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Contact:

LGBT History Project
Archives & Special Collections
Waidner-Spahr Library
Dickinson College
P.O. Box 1773
Carlisle, PA 17013

717-245-1399

archives@dickinson.edu

Interviewee: Deb Fulham-Winston

Interviewer: Amanda Donoghue

Videographer: Kailey Zengo

Date of Interview: April 19, 2017

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Transcriber: Amanda Donoghue

Proofreader: Alette Kligman

Abstract:

Deb Fulham-Winston was born in 1952 in Boston, Massachusetts. She grew up in an Irish-Catholic family with eight siblings, and spent the first half of her schooling in Catholic school. Early on, she had a strong conviction for feminism and social justice which drew her away from the Catholic Church and inspired her to attend Bates College for two years and then transfer to the College of the Holy Cross in Worcester, MA, where she was one of the first 13 women to graduate. She has spent all of her career working with non-profits in the development sector, including agencies such as Planned Parenthood, various college fundraising organizations, and a variety of others. During this interview, she primarily discusses her experience at SCAAN [South-Central Aids Assistance Network], and her experiences with the social connotations of working with an AIDS foundation, the struggles that individuals with AIDS went through, the functions and day-to-day activities of SCAAN, and the annual AIDS Walk in Harrisburg, which she organized.

AD: So, I'm Amanda Donoghue and I'm here with Kailey Zengo, the videographer, and we're here for the LGBT Center of Central Pennsylvania to interview... Deb Fullman--

DF: Fulham. (laughs)

AD: Deb Fulham-Winston. (laughs) Nice to meet you, Deb.

DF: Very nice to meet you both.

AD: Okay. And just for the sake of... If you could just consent, like verbally consent, that you're okay with this...

DF: Oh, yes, I'm okay with this, I'm totally okay with the videography and the video-taping and everything else. Recording.

AD: (laughs) And just to let you know if there is any time that you want to stop interviewing or turn the camera off, you can just say that, or if you don't want to answer a question you can just say 'shut up' or whatever you want, so... (laughs)

DF: (laughs) Never!

AD: Alright. So let's just start off with early history, where you were born, where you grew up, family...

DF: Okay. Well I was born in 1952 in February, in Boston. I have eight brothers and sisters and was raised in a very conservative Irish-Catholic family, which comes into play later. (Laughs) I went to a Catholic elementary school, and then in seventh grade went to a public school, seven through 12 went through the public schools. I was very involved in sports when I was in high school. It was pre-Title IX, so the difference between men and women's sports was massive. In fact, we basically got no support. It was very much gym-class oriented, not competitive oriented. So it was a very different world. Thank goodness that has changed. I went to Bates College for two years up in Maine, and then I did my last two years of my B.A. at the College of the Holy Cross in Wooster, Massachusetts, where I was one of the first 13 women to graduate from the college. They had been a male-only college for two hundred and twenty years or something like—wait no, that can't be right, one hundred and twenty years. So it was a fascinating experience. (laughs)

AD: Yikes.

DF: It really was. Then two weeks after graduation, I got married, moved to Wisconsin, lived there for five years, spent a school year in Italy, then back to Wisconsin, then to here. Since that time, I've primarily done non-profit work and primarily in development. So any kinds of fundraising, donor relations, that kind of thing. For a two-year college, a four-year college, a law school, an AIDS service organization, Planned Parenthood, a hospice organization, public television, and a community foundation. And now I've started my own business doing freelance grant-writing. So, a little bit of everything. (laughs)

AD: Yeah, that's really amazing.

DF: And I have two children, who are both in their mid to late twenties.

AD: Okay, awesome. Just flew through a lot of these. (laughs) Well, okay, back track a little bit. So you said your family was Irish Catholic?

DF: Yes.

AD: So do you want to talk a little bit about that, about like what that entailed, maybe how that played into your own religious beliefs?

DF: Well, I left early on. Starting about when I was 12, I decided this was not something I was interested in doing, there was very little about the Catholic Church that was attractive as a female person, so that has not... I have not been a member of a faith community voluntarily since I was about 13. But while I lived at home, it was my parents' house, their rules, so, you know, you play by the rules. I don't know, I don't have any (finger quotes) religious convictions. I have ethical convictions, but I don't, I'm not affiliated in any way, shape, or form with any kind of organized religion, nor do I really actually believe that there's actually any kind of deity or afterlife or anything else., which is diametrically opposed to my parents. But I just realized recently of the seven of my siblings who are still alive, only one goes to church regularly, and one goes occasionally. And that's it. (laughs) So we all pretty much sort of went our separate ways. But I think it has a big impact on how you approach the world to be raised in that kind of codified environment. Because of the fact that it was not only at home, I, also K through six, I was in a Catholic elementary school when there were still nuns teaching, I never had anything other than nuns teach me when I was a kid. It really changes the way that you look at things, and certainly hierarchies are, you learn them very quickly, and you understand how they work very quickly. Which, that's actually pretty handy. I never got caught for anything in high school, so. But it does, I think it does shape your world-view to come out of something like that, but I think also that being, there were six girls and three boys, and it was a very male-centered household. So I think very early on I realized that things are not so good for women (laughs) out there, so I became a feminist fairly early on as well.

But when I took my job with Planned Parenthood, at that time both of—it was in 2004, I think it was—when I told my best friend about the fact that I got the job she was like, “Thank God your parents are dead.” (laughs) Cause that would have like totally put them over the edge. (laughs) They had a hard enough time when I worked for SCAAN. That was very hard for them, because my mother believed that homosexuality was a disease from which someone could be cured, and I think my father had just never become comfortable with the concept, or just the reality. And I'm sure he encountered folks over the years who were gay, but, like you didn't talk about it.

You never talked about it. And in those early days, people could very easily say, “I don't know anybody who's gay,” because people were so far in the closet that, that of course they knew people who were gay but they didn't *know* that, so they could very honestly say, “Jeez, you know, nobody in my world is gay. That's those people in New York and San Francisco and Boston and big cities. They don't exist other than that.” So it does change your world-view I think, to be raised that way, but I left that behind pretty early on. (laughs)

AD: So you mentioned that you became a feminist early on, so how do you think that has affected, I mean just from what you've said already, it sounds like it has affected a lot of important changes and decisions throughout your life.

DF: Yeah, I think it has. I don't know that I would've made the choices to work at the places, certainly I would not have worked at SCAAN or Planned Parenthood without that in my past, I

don't think. But I think it also had an impact, for instance, I worked at Dickinson for six years in the Development Office, mainly working with alumni, because I was doing annual giving and I was doing class chairmans and the class giving committees and that kind of thing, for reunions. So working with those women and really encouraging them to be active participants, and to take their role seriously, and not always have committees be led by men. (laugh) That there's a place for everybody. But there were... Things have changed so dramatically in the last 20 years, which is really good, 30 years, which is really wonderful. When I first started out, it was very, very common to be treated, even though I was a professional staff person, people sort of assumed you were a secretary. Of course, secretaries don't really exist anymore, so an administrative assistant. But you were not a professional person. But there was also a tendency for men to basically try to pat you on the head. It's very difficult to deal with in a way that is not rude.

AD: Yeah.

DF: Because they didn't understand; they didn't get it. They just didn't get it, that they weren't. The notion of treating women equally in the workplace was so new for many of them that they never really got there. And it's still true, but it's less true because there's so many more men who have come up assuming that they will be working with women. It would just never would have occurred to them that they would be in an all-male environment. Even in the military. Which was probably, well I can't think of any other time, well other than the seminary, you know, I can't think of any other place that's really just sort of all men, or a preponderance of men, anymore. Which is good.

AD: Football.

DF: Football, yeah there is that. But that could be changing too, with all that's going on there. There was a something—off topic. Nevermind. (laughs)

AD: I actually think I know, there was a woman who just got a scholarship for football, a college scholarship.

DF: Oh nice, is she a kicker?

AD: I don't know, I didn't really hear anything more about that but...

DF: That would seem the likely first place. But what I was going to say is I recently heard on a news report, a little short thing done by a gentleman, who had for years been very, very involved in midget football, as a senior kind of organizing person, nationally, and he was saying kids under 12 should never be playing football.

AD: Oh, wow.

DF: Absolutely should not because of the damage to their bodies and possibly their brains. And that by the time that you're 12, a lot of your structure is kind of set, or at least strong-er, but with

those little guys, he was like absolutely not, shouldn't be happening. Woahhh. [Whispers] That's fascinating. That's so different. I mean, five years ago, no one would say that out loud. So it's one of those positive changes that kind of sneaks in when you're not paying attention. Because for somebody that integral to the mission, essentially, to say this shouldn't be happening. It's very different. It's kind of exciting, though, I think.

AD: It is. (laughs) Alright, okay. So, well let's talk about what you primarily came here to talk about, SCAAN, so what time did you start getting involved with SCAAN?

DF: Okay, I started, I first became aware of SCAAN because I was looking for a job. And it was actually the first job. I was looking for a job after having been out of the work force for two years, first living in England for two years where my first son was born, and then coming back into this country, and four months later my younger son was born, so I had been out of the work force for about four years. And I was starting to look for a job, and the market was not great. And it was also—there's a certain amount of.... Lack of, I mean, you've been out of the work force, it's like, who's going to hire me? It's like, what have you been doing for the last three years? Well, I've been diapering babies. (laughs) You know? Not much else. And parenting.

But it's a little intimidating when you first start doing that, so I had been applying and... It was also the time of the year, it was sort of January, so that's not a huge time for people to hire anyway, but I saw this in the newspaper, cause in those days, that's where you went to look for a job. Cause everything was still hard copy. It was, you know, want ads were in the newspaper and there really, I don't think... That would've been two thousand... I mean, I'm sorry that would have been 1992, January of '92. I don't think anything was electronic at that point. It's kind of hard to remember, but I don't think so, in terms of public media. Or if it was it was very low key and small. So looking in the newspaper and saw that. And so I sent in my application, and this being a very small valley, the gentleman who was then the chair of the board was, had been a Dickinson student, and actually had been a student of my husband's, and had been very involved with student stuff when I was working for Dickinson, so I had met him *then*. His name was Jim Cartmell. And I'm guessing Jim graduated...maybe like '89, '88, somewhere in there. I'm not sure exactly. And he was working for a, maybe Capital Blue Cross, somebody big, health insurance, I think. So that was sort of welcoming, and like, woah!

So after a series of interviews with the executive director and then with the board, they hired me, and I was just in-- absolutely elated. I was also, if, I don't know if I was the most naïve person on the planet at that point, but I was one of the most naïve people on the planet when it came to homophobia because it never occurred to me that this would be an issue. These were people, you know, SCAAN was taking care of people who were sick. You know? Cancer Society, Heart Association, Leukemia and Lymphoma... I mean, if somebody's sick, you figure out a way to take care of them.

So then I called my parents and my mother-in-law to tell them about my new job and I was very excited. And my mother had the A answer, and she said, “Whatever makes you happy makes me happy.” I was like, okay, not overwhelming, but that’s okay. And then I was talking to my dad, and his comment was, “I never thought you’d work at a place like that.” Not a great answer. Then I told my mother-in-law, and her comment was, “Don’t bring anything home.” The C answer. (laughs) Or perhaps the F answer. I was almost in tears by the time I got through telling them. And this was my, what I didn’t know at the time, was this was the first reaction that was going to become more common. And more often than not, when I told people other than my close friends about the job that I had taken, they were like, “Why are *you* working *there*?” And it’s like, well, because they’ll pay me. (laughs) That seems like a really good plan. And it’s a non-profit, and I want to do work for a non-profit, and I liked the people I’ve met, cause they were delightful.

It just took several months before I realized, sort of what I had done. Which was being a very— Oh and the other thing that sort of brought this to mind- I’d say I was at SCAAN for about a week when one of our volunteers popped his head into my office, and he asked me the same question. He’s like, “Why are *you* working here?”

I looked at him and I said, “Because they pay me.”

And he was like, “Okay, that’s fine.”

And my sense was that what he was trying to find out was whether or not I was your basic suburban white woman, bleeding heart liberal who had come here to take care of the innocent victims, but without saying that. (laughs) Though that came up later, with other things, but it became clear really early on that I had completely and utterly underestimated the level of homophobia and fear that people had about gay people, drug users, HIV, AIDS. Sort of, “Is it catching? Is it in the air? Can you shake hands with somebody and get it? Whatever, sort of, you know, what kind of contact?” I mean, most people were so stunningly ignorant, including myself, about how sort of transmission: “What is this really? How does this effect people?” We just didn’t know. And we were all on a massive learning curve, along with the NIH (National Institutes of Health) and everybody else, because people didn’t know anything. They didn’t know how to treat it, they didn’t know how to do things with it. So, so it was kind of a crazy transition over time.

It got to the point that I would regularly meet people in business situations where they would not shake my hand, where they would move away from me, and like, literally, physically sort of move back from me. I can still remember going to a training session that was being put on by one of the non-profits in the area about fundraising, and it was free, so my executive director at that time, Peg Dirkers, and Jim Cartmell, who was our board chair, and I all went to see. Because it was also to meet funders, as well, so we thought that would be useful. And Jim had a cold, so he was a little sneezy and coughing. And people, you could’ve... No one would sit near him. No

one would touch, shake his hand. No one would talk to him. People physically moved away from him when he coughed or sneezed, like somehow, like we used to tease in the office that there were AIDS cooties and, you know, what was going to happen was that somebody was going to catch them from us, but it was... And we could laugh about it, but it was actually really serious. I mean, the level of disconnect between the general public and anybody working in the area was massive. The news, and talking to reporters, they didn't know what the hell they were talking about, and they would ask monumentally stupid questions about everything. And there was a huge amount of, I don't know if it was really misinformation or just complete ignorance that had an impact on everyone. Because they just didn't know.

So I was hired as the first development person. Before that, everything had been volunteers. And the organization originally had been all volunteers, and so Peg was the first executive director, and there were case workers and... We had, we were, SCAAN was also of the Pennsylvania AIDS Hotline, so that person lived in our office as well, even though she wasn't on our payroll. She was on the state's payroll, that's where. She was there when we were there. I'm trying to think... Is that everybody? Oh, and we had an education person as well, who was mainly doing street outreach to people, trying to get people to come in and talk to us, people to seek out services. She had hoped to be able to start a clean needle program, but needle exchange was anathema at that point, so handing out a lot of condoms, handing out a lot of booklets, information, that kind of thing. She had a group of volunteers who did street work with her as well, so we were a pretty small group, all—so I'm guessing, I'd have to go back and think, but I think there were four caseworkers, the hotline person, the education person, me, Peg, a receptionist, and a part-time bookkeeper. And I think that was everybody.

And we had an oot-load of volunteers. Many of whom would come in and out at odd times, because some of them were on disability, so they weren't working, so they'd come in and stuff envelopes, and make photocopies, and get the street packets ready for people, which were little plastic bags, little zip-lock bags and there was like a condom, a sterile wipe, what else was in there? Lube. Seems to me there was something else in there as well... Maybe a booklet of some kind. Cause they would, we handed out hundreds of these things to people. I mean, I didn't, but the street folks, those folks did.

And other than that, I mean, during the day, we basically operated as any non-profit operated. The case workers were seeing clients. I was mainly in charge of the AIDS Walk, organizing the AIDS Walk. And we had another. That was in the fall, and then...Is that right? Or was it in the spring? I can't remember now. No, it must've been in the fall, 'cause spring we had something called "Caring a-la-carte," which was a dining program where restaurants would agree to give X percent of the profit to the organization and people would host tables, so like I would recruit a group of people to come to a particular restaurant with me and we'd all sit together and then that would, and that was a lot of fun. But there were very few restaurants who were willing to talk to us. And in fact, several years later when I moved on to my next job, one of the first things I

realized was that people returned my phone calls when I worked for a community college much faster than when I worked for SCAAN. (laughs) So it was, it was just a crazy time.

And of course, it was also, I was working there before the triple-cocktail came out, so there was pretty much EZT and there was another one. DD-something? I can't remember what the other med was. But it meant that people were dying. And it meant that some people died very fast, some people much longer trajectory, some people long enough so that by the time the triple cocktail came, they got their lives back. But it was... We literally watched people disappear. Because they would get smaller and smaller and thinner and thinner, and then all of a sudden they wouldn't be coming in anymore because they couldn't get out of bed, or because they had died. And it was, I don't know how the caseworkers did it, to be honest with you. Because they became very close to the clients. The folks I knew were the folks who were our volunteers, so that was a subset of the group of people that were being served by the organization. But in the two months before I changed jobs, I went to four funerals. And I got to the point that you would—and I think all of us did—that you would walk down the street, you'd be sitting in a restaurant, you'd come into a library and you'd look at somebody, and you'd be like, "They're dying." Because it was so common to us.

I mean, you'd look at somebody and they'd have all the classic wasting syndrome kind of symptoms and everything else, and, now they might not have been dying of AIDS, they could have been dying of cancer, but it was like there was this look that people got when things were starting to go pear-shaped, and it just, you saw it everywhere. Because there was nothing to stop the disease, or, you could slow it down, but EZT also had incredible side effects for people as well, so it was also very harsh. And when the triple cocktail first came out, if I remember correctly it was only effective for like, there was, like 35% of people could not take it. And there was a man who had been, who almost was the second executive director of SCAAN, who was a doc at Hershey [Pennsylvania], who had been outed and then fired for being both gay and HIV-positive. And he sued Hershey and eventually he was known as Dr. X. And Mark was a wonderful man but he was one of the people that the cocktail didn't work, and I think he died in '95 or '96.

But it was a crazy sort of existence because sort of work was one thing, and the rest of my life was completely different. I had two little toddlers. Paul was four and Sam was two, so it was just kind of these two pieces of my life didn't really fit together very well. And I was also working crazy hours, so that probably didn't help either. (laughs)

But, but things were changing, I mean even in that short period of time, cause I worked for SCAAN from, I think it was January of 1992 'til May of '95. And even in that time period, things were really starting to change, in terms of people's perceptions of the disease. Maybe because with the triple cocktail coming in, it meant that it wasn't quite as scary, even though that took a while to kind of all happen. But people... Maybe it's also just that people were talking about it, people were being more open about this. And the other thing it did, it meant that all

sorts of people who had been deeply in the closet couldn't hide anymore. So it changed everything. And all of a sudden people did know people who were gay. (laughs) Some of them sick, some of them not sick, but you know partners of someone who is sick, or people who you'd always assume were good friends, and all of a sudden you were like, "Oh! (laughs) They're partners!" Because you know if you're not looking for something, you don't see it. So it doesn't, and it wasn't of course, in the public discourse it was also pretty much not there either, so there was nothing to reinforce the notion that homosexuality was everywhere. And of course lesbians have also always been able to be more sort of... I don't know if 'hidden' is the right word, but maybe 'hidden' is the right word, than it is for gay men because people don't think twice about two women walking closely and you know talking to each other and ch-ch-ch-ch (mimes two hands 'talking' to each other), having a dinner together, you don't even think about it, because you know best friends have done that forever! Or sisters, or cousins, or you know, whomever. But for men it was much harder.

And there were a lot of people who came out who were outed, and that's also the period where people were outing other people. And it was cruel, because often that person wasn't ready to be public, so it was a big. So it was a big... That was a huge deal when that happened. I'm trying to think of the actor's name, oh foey. I'm blanking, but I mean you know there were public people who suddenly got outed as gay as well, and it, for some of them it ruined their careers. They were done. And that, I mean, now, that... I hope it doesn't happen. I suppose it does. I'm sure there is discrimination. I know there is discrimination, but I don't think it as overt or as deep as it once was, thank God. But at the same time Pennsylvania still doesn't have an anti-discrimination ordinance that covers everybody. It makes no sense. I mean people can still get kicked out of their apartments—

KZ: Carlisle [Pennsylvania] does!

DF: Yes they do, yes! Yes, I went to all of those meetings. (laughs) It was both encouraging and discouraging.

KZ: Scary, yeah.

DF: Yeah. I was incredibly impressed with people who got up and spoke about themselves and their lives, and who may have been saying something in public for the first time. But I was horrified by the sheer number of people who were clearly identifying themselves as people of faith who were saying horrible things about gay people. In public, and owning it. Like (waves arms around) how can that level of ignorance still pertain? And I have a tendency to forget that of course, it does. And I'm an optimist so I want things to get better, I keep hoping things will get better, but that was, that was a slap upside the head, I guess I would say. And I would say that Carlisle is probably pretty representative of most municipalities. I don't... Anywhere in the country, there is going to be that reservoir of people who still cannot accept difference. And...It

doesn't help. It doesn't help build community, it doesn't help build neighborhoods to have that be part of someone's mindset because they're blocking out anybody who's different.

KZ: Mmhmm.

DF: Well, look around the planet. (laughs) I mean, we live in a global society. It's not—you're not going to get less isolated, you know? It's not going to happen anymore, I mean unless you really choose very consciously to be isolated, so that was, that was hard. But I was really proud of Carlisle, because to be honest with you, if I remember correctly somebody had reminded me that they tried to pass—the borough, a group of people in the borough tried to pass a similar ordinance about ten years ago, and it never made it, even, it never even made it to the point of really being considered. So, things do change.

KZ: Yeah.

DF: Things do get better. And the fact that so many people stood up and said, “This is a good thing. This is really a good thing. This is acknowledging that we're all citizens, and we're all full citizens, and that needs to be taken into account, and people need to be protected so that they cannot be abused by people who are hateful.” (Double thumbs up) There's like no downside here. So that's very exciting. And I'll be very interested to see. It's my understanding that there have been no complaints that have been brought to the Human Relations Committee thus far, and the people they recruited were wonderful. Really, really experienced, smart people, so I think they'll handle, sort of whatever lands with them will, I think, be managed very well, but it will be interesting to see sort of, will something bubble up? I figure eventually something will, just because, but. As far as I know, there hasn't been a peep thus far.

So that's one of the good things that has happened, but when SCAAN was still in its infancy, it was just a different time. It doesn't feel like, you know, 1992 it doesn't feel like *that* long ago.

KZ: Yeah, it seems so recent.

DF: I mean really? I mean, that's what 26 years ago? Which isn't that much time, really. Especially in terms of social change, because normally social change is incredibly slow. And what's happened in terms of the US' acceptance and recognition of the rights of gays and lesbians is, has happened so fast. When I was at SCAAN, if you had asked me whether gay marriage would exist, I wouldn't told you you were crazy. But it's here. And it's great! You know? It's so, abrogating anybody's citizenship is a bad thing for the entire community, but we don't often acknowledge that. I don't think. But it does; it has to hurt us. It can't be good to say that someone is less-than. There's just, that means somebody is else is taking the position of being more-than. That's not so good.

So working for SCAAN was kind of a crazy thing, we were very cl—we were a pretty tight-knit group, because I think everybody else faced the exact same questions and comments and

concerns that I did. And there were a certain percentage of people in the male gay community that also didn't really like working with women, so that was a surprise. That was like, "Hmmm." And the fact that I was not only married but also had babies, people found really, like, not quite the thing to do. Yes, I think only one person referred to me as a breeder, and that was basically as a joke, so... But it was a term used for people who were like me, who were working in the whole area of HIV and AIDS, but... And it was usually a real insult. The person who was teasing me about it was one of our guys who was also a drag queen, so he was very funny. He was great. Brian. But, it was, so it was a funny combination of many different factors.

But for me, having grown up in an incredibly white, very middle-class suburb outside of Boston, this was the first time in my life I had stepped outside of the mainstream, and it was, in a weird sort of way, liberating. Because you're not the good girl anymore.

KZ: Mhmm.

DF: Because you're doing this thing. And people would question me all the—I mean people would be confrontational with me all the time about this sort of thing, in mild ways, mostly. But also, doing, you know, being at a social occasion where somebody would tell an incredibly homophobic joke, and when I first was working there it was sort of like (Sighs), just move away, like okay fine just move away. But I did get to the point that I would just look at somebody and say, "Do you have any idea how offensive that just was?" Cause I just, I got to the, I was angry about that at one point. And I don't get angry very easily, but it was so tone-deaf that somebody would tell *me* that joke. Really? Really? Why would you do that? So occasionally it was uncomfortable for people, because I just stopped backing down, and I stopped being polite about that issue, because people were dying. I mean, you can't be in that and not have it change you. And, but it was actually liberating because all the sort of social conventions, normal white woman bullshit was like- it's just that. It's bullshit!

You know, we are human beings, we all have talents, we all have deficits of one kind or another, but when it comes right down to it, we're all the same. So where did these hierarchies of weirdness come from that said, "You're okay. Oh, you're not." And that was even beyond color; that was just gender. So I mean then it goes from there, so then if you're also, you know, HIV positive and a person of color and female, you know, you were like on the bottom rung on that particular ladder. Just because people hadn't, people didn't get it. You know, they didn't understand that, what people were trying to come to grips with.

And the medical establishment was also a difficult place to be. One of the main HIV-AIDS docs was at Hershey, but Hershey had nobody in their emergency room in those days who spoke Spanish. So one of our case-workers would get called out at all kinds of god-awful times of the day or night to go to Hershey and to be able to translate for somebody. You know, since then obviously, many translation is now the online translation services and there's lots of other things. But in those days, that wasn't there yet, and you needed somebody right there. And then of

course, Spanish isn't just Spanish. Because if somebody's from Central America, if they're from Puerto Rico, if they're from Haiti, you know-- well not Haiti, cause that's Creole-- but in different parts of the world, the words aren't, especially medical words, are not always exactly the same, so there would be difficulties even with her doing the translation sometimes trying to do the... 'Cause these are intense and emotional and deep things that people were trying to talk about, so I think it shook up the medical establishment hugely, and in a very positive way, because they needed it, and because they had to open their eyes and be able to treat everybody. And I think a lot of people didn't want to, was my sense. But...

So I was in charge of doing development work, so that means the AIDS Walk was our primary fundraiser, and I don't have the numbers right on hand, but I know in the, each of the walks I was involved with raised at least eighty thousand dollars. And people were wonderful. And there were still gay bars downtown, and I've noticed most of them have gone away. And I was just reading an article, and evidently lesbian bars have almost completely disappeared because they have gotten sort of subsumed to other things, which I think is kind of sad, because I think everybody likes to be in a room where everybody is just like you every once in a while, even if not all the time. It's like being with a group of women, rather than in a mixed group, can be very silly and a lot of fun in a way that you wouldn't have if there were men in the room. But I thought that was kind of sad. But the bars did this thing for months before the walk. They would have jars on the bar to make contributions, and they would have drag shows to raise money, and all sorts of things to raise money. So it wasn't just the money that we raised. It wasn't all associated with that day; there had been people raising money for *months* beforehand.

And as more and more people became public about their health care, their health conditions, of course, that meant more families affected, more friends affected, more classmates. You know, it sort of rippled out. So as people became public about their status, often that meant there was somebody else who started fundraising. Because they saw what was happening, and because there was so little to do for folks at first. Except keep them, you know, trying to keep them to eat, and that kind of thing. We had a volunteer who worked at Hershey. And at the Hershey foods Hershey Chocolate Company annual meeting, when the board came in, they would have lots of chocolate in people's bags, that kind of thing, but as soon as you break open a box, you can't sell it. So he would come after the meeting with like 12-15 cartons of Hershey chocolate products for the caseworkers to give people, because so often people weren't hungry. But sweets more often, you know, they're calorie dense, so they're really good things. And they were like, "Eat these peanut butter cups (laughs) because they have lots of calories. Eat as many as you want." (laughs)

But the AIDS Walks were a very public way too of saying that you were supporting what was going on, so there were- we had people who would support us but wouldn't walk because it was too public. But they would write us a check, they would give us money, they'd do fundraising, that kind of thing. But they wouldn't actually walk. And I don't remember, it's interesting, I don't remember ever having any of the hateful people at any of the walks. I never thought about

that before right now. I didn't—because later in later years, the pride festival in Harrisburg had a parade. And a couple of times when I was with Planned Parenthood, we marched in the parade, cause we had a lot of clients who were gay. And there were always the hate people screaming hideous and horrible things at us. My favorite being, as I was walking down the street kind of near Harrisburg Hospital, and my son was with me, and this hateful street-ministry kind of person goes, "Now here come the baby-killers." (laughs)

Like, "Yes, hi, we're here."

But I don't remember that at the walk. It was... usually they were kind of joyous days because we raised a lot of money and people got together. I think that was the other thing. Is that there was a lot of company on that day, and that was really an attractive thing for people. And there was a committee of volunteers that did a lot of the work for that.

AD: And where did the AIDS Walk take place? Was that...

DF: City Island. So we'd go, we'd start at City Island and go up the river and come back down and come to City Island. And usually it was in the pavilion area, kind of where the ballpark is. Though I think it must've been the '93 walk, about two weeks before that walk, I got a call from the woman who was in charge of Parks and Rec for the city of Harrisburg, and she called me and said, "Well, the AIDS Walk has to move." (laughs, puts hands up)

I was like, "What?!" It couldn't have even, it must have been a week before. It turned out that they were filming part of the movie Major League 2 on City Island, and they didn't think they were going to be done. And we were scheduled to be using a pavilion that was right next to the ballpark. But they didn't want the noise, so they wanted us to move and it's like, I have literally hundreds of people coming on Saturday to do this, are you kidding me? And after much back and forth, the city, and I think they got the production company to pump in some money as well, they moved us down to the parking lot, but they rented us tents and chairs and other stuff so that we could actually stage everything. And it all got done, but there was the 24 hour period there where I was ready to kill somebody because it was like, "What are we going to do! Where can we go? (laughs) How can I reach out to all the people who are going?" Email was... We had email but email wasn't like, email was still very...

AD: New.

DF: New. And not every—most people didn't have it, and certainly people didn't have it at home. You know, they had it at work. They didn't have it at home, and cell phones didn't exist, so it's like how... how...sort of, we don't even know who's coming, so how could we tell people to be somewhere else? We were freaking out. Oh, they also posted signs. So we basically told everybody that we could think to tell. I think they announced it, I think one of the radio stations also announced it for us, if I remember correctly. And the city put out some sort of a notice as

well to help- it was crazy! But, everybody came. We raised a lot of money and it went fine. So it was a huge, huge amount of work, but it was great. It was great.

So I learned a lot when I was working there, there was no doubt about it. Had never used an Excel spreadsheet before my time there, I did learn to love them, but it was a struggle while I learned how to do that. And then, the things changed near the end of my time there. Peg Dirkers was hired away by the state, and a new executive director was hired. And he turned out to be pretty much an unmitigated disaster because he talked a good game but he really didn't know what he was doing. He was very optimistic, but he wasn't practical. And he was a terrible manager. (laughs) So he basically came very close to running the program, running the agency, into the ground. And I can remember around the time that I decided it was time for me to move on was when there was some talk about whether or not we'd be getting a paycheck that week. I was like, "Hmmm. This is not good."

AD: Yeah.

DF: I have two kids and daycare bills. This can't go on. And I was also just getting fried anyway. So that was when I really, when I decided to leave, cause he was such a disaster. The worst day being, one of the worst day being the day that the bookkeeper knocked on my door and said, "Can I talk to you for a few minutes?" And I was like, "Sure!" He was a very nice guy, and then he closed my office door, and I thought that's not a good sign. And it turned out the executive director had been using restricted moneys for unrestricted purposes, and he had just realized it because he was working on our books.

Well, as soon as he told me that, I then become essentially a mandated reporter. So I had to go in to the executive director and say, "If you don't fix it... It's been brought to my knowledge that this has been happening. If you do not fix this, then I have to report you to the attorney general's office, and I have to do it very soon." Because it would also be about me.

AD: Yeah.

DF: Because I now had that knowledge. And he, "Blah blah blah, I'll fix it, I'll fix it." And he did fix it, but that was like, I'm done. I can't, I can't have that. I cannot be in a situation where somebody would be doing something that, not only unethical but also illegal, and apparently not worry about it. It's like... no... I think I had a very stiff drink when I got home that night. But that was, he was just bad at what he was doing, and it can happen to any given, but if it's a really small organization, the impact was really vast. And Peg had been, Dirkers had been, a phenomenal administrator and had really kept things very tight and very moving, and was a really ethical person (laughs). So that was bad. So I left then in '95, and things were really starting to change then because the triple cocktail had been put into use. I don't know how early, maybe early '95, late '94, I'm not sure, I'd have to go back and look. So it was an extraordinary experience, and I'm still friends with some people I met from that time, and it was crazy.

But it really changed me, it changed me more than any other job that I had ever had. Probably next most would be when I was working for Planned Parenthood. Again for some of those same reasons, that you are on the fringe but you are also dealing with seriously life and death issues that affect peoples' lives in a very immediate way. And if you have an unwanted pregnancy, your life stops, at least for a while, while you make the decision about what's next.

And it's never an easy decision for anybody, and if they chose to have an abortion and move on with their lives, that's probably the best thing for them to do at that time. And to be honest with you, I don't know a single woman who's had an abortion who doesn't think for her it was the right decision at that time. This whole trope about women "I should never have done that!" I think it is incredible crap, I just don't think it's true. I mean, it's a hard decision, it's a decision that nobody wants to make, but once you make it, either because you already have children, or because it's not a time in your life—you couldn't support a child, or whatever. I don't really care what the reason is, actually. I don't care if a woman has a reason. If it's the wrong time, it's the wrong time. Be done. And move on. Because if you're not ready to be a parent, you should not be a parent. (laughs) But SCAAN was that same kind of thing that it was dealing with things that... We were, every bit of money that we raised went into services that were for people who were sick. And for some of those people it meant that they stayed alive long enough that they would be able to take advantage of the triple cocktail. Or that the quality of their life was as good as possible for as long as possible, that kind of, you know, you don't know. So it was sort of exciting and terrifying, but amazing and wonderful at the same time, so...

AD: Yeah, that's amazing. Just for the sake of anybody who might watch/read this in the future who doesn't know, could you just talk like, I guess I should've asked this first but what, I mean you talked a little about what SCAAN does, like education, but maybe like case workers, what they did.

DF: Well mainly... Mainly what people were trying to do was trying to figure out a way to help people live longer. And since a fair number of our clients were either, were IV drug users, their systems were already affected by the drug taking, so their immune systems were already in pretty shitty shape before they got infected. So, for those folks it was a real struggle to stay healthy because they were dealing with, they could be dealing with multiple things as well as their addiction, but they were dealing with multiple things. Maybe they had Hepatitis, maybe they'd *had* Hepatitis C. You know, there could've been other whacks to their immune system before HIV, so they were always in a delicate balance about sort of what meds might work, what meds don't work, and people would try the different kinds of meds and they were constantly working with their doctors to try to find something like the right, sort of the right formulary that would work for them. Because there's also pain and, you know, discomfort of various kinds, and trying to create that balance was always difficult. And the meds made people not be hungry. Well, there's only so much body fat that you can lose before you don't have enough body fat to be able to fight an infection. And that's what happened to a lot of people, that they would get something like pneumonia- they would have no reserves left to be able to fight the infection because of the

wasting syndrome that set in, when they... Between the meds and the not eating, that created a really unhealthy vortex for folks. And so they were, they were stripped down in terms of their immune system, and people also didn't really understand how HIV and AIDS worked. It was like, "What do you, what do you do?"

So there was this constant struggle for doc trying to figure out what somebody could take and not take, can they actually withstand these, cause these were incredibly powerful medicines. And they didn't know at first sort of how much is enough, how much is too much... So there was always that struggle as well. I know many of their case workers told their clients to find marijuana, because often that would be, if someone got stoned, they'd be hungry. And they'd actually eat. And it's the same thing, one of my sisters had breast cancer. She's fine at the moment, but she, during the time that she was doing chemo, she basically ate fruit and yogurt, cause she just, she had no interest in eating when she was in the chemo, and the AIDS was, the HIV meds were similar. I mean, you felt like crap, and eating? Was like... No interest, whatsoever. But that creates a very bad situation moving forward, cause people lost weight so fast.

So the caseworkers would often be trying to help with any kind of medical things but also, there were people who got kicked out of their apartments, got kicked out of their homes, there were parents who basically said when their kids came out to them, kicked them out. Just kicked them to the curb, which I don't know what it would take to kick one... If one of my kids came home to me and was sick, I don't care what they're sick with. You know, of course I would take care of them. But this was, and they would just kick people out. So there was a homelessness issue as well. So trying to find places for people to live where the landlord knew the person was HIV positive. And lots of landlords would say no. So they were constantly in a struggle of trying to, working with... Some of the churches really stepped up at that point. And so some of the churches were incredibly helpful in trying to find places for people to be able to live. But they would spend hours on the phone just trying to get somebody settled and safe, so that they were housed, and warm, and fed, and not scared about being on the street, because of course being on the street increases your possibility of getting all kinds of infections because of your exposure and everything else, and probably badly fed and not sleeping, and not sleeping. We've come to realize that not sleeping has massive ramifications for people's health, especially if their health is fragile to begin with, so the caseworkers were always trying to get people settled and safe in some place, any place.

There was only one, there were only two, hospice houses at that point: One in Lancaster, and the Hospice of Central Pennsylvania, which was in Harrisburg had one. I can't remember the name of the one that was in Lancaster. I don't remember, but they were active very early on and took people in when no one, early on when no one was doing very much at all, and gave people a quiet and warm and peaceful place to die because they'd been kicked out. Or their partner literally could not take care of them anymore, maybe somebody was too, you know, was literally physically unable to help move someone because they weren't strong enough, or they might've

been sick themselves. So those were the only two that I knew of, and then those were always full because they were actually willing and able to be able to deal with it. So the caseworkers spent a lot of time, I mean that was their primary goal.

The education people was just trying to educate everybody. I mean, I'm trying, I can see the woman's face who was our educator, and I can't think of her name, but she would speak anywhere- churches, schools, fire halls, anywhere she could actually get somebody to let her in. And she was a very warm person, so she came across as this sort of practical, no muss no fuss, kind of nurse almost aura to her, and she knew her stuff inside and out. So she was often very good at getting people to kind of open their brains a little bit about what was going on.

And then the Unitarian Church in Harrisburg was very, very helpful. Saint... Stephens was also. They're Episcopalian. And oh shoot, there was another one that's right—Pine Street Presbyterian were also, they were feeding people. You know, so it was interesting to see the community start to come together, but it took a while. And it was definitely the religious community, the religious affiliated community, stepped up first, which on some levels makes sense.

The other thing that happened was that the foundation, was then called the Greater Harrisburg Foundation, scored a grant from the Feds to do education but also to support HIV and AIDS education and services. And their board was really of two minds when they went to get the grant, but the foundation really stepped up and provided a lot of money for the small non-profit organizations dealing with HIV and AIDS at a time when there was very little money to be had. Because... And then at the same time, there was Ryan White, the Ryan White Act. So the Ryan White money really made a huge difference in terms of being able to serve people, and that was funded through us. We were funded through, that money came through the Family Health Council, which was the subcontractor for all the Ryan White Money, and then they spread it out to all of... We would apply to them, so they were the funnel through which that money came. And the Greater Harrisburg Foundation was another set of money that we could get money from them, again for direct services.

But it was all very new, and for the Greater Harrisburg Foundation, which was a very conservative organization to step up and do that, I think had a great deal to do with their executive director, a woman by the name of Janice Black, who sort of saw what was going on and said, you know, "We need to do something, cause this is bad and who else is around?" And being a community foundation, you're in a position to be able to manage large grants, as well, and also to distribute them because that's what you do. So it fed; that was kind of a natural feeder once that was put in place. And those dollars really made a difference for a lot of those programs people were being fed (coughs) and housed... So but it was, it was a very kind of fractured funding scene for a long time, because again people just didn't know what was going on.

So the education people did a lot of street outreach both day and night, and they had, she had, a smaller group of volunteers that would go out at night and hand out kits and talk, just talk to

people and say, “Come in,” you know, sort of. Because part of it was also, if you’re a person of color and poor and a drug addict and a white woman says to you “Come into our agency...” How much trust is there? So it took us, it took time for that trust to build for the word to get out on the street that you could come to SCAAN and get assistance and there was not... There was nothing negative about getting there.

And the office was located in a shopping center called Kline Village, which was the first shopping center in Harrisburg, right across the street from Harrisburg High School. So the neighborhood is very mixed. Parts of the neighborhood are really nice. Parts of it are pretty hard core, but it was easy to get to because we were on a bus line. We were on a good bus line, so a lot of people could come to us that way. So that made life easier for folks who were right in the city. But in terms of the day to day, we worked like any other non-profit: we had clients, we tried to take care of them, we had lots of volunteers who came in and did all sorts of stuff for us. There was a group called PFLAG, Parents and Friends of Lesbians and Gays, and the PFLAG moms were great, and they would come in all the time to help us with mailings and stuffing envelopes and doing the kits and anything we needed they would come in and be helpful. And for a lot of these folks their lives had been completely turned around. Because more often than not, their child had not been out, and now all of a sudden they’re out and they’re ill.

AD: Yeah.

DF: So I mean, but these women stepped up. They were- and it was more often the moms. The dads it was harder. But we had several that would come regularly to help with things as well, so... They were wonderful people. I can’t even imagine how hard that would be. I literally have no idea. I mean if your kid comes to you and says, “Not only am I sick, but I’m dying, and there’s nothing to be done.”

AD: Yeah.

DF: I-I... and then the social approbation. I mean the closest analogy I would think right now would be folks who have children who have addiction issues. And I’ve noticed just recently that I’ve seen two different obits where people recognized their child’s struggle in the obit. Where otherwise it’s, you know, “died unexpectedly at home,” “died unexpectedly,” that kind of thing. But in the two articles that I saw recently, somebody said, you know, “after a long struggle with addiction,” and I thought that was so brave, so brave... But that’s- It’s that kind of breakthrough that we need, so that people start to recognize. And it was true with HIV and AIDS as well. You know, I would read the obits every day because I would know people and more often than not nothing was said, but as time went on people did say things in their obituaries, which again was stunningly brave to be able to do. But it was part of that change-point, where something goes from being very sotto voce to suddenly being part of the public conversation. Doesn’t make it any easier, but it does, you can sort of see the seismic shift that happens when that changes.

What other, I'm trying to think of other things about, I think there was something else we used to do, there was another event, but now I'm forgetting what it was. There were often drag shows to support the organization. That was pretty regular, but that... But they would do that on their own and then invite us to come, but they would basically just write us a check or bring in the proceeds on Monday or that kind of thing. And there would be small fundraisers often by church groups or family groups. Somebody would have a birthday party, you know, where they take up a collection and that kind of thing and people would occasionally just appear on our door and say, "Here, we did this over the weekend and here's some money." Great! (laughs)

AD: 'Thanks!'

DF: You're so good! But it was, it was a cra—it was a crazy time. It was a crazy time. And people didn't know. I mean, there was so much we were ignorant of, in terms of everything about the course of the disease and for a long time about transmission. It sort of, how did this all, where did it... Having ignorance and... And, well it's all ignorance because even when people are prejudiced it's mainly about ignorance. But having huge, sort of ignorance from every direction, was hard. But the people I encountered were people who cared so much about what they were doing. That yes, I mean, it was a job, there's no doubt about that, you know a paycheck is a good thing. But you don't do that just for the sheer old hell of it all, and obviously there was huge self-selection in terms of who would come to work for a place like SCAAN as opposed to, I don't know, American Cancer Society or Big Brother Big Sister, or, you know, any other kind of agency. So, they were wonderful people.

AD: That's amazing. I can only really think of one more question. Outside of SCAAN, I know you mentioned you did some stuff at Planned Parenthood. Was there any other LGBT activism that you ever did through work or volunteering?

DF: No, just more just keeping in touch, you know, keeping in touch with people and sort of supporting the Center with an annual contribution. (laughs) That kind of thing, but part of... When I left SCAAN, first I was working for the Harrisburg Area Community College Foundation, and then we lived out, we went out to England for two years because my husband was running Dickinson's Norwich program again, so we went back to England again for two years, so that sort of broke off connections. You leave town for two years, and it's amazing how—especially pre—then we had, by that time email was there but it was still not, it was still pretty much at work, not at home. And you just lose track of people. So I've sort of been able to check back in with a few people that I knew from that time, but not very many... And just kind of going to events occasionally, that kind of thing, so not terribly active other than sort of vocally supportive of... (laughs)

AD: Yeah.

DF: ...of the community because... To not be as foolish. I mean we're all, we've got one planet. If we don't work together, we are screwed. And anything that we can do to make sure that we are

working together is a benefit. So other than that, no not really. Partially too because of where I've worked, I was always working kind of crazy hours because non-profits... The idea of working a 40-hour work week and working for a small non-profit is not usually really a good combination. (laughs) Cause things happen and you have to address them, or there's an event, or there's a crisis of some kind, whatever it is. And if there's work to be done, it's all hands on desk and anything you can get done. So other than that, not so much.

AD: Okay so last thing I guess: we like to ask if there's just anything you'd like to say about your experiences or messages to people or...

DF: Well, I have such huge respect for the people I worked with and for the people who were activists and volunteers at a time when that was really a hard thing to do. And people stepped up and did it anyway. And they helped change the world. I mean, I don't know that people sort of recognized it at that time, but to have these incredibly fearless people get up and self-identify as somebody who was either infected or affected in public, talk to their legislators, talk to municipalities, talk to their churches, talk to their parents, you know. I mean, people stood up in an extraordinary way that was very, very brave, and I don't know that if... Unless you were alive at that time so had a sense of the zeitgeist, you know what was going on in the country to realize how brave those people were, because they risked getting fired, they risked getting kicked out of their apartments. They risked everything, and they still stood up. And I have, I have just immense respect for those people who did that because they were brave. They really were. And I don't know if there's, I don't think there's an analogy to it that's close, because even—The closest thing, I mean sort of the opiate, in terms of the impact on families, but even that is, the level of fear attached to people who had HIV was immense. I mean I was just working there, and I got a blowback. I can't even imagine, to be a patient and to walk into an office, a doctor's office, and have to deal with staff that might be terrified of you... I don't, it's bold, it's brave, and it had to be fucking terrifying. But the people stood up and they made a difference, and I... (laughs) Every time I hear the name Anthony Fauci, who is the current director of the NIH Infectious Disease Area, he was the guy in the federal government who stood up and said, "We have to do something, and we have to do it now." And he took huge heat for it, and he didn't shut up; he just kept talking and talking and talking and making things happen. And every time I see him, he's gotta be getting close to retirement, but it's just like, "Thank you for what you did!"

But that's what it takes in a situation like this. It takes people who are have conscience and who have ethics and morals and say, "This is not right." I mean it's the people who stood up against slavery, it's the people who said women need to have the right to vote, it's those people who put themselves on the front line and say, "This is wrong and it has to change." And with this particular situation, it was people taking their lives in their hands. Cause people got beat up, people got shot. I mean, people got hurt when they stood up. And gay folks were getting beaten up all the time. I hope that's changed, but, I mean, at that time, that was a real issue. You know, coming out of a gay bar, and there's be a bunch of yahoos who would beat people up. So I have

just the huge respect I have for the people who did stand up and really made a difference for everybody because you can't... If you have something that's happening in terms of the arena of public health and you don't pay attention to it, then you put millions of people at risk, and they did it. So. I'll get off my soap box. (laughs)

AD: That's a good place to end it. (laughs)

DF: Well, thank you.

AD: Thank you so much, that was amazing.