: Oh, yes.

AS: Yes. And you would go to various places too?

DF: Definitely. I remember there would be clients who would come from all over the city, for sure. And then we would go out to meet clients in different places. Especially in the very early days we would be meeting clients in restaurants or out, because there just wasn't any private space to have those conversations. Also, it was preference. If people didn't want to come into the office we would go out to meet them. And we would go to sometimes it might be in a public space, but it also might be in people's homes ... I remember back then and going east to somebody's home because they didn't want to come into the office. It was for people living with HIV who didn't want to come into the office.

GK: Do you remember if people who came in to get support from Black CAP, who were living with HIV, might have had difficulties getting access to treatments? In that context, were there any connections with groups like AIDS ACTION NOW! or other AIDS groups?

DF: I'm trying to think around... So, when I was doing support, part of my work was also linking back then. There was a group of physicians who were... the Toronto HIV Network, was it? No. There was actually a group of HIV physicians...

GK: Yes.

DF: Alan was a part of it, Alan Li.

GK: Right.

DF: And, in fact, a number of clients that I had worked with, I would refer them to Alan. Because, I think, at the time he was working at Regent Park.

GK: Yes, I think you're right.

DF: And for a period he was also at Casey House. So, Alan Li was actually one of the HIV physicians. That would probably be a good person, because I'm sure he's over the years had many Black clients, but also different racialized clients. I remember referring to him a fair bit back in those days. One of the things I did remember about treatments was sometimes the differential impact of some of the drugs on Black people's bodies. A couple of things that were really noticeable, and I don't even remember what drugs specifically, but that there would be, from the treatment, it would cause people's finger nails to turn dark. And that was a noticeable thing; it was undeniable and related to the meds that they were taking. The other thing that was noticeable was the texture of people's hair would change. I remember that people's hair would actually become a bit straighter, those kinds of things, from particular HIV meds that they were taking. I don't know if anybody ever did any research on that.

GK: Do you want to talk a little more about that in terms of the differential impact on different bodies that might have affected Black bodies in different ways?

DF: I definitely and distinctly remember those two pieces, because people talked about that. Like, "My hair is different. My hair is straighter," or "There's a thinness. My hair has thinned out." It was a physical manifestation. And the finger nails, because that's also very visible. And it was a noticeable thing from "before I was taking the drugs" and "after I was taking the drugs." So, those are the two things that have always stayed with me.

AS: And there's probably those things and then many more things. There are all these drugs now that no one would take anymore. Like, I've done research on the ways that women's bodies experienced and revealed HIV and there are certain things that we're just never going to know because no one was paying attention, no one was studying them, no one was saying, "Oh, look. This is a common thing, and what does this tell us about what is happening?" And maybe it wouldn't have mattered at all and maybe it would have mattered a lot if someone had been paying attention.

DF: But I think that these issues are part of that larger piece about who does research get done on? Who is the primary taker? Like, it's a certain body type, certain bodies, certain race, certain gender – so male, white, of a certain body. So, if it's a big guy or a small guy, because there's this *average*.

GK: Right, the average white, male body. [laughter]

DF: Yes! And that's a part of it around drugs, and actually coming back – Gary, you were asking about AIDS ACTION NOW! – I remember going to this meeting... It was around AIDS ACTION NOW! and I don't even remember the details of it. I remember Loralee was there, Tim was there, Darien was there, so this was an AIDS ACTION NOW! meeting. But also, Black CAP worked with different groups including AIDS ACTION NOW! around the establishment of PASAN (Prisoners' HIV/AIDS Support Action Network). At the time, I remember me and Julia Barnett in my office, and we were all working on this brief, talking about getting stuff happening for prisoners, and the fact that a fair number of prisoners were also Black, a disproportionate number. I do remember that work together in terms of getting this other group started.

GK: We can find that out. But, it is the twenty-fifth anniversary of PASAN this week.

DF: Yes.

GK: Or at least they're celebrating it this week, or next week.

DF: That's true. Twenty-five years, so early '90s. Yes. But I remember us working together on that brief.

AS: And so that would have been something that had lots of different interests and commitments coming together, but having its own specific issues and focus.

DF: Yes, definitely. I think that back also in the early days around HIV, and in Toronto... Because you were asking was Black CAP getting support, and the support of funders? So, even the AIDS Bureau at the time, the people at Public Health... Because even some of the folks who were involved with Black CAP at its very inception had worked or were working at Public Health – Toronto Public Health specifically. There was that connection around the work. It just made me also remember that. You know how these things just pop into your head? [laughter]

AS: Yes.

GK: I do. When you start to think about things it just all floods back in.

DF: Yes, yes.

GK: So, one question while you're still involved in Black CAP is, clearly there must have been some of the clients of Black CAP who actually died during those years. Do you have any memories of any of those people? Part of what we're trying to do in this project is to also remember people who died. We can talk to people who are still around, but we have to

get memories of people from people who were around then, and not necessarily specific individuals, but if you remember specific individuals that would be great too.

DF: I mean the challenge around talking about some folks is that they may not have disclosed. I don't know if I would actually be able to name names, but I definitely remember a time of going to funerals. Like, I remember that. I remember going to Rosar-Morrison Funeral Home & Chapel up the road numerous times, because that was a very popular funeral home that was used. Are you guys familiar with Rosar?

AS: But say something, because people who are reading the transcript might not know.

DF: Rosar-Morrison, it's right at Wellesley and Sherbourne here in Toronto. That was a place where a number of funerals were held, so I remember going to many, many funerals because there was a time – less so now – in HIV where people were dying and dying quite frequently. Like, you'd go to a funeral this week and then maybe next week or two weeks from now somebody else had passed and you're going to another funeral, so I remember those times. I even remember clients with really big addictions. I remember this one guy. He was really, really sick, but also his world was still addictions and just the kinds of things that would happen, even while he can't move out of his bed. And his "friends" who would come around, and the kinds of people that would come around, and just be in some cases also leeching off of him. Like, this guy's in a really rough place and that's the kind of stuff you're doing around him? Anyhow. So, there are stories like that.

Jeez, I remember 127 Isabella, which was also a place for people living with HIV and providing supportive housing back in the day, right beside Casey House. I remember that time. This was pre-ARVs (antiretrovirals), pre-HAART (highly active antiretroviral therapy), you name it! Whatever the acronym. [laughter] It was a time of lots of deaths. One of the things that was hard about that too is the fact that – and even today – you can't name it. So, people didn't necessarily always talk about that that person died of AIDS, because that was a hard thing to say. And even as people could see the end is near, couldn't talk about it. Or, "After I'm gone, don't say I died of AIDS," so that being an explicit wish. Because you know that there are way more people than sometimes credit is noted for. So, I do remember the frequent funerals, and being at Rosar-Morrison, and even having to go and deal with funeral arrangements for clients. At the time, as somebody who was doing support and dealing with if people didn't have money, having to deal with the City around paying for and getting them to be buried..

AS: And they might not have family that were going to do that.

DF: Yes. And in some cases, too, some of the clients that would come to Black CAP were in Canada alone. They didn't have a lot of support systems. Like, their family was back home, wherever back home was, so whether that's somewhere in the Caribbean, whether that's somewhere in Africa on the continent. And so they were here, they had immigrated here and they may have had some friends or a church, but they couldn't say because those places weren't welcoming, weren't accepting, were not loving. And so they kept all of that in.

GK: So, maybe before we move off of Black CAP, are there any other things about Black CAP that you think would be important for people reading this interview to know about?

DF: You know there's a video as well about Black CAP?

GK: Tell us more about it.

DF: Oh, okay! [laughter]

GK: I mean I have heard of the video, but I haven't seen it.

DF: You've heard of the video. Okay, so Black CAP had done a video themselves to sort of capture some of the history... Yes, Alison Duke had done that video and, again, people such as myself and some other folks who, in fact, might be useful to talk to for this project as well. So, there is that kind of history. Now that you've taken me back to the corner in Harambee, which is still now a present image for me, like, "Oh yeah, we were all over there," and then at 597, over the years the growth. Actually, that does make me think of a story as I think about growth and how Black CAP was growing and how we needed to move. We needed to move from 597 Parliament and find a new space. Finding that new space, now talk about racism – racism, homophobia, HIV discrimination... Like, all of it just coming together in trying to find a new home for Black CAP. Interestingly, I was working with Kristyn Wong-Tam, who is now a Toronto City Councillor, but her previous life was as a real estate agent, and us working together to try and find space for Black CAP. But yes, it was just brutal, just encountering straight up racism, AIDSphobia, you name it. It's like sometimes what black people go through when you say your name, and it's like, "Oh, there's no more... Somebody's rented the space already." "Yeah, but when I called you this morning they hadn't. Okay." You know what I mean? It's funny because I do remember an article that was done in *Xtra* way back when, just talking about this experience that we were having about trying to find a home. Eventually, we ended up getting space from the Woman's College Hospital ... What's the address? It's on Bay, right at the corner of Bay and College. So, that was where we ended up finding space and, again, that was also part of the organization's growth. We had more staff, more projects on the go, and the need for a bigger space, but just the struggle to find a place to live.

AS: I'm just thinking back also to that question of meds. I'm curious if there were connections with CATIE [Canadian AIDS Treatment Exchange], or when it became CATIE, would you do like, helping people understand treatment news, helping them think about treatment options, was that part of the work?

DF: It would have been referring people to CATIE. Yes, for sure. I mean this was CATIE back when it was *Community AIDS* versus Canadian, right? So, somebody would have been referring people to CATIE to get that kind of help, because that's where the expertise was.

AS: Yes. So, you didn't do special versions of treatment news specific for Black CAP.

DF: No. Definitely, it would be CATIE, and Sean Hosien. [laughter] That's where the expertise was and so that would be where the referral would be. And Alan, as the doctor. So, I didn't really deal

as much around treatment because that wasn't my expertise. My expertise was more around psychosocial counseling. And so where that referral needed to happen, that happened.

AS: We talked a little bit about helping start PASAN. Were there also ongoing connections? Like, there was a protest early on at the Don Jail...

GK: That's pre-PASAN. That's an AIDS ACTION NOW! demonstration.

AS: But it's one of the things that started PASAN, right?

GK: Yes.

AS: Do you remember if there were spaces where Black CAP would be invited – come to this action or come to this demo?

DF: I'm sure. I'm trying to think of... I can't remember myself going to any of those specifically. Nothing's ringing a bell. I remember going to demos around racist police violence. Similar to what's happening in 2016. But I don't remember specifically. I'm trying to remember any of the AIDS ACTION NOW! ... Like, even the die-ins, and I'm not remembering as much.

AS: Do you remember if any of the other AIDS activists would come to your demos about racist police violence?

DF: I'm sure, because some of the folks who are involved in activism were *activists*. The issues are connected, so if it's an issue around gender they'd show up as an ally; if it's around racism, show up. And I'm certain I would have gone to demonstrations, but I'm not thinking of any that are really sticking out in my mind.

AS: They also blur after a certain point. [laughter]

GK: They're all the same.

DF: The memories... It's like when I had gone to a memorial service and they show old pictures – “Oh yeah! Oh yeah! We did go to that!!” Back in the day when Pride was a demo, you know what I mean? [laughter]

AS: Yes, it's different.

GK: So, I have one more Black CAP related question. My understanding would be – and correct me if I'm wrong – that Black CAP emerges largely from people who would have connections with gay and lesbian scenes, but obviously the groups of people who live in Black communities that Black CAP's reaching out to is much broader than that.

DF: Actually, I would say both. And you made me think about something else around Black CAP. So, because people were coming together... I mean we were coming together around race. Like,

there were things for PHAs – the people living with HIV – who were connected to Black CAP. Like Black CAP had a support group, but it had everybody in it. It had men, it had women – I’m trying to think if it had anyone who identified as lesbian – but it had gay men, straight women, bisexual women, bisexual men, and I think that was unique, right, that you had that support. And that lasted for quite a while. And Black CAP would even have retreats and it would be everyone coming together. I think that was a very, very different and unique piece of where people were bonding. Race and living with HIV were also bonding people together. So, in terms of sexual orientation, it didn’t become as much of a “drawing this line.” So, I think that was actually something that was something different. You made me think of that as you were saying that. But, what was the original question?

GK: The question was really were there ever tensions or contradictions between more lesbian and gay identified people involved in the group and people who weren’t as the group expanded into broader Black communities? I mean you’ve actually in some ways answered part of that.

DF: And even in the set up of Black CAP it was about bringing all of that together. Because some of the folks who were at the beginning were gay men, were lesbian or bisexually identified, were also straight identified, and so it was bringing that diversity together. And even in the Coalition, and who would be a part of that Coalition. I think that there were tensions and homophobia, but the Black lesbians or bisexuals or gay men... It’s like, “We’re not going anywhere,” you know, “Fuck off.” [laughter] This is the work that we need to do and so we’re going to do this work, we’re going to be here. And other people either stayed involved or left. And, again, perhaps this is one of the unique pieces, I think, with Black CAP, too, in addition to doing the HIV work it was also a place where people came to also work through their sexual orientation. So, “Am I gay? Am I straight? So, let me volunteer,” and they hear about this place. And they know that there are Black people who were Black, were gay, were bi, were lesbian, were out, and so therefore it’s a place where you can come and try to figure yourself out and have people that you can talk to that’s also welcoming, affirming, loving, that’s not going to be judging you, that’s not going to be ostracizing you. So, that was also, I think, a unique piece around Black CAP, was that it became a place where a number of folks also came as they’re going through their coming out process, or just trying to have a deeper understanding of who they are. Also, who they are not only in terms of sexual orientation, but in terms of Blackness. Like, who am I? What does it mean for me *as a Black person*? To be in this space that was affirming about Blackness, that was affirming about being gay, about womanhood, and so whereby I’m also doing political work. I’m doing good work. I’m also taking care of my community. I think, all of those different pieces Black CAP brought together.

AS: Yes, and partially Blackness is a political formation coming out of there being people from the Caribbean, people from the continent.

DF: UBecause we weren’t all the same, right?

AS: Exactly.

DF: And I think that a piece of it was there was a sort of heterogeneity. Like, we were diverse in terms of where we came from, even religion, because there were Black people who were Christians, there were Black people who were Agnostic, there were Blacks who were Muslim – the range. And I do remember that support group was something that was *really unique*. Like, you had men and women just working together. Even for the retreat, and people having to cook and organize, that was also a really, really important time.

AS: Super interesting.

DF: You made me remember that, yes. Indeed.

AS: Thank you for remembering that. [laughter]

GK: So, unless there's more memories about Black CAP – and we can always come back to it – maybe we could talk a little about what happens after it for you in terms of AIDS related work. Do you have another question?

AS: I have one. It sounded like maybe you would have been in the ED role at that moment when HAART comes out. I don't know if this is right, but there was that conference in Vancouver.

DF: Yes.

AS: And so I just wondered if you were there when there was this transition from, kind of a situation where everyone was dying quickly to, pretty suddenly, people not dying so quickly if they had access to HAART.

DF: Yes, I would have been because I was at Black CAP in that mid-to-late 1990s ... I would have left in the late '90s. I think I left Black CAP as a staff person around '98, or so. Yes, it was noticeable that there were less people dying, less funerals. And I was on the Board of the Canadian AIDS Society, I was also on the Board of the Interagency Coalition on AIDS and Development, so my involvement was in a few other places as well around HIV. Just noticing those differences, and even noticing – I mean you guys know this – but even in *Xtra*, from pages and pages and pages to less pages, less pages, to two pages, to just this one page, to half a page of people dying from AIDS ... You know, and just witnessing that and those changes.

AS: Do you remember how that felt?

DF: I don't know if I remember how it felt, but if I reflect back on it I think, obviously, it was an amazing thing. I think a couple of things about it. I think that, one, it was an absolutely amazing thing that meant that people were living longer, but I know that it also has a certain sadness for me, because there are people who didn't get a chance. Like, I remember friends outside of my work capacity, but also just personal friends in my life that, had they lived another year or two, they might still be alive today. And so I think that there is also that sadness around the fact of all the people who died beforehand. [...]

GK: So, you leave the staff position at Black CAP around '97-98 it sounds like?

DF: Yes, I think probably about '98, '97-98. Yes.

GK: You obviously are still involved in AIDS related things. What do you do next?

DF: After I left Black CAP? I actually worked at a community health centre. While I was the ED at Black CAP I had also gone back to school to do a Master's degree. And so in finishing that up I went to do an interim ED position at Access Alliance Multicultural Community Health Centre, and from there I left and went to what was Lawrence Heights Community Health Centre and I was the clinical director there, but Lawrence Heights no longer exists. It merged a couple of times, it moved from being Lawrence Heights to being New Heights to now being Unison Community Health Centre, or Community Health and Social Services. And then after I left Lawrence Heights I became a full time consultant. So, I'm still working in HIV and with different groups now as well as doing leadership and life coaching. And I was part of the Ministerial Council on HIV/AIDS for a few years... I was going to say something, but then I thought I'd hold my tongue. [laughter] Before those awful Tories came in!

GK: So, we're moving towards the end of the interview.

DF: Okay.

GK: We have two standard questions that we ask at the end, which is, first of all, as we've been talking is there anything that's cropped up for you that you haven't had a chance to express, around any of the questions or other memories that have surfaced as a result of the conversation?

DF: Well, one thing I think about is how now my work in HIV also has a global component to it.

GK: Right.

DF: And so some of my work now is actually going to different African countries, and sometimes going to very rural places, like way, way, way out where there aren't services. And I see even today some of the things that I saw back even in those early days. Again, coming back to the question around the fact of the introduction of ARVs (Antiretrovirals). I remember even when I was first starting to do some of that international work, and even visiting people, again seeing people in that same place where they're wasting and the end is near, and then over time seeing how, with treatment, much less of that. And the way that communities take care of each other, and different kinds of communities, so geographic communities, identity communities... Like, just that, taking care of each other, even in the face of opposition, even in the face of discrimination. And so I still see some of that even in the work that I do today in terms of a global arena. But also I see the impact of treatment, including – from going to different places – people talking about, “At one point, I was at death's door and because of treatment I am...” Well, you know, people tend to talk in very religious and Christian terms, “I've been resurrected.” [laughter] It's those kinds of terms.

But, really noticing how powerful that is, and the need for that to even move faster, because there are many places still where it's a struggle around treatment, but I do see it, and that gives me hope and optimism that, "Yes! Look at the difference." People are still alive. The grandmothers are not having to take care of their grandchildren and great-grandchildren because their kids have passed on. So, I've just noticed some of the similarities over the years in terms of that.

What else? I mean I've also noticed and I find it interesting that some people have stayed involved over the years. Like, there are people from way back when, or even seeing how people were involved and kind of took a little break and then they came back. And these are people who are living with HIV, but also people who are HIV-negative. They remain committed to the AIDS movement and committed to HIV, and committed to continue to fight whatever form that fight takes because over the years it's been different struggles. You know, you struggle for something, you gain it, so you've got a new struggle to pick up. And I think that that kind of commitment remains over many, many years. So, some of the people who twenty-five years ago when PASAN was starting I still see them around today, including knowing that I'll still see some people because of treatment. And in a number of cases it would be a lot of guys that wouldn't be here. And even some of the women that I see who have remained involved also over the years, and I know the impact of treatment and the impact of activism that has helped to make that possible. Like, I know that there's been different points of "is the movement activist enough?" Or, "is the movement not..." like, these are those constant kinds of tensions. So you speak of tensions, right? Like, "Do we need to be doing more? Or do we need to be doing less of this? Is this becoming more professionalized?" And these are part of evolution. There are still some struggles that remain, because the reality is that some of the kinds of discrimination, whether it's around racism, around sexism, economic exploitation from thirty years ago, it's still present today, so that struggle still continues. We've just got to keep going. But, there's also been change, and I think it's also important to acknowledge that, to recognize it, to celebrate it, and to also celebrate the people who actually made that possible. Sometimes people who have been there and they have struggled through, they're not in high positions, they're not making oodles of money, life is not all grand, but they believe and it's like, "You know what? Fuck it, I'm going to keep going." But, you know, sometimes it's just like, "Ugh!" But I do think that we have to give thanks to some of those folks who are still around, and who aren't around but were really important in getting us to the spot where we're at today. And, for me, like I said, I really wish that some of the Black people who were there and who did their part, that their names could be there, but... you can't.

AS: It's the complexity of honouring what they did...

DF: And so I've got to hold them in my heart, I've got to remember them. I know their name and will say it in silence and in appreciation and gratitude.

GK: We are trying to do some aspects of that in terms of the project. Did you ever run into Kim Bernard?

DF: In Nova Scotia. Yes.

GK: We've talked to her and her interview is up on our site, and her doing work with the Black Outreach Project. We also hopefully will have an interview with one of the early Haitian organizers in Montreal. Hopefully, we'll at least provide some of this.

AS: We talk a lot about the politics of memory. So, what happens when some things aren't for public memory. It doesn't mean that they're not politically remembered, it just doesn't necessarily have to be part of this. And part of that is about, for some things, the memory is only meaningful in a context. I think it's one of the things that, in this project, we balance a lot – this voracious desire to have all the stories, to share all the stories.

DF: And, you know, as you talk about activism, one guy who does come to mind – not a Black guy, a South Asian man – was Kalpesh Oza.

GK: Yes.

DF: [laughter] I always think about him.

GK: If you want to tell us your memories of Kalpesh, because he is one of the people that we are trying to construct a memories section about.

DF: Okay. Kalpesh was an activist. His name came up the other day, for me anyhow, because for lots of people it's like, "Who's that?" But, Kalpesh was a gay man living with HIV who was out and who was very... I remember Kalpesh's thing was like, "You know what? If you don't say you're HIV-positive you're not representing me." He was really big about disclosure, naming, and just right out there. I remember I was having a conversation about disclosure and then suddenly Kalpesh came into my consciousness just because he was really strong and vocal and *bright*, smart, smart man. I just remember that fire! Kalpesh had *fire!* But, like a good fire. It's that kind of fire that has brought us to this place. And he was one of those people who, had treatment come along sooner – who knows? So, Kalpesh has obviously come up before.

The other thing is that activism has multiple forms, so that kind of energy and fire and like, *ugh!*, is one form, but I also think about an activist like Darien Taylor, who is much calmer but *powerful*.

AS: A steady...

DF: *Powerful*, because I remember Darien from early days. Again, don't need to raise my voice, don't need to, but I can say what needs to be said and it's going to be strong. It's going to be powerful. So, I also think about the kind of range when it comes to activism and the ways in which activism is manifested, and in the kinds of different bodies. I don't think it's just about gender, so doing that kind of juxtaposition, but I think it's just a different form. And are you talking to Alix Adrien in Montreal?

AS: No. No one's ever said their name.

DF: If you're talking especially around the Haitian community, Alix is a physician and worked – I don't know if he still works there, he probably does – at Montreal Public Health. He's a researcher and he's done a ton of things in relation to HIV, the Black community in Canada, the Haitian community in Montreal... Oh yes. Like, if you're talking about the Black community and HIV, specifically the Haitian community in Montreal, you definitely have to speak to Alix. Alix would be a critical, critical person to speak with. And you know that there's stuff happening now still around blood services, right? Like that Black CAP's involved in, and ACT is involved in, and OmiSoore

GK: OmiSoore, yes.

AS: So, you've also mentioned Erica Mercer.

GK: You've actually already led into our last question, which is, were there other people who we should talk to? You've mentioned a number of the Black CAP people, so we've got that. We're going to have to figure at some point how many people we can interview. Ideally, we'd like to interview all of those people.

DF: When you speak with Douglas he would know a lot more, especially at the very, very beginning, so there might also be people who were there when Black CAP was an idea that he was talking about. He would have that kind of information. I'm just thinking if it's around AIDS activism in Canada, definitely Kim Bernard in Nova Scotia, Alix in Montreal – no ands, ifs, or buts about that one – it's a must, for sure. In Vancouver there was a little bit happening. There have been different things happening... John... What's John's last name? Oh, are you talking to Trevor Gray?

GK: That name is really familiar.

DF: Well, Trevor works at PASAN, but Trevor's also been around for years, was on the Board of CAS [the Canadian AIDS Society]. And, again, Trevor's memory is probably better than mine in terms of the stories, too. There were a few other folks, but their names are not coming to me. In terms of the ones that I've said – for sure.

GK: All these stories just are flooding in! [laughter]

DF: The memory is fading, yes. I do think that the Black CAP video would be a good thing for you to have a look at. And, actually, if you're talking about AIDS, I don't if you have Frank McGee on your list. Frank is a funder, so he works for the AIDS Bureau, but Frank's been around since...

AS: People have mentioned him, yes.

DF: And talk about people who have a memory like a steel trap. Frank will remember a story from 1985, so again one of these strong memory people. Frank would be a really good one because he has been around since some of those very early days. He's worked at the AIDS Bureau for a lot of years, so there's also a funder perspective as well as a community/personal perspective that he can bring.

AS: And a lot of those people ended up helping people write grants, telling people this is how to write a grant.

DF: Exactly, because back then there was also different kinds of activism.

AS: Good.

GK: So, this has been really wonderful.

DF: Oh! I think though, one of the other things is in addition to Black CAP there were – after COMBAT years later – there were other organizations that were started. There was Africans United to Control AIDS [AUCA], which came afterwards, and then after there was APAA – Africans in Partnership Against AIDS. There have been also different groups that have started. AUCA was also a part of African Community Health Services [ACHS], so that was the larger grouping of which this was a project within. And then out of that group also APPA came. There have been these different groups and different people who have been involved in each of the organizations, so that just to think that in terms of AIDS activism and Black communities, I mean, yes, Black CAP was there, but years later these other groups were also there. There would be value in connecting with some of those people who were involved. For example, Fanta, who's the Executive Director at Africans in Partnership Against AIDS would be good, because Fanta's been connected for many, many years. And in fact, also used to work at CATIE, so from way back when, providing treatment info. In fact, Fanta Ongoïba would also be able to talk about some of the treatment issues, because she was on staff at CATIE years ago as one of their treatment counsellors. I don't remember what the titles were. That would also be another person I would say that would be valuable to talk to.

GK: You brought up other organizations, you mentioned Jackie and COMBAT early on. Is there anything else you'd want to say about COMBAT? I mean COMBAT disappears. We haven't been able to locate Jackie.

DF: Well, I think she was originally from the States, so maybe she moved back. And I think way back then, in addition to doing COMBAT, she was doing a PhD or something.

GK: I think in Anthropology.

DF: Yes, so I think she was at school. It's possible that she lives somewhere else in the world teaching somewhere if she finished the PhD. It's been like...

GK: It's been a long time.

DF: Yes it has been a long time since I saw Jackie. It would have been from those early days, and I don't even remember if I've bumped into her in a long time.

GK: I don't know if she's still in Toronto. My only memory of Jackie is that she came to an AIDS ACTION NOW! retreat. That's the only time I've ever met her. But she had quite an intense impact.

DF: I was going to say, did she raise some hell? [laughter]

GK: For sure. [laughter]

DF: I do think it would be good to, if you're talking about activism, Black communities, those other groups... The other person, but I don't know where she is now, would be Vuyiswa Keyi, but I actually don't know where Vuyiswa is. She was involved in Africans United to Control AIDS, but I'm not even sure if she's still in Canada or if she's left. I don't know. She would have been also another person who would have been around for a long period of time. Fanta has also been around for a long time and has the CATIE connection.

AS: What's Fanta's last name again?

DF: Ongoïba. O – N – G – O – I – B – A. Hope I've spelled that right, with double dots [umlaut] over the 'I' if I'm not mistaken. And she's the ED at Africans in Partnership Against AIDS now, so she's easy to find.

GK: So, this is has really been quite helpful. Thank you very much.

DF: You're welcome.

[END OF TRANSCRIPT]