

A C T U P
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P R O J E C T

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Interviewee: **Terry McGovern**

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Interviewer: **Sarah Schulman**

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ACT UP Oral History Project
Interview of Terry McGovern
May 25, 2007

SARAH SCHULMAN: Okay, so the way we start is you say your name, your age, today's date, and where we are.

TERRY McGOVERN: Terry McGovern, 46. May 25th, correct?

JAMES WENTZY: Yeah.

TM: Twenty-fifth –

SS: 2007.

TM: 2007; 320 East 43rd Street.

SS: At the Ford Foundation –

TM: At the Ford Foundation.

SS: – where you are the HIV officer. We are so proud of you. So you grew up in New York, right?

TM: Yes.

SS: What neighborhood?

TM: Well, I was born in the Bronx; lived there for a bit, and then lived in East Meadow, Long Island as a high schooler.

SS: And were your parents born in this country?

TM: Yes, yes. One was born in the Bronx, and the other in Queens.

SS: And when did your people come over?

TM: Probably 1916, I guess.

SS: Oh, okay. So it's your grandparents?

TM: Yep. Only to New York, nowhere else.

SS: Now, did you know your grandparents?

TM: Yeah, yeah yeah, sure.

SS: And were they politically active in Ireland?

TM: Yes. I mean, they themselves were too young. But my relatives, particularly on one side, were very active in fighting the British. And doing Hedge schools, you know, teaching Gaelic and that kind of stuff.

SS: So were you raised with Irish politics in your household?

TM: Certainly, I heard a lot about it from my grandfather. But my parents were both kind of Democrats, serious Democrats. So I was definitely raised with lots of questions about authority and Catholicism. My father was actually extremely active in the church, but more like a social progressive Catholic. He did a lot of work with Central American immigrants, and that kind of stuff.

SS: So would you say they were Kennedy Democrats?

TM: Mm-, they were complicated. Maybe. Probably my mother more than my father. But you know, they were not big fans of war, imperialism, misuse of power. And my mother in particular was a huge arts person, so anything that was about censorship or anything, she was never going to support, so.

SS: So did your parents take you to your first demonstration?

TM: No, no, actually, I did that on my own. My mother did take me a lot to theater my whole life, which often was kind of I saw stuff that was pretty revolutionary.

SS: Like what?

TM: Well, like [Theodore Dresch] plays. Anything that opened that was old and kind of lefty, she'd take me to see. So I guess that was her form of kind of introducing me to leftist politics.

SS: And do you remember discussions about the Vietnam War or the civil rights movement as you were growing up? Or was that –

TM: Yeah. Yeah, but I mean, it was more like – it was more like we absolutely didn't support the war. My parents were totally not. They taught us that diversity was absolutely the best thing you could have. So we were kind of all raised not to discriminate and to, we kind of supported the civil rights movement, but they weren't actively going to demonstrations, or anything like that. It was more in how they lived. So.

SS: Like in what way?

TM: My mother was just really, just whatever it was. Any kind of abuse of power just drove her crazy. So anything that went on where people were racist or whatever, she would always kind of personally get involved. And I guess they really were not, they really thought difference was kind of the way to go. They were both serious Irish Catholics, right? They came out of, my mother said, in the Bronx, multicultural marriage was like marrying Italian. But her best friend, when I was a kid, was Jewish. She always had a lot of diverse people in her life. So they kind of spent their lives reacting to being brought up in these kind of ghettoized Irish Catholic situations.

SS: So that kind of background, how did that play out in your high school?

TM: Heh. Well, I was sent to this all-girls Catholic school. I mean, they were contradictory, right? On the one hand, they were rejecting a lot of this stuff; on the other hand, they sent us all to Catholic school.

So I was sent to this all-girls Catholic school that really kind of emphasized marriage and love and being a lady and that kind of stuff. So my activism really started then. Because – this was a school that was on the North Shore of Long Island. And there were a number of us who came from the South Shore, which was, you know, economically much lower class, I guess you would say. And there were a lot of girls that had lots of problems, were having sex, got pregnant, had drug issues. And the school was like idiotic. So my activism really began there, in kind of organizing against what I found to be just truly idiotic rules that were hurting my friends.

SS: So how did the school react to you?

TM: Well, it was a weird thing. The first couple years, I didn't really, I just, like, you know, acted out a lot. And then my third year, I ran for student council. And I was friends with the kind of druggy group, and then I was friends with the, we were grouped according to how you did in school, so I was in the first grouping. What do they call it – tracks?

SS: Um hm.

TM: So I was with the smart kids. So I was friends with them, too. And then I was friends with a whole bunch of different people. So I ran for student council

for, just almost as a joke, because I had lots of issues, and I was in trouble a lot. And I won; I became class president. And then I started actually really, kind of instead of using the mission drives to give money to missionaries in Africa, I gave it to Covenant House then. I started to try to involve the school in working with runaway kids. So I immediately got into many, many big fights with the nuns.

There were also many nuns who were very supportive, and probably had an impact on me, who were much more leftist. And some of them were the people going to Central America and doing work. So it was a mixed bag, as it always is with the Catholics. But I really did a lot of activism, I guess, in high school, although I didn't see it that way.

SS: Now when you went to college, were you already out to yourself, as a lesbian?

TM: No.

SS: No.

TM: I didn't, I knew that something was off, but I wasn't sure what. And then I took Intro to Feminism my first year. I went to the State University of New York at Albany. And that's when I first people who were out as lesbians. And realized that that was probably what I was.

SS: And did you have some great teacher, or something?

TM: Yeah. Well, I just had, it was run by a collective, actually; it was nineteen-seventy-whatever, see? And they were, often the professors were English professors, and they were doing women's studies, so I had them in all these different

contexts; they were my teachers in different contexts. So, yeah; they were really smart, and it was very challenging. And then I started realizing that a lot of them were lesbians, so it kind of shook me up. And, by the time I was 19, I had come out.

SS: So did you continue to work on Central America? Or were you involved in gay organizing?

TM: No, not at all.

SS: Not at all.

TM: I did, like, Seneca Peace Encampment –

SS: Oh, that's a big lesbian thing, Seneca Peace Encampment.

TM: Yeah, and I did a lot of antinuclear stuff. I worked on that Battery Park – it seems like ancient history, uh?

SS: Mm hm. It is, yeah.

TM: So I was involved in all that more like lefty stuff. And some women's movement stuff. Chain Around the Pentagon, all that.

SS: Oh, Women's Action at the Pen– ?

TM: Yeah.

SS: But these are classic lesbian actions. I mean, Seneca was like naked women mud wrestling.

TM: I guess so, I guess so. I mean, I, yeah, I guess. I mean, it was all, like, it was all kind of my introduction to serious demonstrations and stuff. So –

SS: But you stayed at Seneca?

TM: Yeah. For like two weeks, yeah.

SS: And you didn't have sex with anybody –

TM: Well, then I think I, I was already out by then. So I was already –

SS: Yeah. Because there was a whole scene.

TM: Right.

SS: It was a subcultural scene.

TM: I, I, yeah. I mean, I'm not, I remember being in a very small tent, right? And everybody making a lot of noise. That's what I remember the most –

SS: {LAUGHS}

TM: – about Seneca. But I was there.

SS: Okay, so you were mostly on war-and-peace issues.

TM: Yeah. And I guess women's rights issues. And violence against women, and – it's so much more complicated now. But yeah, I was at all, I was like, you know, Take Back the Night –

SS: Right.

TM: – remember that?

SS: Right.

TM: I read all those classic feminist texts, and I took a lot of women's studies classes there, and I eventually ended up teaching Intro to Feminism in the collective. And, ha! So, you know, it was great. Compared with, I mean I have to say, I went from this Catholic school — I had been 12 years at Catholic school — to this huge state university, so I loved it. I didn't have to wear a uniform; I could demonstrate. So I was a Denny's waitress. There were many high points.

SS: Now did you go straight to law school? Or –

TM: Yes. I went straight to law school.

SS: Okay. So when you decided to go to law school, did you know what kind of law you wanted to practice?

TM: Yeah, I wanted to save the world. Social justice, I guess. I wasn't sure exactly what form that would take. But I was going to change the world.

SS: Okay, philosophical question: Many people go to law school to save the world, but very few actually do.

TM: Yeah.

SS: What do you think has kept you on the track to social justice all these years?

TM: I guess I had a moment between my second and third year, where I could have gone to work at a law firm, which of course would have given me more money than I'd ever seen in my life. And I actually accepted an internship at a law firm in the city. And then I saw the sign that said, go work on the border between Tijuana and San Diego defending people. It was just, it kind of gripped me, this sign, because you would actually be in court, representing people. So I changed my plans, and I went and worked for Federal Defenders of San Diego, which actually defended people who were caught in the whole border area.

And that summer, it was crazy, right? You'd be, I was a student, and I'd walk into a holding cell every morning, and there'd be 75 people, and I'd have to represent them in front of the magistrate. And then I went to the jails of Tijuana, and

spent a lot of time seeing people who had suffocated to death in the cars. And it really changed my whole kind of path. Because I had done kind of lefty stuff in college. But I hadn't kind of seen it directly.

So that was one of those moments that really, I feel like there was no going back after what I had seen. And so when I went back the next year to law school, I ended up working for Migrant Legal Services, and then clerking for a judge who was doing family court cases. And so I never went back after that.

SS: And what law school did you go to?

TM: Georgetown.

SS: Okay. So that was, you were against the grain there.

TM: Oh yeah. Yeah. I mean, Georgetown, when I was there – it's totally changed now. But I was there when Reagan was president, and the gay and lesbian group wasn't allowed to be recognized, even though it was a mandatory student fee, so there was a lawsuit. They wouldn't let the reproductive rights group exist. It was very conservative when I was there. Which was also a huge shock to my system, coming from SUNY Albany. And also, generally, there were a lot of very wealthy people there, which was also very different from SUNY Albany. So it was, I always say, it wasn't very pleasant, but it was a very good place to learn to be a lawyer, because I had to, like basically, nobody agreed with me, so I had to learn, actually, how the other side thinks a lot.

SS: So when you came out of school, what was your first job?

TM: I went to Legal Aid downtown and did criminal, appellate criminal defense work.

SS: And that's how you became an AIDS lawyer; is that correct?

TM: No, actually –

SS: No?

TM: – that was criminal defense work, and I did that for a bit. And then I ended up saying I wanted to do civil legal services. Which, there was a, under Carter, there was this civil legal services program created for people who were under the National Poverty Index. And it's tiny now. That's why I'm giving this history. But at that time, there were neighborhood offices, there were rural offices, there were, it was a huge program.

So I decided that I didn't want to do criminal, that I wanted to do civil legal services. And I got placed in what was then the Hell's Kitchen office, which is no longer there. It was on 51st between 9th and 10th. It was actually, I'm sorry, on 10th between 51st and 52nd. And I was there, supposedly, as a housing lawyer.

But what happened in those offices is that there'd be an intake day. And there were huge numbers of people who just met the poverty criteria, who'd come in with any kind of civil legal problem. So it was in doing these general intake days that I started to see all these HIV cases. So that was like maybe 1988, I guess. And that was where I first started to take those cases.

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SS: Now had you had any personal experience with AIDS before that?

TM: Well yeah, certainly I had known men, friends, who had HIV. And I had certainly known people who'd died. So I knew something about it. And I think that as a poverty lawyer, I always felt like I kind of had to exist between the cracks. There was a lot of homophobia. On the other hand, I felt like often when I was trying to deal with, kind of get information from some of the other groups, they also didn't understand the poverty issue. So I felt like I was stuck. I was in this cross, I was working in the cracks, in a sense, as a poverty lawyer, already. So I knew a little bit about HIV. But certainly, I couldn't believe what I was seeing, actually.

SS: What were you seeing?

TM: Well, I mean, basically, because people would come in, and they would tell you whatever their problems were, I was seeing extremely sick people. Women, gay men of color, who lived in the projects, who wouldn't say they had HIV/AIDS, but they were clearly dying of HIV. I knew that that was what was happening. But it was just impossible to get them to talk about what was happening. And nobody in the office, because often they were so sick — they looked extremely ill — the other lawyers in that office at the time didn't want to take the cases. So I just started taking the cases. And the reason I ended up starting the HIV Law Project is I wasn't funded to do that. I was funded to do housing, and eventually that became a problem.

But very early on, in the Poverty Law offices, there was huge stigma. I mean, in one office, they used to spray the seats with Lysol after my clients came in. There would be these intake meetings where people would say, I can't take it, I have a family. So I ended up taking the cases. And it was a variety of things. Some people

were being evicted. Their lover had been, and maybe they lived in the projects. Their lover had died; they weren't on the lease; and they were getting evicted, and they were also extremely ill.

And this issue of succession rights had been dealt with in the rent stabilization, rent control context. There were a lot of cases, the ACLU, Lambda. But nobody had thought about people in the projects.

So what I was seeing was the HIV lens, the poverty lens on HIV, which had everything to do with homophobia, sexism, all these other issues. But it was kind of a population that was not being dealt with, because the poverty law community certainly failed these folks. A lot of the groups that existed in the communities that this was happening to wouldn't touch it. And then there wasn't the expertise among, at that point, the gay male groups to deal with, you know, women with kids, and kind of the poverty stuff that – poverty law, and dealing with public housing and all that stuff, it's a whole separate field. And at that point, there was nothing known about it.

SS: So you're saying that the housing protections that were won did not apply to public housing.

TM: Exactly.

SS: That was the problem.

TM: Exactly.

SS: Okay. So what –

TM: Exactly.

SS: – how did you –

TM: Well, so anyway. So two things: one is that it was clear to me, in all these contexts — in housing, the whole issue of getting Medicaid and Social Security disability and qualifying for benefits — that there was something really off with these clients I was seeing. They weren't able to qualify. So that was one set of problems.

Then, in terms of the housing, obviously the Housing Authority, the kind of same fights that had gone on in the context of rent stabilization/rent control needed to happen against the NYCHA, the New York City Housing Authority — all the public housing — Section 8, etcetera. But likewise, in the context of clinical trials, there was also this problem where women couldn't get in. I mean, it almost was like everything you looked at, as a lawyer, you couldn't fix it. Like you couldn't just have the hearing and win, because the problems were at the top. And I had never seen anything like that.

So actually, what originally took me to ACT UP — so I started taking these cases, which led me to have a reputation of taking the cases, which meant more people were coming in. And I really didn't know that much. And certainly, I called GMHC's legal, I called around. And people were helpful, but they didn't have the expertise in this set of issues, really. So the one, the only kind of legal services, poverty legal services for HIV was Lauren Shapiro in Brooklyn. But that was it. And there were legal services offices everywhere.

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Anyway, so what led me to ACT UP is this had happened before, but this man came in, extremely, extremely sick — convulsing, practically, in the interview — and after a long time, told me that — and it was very difficult to get the story out — that his lover had died of AIDS. They had been, I forget how many years. They'd lived together

years and years, actually in the Douglass Projects, up on 100th Street and Amsterdam.

And basically, his lover had died; he was dying himself; they were evicting him. And he really, I said, we have to, we're going to have to disclose that you were partners. And the first thing you do is you have a hearing with the local project manager. And we had to prepare a lot, because he was very nervous.

And we went to this hearing. And again, he was so ill. And they were horrible to us. I mean, vicious. You're telling me he's gay. Vicious. Homophobic but also just so insulting, and –

SS: Who's they?

TM: They were the local, you know, each housing authority has a project manager. It's been years, so I can't remember the exact terminology. But the woman in charge and her assistant. And it was one of the most insulting, vicious kind of encounters I'd ever had.

So basically, I said, they threw us out of the office, actually. This is flashing back to me. And just so openly homophobic and awful.

Anyway, I was really shaken by this whole thing. I waited a couple of days, started calling the client; and he wasn't answering, he wasn't answering, wasn't answering. And basically went there, and he was dead in the apartment. And I don't know whether he committed suicide; I don't know what happened. But it was just horrific. And I just felt like there was nothing; there was no legal means of doing anything at that point. And this woman and this man were going to completely get away with this. And how many people more, in the projects, were probably living with this

same situation. I had been able, in other contexts, to cut deals. But the larger issue remained that there was no way for same-sex couples to add somebody to the lease. Not to mention the stigma, etcetera etcetera etcetera.

So I went to ACT UP for the first time. Because I had certainly read in the papers about the demonstrations, and I thought it was great, and so I found out where the meetings were, and went down to the Center. And basically went on the floor, and told what had happened. And that was, and basically asked people to do something. And we did a demonstration.

But it was at that meeting where I was sitting, waiting to go up, where I heard people talking about the CDC definition of AIDS. And I heard, the women's caucus, or whatever it's called. And I, of course, was seeing this problem. Like, I, I, I didn't, I mean, what I saw were all these women who couldn't qualify for benefits because it said, HIV-positive, not AIDS. And then they were dying before they qualified. And I didn't know what was going on. I was trying to figure it out. And then, so I go to ACT UP, and these women are like, oh, the CDC definition of AIDS excludes women. Uh huh.

So that made me go back and really begin to get onto that trail. And obviously also I had, as time passed, I had more and more clients coming out of Bedford Hills, where Katrina Haslip was, and ACE [AIDS Counseling and Education] was there. And they had done a bunch of work on the AIDS definition, and were saying that women had different symptoms. So all this information started to come in about kind of the activists identifying this. And that made me go on this whole strategy.

SS: Okay, I have a couple of questions here. What year did you go to ACT UP the first time?

TM: You know what? I have no idea. Probably was '89.

SS: Okay. Why would people from ACE know to go to you? What was the connection? Did you know Judy Clark and those people?

TM: No, just if you were coming out and you were a woman and you had issues — Social Security issues — I was the only one to see.

SS: Because you were the HIV Law Project at that point?

TM: Yeah. No no no —

SS: No.

TM: — well yeah, at that point, I was, at some point, I got a \$30,000 grant to do HIV only. So I was still at Legal Services, and I was beginning the HIV Law Project around '89.

SS: So were people referring —

TM: Yeah.

SS: — people to you? Okay.

TM: Word of mouth.

SS: Can you just give us a little bit about Katrina: how you first met her, what she was like, and your experiences with her?

TM: Yeah. So I just, I was basically telling you those first clients that I saw. But then eventually, I got a small grant — I think this was 1989 — from New York Community Trust, to be the full-time HIV lawyer. So then I moved to Avenue A

between 5th and 6th, and then began doing full-time HIV. By this point, particularly for women, word began to spread that I would take these cases, because there was a real problem with women qualifying for Social Security disability and Division of AIDS Services and this definitional problem. And I started to take referrals from Women's Prison Association. So I started to see a lot of women who were coming out of Bedford, and they all talked about that they had been helped on the inside by this woman, the Muslim lady who worked in the law library. And I was amazed, because they had had, pretty good, they had their medical records; they kind of knew what was going on; they understood the whole issue of the definition. And so I kept hearing about this person who had helped them. And that was Katrina. And not only did I see the evidence of how good her work was, but they all loved her so much. It kind of fascinated me, because their faces would light up about Katrina, and they'd talk about her.

And I guess the other thing that struck me was her coming out as HIV-positive was huge. They all talked about how shocked they were to learn that she was positive, and that she was fearless. So I kind of felt like I had a relationship with her, even though I didn't know her.

And then, I guess at some point I tried to get, we started to more actively communicate with ACE on the inside; getting what they'd written, and that kind of stuff. So we began to know of each other, I guess, through '89 and '90. And certainly – I wish I could remember – there were all these women. Some women going in and out, and some that worked for ACE OUT. There was ACE on the inside, and then there was a group called ACE OUT that was with the Women's Prison Association for a while. And

they were working with women coming directly out of Bedford, and they referred to me. But somehow through that, we communicated a lot about the lawsuit. So I've skipped ahead, but that's how I heard of her, through women.

SS: And how did you first meet her?

TM: So all of these cases and kind of being, learning from ACT UP about the CDC definition, and from the women inside Bedford; I started to work on a legal, I was trying to find a legal way to get at this AIDS definition problem. And you can't sue the CDC; they don't give away the money. They do these definitional things, in terms of benefits programs. So I had to figure out a legal strategy to get at the benefits programs for using the CDC definition, which wasn't a fair definition.

So I ended up being able to figure out a way to do that legally, and actually surveying all the poverty law offices and gathering a big group of plaintiffs who had been denied Social Security disability, and it was all because the AIDS definition was skewed. And filed a class action on October 1st, 1990, actually. And we worked with ACT UP very closely. And at the same time as I filed the lawsuit in the morning and then got on a bus to go to Washington. And they planned, we together planned this big women's demonstration in front of Health and Human Services.

And it was really, I think, it was an amazing thing, because ACT UP had the resources to pay for all these women to go. So as far as I know, it was the first kind of big, certainly in Washington, women's demonstration. So all the kind of stars, early stars, were there. Like Phyllis Sharpe and I guess Katrina had been released two weeks before. So I had talked to her; I had been communicating with her about the lawsuit. She

knew the day it was being filed. And she was really upset because she couldn't, she was on probation, so she wasn't allowed to go to the demonstration. So I filed the lawsuit, and went to Washington, and there she was. She showed up anyway.

So that was the first time we met, which was at this demonstration. And it was, it was amazing. And there's footage of the demonstration that I have. And she speaks. So that was when I finally met her.

SS: So how many women with AIDS were at this demonstration?

TM: I don't know, maybe 30 or something. But that was a lot, at that time.

SS: And they were all sent by ACT UP?

TM: Well, a lot of them were my plaintiffs, but ACT UP paid for them. And ACT UP organized the buses. I think it was like Marion and Maxine and Heidi. There were a lot of folks involved. And who spoke at the demonstration were Iris de la Cruz and just Lydia Awadala, and all those women who were kind of, some of them from LifeForce, some of them from ACE OUT, some of them just plaintiffs, clients that I had. But all of whom ended up kind of really playing a huge leadership role. All of whom are dead now.

SS: What was the impact of the demonstration?

TM: I think the combination of the, I think the demonstration, particularly because it was linked to like a lawsuit that somebody had to respond to, was very powerful. I mean, what was incredible is that they could just continue to ignore this population, right? They were all, by this point, the AIDS industry had begun, right? So

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people were having meetings, and really, this population was completely excluded from everything. And ACT UP had been consistently raising that, and had been really effective in raising that. But I think the combination of having the litigation and the demonstration and all this ACT UP work that had gone on finally started to scare the government a bit. Because they had to respond in court. And they could see that the ACT UP, all this ACT UP work that had gone on had really, really kind of big allies were developing at this point. I mean, the American Medical Association came in on the lawsuit, which was crazy, unbelievable. ACT UP had gotten a lot of very prominent groups to sign on to this stuff. So I think they really started to get very nervous. And I think in terms of positive women, suddenly people were seeing positive women as leaders, also. Who were saying I've been denied disability. This is, so it wasn't just generalized complaints. There were specific things that needed to be changed. So I think it was an extremely powerful moment in this whole struggle.

SS: What is the relationship between street demonstrations and litigation? Can it really influence courts?

TM: I think so. I don't think there's any. The way I always tried to practice is, you can't, you're not going to win on just a lawsuit, if you're talking about something that's more about a social movement, as far as I'm concerned. And I think in some cases if the government really, really feels like it can ignore the population, the demonstrations may not be enough. And in this case, I think having to actually answer in court really shook them up. But the day that, one of the days that the federal court refused to dismiss the case, the government littered us with papers and tried to basically

kind of outwork us; the judge in the case read from some *Times* article about a demonstration. And so they really, really worked together.

I think that one of the things that was really great is that the legal work that I did to figure out the Social Security Administration and how the definition was being used by all the various agencies to actually — which led to this discrimination — I worked really closely with ACT UP to transform that into Teach-in materials. So everything that they taught me, then I was also bringing the piece of how the systems were misusing this stuff. And then together we were doing really widespread community education, which I think not only affected all these positive women, but it also affected providers — you know, it was hugely important. So the movement building was a joint effort, I think. Certainly, ACT UP, kind of doing all this stuff to bring all this attention, and then, I guess, the lawyer piece just adding this technical, how this really plays out, and how we could get at changing it; some things that they could do.

So I think it worked because it was a joint strategy. And certainly, I was always very clear that a lawsuit was never going to be enough if there weren't this massive community organizing and it wasn't done in the context of activism. Because, because basically, nobody cared, otherwise.

SS: Now, were you aware of differences of opinion inside ACT UP about the priority of this campaign?

TM: Yeah. I mean, I actually was really so busy, kind of. And what happened is, I had a grant to fund myself to do this work. And then the volume of clients became really, really high. And like I said, you couldn't work on their cases without

fixing these larger issues. So I was pretty much overwhelmed. And actually, I know that there were all these differences of opinion within ACT UP, but there's a lot of men from ACT UP typing the papers at night, and there was a huge volunteer effort from within ACT UP, and not kind of the most known people. Like these guys who would come and help me a lot.

SS: Like who?

TM: I – I can't remember. There's this guy whose face is in my brain right now whose name I can't remember. But he was not at all one of the most prominent people. He just really got it, and cared. And there were a lot of guys like that, who just came in and came out. And I was at PS 122 at that point, right? We had a classroom at PS 122. Did it just fall? I just heard a big, felt something –

JW: No.

TM: No?

SS: No, you're fine.

TM: Okay. You know, so we were doing these lawsuits with a big Plaster of Paris horse, right, in the room with us. So I felt that there was a lot of support from a lot of ACT UP folks. But certainly I knew that there were these other big battles. And I think I kind of tried to stay out of that, because I was just trying to get as much help as I could. So I knew about it. But at that point, to me, it seemed like such a huge thing that people were willing to pay for these clients to go on buses to, that was a lot of resources.

SS: Yeah. Well, ACT UP had money.

TM: Right.

SS: And why did they?

TM: Well, they had money because they, the men who were members of ACT UP had a lot more money, certainly, than the clients I was seeing. So, yeah, the resources were incredible. That was the other thing that I didn't, that I neglected to mention. The creativity, the press capabilities, talking about why the lawsuit was successful, you're sitting on Avenue A, doing this lawsuit. And then Robin Hauser and Laurie Cotter come, and they're the press people from ACT UP. And they sit with me for half an hour, and they write this press release. And then we file the lawsuit; we're in Washington. And it's on the front page of the *New York Times*. That was ACT UP. Those were, it was also that the lawsuit was credible, and for the first time, I think part of the strategy that was unique to the press was that they could speak to women who had gone through this trainings and could really describe the way in which they were being denied disability, not just, like, make this generalized complaint.

But the level of resources that ACT UP brought to this thing was incredible. So you had people who had many, many resources, to begin with. So it brought everything to a whole new level.

SS: Okay. Let's change tapes.

SS: Okay. So let's continue with the suit. Because it took how long, ultimately?

TM: It was filed in 1990, and then actually, the Social Security criteria were changed in January of '94, and the definition was expanded in December of '93.

SS: Okay, so it took three and a half to four years.

TM: Yeah. But then it was like a year before, we had started a year before filing, so yeah.

SS: Okay. So five years of your life.

TM: Yeah.

SS: Yeah.

TM: Yeah.

SS: Okay. So now we're up to the Health and Human Services action.

And how did it go from there?

TM: Actually, the fact that this demonstration happened and we ended up on the front page of the *Times*, it almost touched this nerve throughout the country. All these people — providers and drug facilities, prisons, women's doctors, people in community health clinics — we got hundreds of calls from people who were dealing with HIV-positive folks who couldn't meet the definition and were having these disability issues. And we were contacted by a lot of little positive women's groups around the country. Everybody wanted information; everybody wanted to start doing these teach-ins. And so it really, I think it was a way for people to organize, in addition to the CDC definition, also organize against kind of changing criteria in all these different contexts. Because the AIDS definition was used by Social Security as the gate into getting benefits automatically, but it was also used in all the local programs for you to get local benefits or the gateway to housing for people with AIDS; it was used everywhere. So this was hugely important, to get that definition expanded for women, and also for low-income people. I mean, the thing is, everybody always focuses on women because that was very

obvious. But the original AIDS definition was not looking at the concept of converging epidemics. So tuberculosis wasn't in it; bacterial pneumonia wasn't in it. So it wasn't just women; it was lots and lots of poor people, if you had to pick a denominator.

So we began, really, kind of helping people and sending out more and more. And then the Washington groups got involved. Which led to its own problems.

SS: Which Washington groups?

TM: I don't know. Where was Ruth Finkelstein at the time? AIDS Action. All these, the –

SS: You mean Washington AIDS and gay groups, or –

TM: Yeah. The Washington Women's, AIDS, whatever; groups started saying, what is this? Send us the materials. And in some ways, that led to other problems, because they, of course, began getting invited to the meetings instead of the folks from ACT UP or the positive women or us, right? So that, there were a whole bunch of struggles then that the AIDS industry not move in and start negotiating on behalf of women with HIV when they hadn't even been aware of the problem.

SS: Okay, let's stop for a minute. What is, conceptually – I mean, how do you understand that mind-set, of a gay woman who's an AIDS bureaucrat substituting herself for women with AIDS, for example?

TM: I think that you'd say, okay, this is a problem. So I'm in this position, so why not go to this meeting? Except that – it's still true today, and this is a lot of what I see in this job – that women with HIV, directly affected women; if a little work is done jointly with folks who can really work to kind of upscale their understanding of

the policy mechanisms that lead to the discrimination, their experience is absolutely crucial.

So I can't tell you how many times I've seen, in my work in HIV, that I can stand up in front of Congress, or I can stand up at the UN and say, women are being discriminated against. It's nothing like a woman standing up and saying – something that I just saw – Gates is saying these many women were tested, but this is how many women are actually getting antiretrovirals; eight percent of that. And this is how many women are dying. And these are the reasons. There's absolutely no money for violence. There's no, women are giving the drugs that they get to their families. The actual experience really explodes a lot of the, we're in a moment now, and we have been all along, where people are looking to say, we have the solution. This many people are getting tested, and people can get drugs. And all of the rights issues that surround that in people's lives. Nobody can speak to that as effectively as HIV-positive women.

Tape II
00:05:00

And I think, I have always really seen our role — lawyers' roles, or anybody's role — as kind of working together so that the women can do the best advocacy job possible. But also moving out of the way when you can so that they can take the seat. And that's just not the mentality of a lot of folks that are in these Washington groups, etcetera. They think they're the best representative, or maybe a more cynical read is it's about the power and the access. But I think who ends up suffering from that are the directly affected people.

SS: But do you think that they can do a better job?

TM: No.

SS: No.

TM: No. Absolutely not. I mean, I do think, on the other hand, it's a joke to think that a woman who's living with HIV is going to understand how the UN works or how the FDA works or how Social Security works. There has to be a mutual exchange; there has to be technical assistance; there has to be advocacy, capacity building. But it's completely, we proved in these early years that it's completely doable, and a way more effective strategy. You know, again, those reporters, it was ACT UP knew how to write the press release. But we also had spent hours and hours and hours training the women so that the reporters were like, wow, these women can actually really talk about Social Security. And certainly it's much more empowering, too.

But that wasn't the mentality. I think it was really that we need to speak for these poor women. And then a lot more compromises were going to happen. Not to say compromises didn't happen anyway. But they would have happened a lot earlier. And I think we would have gotten a lot fewer results.

SS: Now this in general — and we'll get back on track in a minute — but these Washington-based organizations, like HRC, Gay Task Force and the AIDS groups — do they initiate anything? I mean —

TM: I mean, some do. I think the really important question for all of them is, really seriously: How are you developing leadership? How are you sharing power? How are you making sure that these voices that are directly affected, that are emerging, whatever, really, really get to participate in a meaningful way? Meaningful participation is supposed to be a really important part of the human rights work. And to me, it's kind

of, it's a huge issue. It was an issue, it's an issue in HIV still today. And I think there's not a lot of accountability. And certainly, in the early days with ACT UP, ACT UP had done all this work, way before even I got there, right? – on the AIDS definition, on women. And suddenly there was this lawsuit. And then ACT UP and us were completely excluded from all these meetings at the CDC, from all these meetings. All these folks were suddenly meeting, and not even telling us.

SS: Like who? Who was meeting and not telling you?

TM: Well, there were some issues with some folks from GMHC, and there were issues with folks from the ACLU, and there were issues with folks in Washington. And I can't, a lot of the, it's a complicated thing, because you wanted these groups to begin to work on some of this. But you wanted them to also be respectful, and actually let the people who are most appropriate be at the meetings. So –

SS: I have a question to ask you right here on this point. Now, as we mentioned before, there was a power struggle inside ACT UP around some of these issues.

TM: Yeah, which I actually, like I said, I was tangential to.

SS: I know. But were some of the TAG guys and the other more policy-oriented men in ACT UP who were not working on the CDC definition, could they have been power brokers in those kinds of relationships with GMHC and that sort of thing, at that time?

Tape II
00:10:00

TM: Yeah, I think they could have been. I had no interactions with them. And I think to some extent — and like I said, I wasn't around for some of these battles —

but this was set up as oppositional. Which of course is just like what's happening now with Ryan White and the South versus the, it's just stupid. I mean, there should have been more money for everybody. And if the pie was going to stay the same, something I heard a lot was, the pie's going to stay the same, so that means we'll get less. And I just think it wasn't, but I didn't, I also didn't, at that point, because I didn't know the landscape. I didn't approach anybody and say, could you? But in retrospect, sure.

But I think, again, because a lot of the men had the education, had access, had a sense of entitlement, and also had the skills. I mean, not to say that they didn't have to be really activist and really push to get in the door. But it was a whole different level of access than certainly the people that we were dealing with. I think the CDC and all these folks felt much easier about just excluding the likes of us; the likes of even me, as a poverty lawyer, and ACT UP, and a whole bunch of mostly women of color. So I think that dynamic was real. And I think, because I had the litigation and I had completely my own problems with that whole situation, and being completely, the lawyers say, papered to death by the government. And I was really afraid this thing would be thrown out of court, because it was a kind of a wild legal strategy. So it was very scary from a lawyer's perspective. I was very young. So I wasn't getting involved in the rest of that.

SS: Sure.

TM: But it was, I think that in retrospect, it's kind of sad the way some of it played out.

SS: What made the legal strategy so wild?

TM: Well, I mean, I was not even 30 or something, and doing this class action against the federal government, and saying that the Social Security Administration was violating its responsibility to fairly define disability by using a definition that was based only on one portion of affected populations. It was a risky thing, right? It could have been thrown out. And it would have weakened the activists.

SS: In a way, you're making an argument that's very consistent with the kind of feminism that you were trained in. Which is that the male model should not be the neutral, objective model.

TM: Right, right –

SS: And that other people's experiences –

TM: Right. No no, absolutely.

SS: And this is the argument of feminism.

TM: Well, this was the right, I mean, it was race and sex discrimination. But that doesn't mean the law addresses that. I knew that. But you're never going to be able to prove that. We didn't have the evidence, because it's such a high standard to prove discrimination at this point in the U.S. courts.

So I had to come up with an argument that was really about the violation of the Social Security's mandate. And that was ultimately the argument that kept us, moved us ahead. But they moved to dismiss. The U.S. government moved to dismiss three times. And the –

SS: This is under which president?

TM: This was Bush, right? I mean, this is, when Clinton was elected is when everything kind of broke open.

SS: Okay.

TM: So yeah, it was Bush. Yeah. And we had the Center for Constitutional Rights; we had Jill Boskey, who was MFY Legal Services; we had Leslie Salzman from Cardoza Clinic. It was like, it was crazy – taking on the government on this thing. So we had to do a lot of work. We had to get doctors to publish what they had seen in their clinics so there was evidence. It was a lot of things. There was the ACT UP piece, but there was also the creating-the-medical-evidence piece. There was a lot to be done in that moment.

So I didn't really get involved in whatever was happening internally in ACT UP, except for asking for help all the time. On the other hand, I did get really incensed and involved when I heard that there were high-level meetings going on with the CDC or with Social Security, and there were people at those meetings that I'd never even spoken to, supposedly negotiating on this topic. Just because I thought, how could they possibly know what's going on with this? Don't you think they should meet with those of us who developed the claim? And what about our ability to kind of push them, that there should be positive women who can speak to this issue at the meeting.

And ACT UP, of course, had its own justifiable rage, because they were the reason this was even on the map to begin with, and they were suddenly excluded from everything. So there were a lot of, there was the famous meeting where they handcuffed themselves to – there was some kind of meeting that I also wasn't at, but there were a

bunch of ACT UP people, I think including Juan, handcuffed themselves to the institutional representatives who were at the meeting.

SS: Tracy Morgan.

TM: Yeah. I don't remember. So there was a lot of stuff, like skirmishes like that.

Tape II
00:15:00

SS: Okay, tangential question here: so you mentioned the Cardoza Clinic. And there was someone we just interviewed who was doing work, when they were in a law school clinic at CUNY — who was it? — at CUNY Law School.

JIM HUBBARD: The only lawyer we've done recently is David Barr.

SS: David Barr. What was the role of law school clinics? Was that an important place for developing litigation around AIDS?

TM: I always felt like there were all these clinics who would take cases from us at the HIV Law Project. Like there was an NYU clinic. Clinics generally are willing to take on difficult issues. And Leslie Salzman was just this fabulous person who also, I guess, had — I don't even remember. I can't remember where I even knew these people. But she involved that clinic there, and was hugely helpful. So I would say, yes. And I ended up teaching at Rutgers Clinic at some point in my years at the HIV Law Project. So law clinics are a place that you can get, that are more willing to take on kind of creative strategies than not.

SS: Okay. So now we're at the point where you're starting to get usurped. So then what happens after that?

TM: So then basically, I guess there's all these kind of fights and demonstrations. I mean, there continue to be these demonstrations outside the CDC. This is way after litigation has been filed. We're having demonstrations. And there still weren't really formal meetings with anybody who'd been involved with any of this. I mean, it just never happened. Until, we had a series of kind of, they moved to dismiss, I think, three times; they weren't successful. We got the AMA to join the lawsuit; we got a lot of medical support, suddenly. A lot of the folks who had been seeing these clients started publishing their articles. So there became kind of a shift, where I think the medical community — people like Helen Rodriguez-Trias; a lot of people had started really saying, we're supportive of this effort, and this is right, and this is a huge problem. And I think they started to get nervous that they might in fact lose the lawsuit.

And then of course there were issues like the plaintiffs' dying without ever having gotten disability. That was, of course, that was something that I wanted to say before. The demonstration, a lot of the signs said, "Dead But Not Disabled," because that was the language in a lot of the cases, after people, people had died, and the decision came denying them disability. And we blew that up, and again, that's a place where lawyers and activism working together is very useful, because you could see; this was evidence of what we're talking about. And it made for great graphics.

So somewhere, I guess around '92, things really shifted a lot. Then I guess Clinton was elected. And there began to be some movement that they were going to expand the AIDS definition. And that's where a whole new set of, by this point, there had been, lots and lots of infighting in ACT UP, some of which I didn't even, I didn't

even know what was going on. But there was a lot of fighting. There were people disagreeing about what should happen. I think there was probably some resentment of me, feeling like I got too much attention because of the lawsuit. There was a lot of factors going on. And the CDC, I think it was the summer of '93, decided to hold a meeting to talk about what the new AIDS definition should look like. And I remember this because I was traveling; I wasn't in the office. And the whole meeting had been set up, and I hadn't been invited. Or had been invited but I hadn't responded. So there was huge upset about who was going to be at that meeting, and what they were going to say. And at the last minute, I was added to the meeting. But clearly, what happened was that the CDC understood that it needed to expand that definition, and they were looking for some way out of this thing.

So the ACT UP list of what should be added to the definition was, it included things like pelvic inflammatory disease; it was a long list of stuff. And the CDC wanted to do bacterial pneumonia, tuberculosis, and anybody with less than 200 T-cells. So there was a lot of disagreement about what should happen. The one female-only condition for which there was the most medical evidence was cervical cancer, right? So I was always looking at it from the perspective of what was legally provable, actually. And the activists were rightfully looking at it from what should be there.

So at that moment, there began to be a lot of kind of fighting about what should happen. Should we support this? Shouldn't we? Should we be fighting against the 200 T-cells, because it's kind of like a catchall as opposed to really listing things? Should we not?

Tape II
00:20:00

And there was a huge difference of opinion about that, among everybody, including positive women, positive men. A lot of people felt the 200 should be there because a lot of people would come in under it, and that was more important than the listing of PID. Other people felt differently. A lot of the physicians that we worked with were saying to us, this is as good as it gets, and don't be stupid; push to get cervical cancer on there so that there's at least a signal to the world that women and gynecological disease is part of this. And that's the only one you're going to get.

And some of the physicians that had been really closely advising us on this were Michelle [Helen] from Bellevue; Helen Rodriguez-Trias. I was getting very strong advice from them that you should push for one female condition, but there's not enough medical evidence on this other stuff. And I think a lot of the activists felt like, forget it; we should bag it; we shouldn't compromise at all. And not to say that, the CDC said to us, what should we do? But the question was whether to even participate with them at that point, and push for cervical cancer, or just drop the whole thing, or do what? So I remember a bunch of meetings at PS 122 that I think people – actually, Katrina died in December of '93. It must have been around that fall when this was all happening. Clinton had been elected and there were a bunch of blowout meetings at PS 122, with some people storming off, and unclear about whether we should stay in or not stay in or endorse or whatever. And ultimately, I think we took the position that we were going to push for cervical cancer and push them to expand the definition rather than just stay out of the whole thing.

SS: Let me ask you a question. How many people would have been denied benefits if cervical cancer had not been on the list?

TM: I can't, it's very hard to answer that, because I don't know the numbers. But I do know that again, part of this whole syndrome was the failure to see that gynecological disease, period, could be an indicator of immunocompromise.

SS: So you're saying it was more of an ideological point than an actual numbers point?

TM: Yeah. I mean I think honestly, in the context of cervical cancer, I mean more women were getting PID; more women were getting some of these others; but really, at that point, it hadn't dawned on the provider world that women were at risk. So it was a much larger issue. And all along, we'd been working on, also, the guidelines and assessment and getting doctors to understand that these could be indicators. But at that point, kind of getting a woman-specific disease was hugely important. And the CDC kind of didn't want to do it. But the only thing they would do it on would be cervical cancer, because there was some data, and there wasn't data on anything else. So that was really the issue.

JW: Could you pause for a second? Hold that thought.

SS: Okay, so –

TM: So basically –

SS: But this meeting that you went to: now, who was there?

TM: The one at the CDC or the ones at the –

SS: The one at the CDC.

TM: Liz Cooper was on a panel; Marion Banzhaf; there were definitely some ACT UP people there as well. A lot of medical people. But it had become, it had already kind of become something else. I was at the meeting. I was given five minutes or something. But it had kind of turned into something else already. In a sense, I kind of knew that we had done our work, because this had become, now it was in the CDC jargon, like we have to expand the definition, and how are we going to do it. And at that point, particularly because there were fights happening about whether you should be at the meeting or not be at the meeting; the way I tried to handle it was really, I talked very closely to this group of positive women who were plaintiffs, and Katrina, and asked them very closely, what should I do? And often they gave me very different advice from what the activists were saying, because they felt like it was hugely important; the 200 T-cells was really important because so many people they knew had died with six T-cells and didn't qualify, so they didn't really care. They were afraid that, you know, so –

Tape II
00:25:00

But it was a hard time, because definitely, it was just weird to suddenly be winning. And the other thing was, around that fall, everybody started to die; all the women started to die. There was just SP, which was the name of the lead plaintiff in the lawsuit. It was just really, really confusing, actually, to watch, suddenly. Also the CDC have a meeting on how will we expand the definition. I mean, I could kind of understand the activists' disdain. On the other hand, it needed to happen, and if this is the way it became, like, a horse-and-pony show, and they would take credit, and the activists would never be, would be a footnote, that's the way –

SS: So there were no positive women at this CDC meeting.

TM: There were some. But they weren't, I don't think they were there were definitely positive women there, but they weren't the, it wasn't like Katrina, although she was ill by this point. And I barely got into the meeting, too. So it was weird. There were some ACT UP people there, though. Like Marion was a very strong person. But she was there representing New Jersey Women and AIDS Network. And I think Mary Lucey might have been there. I don't know. But there was definitely upset. And I always felt like I could understand both sides, because it was weird.

SS: Did that change your relationship with ACT UP?

TM: Somewhere in there, my relationship with ACT UP got changed. And I think it's true that I also began to get pulled into these serious conversations about how to develop the new Social Security criteria. So what I did was I brought positive women and the physicians to kind of help figure out, how do we write these guidelines. And it was really a very difficult situation to be sitting there with these very conservative government people, pushing for as much as you could possibly get. It was very hard for me to make a judgment about how far to push, when you were going to lose everything. And in some senses, I, a lot of times, the positive women were really thinking about how many people would lose benefits and how many people would die if we pushed too far. So that was very hard for me to navigate.

SS: Did you feel that the women activists from ACT UP were not good at negotiating?

TM: It was a mixed bag. Some people were very pragmatic. They're like, look, they're going to go ahead and do this. We better friggin' fight to get cervical

cancer in there. They're going to do it and it's never going to be, the credit is never going to go where it should go. So let's do something in this final moment.

Other people felt like, fuck it. Now it's going to become this show. So it was mixed. It was mixed. But I could understand both sides. It's just, I was in a different role, because I was also responsible for this lawsuit and I had to actually act in that role as well. And therefore, I worked for the clients. So that, in some ways, was helpful to me. But very difficult with some of the activists, because often I felt like what they were saying was right.

SS: But what happens when you reach that moment when you start to become effective and then you have to negotiate?

TM: It's very difficult. It's very difficult. I think then you have to figure out, I think you have to figure this path that is not compromising too much. Because you can always push more than you think in that moment. But you also have to, I think somebody — I'm not saying everybody — I think lots of people are really effective never getting in that role. But I think somebody has to stay in there who isn't totally just about themselves, or else all will be lost. And I'm not sure that that's a, some people only want to be in that role. But I think it's really good for people who are complicated and have disdain at the same time to be in that role. And I'm not just talking about myself. I'm talking about people like Heidi Dorow, at the time, or Marion. I think it was crucial that they stayed involved. Because the compromises would have been way worse. And I think it would have been ceding all this work to these folks who didn't know the issues as well. So, it's hard, though.

SS: Right. Okay, so then what was the result of all of that?

TM: So then in December of – I’m confusing the years, aren’t I?

December ’92? Yeah.

SS: Three.

TM: Ninety-three? Ninety-four?

SS: Well, you said Katrina died –

TM: I’m 600 years old now. Ninety-three? Anyway, Katrina died in

December of ’92 — I’m confused — in December of –

SS: Oh, okay.

TM: When did Clinton get elected?

JH: November of ’92.

SS: November ’92.

TM: Okay, so it’s ’92, ’93 we’re talking about then. Okay, sorry. So Katrina died December 2nd, 1992, right before that. This meeting that we’re describing happened in September of ’92. They announced they were expanding the definition. So there was about this six-week moment where all this fighting was happening about cervical cancer and whatever, whatever. They announced that they were expanding the definition in December. She actually was dying in the hospital. And we went and we told her — I went and I told her. And she made a statement for that. And another positive woman read at the press conference, basically saying — which I probably have somewhere — basically saying, I’m not going to smile. This is only happening because of us, and you let us die. It’s a very moving statement.

Tape II
00:30:00

And actually, the definition was expanded in January.

And just to kind of go back to this two-track kind of lens I had: Katrina was a client. And she didn't qualify. She didn't have AIDS, even though she was dying. She had bacterial pneumonia. And she had no T-cells, but the definition hadn't been changed. So bacterial pneumonia wasn't there. So she actually didn't qualify for Division of AIDS Services, and therefore couldn't get a home attendant. And she kept falling in her house. And I kept sending positive women who were volunteers with HIV Law Project to pick her up and take her to the hospital.

So she was a victim of the AIDS definition, actually. She really didn't get the care that she needed. She had to fight every step of the way to get anything. And it was incredibly tragic, actually.

And so it was difficult for me to maneuver with these compromises because I didn't want to hold up people being, qualifying for benefits, because the results were so horrible. And they were right there in my face, even among the people that had been so activist.

So Katrina herself, even though totally disgusted, was saying, we've got to get this moved, we've got to open it up. So she died, and never qualified, never met the AIDS definition, which is just quite incredible.

So it expanded January 1st. They added cervical cancer, bacterial pneumonia, pulmonary tuberculosis, and anybody under 200 T-cells. And now, it's so funny. You talk about this phenomenon. I work at Ford. I'm at presentations all the time. I see AIDS timelines. And it's never there. My first day here, there was a big fat

timeline, you know: Rock Hudson. No mention of it. And even more amazing is, I sit through these conversations about the epidemiological history in the U.S., and amazingly, in 1993, there's this huge rise in the number of cases. And it just happened organically. Isn't that so interesting?

So I'm in a position constantly here, and it's absolutely never ever ever acknowledged. And even like, it's just incredible to me. Even with me sitting there.

So the definition was expanded. Many many many many — and I don't know the exact number — but huge numbers of people, the numbers went up in every category. The Social Security criteria were expanded that July. And I had a bunch of these doctors who were the kind of frontline clinic doctors involved in writing the criteria, rewriting the Social Security criteria. So they used a whole different set of criteria that made it much, PID was there. It made it much easier for people to qualify. They weren't perfect, by far. But definitely much better, and not just the AIDS definition.

But by the time that happened, there weren't widespread celebrations by the ACT UP people. First of all, a lot of the women who had been at the demonstration were now dead. The ACT UP people, now it had become almost like a, even though it's still not on the timelines, it had been kind of the CDC was taking credit, and it went the way these things go. So it happened. And I think it was a victory that was very confusing.

Tape II
00:35:00

SS: Okay. Working with all these people who were dying all the time: looking back now, in the long term, how do you think it's affected you personally?

TM: Well, I mean, I think that it gave me, definitely, a very different – as an advocate, it really, really grounded me in kind of my own inconsequentialness, so to speak; and how important it was to actually figure out the right balance. To not overplay your hand, in certain instances. Yet what the stakes were. I think, how has it affected me? First of all, I have a very comfortable relationship with death, to tell you the truth. I mean, I feel like the vast, there's just so many, so many people, as we all have had died; so many people have died, it doesn't scare me at all. I'm totally used to it. But it informs everything I do. And therefore, even in this job, I'm really very serious, deadly serious, about people with HIV having meaningful participation. And I don't tolerate very well the AIDS industry, because I think some of the most effective work has always come from directly affected people. And I can't, it's really hard for me to watch people who have not kind of been exposed to the massive amounts of death that we've all been exposed to, kind of easily give away big points, or make concessions.

So I think I carry all those women with me, in a way, and all those men. And I just think it informs everything I do.

SS: Now when your mother was killed –

TM: Yeah.

SS: – and you looked at that event, the 9/11 event, as an insider: did you look at those events next to each other — the AIDS crisis and 9/11 — at any point?

TM: No. Actually, interesting. So I had been at the HIV Law Project till 1999. And it got big around 2005. And I really was best, and what interested me most,

kind of intellectually, was strategy, and how to figure out strategies. And I didn't want to run a big AIDS organization. It was great, in some ways, a huge, booming immigration practice. We grew the project. We did a lot of direct services. But I was really burnt out. And of course, the last big fight was mandatory testing, and I was completely demonized by Nettie Mayersohn, and I went from AIDS hero to baby killer. So I decided I was going to leave and teach, and I got a fellowship from OSI [Open Society Institute], and I was going to kind of recover. And I wanted to have a kid. And anyway, so of course, lo and behold, I leave around 2000. And I get pregnant; I have a kid. Six weeks later is 9/11; my mother's killed.

It was really difficult. Because of course, you had the invasion of Afghanistan, and United We Stand, and patriotism, and all this crazy stuff, which my mother was, like, a really funny, cynical. So it was like, how could we be caught in this thing? And on the other hand, the left was saying, we deserved it, and chickens coming home to roost. And I felt like — I was teaching at Columbia at the time — that I needed to take a leave, because I couldn't listen to one more lecture about how we deserved it, because my mother was friends with a lot of people from around the world; their families couldn't get visas to come. I was just watching this exploitation of this event, and not a lot of complexity in the discussion of it from either side.

And personally, my mother was killed, my sister worked there and she was injured. My father died a year and two months later. I had this baby. So it was really, really a difficult time for me.

And this is all leading to a point that has to do with ACT UP.

And I felt really, for the first time in my life, that I had totally lost my voice. Because I couldn't, all those media contacts I had had from the HIV Law Project converged on me. And all they wanted to do was hear about, did she jump, did she call, how'd she die? I'd say all this stuff about you're exploiting us; Bush is not speaking for us. And the only thing that would be in the interview was that I had a six-week old, or that my sister was there, too. All those skills were completely useless in this tidal wave.

Tape II
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And it was just completely sickening, and I couldn't break through. And I didn't feel like I fit anywhere. I had to take care of my family situation during that first year, so I couldn't get involved with organizing to demand a commission. But to the extent that I even did, it was so different — I mean, dealing with all these families — than anything I had ever been part of.

And like I said, I had, my father eventually died, and I had to take care of all of this stuff. But as I began to emerge, I thought, I'm going to start attending the commission. I have to go to the commission. I can't take this anymore.

I think the fact that I wasn't able to break through really disheartened me. And the fact that I was going to parties and people felt compelled to tell me that we deserved it, and I just was like, I lost my voice. I just shut up. Except that I did this interview project, which is this theater thing now. Because I didn't know what else to do. I had to document this other experience.

But anyway. So I started to go to the commission. And it was very weird. Of course I'd been to Washington so many times for the HIV Law Project. And suddenly

I'm involved in all this stuff. And I didn't really know what I was going to do. Was I going to talk to the media, not talk to the media? And there –

JW: This is awkward –

TM: Okay.

Tape III
00:00:00

TM: So I started to attend the commission hearings. And they were horrible. Both because we were never given any information, family members. They knew, obviously, how many people were killed when the planes hit, and how many people were trapped, and which doors were locked. And these are the kinds of things that people wanted to know. And they never did a briefing for us; they never gave us any information. Anything you ever found out, you found out in the newspaper, including whether remains were identified was in the *Post*, often, before people were told. It was FEMA. And a lot of these hideous details never kind of, never came out, because people were too, it was too horrific.

So you were finding out, for the first time, the families sat in this caged area, right? With press everywhere, with big lenses in our faces. And it was the same business, right? They only wanted to hear from us about pain and suffering. We would see, for the first time, something hideous: the doors were locked, the terrorists getting on the plane, the tapes of the stewardesses calling; the cutting of the throats, all this stuff. And they'd film our reactions to it. And then instead of asking us the minute it ended, how do you feel about the fact that there was an hour between the first plane and that the planes, the FAA put the call on hold, and that your mother was told to return to her desk; instead, they'd say, how did it feel to see that locked door, or did you know your – often

people realized that their loved one had jumped, because you'd see the footage up close for the first time. So it was horrific. And again, it was very difficult to get the media to focus on the issues. So I began to actually really talk to the other families about, we could start with, we can give them a little pain and suffering. Let's get a live interview. Begin with, she was on the 93rd floor, and then flip it. And these were things that I had learned from ACT UP, of course.

But more importantly, personally, I still was really shaky about what is my voice in this thing. And there was just so much stuff that kept coming out. And I had seen Condoleezza Rice over and over again on TV, saying we never could have known, we never would have known. And I was particularly horrified, because my mother was in the second tower. And they told them to stay. And she had been walking around saying, let's get the hell out of here, they're morons. But she got caught too long.

But I had paid a lot of attention to what they were saying. And as cynical as I am, and everything I'd ever lived through, I still couldn't have ever imagined what played out at the commission. So I was sitting at this hearing. And suddenly, Condi, who's been on TV over and over again, says, is saying that of course we could have never known; of course, no one could have ever imagined this. And of course subsequently we learned they had run tests of planes hitting buildings. And I mean, it was endless.

But at the hearing, she says, they start questioning her about the presidential briefing of August 8th. And finally, she says, under questioning, the name of the memo was "Bin Laden to Strike Within the U.S." And I swear Katrina and

everybody, just like, entered my body. And I stood up, and said, Shame! And it was, it was a huge turning point for me. Because, not only because it was like, kind of re-embodiment myself, in a way. But I also felt this very strong kind of energy coming from all these people, to get the fuck up. And it was really scary. Because you had, this was like the highest levels of government. This was even beyond anything I'd ever seen with ACT UP.

And what ended up happening is one of the reporters who had covered the HIV work came up to me, and was like, is that you? Where have you been? And she ended up there. So there was a lot of, it opened up this whole new space where I started to do a lot of advocacy on TV about the commission and this BS and how much the administration was getting away with. And I kind of stepped back into myself, in a way. And it was really, it was really ACT UP, I mean, that kind of taught me all that stuff. And it was really all those people that I had lost – and now my mother, on top of it, and all the BS.

Tape III
00:05:00

So it was just really, it was just a really interesting, important moment that I didn't see coming at all. And of course, "Shame" was pure, vintage ACT UP.

SS: Now that constituency appears to be a fundamentally conservative constituency. Is that accurate?

TM: No no no. I mean, basically, the media framed this thing in a certain way, and you heard from certain people. This has been the most kind of managed, exploited event that is imaginable. I think there's really complicated, interesting people, lots and lots of people, and they've just never been heard, there's no venue for them. To

the extent that they even said anything interesting, it was never on TV. It was just absolutely impossible to break through the 9/11 Show. And those of us directly affected were just completely left out of this, this whole –

SS: So then you're saying that even though on the surface, it looks like, when a thousand people with AIDS were dying a day and nobody cared; it looks like these lives matter, and those lives don't. But you're saying that actually that's not the case.

TM: No, it's just the staging of it. The lives don't really matter at all. Particularly the lives that are more marginal, which I would classify as women, people of color, immigrants, low-wage people. All this stuff about how much money people got. My mother was initially valued at zero, because she was over 65. It was really, I mean, it's just, it's massive exploitation, for everything, frankly, that I hate. Not only did you have to deal with the fact that we were completely exploited; they didn't handle it well at all; you weren't given even basic information; it was all secret, what they knew about how people died. And they were protecting people at every turn. But then, of course, it's used to invade Iraq, invade Afghanistan. Politicians, Giuliani's still running for president on it. We know better than anybody that this was one of the biggest failures in U.S. history. I mean, how is it that it's been turned into a victory for everybody?

So, no, it's just a show.

SS: Okay. Thank you for going into that. So the only other big AIDS topic I have to discuss with you is the mandatory testing issue. Do you have the energy for that?

TM: Yeah, sure.

SS: Okay. So can you explain what that was?

TM: Yeah. From when I first started doing cases, in '88, until '94, the fight was to get women acknowledged; to get the whole world to understand that women were at risk; that everybody needed to be thinking about women as potentially HIV positive. And suddenly, it went from women cannot be, let's just ignore women, to let's blame women. So there was this tremendous leap from let's pretend that women don't become positive to, they obviously are going to intentionally infect their children. Which came as a bit of a shock to me.

Now, this is something where it was the opposite. The ACLU and some of the other groups were involved in this mandatory testing stuff. And I hated it. I didn't get involved with it at all. I was, because I always was involved by what came through the door. So the mandatory testing stuff wasn't necessarily coming through the door yet. But in 1995, I think — again, my dates are all off — but basically, I had seen so many women die of HIV and so many children die of HIV, and so many women die right after their children died. So the idea that the level of discussion would be women want to knowingly infect their children, or would knowingly infect their children; I just couldn't believe that it could take hold. So I just kept ignoring it, because there was absolutely nothing worse to see. And most of the women would have taken, you know, chewed bullets if it would have prevented transmission. So I kind of kept hearing mandatory testing, and I just didn't think it would happen. And of course, Nettie Mayersohn realized she could get a lot of attention by making much of the fact that newborns were

being screened for HIV for these anonymous CDC screenings, but the results weren't being told to the parent. And –

SS: And who was Nettie Mayersohn?

TM: She was an assemblywoman from Queens. She's still there. I think it's in the *Times* today, about she's pushing mandatory testing of something or another. So she made this big thing about these children dying, neglected, and nobody taking care of them because the mothers' rights were being protected.

Now, mind you, there was never a law that required mandatory counseling or an offer of testing to pregnant women. So, you know, here we were, basically saying these women were willing to let their children die, when nobody had ever offered them a test; there was no requirement. Because remember, we'd been ignoring women.

So basically, this whole big thing began about newborn testing. And of course, some groups were opposing the unblinding of the newborn test because obviously it would trample over the rights of the mother, who had never been asked. And it would make a lot more sense to have voluntary counseling and testing during the pregnancy than waiting till the baby is born, and how about fixing that problem.

And anyway, basically, Nettie Mayersohn really wanted to change the public health law that required informed consent before testing, to except pregnant women or except newborns. And she was trying to get the votes to do that. She didn't have them at that point. So this organization called ABC [Association to Benefit Children] — she's also gotten quite famous off this — Gretchen Buchenholz — brought a lawsuit — [Dennis C.] Vacco was the attorney general at the time — on behalf of,

Tape III
00:10:00

supposedly, the infants, saying, unblind the tests; challenging the public health law. And of course, Vacco, who was extremely right wing, was going to agree to this lawsuit, and this is how they were going to kind of do this fakey collusive lawsuit and change the law.

So there's this weird mechanism where you can intervene in a lawsuit, and say that the state isn't going to adequately represent the people of the state. So we got together a huge number of groups. And a lot of the HIV groups, people of color groups — a whole list — and intervened in this thing. Which of course brought Gretchen Buchenholz, who's like, Tipper Gore wrote a book that she's one of the great women leader heroes. Anyway, it really, next thing I knew, I was being attacked by everybody, Nat Hentoff and Nettie Mayersohn and just endless, horrible. They went after our funding. We got audited by Vacco. We were really, really, we lost money.

SS: Who's we?

TM: The HIV Law Project.

SS: Okay.

TM: It seriously brought completely debilitating levels of attack. Because not only, again, and I was back at this issue of, should I be doing this, because it may mean that all these folks can't get lawyers, if we lose all this money. Because we, all of our state contracts — we had small contracts to provide legal services. They were all jeopardized.

And anyway, basically, they ended up, I forget what happened, but somehow they ended up changing the law anyway. So they began this, and we didn't really have any chance of changing it, but we wanted to register our objection; that we

knew that this was a collusive lawsuit, and that it was just total BS, given that they had never even implemented appropriate counseling and offering of testing.

Somehow, in the context of that litigation — I can't remember all of it — we basically moved for a preliminary injunction to force them to start offering testing and counseling to pregnant women, because that hadn't been done. And I think we were successful on that. So the law was changed that women had to be offered testing and counseling. But basically they started this mandatory newborn testing, and the plot thickens at that point. So they changed the law; they start the newborn testing; and we start getting these women who are coming in whose newborns were tested when they gave birth, but then they went home and breast-fed for a month. And lo and behold, at the fifth week, they got called back, and told that they were positive, and they had been breast-feeding the whole time. Because of course nobody had bothered to think about that, because they were so concerned about newborns.

So we went back to court, and basically said that this wasn't even a medically efficacious thing, and that they had, there were these rapid tests available. They cost a lot. And got some of the same doctors again spoke to the *Times*. And there was an editorial. And of course, again, some of the activists were mad at me. Because they're like, why are you, like, trying to make them do speed testing now? I said, because they're doing it anyway, and I have six clients whose kids are positive because they were tested to no avail.

Tape III
00:15:00

But the whole thing was horrible. I think we did really embarrass Nettie Mayersohn. Because obviously, this wasn't about saving infants; it was just totally

idiotic. And we got money for, Dick Gottfried gave us money to have a hotline for women to call, and she completely blocked that money. We had to give it back.

So to me, it became all about demonizing, and that life is strange. I was grouped with the ACLU and GMHC and all these gays are holding up the lifesaving treatments for newborns. And all those years that we were fighting to get women recognized — and kids, by the way; the Social Security lawsuit was also about children, because they didn't have adequate criteria for children — we never heard from Nettie Mayersohn. So it just became a total —

SS: And what is the status now?

TM: New York State has mandatory testing of newborns. But they do now rapid, you get the results immediately. We went back to court, they then had to change the, they had to actually give the test results before the woman left the hospital. I mean, we have mandatory voluntary counseling and testing during pregnancy.

SS: Okay, now here's my question: '95 is after the demise of ACT UP.

TM: Right.

SS: And even though there are a lot of AIDS organizations, there's very little street activism now.

TM: Right.

SS: Do you think that this would have played out differently if there had still been an activist movement?

TM: Yeah. I think she got away with murder. I mean, there was a handful of us going on all those hideous right-wing news channels. And actually, here's where

things shift. Some of the folks we'd been mad at because they willingly took those seats in the early years? They were up there on the testing issue, taking abuse. So, yeah. I think she totally got away with it. And, frankly, some of the groups were, like, it's okay to amend the law to except women, or pregnant women. Those are the same groups that are saying it's okay to amend the law to except people accused of crimes; it's okay to, we should have mandatory testing in prisons. Again, they never think about, for what? What are you going to do? So what?

SS: So, okay. So with the removal of the activist element, and going through this round, do you think there was a significantly different role for positive women in this debate without the activist movement, as there was the first time around?

TM: No. Without the activist movement, it was, I couldn't even get it. We were like, we were just like a hangnail; irritant. I mean, we were registering an objection so it would be there. But we were so losing. And she was getting away with this. I mean, with ACT UP, I don't think she could have ever gotten away with making me, for example, into a baby killer. And she did. Or, a gay ACLU, civil liberties, I forget all the things. But it was like, all those years, I had been doing direct services. And all those years, it was ACT UP, only, talking about women. So yeah, I think again, in the context of the AIDS definition expansion, and the Social Security, it was the two together. And in this case, I will say a lot of the kind of more fringy AIDS organizations were the ones who were plaintiffs in this thing. But we all paid consequences, serious consequences. And I don't think they would have gotten away with that with ACT UP,

either. Think about it. Way back in the day of ACT UP, I don't think that Vacco could have sat and audited the HIV Law Project like that.

And the AIDS industry had been born by this point. So there were institutional interests everywhere.

SS: So AIDS industry with no AIDS activism equals bureaucratic mess.

TM: Yeah, I think so. Often, yeah.

SS: Okay. Well, I only have one final question for you. And this is, looking back at ACT UP, can you tell me what you think its greatest achievement was and what you think its greatest disappointment was?

TM: I think – what's its greatest achievement? I think it achieved so much. I think, kind of a blending of being really smart; understanding the policy issues; creativity; and fearlessness about kind of upsetting authority; that that was a combination that when I look at all the HIV work worldwide, it's like the access-to-treatment stuff; that is the only combination that I think works in the context of this epidemic. So I think ACT UP was responsible for so many things. Hugely important.

I think that aspects of it really did, I think, what was its greatest downfall? I mean, I suppose, I don't know how you could have avoided all the infighting. That's the role of activists: to question everything; to question me, too. I don't know how you make that transition to kind of becoming institutionalized — some people had to — and still stay activists. So I think some of those conflicts were not resolvable.

I do think that some of the, in retrospect, some of the nasty infighting probably was not so smart, if you were looking at the larger objectives. So maybe the biggest downfall was that. And even I, some of the people that were my archenemies, I now can laugh with them. Because I think in some ways we lost sight of the big picture a lot, with some of that infighting? So maybe that.

SS: Okay. Thank you so much, Terry.

TM: You're welcome.

SS: Thank you. Oh, it's a sad story.

TM: You think?

SS: Well, the ending is.

TM: Yeah.

SS: – but no one to make anybody accountable.

TM: Right, right. It must be interesting to have this overview, to see what the hell happened.

SS: Yeah, well, we're starting to figure it out.

TM: Really?