Transcription of interview with Carol Dunphy, former Nurse Practitioner with the Seattle-King County Department of Public Health AIDS Prevention Project, interviewed by Michael Brown on June 22 2015

MB: It's June 22, 2015, and I'm speaking with Carol Duffy.

CD: Dunphy.

MB: Dunphy. How do you spell your last name?

CD: D U N P H Y.

MB: I'm Michael Brown, and we're here to talk about King County's response to HIV and AIDS. So could you tell us how you worked with the county?

CD: I worked with the county as a nurse practitioner.

MB: And when was that?

CD: I started in 1983 when the program first started and I worked 20 years.

MB: And what was the program?

CD: It was the HIV-AIDS program. When I originally started, there wasn't even a diagnosis of – they had not even discovered what caused AIDS at that time, so there wasn't an HIV-AIDS program.

MB: But the program started in response -

CD: To what was going on in the community.

MB: And what was the state of knowledge at that point?

CD: Probably they had good information on how it was transmitted and at that point when people got HIV it was something they were going to die from. Those were the two main points that I think operated at that time.

MB: What were you doing prior to working with this program?

CD: Prior to working with the program I'd gone to graduate school and I worked as a nurse practitioner in the jail, and prior to that I went back to school to get my nurse practitioner degree. My nursing history basically working in all different fields of nursing as an RN.

MB: So you had worked with the county before?
CD: I'd worked with the county before, as a temp, and my jail position was also county.

MB: So how did you come to work with the program?

CD: That's an interesting question. I finished graduate school and I got an advertisement in the mail of the job and I was desperately looking for a fulltime job at that point, I was working three part time jobs, and I applied for it and got an interview and eventually ended up with the job, not even really knowing what it was about.

MB: What department was it? Was it public health?

CD: Public health.

MB: And what sort of things were they looking for?

CD: They were looking for someone basically with experience working with the gay community which I didn't have. They were looking for someone who – that's an interesting question. I think they were looking for someone who would work well with patients and had experience working with a diversified population which I had. And my nurse practitioner background – I went back to graduate school and got a degree in psychosocial nursing.

MB: What sort of work was that?

CD: What did it involve?

MB: The psychosocial nursing, what sort of nursing is that?

CD: It's doing counseling and the main job working with a psychosocial degree was doing counseling or working in a psych unit in a hospital. I just had completed the program, I had not worked with my psychosocial nurse degree yet. They thought it would be really good for this job, and it turned out that it was.

MB: And what was the job description?

CD: I don't recall what the job description was.

MB: Well, what did the job end up being?

CD: It ended up being a lot. It changed a lot over the years.

MB: Can you walk us through that?

CD: The initial job was working with gay men and we didn't know what the cause was and there was no test, so I saw gay men who were concerned about their risk for getting the disease and I basically did a history, physical exam, I did skin testing which was looking at the part of the immune system that was damaged with HIV, that was the only testing we could do for the immune system.
MB: And what sort of test was that?

CD: A test for antigens. Used a preparation of mumps vaccine, diphtheria tetanus, injected them under the skin, looked for an area of redness and if it turned red, that meant that their immune reaction was okay. But I don't know that it was really predictive in the long run, but that's what we did.

MB: That's all you could do.

CD: Yeah.

MB: And was that kind of standard, happening generally in the medical world across the country? That kind of –

CD: I don't have any idea.

MB: You just did it.

CD: I just did it.

MB: So that was sort of the early part?

CD: Yeah.

MB: When did things start to change in terms of your job?

CD: Things changed dramatically – well, they changed, I don't know what the exact timing was, but they changed quite a bit when they found – discovered HIV, that was a big step to know the cause. The next big change was when the HIV antibody test came out in 1985.

MB: They could actually do a test.

CD: Yeah, and that was really a big, big, big deal. One of the interesting things is we went – we had saved blood on all the people that I'd drawn blood on and when the antibody test came out, we went back and tested all the blood for HIV and in 1983 like 22 percent of the people I'd seen were infected already with HIV.

MB: Where was your work mainly done?

CD: It was done in the Public Safety Building at Third and James.

MB: Which floor?

CD: 14.

MB: And Public Health had an office there but that wasn't – was that still an STD clinic?

CD: No, it was a maternal-child – they could do STD, family planning. Mainly the downtown public health office. That in itself was interesting in that not all the staff on that floor were really
I think they had some bias against gay men and I think the issue of it being a communicable disease, and also us taking over territory.

How did that manifest itself?

I personally didn't see discomfort but I had a couple good friends on the floor who commented on it.

And how many people were you working with? What was the team?

I was only working with one person, doing the clinical work, and that was Will Jones.

And who was he?

He was the original person hired for the HIV AIDS program and he did the hotline, he helped me with getting people ready for me to see them. He had them fill out a history.

So it was just you two? And was he a nurse?

No, he was just somebody who was hired, I think because of his big experience with the gay community.

And so it was just the two of you?

And the medical director, Zeke Halgerson, and the regional divisional director, Patricia McInturff.

And there were county employees there, from public health?

County employees, yeah, the administrative part.

I see. So they weren't just working on HIV?

No, they weren’t.

But HIV kind of fell under their job?

The regional division had the communicable disease area of the health department so that's why they got it.

Can you describe what things were like in terms of the state of knowledge and the fear and the uncertainty in the early days around '83?

I think the patients, they were all terrified that they were going to die. They had some information - a lot of people had not had a chance to talk to anybody about HIV at that point, so
they had a chance to talk and to ask questions, so that was important. I forgot the question -

MB: Just the level of knowledge, and the fear and the uncertainty.

CD: Oh, people were certainly afraid of getting HIV. I also did a lot of public speaking, educating people about HIV and that's where I mostly saw the fear. I remember doing a presentation at Seattle Housing Authority and I was totally shocked at the level of fear, because they were afraid that a gay man would be living in one of the housing units, and that if they cleaned it or did anything in the unit that they would get HIV.

MB: Who is they?

CD: The working staff.

MB: Correct me if I'm wrong, but in those early days people were sort of saying this seems like hepatitis, it seems – people were sort of grasping for what is HIV like, comparing the unknown to the known. Were you aware of that?

CD: Not in particular, but certainly the means of transmission in the population were in the hepatitis realm.

MB: Right, yeah. A lot of those people would have had hepatitis.

CD: Right. Yeah, they definitely had had hepatitis.

MB: And so I'm trying to just understand the kind of division of labor in the health department.

CD: Okay (laughs).

MB: So there's an STD clinic, right? And then – but you weren't working in the STD clinic.

CD: No, I was not.

MB: So this is more sort of outreach and health education about – and then testing.

CD: Right.

MB: Could you describe what was the relationship with the STD clinic or the people who worked in STI's?

CD: I think at that point I actually was housed at the STD clinic and I don't remember, I don't think they were doing testing at that point. It was just me doing the testing, but they were certainly seeing a lot of gay men for STD screening, so we were working with the same population, but I was doing the HIV part.

MB: And you were in the same building?

CD: Yeah, that was at Harborview STD clinic.
MB: So when did you move from the Public Safety Building to Harborview?

CD: Must have been late '94, early '95, sometime in there.

MB: Now would you – so you'd do the blood draw when you were doing the testing. Would you also counsel people with the results or was that somebody else?

CD: At that point I was giving the results also and people had to come back in to get the results, we didn't give them over the phone.

MB: How long did it take?

CD: For people who were negative, it didn't take – you know, maybe ten minutes at the most. But for people that were positive, it could easily take an hour.

MB: How long did it take to get the results from the lab?

CD: It took a week.

MB: [off mike] rapid.

CD: Definitely, yeah.

MB: What was that like, to have to tell somebody they were HIV positive at that time?

CD: It was really hard because at that point there was still no treatment and people were seeing that as something that was going to end their life. So it was not an easy bit of information for people to get. They're going to be afraid of transmitting it. It put people in a state of crisis was what it did. I remember counseling – there were some people that it just dramatically affected their life.

MB: What resources could you point them to, and what was sort of the lay of the land in terms of the local response to AIDS? This is sort of '83-84.

CD: Huh. I don't know when the Seattle AIDS support group started. That certainly would have been one resource that I used. And the Seattle Gay Clinic. Those are the two that I remember. But I don't remember the exact date when community resources started coming onboard.

MB: What about when things like AZT and DDI and all that, early 90s – did that change things?

CD: Um, it did. People were glad that there was some treatment. The difficulty was getting them referred to a physician. Because there weren't that many docs that saw people with HIV and a lot of referrals went to the AIDS clinic at Harborview.

MB: When did that start?
CD: Probably started – that's a good question. I don't remember.

MB: Do you remember who was working there?

CD: Hunter Handsfield and Bob Wood. There were other physicians too, but I don't remember who they are.

MB: So when you first started this job, it was just you and this other person?

CD: Right.

MB: Did that grow? Were there more of you as time went on?

CD: We got a research grant from the CDC, it was called the Demonstration Project, and that's when we hired other staff. I don't remember the exact date. At that point we hired disease and intervention specialists to help do the counseling/testing, and do history and do education about transmission and just give people mainly emotional support. That's when we moved to an office where everybody was housed. Tim Burak was the manager.

MB: Where was that located?

CD: Seneca – the same building as the methadone treatment program.

MB: Downtown?

CD: By First Hill. Right by the First Baptist Church.

MB: How many people would have been working there?

CD: Five seems to ring a bell, but I can't say for sure.

MB: Do you remember some of their names?

CD: I sure do. ___ Allen, Mark Chironis, Mark Fleming, Mark Alsted – I don't remember exactly when, who was hired initially at that point, but those are some of the people. We did end up hiring a part-time nurse practitioner to help do physicals on the people who were positive at that point. Her name was Joanne Chilton.

MB: So how were you working with the medical staff? Did they give you your marching orders or did you have a certain degree of autonomy?

CD: I had a fair amount of autonomy but the policies were developed by the management, by the administrative staff and I followed the policies.

MB: Was there any kind of either concurrent or before AIDS and HIV, a sort of analog disease and disease response from public health? Do you know what I mean? To what extent were people making it up as they went along, because this was brand new, and to what extent were people saying well, you know, it was this epidemic or this outbreak so we're going to kind of
CD:  Huh. That's hard for me to say. I think that the initial program was based on all the evidence that was known at that point, doing the best that could happen with the limited amount of information that we had. And as time went on, the policies reflected more the state of ours around HIV and AIDS.

MB: You mentioned that you were originally hired to work specifically with gay men or men who have sex with men. To what extent did you see people who didn't fit that demographic?

CD: I definitely saw some, especially when the testing came on. Probably women who thought they'd had sex with a bisexual man. This is weird, but I guess something that's really striking in my mind – when the test first came out, all the Rajneeshi people were told to get tested so the STD clinic was lined with people dressed in red, and they weren't really at risk, but they'd had more than one sexual partner.

MB: Did you see IV drug users?

CD: I saw some but not a whole lot of them.

MB: Was that more following the demographics of who was testing positive or was that – that was a harder group to get -

CD: That was a harder group to get access to, and at that point they weren't testing positive nearly as much.

MB: To what extent were you working with community organizations?

CD: My role working with community organizations was I went to meetings where all the community organizations met together, so I was part of the team, and that way I got to know who to refer people to and got to know individuals who worked with the different agencies like the Northwest AIDS Foundation, Seattle AIDS support group, gay clinic – in working with the gay clinic, I did testing at the gay clinic also. The education team was more involved in community based organizations.

MB: So you did testing at the gay clinic?

CD: I did.

MB: Like on Saturday morning? (laughs)

CD: Yes, I did. I was there Saturday morning, yeah. I felt kind of like a fish out of the water, but it went well.

MB: How did you feel like a fish out of water?

CD: I was a woman and I had not had a lot of experience working with gay men. My brother was gay, so I had that in my background, but other than that, I was pretty green (laughs).
MB: Would these be different sorts of gay men than the ones who would come to the clinic at Harborview?

CD: I would say they were kind of the same.

MB: [off mike] increased access.

CD: Right. Probably at the STD clinic I would see more men who were bisexual, didn't see them at the gay clinic, but certainly saw a lot of bisexual men.

MB: When did you stop this work?

CD: I worked for 20 years, so it was in 2003, I got laid off.

MB: Oh! (laughs) What happened?

CD: They wanted to use my salary – at that point I was only working with part time funds. I was also working at the – I can't remember the name of the program. I was doing research on people at the primary infection clinic, so I was doing that part time and working part time with the health department, and the health department found enough money to keep me fulltime, but eventually they needed to use my salary for doing education, so I got laid off.

MB: Now by 2003, people who were working in the STD clinic -

CD: They were doing everything, yeah.

MB: When did that kind of shift from being just you and very specialized to something – more general STD -

CD: I'm not sure. It probably didn't take very long. Maybe within a year? The shift happened fairly quickly, because I couldn't do all the testing.

MB: What do you –

CD: The volume.

MB: One person couldn't do it?

CD: And I think the STD clinic, they saw gay men, they also did testing on people with other risks, like heterosexual people that came in to get STD screening, they would get an HIV test too if they wanted one.

MB: What about the sort of issues of confidentiality? How were those handled? Patient anonymity and all that?

CD: I have to think about that. I don't remember. We didn't ask for last names, I think we didn't take last names. People were definitely worried about the confidentiality. We did take their whole names because they were registered with the health department, people were
concerned about their confidentiality and we would tell them that their records were protected because they were STD records so they had special confidentiality over just general medical records. But there definitely was an issue – if people were concerned about confidentiality, they were encouraged to go to the Seattle Gay Clinic to get tested because there they didn't have to give the correct information or any information.

MB: Were there other parts of the County, that you worked with other branches or units?

CD: I worked with the TB clinic.

MB: That was still in public health?

CD: Yeah, that's still in public health, but I didn't work in any other county organizations.

MB: So by 2003, what was your job mainly involving?

CD: Along the way, and I can't tell you what date it was, we started doing a program called the one on one program and that was we basically saw people who were HIV positive, did the history, physical, talked to them about – actually did CD4 testing so we could tell them what their CD4 count was and give them an idea about where along the spectrum of HIV they were. And did a lot of counseling, emotional support and referred them to physicians in the community. It was really a good program. My favorite part of the job, the one on one program. I liked working with HIV positive people.

MB: How come?

CD: Um, because I was able to really be a nurse, the caring, helping people, doing emotional support, problem solving – all the things that nurses do.

MB: How many clients or patients would you see in a day?

CD: Probably – it would depend on the day. The one on one program did not break fulltime. I maybe saw four or five people a week. Because at that point I was also a supervisor so I didn't have time to do the one on one program all alone. We hired somebody to do it part time.

MB: Again, this was funded by the health department?

CD: Yes.

MB: As the disease changed and treatments changed, how did your work change? Into the 90s.

CD: I think two things happened that changed the job. One was giving test results over the phone, because for years we only gave them to people in person, even if they were negative, they had to come in to get the results. Then we changed our policy and gave results over the phone. So that was one major milestone. The other one was the rapid test came along where we could get the testing done right when they were in the clinic.
MB: Which meant they wouldn't have to come back, or phone.

CD: Right.

MB: Why was the shift made to the phone calls?

CD: I think probably at that point we felt like there were enough resources in the community to give people that information over the phone. Staff time was an issue. And it was being done other places. We were still one of the only people that was giving results out in person, so we wanted to step up and do it over the phone, which worked okay. It was okay. People could come in if they needed to come in and they were still referred to the one on one program, they still got the same education they would have gotten if they'd come in, it was the same process.

MB: Did you see the demographics of HIV change over time or was it mainly still all gay men?

CD: It was still mainly gay men. We had some injection drug users, we had some women who had tested positive, they had a bisexual partner, but it was still mainly gay men.

MB: How did attitudes change around HIV?

CD: That's another good question. I think the attitudes of the general public changed some. People became more accepting of HIV, more educated about it. A lot of people knew somebody who was HIV positive towards the end of my tenure with the AIDS project. Staff attitudes – I think staff became more comfortable. Big hurdles were giving results over the phone, people became more – their attitude went to the point where giving people a test or giving results in the same visit was okay. But a lot of people that worked with us knew people that had HIV or people that had died of AIDS so the empathy and caring and concern were still definitely there, that didn't change.

MB: Were you working with gays and lesbians in the health department? I mean was that part of -

CD: It certainly was. Many of the staff were gay men, though not all the staff. We had some women, we had a couple straight men, but I think it was important for the community to have gay men there as counselors and testers. It was important for us to have the connection with the community.

MB: Do you feel that was a positive relationship?

CD: I think it was a positive relationship. There certainly were people who thought because we were the government they didn't trust us very much. We couldn't change the fact that we were part of the government (laughs), we just were. But I think we had a good reputation overall.

MB: So prior to working in this program, you had not worked with public health?

CD: I worked with public health and I worked in the jail, but I wasn't –
MB: That's right, you worked with the jail. What were your duties at the jail?

CD: Seeing inmates who had an illness or symptoms, something going on that they wanted to have checked. It was like being a primary care person.

MB: And there was no M.D.?

CD: There was physicians there.

MB: There were as well?

CD: Yeah.

MB: So you worked with physicians?

CD: Yeah.

MB: And this was the jail downtown?

CD: Yes, it was the jail downtown, before it moved to the new jail.

MB: And so you wouldn't have seen HIV, or if you did, you wouldn't have known what it was?

CD: Um, I did not see any HIV or AIDS when I worked in the jail. That was in 1980. I know at that point there certainly were people dying in Seattle. But I don't remember even talking about it. The first mention of it was at the interview.

MB: How did that come up in the interview?

CD: Ways of doing – my ability to do counseling with people. I remember it was a really interesting interview and I was kind of tested to see what my reaction to certain things were going to be, like what certain sexual practices were called other than anal sex.

MB: But you passed? (laughs)

CD: I passed, I did. Will was really looking for someone who was going to be perfect. He didn't make the ultimate decision, I don't think. In some ways I was kind of shocked at some of the questions, but my life experience was such that – it just kind of was, and I really wanted a job, one that I could use my master's degree doing it. So I just carried on (laughs).

MB: Now in the sort of early days, given that there was no treatment and things could progress very rapidly with overall AIDS and whatnot and infections, how sick were the people who were coming in to see you? Were they just HIV positive or were they people with full blown AIDS?

CD: I saw some people with full blown AIDS that I immediately referred them out to see a physician. There were a lot of people with lymphadenopathy which was went along with the HIV AIDS, people with yeast infections in their mouth. So I was seeing some signs of HIV
along with people being sick.

MB: What about the pneumonia?

CD: That's the people that I saw that were really sick, the people who had pneumonia. I remember seeing KS [Kaposi sarcoma].

MB: Would you know when these people died, or would they just go away and get referred to physicians and then you'd never see them again? Did you ever have to do follow up?

CD: I didn't do follow up but I did sometimes hear back about the diagnosis and I sometimes was made aware when people died. I also did some work in the AIDS clinic myself and had a couple of my patients die there. But there wasn't a whole lot of follow through unless the patient called me back again.

MB: And would that happen?

CD: Um – I would say not very often.

MB: So you were really kind of there by yourself on the front line.

CD: I was, definitely on the front line. All by myself.

MB: How were you keeping up with the current state of knowledge around HIV? Where was the information coming from in your work?

CD: Probably mainly through the medical director, because I met weekly with the medical director.

MB: And who was that?

CD: The person I met with weekly was Bob Wood, he was my boss.

MB: So he'd sort of tell you what was going on with the medical advances?

CD: Right, and we talked about them in the clinical staff meetings. Gary Goldbaum was also my supervisor at one point. And I went to a couple conferences which were really good.

MB: Being on the front lines, could you see patterns and tell the medical director about them?

CD: I don't know that I could see patterns, but I consulted with the medical director on certain patients and we would talk about who I was seeing and they also collected data and we'd look at the data, see what people's risk was, who was positive and who wasn't.

MB: Which was information you were getting with the interviews?

CD: Right.

MB: And you never did any like contact tracing?
CD: No, I didn't do that.

MB: Any disease investigation? Did you work with those people?

CD: I did. They were the people that we initially hired to do the demonstration project. As time went on, it became more okay to do contact tracing. That was another big leap.

MB: And when was that?

CD: Probably in the late – it was when we were more closely affiliated with the STD clinic.

MB: Because the STD clinic would have been doing contact tracing.

CD: Probably in the late 90s, I would say. It also involved notifying people who had tested positive but didn't come in to get the results.

MB: But that wasn't your job.

CD: No.

MB: So your job must have involved a lot of trust. How did you build up that trust?

CD: I think I had a reputation – I was a good listener, was probably the main way that I built up the trust. I am or was very empathic, so people generally feel comfortable with me. But there were some people who didn't trust very well. It changed over time, but there were still people who had a really hard time trusting other people. It was understandable, they had a highly stigmatized infection.

MB: When you started the work at first, where did you think it was going to go? Did you think it was just going to be a short term contract?

CD: I didn't have any idea. (laughs)

MB: Twenty years of HIV front line work? You just followed your nose?

CD: I just followed my nose. It could have lasted a year, but it ended up lasting twenty years. Through that many changes, there was that need for that whole time. Then the disease intervention specialists started, they were part of the STD clinic.

MB: How do you think HIV and AIDS changed public health as an institution in King County?

CD: I think that it made the community more aware of public health. Public health was not something that people thought about. With HIV AIDS, the health department was more active in things in the community. We marched in Gay Pride. Television interviews were done, conferences were put on.

MB: To what extent from your perspective do you think Seattle's experience with AIDS and
HIV was similar and/or different from other cities?

CD: I think initially we kind of got a late start, based on what going down in the Bay Area, but the fact that the program happened at all was just really, really great. I'm not sure, I don't remember the history of how it happened, but it happened. The community worked with the health department and the HIV AIDS program happened.

MB: Did you do the community outreach education?

CD: I was doing some community outreach education but that was not the main part of my job. I would do presentations to some of the community organizations.

MB: But that wasn't mainly your job?

CD: Did a lot of community speaking which I was terrified about. When I took the job, you had to give a little short speech, and I think I almost read mine. I was really afraid of talking in front of people. But I had to really deal with the fear when I started the job and after the first couple of education sessions, it was good, it was fine. I didn't worry anymore.

MB: What sort of community organizations? Were you only talking to the gay community or were you talking to schools or clubs?

CD: Did a lot of time talking with nurses – I'd say that was the main part of the education part that I did.

MB: In different – like what settings, what kinds of nurses?

CD: Nurses in general and mainly at conferences. I did presentations at a lot of different things. I did – I can't remember all the places that I did, but I did a big variety of different places where they wanted HIV training. As the education department grew, they took over more of that role and I stayed more with health care providers.

CS: [off mike]

CD: Basically giving them the positive test results and then dealing with their reaction which could take anywhere from 10 minutes to an hour for some people because they were just so shocked. Then doing the counseling education and getting people referred to agencies in the community, that was a big part of it. Some people just needed time to talk, just time to be with me. They'd also talk about how they were going to tell their partners. So it was easy to take a long time.

CS: [off mike]

CD: It was hard. But it was also satisfying because I felt like I was able to help people, a lot of jobs that you have you don't feel that. But I was able to be with someone for that time and help them come out of the state of shock, at least somewhat from the state of shock, to get ready to go out and do their life again, still.
CS: [off mike]

CD: Um, I think about the group of people that worked for the HIV AIDS program and how compassionate and caring, well educated – it was really a big pleasure to be part of that group of people and the number of people grew over time. I got to connect with – we ended up with a needle exchange, I would go down and do testing at the needle exchange. So just working with a program that did so many things for people with HIV risk, that and working with HIV positive people. I did get an award, Nurse of the Year, with King County Nurses Association for doing my job. So add that in there.

MB: What year was that?


MB: Who are some of the individuals you remember in terms of the people you worked with? You mentioned Bob Wood. Who else do you remember?

CD: Edith Allen, Barbara Newland, Joanne Tilton, Mark Alsted, Karen Hartfield, Ann Downer, Will Jones, Kathy Silverman, Diane Perreiro, Michelle Perry, ___ Medina, Tim Burak, Frank Chaffee. Frank was originally hired as someone to do counseling and testing, and then ended up being the program manager which he's been doing for a long time from what I understand.

CS: [off mike]

CD: Um, I felt that the County was supportive, but I was not involved in budget negotiations so I didn't deal with the budget on a day to day basis, so that was kind of distant from my role.

CS: Did it feel like over time the support [off mike]

CD: I think it increased.

CS: How did it compare to the jail?

CD: Working in the jail was incredibly frustrating and not particularly rewarding. Working with inmates was hard. You didn't know who to believe or what to believe, so there was a huge difference. And the County was supportive of the jail, but probably in a different way than they were supportive of HIV AIDS program. There was a lot more political activism in the HIV AIDS program than there was at the jail. Big difference.

MB: One of the things that people have talked about in terms of the county health department is the role of UW, its association between the research side of things and the public health, treatment side of things. Did that relationship affect your work?

CD: It did because we did several studies with people that worked at the U. We did one on oral health, we worked with Roger Rothman and his safe sex program. I think those were the two main people that we did research with at the U.
MB: And those were specifically HIV related research?

CD: Yes, they were.

CS: [off mike]

CD: I don't think that I – I know the police were afraid and the firefighters were afraid, but I don't think I did their education, I think maybe the medical director did them.

CS: [off mike]

CD: I think the stigma decreased, but there was still people who were really afraid of getting it, and dealing with the issue around education around safe sex, were people practicing safe sex or were they not – that was a big issue. We did a lot of counseling about that, but behavior is hard to change. One of the other things that we did was we did counseling and testing in the bathhouses.

MB: Who was we?

CD: The HIV-AIDS program did it and the disease intervention specialist took turns going into the bathhouses.

MB: And you went as well?

CD: No, I didn't. That's one thing I didn't have to do (laughter). I was open to things, but not to that. They would not have liked to see me in a bathhouse. Although I did have a tour of one, but it was closed. I got to go on a tour. That was interesting. I don't remember which one it was. That was definitely part of my education.

MB: What do you think the legacy of the program was or is?

CD: I think the legacy was identifying and creating a program and doing the ongoing program with changes according to what is going on in the research. I think that's the legacy of the program and the fact that it worked really hard, worked with the community and the community based organizations. I think that's the legacy. It's interesting, people ask me what I did when I was working and I tell them I worked with the HIV AIDS program. I think people are kind of surprised. I think they maybe didn't know there was an HIV AIDS program and what to know what I did. My family and friends were supportive of me doing it. I look back and it's really amazing to think about what I did and how things changed and how much a part of things I was.

MB: Yes, you were.

CD: Yeah, I was right there.

MB: Did it seem extraordinary at the time? Did you have time to reflect in the moment?

CD: I think initially when we started doing counseling and testing it seemed very extraordinary, we were doing something that nobody else was doing, and there was a great need
CS: [off mike]

CD: Eventually it was available everywhere, but people wanted to maintain their confidentiality and didn't want that information in their medical record, they would come to get tested with us. Yes, it was in their medical record but it wasn't part of their actual medical record in their physician's office, especially if they were not positive.

MB: You said you were doing education with the nurses. Were you doing any education or outreach with GP's? Doctors in the city? Or was that someone else?

CD: I think probably the medical director did that.

MB: What were some of the sort of misinformation, the confusion that – [break] I was asking, going back to when you were doing the education and the intake and the questions people had, sitting across from you, your patients, what were some of the confusions or misunderstandings or ignorances they had?

CD: Um, I think when treatment became available, the issue of people having a chronic illness versus people dying, that was a piece of misinformation that people had and at that point the trust had not developed as far as the treatment. It was new and they didn't want to take medication because of side effects. That and one of the big issues was kissing, could kissing transmit HIV. That was a hard yes or no. But people generally had – I think over time the attitudes, the knowledge around what was safe and what was not safe, people had pretty good information. Again, it was behavior change was the issue.

MB: Is there anything else that you'd like to talk about?

CD: I think with the HIV AIDS epidemic the response was different than it was to other epidemics. A totally new population were affected, the scope of the problem, not really knowing for sure when it started up, like in Seattle, but again knowing that 20 percent of the people that were coming to the HIV AIDS program initially already had HIV. That was in 1983. So around other epidemics, there weren't active community based organizations that developed around an epidemics, and funding was different – just the whole magnitude of the epidemic. And now to see and know people who have had HIV for 20 years and are doing fine, which never, ever, ever would I have imagined when I was working with HIV.

MB: No?

CD: It got to be a chronic disease, but for people to live as long as they're living, that's something that to me is still wonderful, that people can keep doing well over the years. That's the biggest gift that has come from HIV – education and the biggest gift to the population that's infected. The big question still is how do we help people change their behavior in all different realms, not just sexual behavior. We're better at doing that, but it's still a really difficult thing to do. I think that's one of the things that challenged me most, knowing that you're giving people information but their ability to transform it into actual behavior, which is not easy. It's easy to talk about it, but to do it is another thing.
CS: [off mike]

CD: I think the education people would know that more than I would.

CS: [off mike]

CD: I didn't feel it, and I didn't think twice about it, either. It was just something that you do. It wasn't shocking. It was appropriate to what we were doing and to the populations that we were working with. One of the big controversies was opening the needle exchange.

MB: And that was done through the AIDS group at public health?

CD: Yes, it was.

MB: But you weren't a part of the needle exchange.

CD: No. I did testing at the needle exchange but I did not actually work there.

MB: So you worked – you did blood draws basically.

CD: Right.

MB: At the STD – at the Public Safety Building, the STD clinic at Harborview, the Gay Clinic and the needle exchange.

CD: And the building on Seneca, I did.

MB: So they just sent you all over.

CD: I went all over, I sure did. I turned up everywhere. You never knew when I was going to turn up. I got to be a really good blood drawer – we all did. When you drew blood, there was always concern around getting a needle stick, but as a project we were pretty lucky.

MB: As a nurse, was the whole – universal precautions are now pretty standard, they weren't necessarily in the 70s. Did you see that change?

CD: I did, and I think the hardest thing was for people to use gloves when they're drawing blood, that was a big controversy when we first started doing universal precautions. Because they would say they couldn't feel the vein or they couldn't draw blood with gloves on. Now nurses wear gloves for everything. I think it's really great that you're doing this. This program deserves to be -

CS: Definitely. It's really exciting that everyone's eager to tell their story.

CD: Mark Fleming sent me a message on Facebook about it. We're Facebook friends, that's how I found out and that's how I got –

CS: Oh right. So how many of the people that you worked with in the program are you still –
CD: Maybe ten? Not a whole lot but at least ten people.

CS: [off mike]

CD: Yeah, we do.

CS: Thank you so much for your time.

CD: Thank you for your time.

MB: And your stories.

CD: It was a great job.

[End file]